Inclusion London

Care Charging Unmasked

A barrier to independent living, choice and control



About this report

This report is produced by Inclusion London, a leading pan-London disability equality organisation with national reach. We are run by and for Deaf and Disabled people.

We work with more than 50 other Deaf and Disabled people's organisations (DDPOs) and draw our authority not only from this long-standing representative role, but also from the substantial body of evidence we have built through direct support to Disabled people and carers facing social care charges.

The report brings together frontline casework, lived experience, and policy expertise to expose the human cost of social care charging.

All names and identifying details have been anonymised to protect privacy and dignity, but the patterns are unmistakable. The evidence is clear: this system is causing harm, and it must change.

About the author

Jon Abrams is Campaigns and Justice Coordinator at Inclusion London. He has more than 20 years' experience working in Disabled People's Organisations, with a focus on campaigning, policy development and co-production. His work has covered a wide range of issues, including welfare benefit cuts, social care, housing, accessible transport, mental health and public health.

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Illustrations by Phyllida Jacobs.

Scope and terminology

This report focuses specifically on non-residential social care charging. This is where local councils require adults to contribute towards the cost of care and support they receive while living in their own homes or in the community, rather than in a residential care home.

Throughout this report, the terms "home care charging", "social care charging" and "care charging" are used interchangeably to refer to non-residential social care charging, unless otherwise stated.

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Social Care Charging: Lived Experience

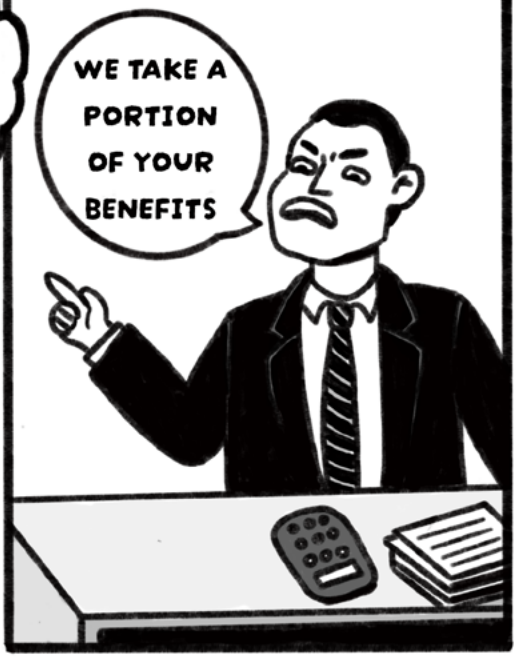
1 APPLY FOR DISABILITY BENEFITS (PIP/DLA)

You apply for disability benefits to help with the extra costs of being Disabled.



2 SOCIAL CARE FINANCIAL ASSESSMENT

The Council calculate how much you must pay towards your care, based on your income and savings.



3 DEDUCTIONS FOR CARE CHARGES

Money intended to help meet your higher extra costs of being Disabled is siphoned off to pay for care and support instead.



4 DISABILITY RELATED EXPENDITURE

The Council didn't tell you, but you find out you can reduce your care charges by asking them to consider disability related expenditure (DRE).



5 APPLYING FOR DRE IS A HUGE BURDEN

Paperwork is more difficult for you, but you have to spend hours gathering evidence, completing forms and submitting everything the Council demand.



6 DECISION BY LOCAL AUTHORITY

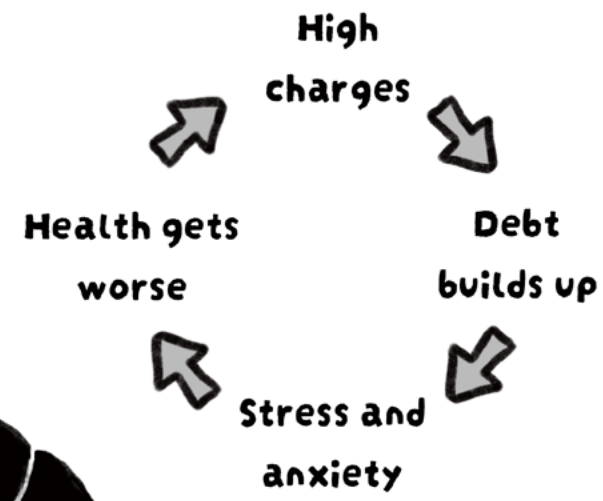
A panel decide what costs, if any, are allowed. These could include things like extra heating, incontinence products or wheelchair equipment.



7 THE RESULT: DEBT AND DISTRESS

Disabled people face a system that is:

- Complex and hard to understand
- Inconsistent and unfair
- Lacking clear information
- Time consuming and stressful
- Pushing people into debt





by Phyllida Jacobs

Foreword:

Dignity, choice and independent living – for everyone

Our vision is simple: we should all be able to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing the things that matter to us.

Our vision is simple: we should all be able to live in the place we call home, with the people and things we love, in communities where we look out for one another, doing the things that matter to us.

Good social care must go beyond helping people with washing, dressing, eating or preparing meals. It enables us to maintain relationships, work, learn, contribute to our communities and live with dignity, choice and control. It enables us to live gloriously ordinary lives.

Unlike NHS care, social care is means-tested. Charges for care and support in people's homes and communities are a major barrier to a dignified life for all. Disabled people can be required to pay from already limited incomes, including benefits intended to meet the additional costs of disability. Charges push people into poverty and debt, restrict participation in community life and cause some to reduce or give up support entirely. This can worsen health and place additional pressure on the NHS and unpaid carers.

On the 29th of September 2026, Prime Minister Andy Burnham set out his vision for social care reform. We welcome his commitment to transforming social care and a vision of person-centred, good quality care that starts in community and is free at the point of use.

But his promise of a Britain where people feel their country has their back is limited to people over 65, while younger Disabled people are facing the same and often even more punitive charges, financial hardship and barriers to independent living as older people.

Burnham asked us to imagine "a Britain for everyone". Working-age Disabled people could be forgiven for asking: who has our back? We are among those whose benefits are taken to pay for essential support, who face mounting care debts and who must decide whether we can afford the help we need to live our lives.

He rightly and importantly told care workers: "You are not invisible to me." Care workers deserve that recognition. But are working-age Disabled people invisible in his vision for social care? Our needs, our rights and our futures must carry equal weight in the commitments being made.

The Government has rightly recognised that older people should no longer face care charging. We welcome the difference free personal care would make to older people. We know that the injustice of care charging does not begin at 65, and neither should the commitment to end it.

We previously welcomed Burnham's recognition that the current system "does break people" and his willingness to listen to Disabled people facing unfair charges simply to live their lives. **This report documents precisely that harm. Recognising it must lead to action for everyone affected.**

As a Deaf and Disabled People's Organisation, Inclusion London has worked for many years alongside Disabled people, carers and other Disabled People's Organisations to challenge unfair social care charges. Through frontline support, casework, training, policy, campaigning and the development of our Disability-Related Expenditure chatbot[1], we have built substantial evidence of how charging operates and its impact on Disabled people's everyday lives.

This work sits within a wider body of thinking and campaigning developed collectively across the Disabled people's movement. Reclaiming Our Futures Alliance's Independent Living for the Future[2] set out a shared vision for a universal right to independent living and a national independent living support system free at the point of need.

Care Charging Unmasked builds on that vision by providing current evidence of how charges for care and support in people's homes and communities drive poverty and debt, prevent access to support and undermine independent living, focusing on the experiences of working-age Disabled people.

Our central recommendation is that these care charges be abolished for everyone and be replaced by collective public funding, so that social care is provided according to need and free at the point of use.

Summary of key issues explored in this report

Overall, the evidence shows that home care charging is not merely flawed in its administration but fundamentally unjust in its design. It deepens poverty, undermines wellbeing and independence, and leaves many Disabled people, older people and carers trapped in silence, hardship, and fear.

Disabled people face significantly higher rates of **poverty**, driven by lower incomes, barriers to employment, and the unavoidable extra costs of disability.

Social care charging **penalises people for their disability**, taking money from people who are already struggling financially and treating disability benefits as if they were spare income.

Disability-Related Expenditure (DRE) is intended to protect people's income, but in practice, the process for claiming it is **complex, unclear, highly bureaucratic**, and applied inconsistently across local authorities. Councils often fail to inform people about their right to claim DRE. This leaves many unaware and overcharged, resulting in inflated and potentially unlawful care charges.

Financial assessments are often **opaque and poorly explained**. Many people receive invoices, demands, or enforcement letters without any clear breakdown of how their charges have been calculated.

This report identifies systemic **maladministration, including unlawful blanket policies**, failure to follow public law and statutory guidance, inconsistent decision-making, inaccessible processes, and poor understanding of Care Act duties.

Bureaucratic barriers and inaccessible communication particularly disadvantage people with sensory, cognitive, learning, or mental health impairments, or people with English as a second language. This makes it even harder for them to challenge errors or assert their rights.

Delays, refusals, repeated reassessments, and burdensome evidence requirements make the DRE process **exhausting, time-consuming, and damaging** to people's mental and physical health.

Harsh debt recovery practices and backdated charges push individuals and families into **crisis**, often without proper notice, explanation, or lawful financial assessment.

Carers are left carrying an **overwhelming burden**, forced to navigate complex systems, chase unresponsive councils, and deal with threatening correspondence, all while supporting loved ones with high levels of need. Disabled people who do not have anyone to help or advocate for them can end up using their support hours to navigate the social care system, instead of meeting their eligible care needs.



Introduction

This report is produced by Inclusion London, a leading pan-London disability equality organisation with national reach. We are led by and for Deaf and Disabled people.

Our evidence is grounded in practice. It comes from working directly alongside Disabled people and carers across England who are trying to understand, challenge, and reduce unfair care charges. Through this work, we have seen first-hand how charging policies operate in people's lives and the harm they can cause.

Over the past five years, Inclusion London has built a substantial body of evidence on how social care charging operates in practice and the impact it has on Disabled people, older people and carers. Our work has combined **direct casework, legal and policy analysis, co-produced tools, and sustained engagement** with people affected by charging across England.

> ***"They send an invoice to me every month. I can't afford to pay this.***
>
> ***I am very scared.***

During this period, we have designed and developed a specialist **chatbot**[3], co-produced with Disabled people and carers, to help individuals identify Disability-Related Expenditure (DRE) and challenge or reduce unfair care charges. To date, 1,129 people have used our tool, with the average annualised DRE claim identified amounting to **£7,899.99**.

We have also delivered more than 30 online workshops involving over 500 participants, supporting Disabled people, older people and carers to understand their rights and navigate a highly complex charging system.

Alongside this, we have provided individual support on financial assessments, DRE submissions, complaints, Monitoring Officer referrals, Ombudsman complaints, and matters involving judicial review, as well as face-to-face support to people in crisis because of charging practices.



Photo: Age Without Limits

This practical and extensive work exposes deep-rooted and widespread failures by local authorities in applying the Care Act 2014 during financial assessments and in the calculation of Disability-Related Expenditure. It reveals repeated breaches of statutory duties, entrenched misinformation, inaccessible systems, and harmful bureaucratic practices. These are not isolated mistakes. They are systemic patterns of overcharging that push Disabled people, older people and carers deeper into poverty and deter them from accessing the care and support to which they are legally entitled.

This combination of representative reach, lived experience, casework, and practical tools gives Inclusion London a strong and distinctive basis for this report. The findings that follow are rooted not only in policy analysis, but in the real experiences of people who have had to fight to protect their income, defend their rights, and avoid being pushed deeper into poverty by the social care charging system.

Charging as a barrier to independent living

This report is grounded in the Social Model of Disability[4]. It recognises that people are disabled not simply by their impairments, but by physical, financial, attitudinal and institutional barriers. Responsibility therefore lies with society to remove these barriers, rather than expecting individuals to overcome them. Social care charging must be understood as one such barrier.

Independent living does not mean living alone or managing without assistance. It means having the same freedom, dignity, choice and control as non-Disabled people, including control over where and with whom to live and how support is provided. Social care is not charity: it is practical support that enables equal participation in society.

Article 19 of the **United Nations Convention on the Rights of Persons with Disabilities**[5] recognises the equal right of Disabled people to live independently and be included in the community. This includes choosing where and with whom to live and having access to the personal assistance and community support needed to prevent isolation and segregation. The UK has ratified the Convention, and Article 19 provides an important standard against which social care policy should be assessed.

Charging is therefore not simply a way of raising revenue. It places a financial condition on support that Disabled people need to exercise their rights. An entitlement to social care has limited value if using it requires people to give up income needed for everyday and disability-related costs. Charging can restrict choice and control before support has even been provided.

This rights framework should inform how the evidence that follows is judged. **DRE assessments, bureaucracy, debt recovery and distress are not merely administrative problems; they can create and reinforce barriers to equality and independent living.**

Disability and poverty

The economic challenges facing Disabled people

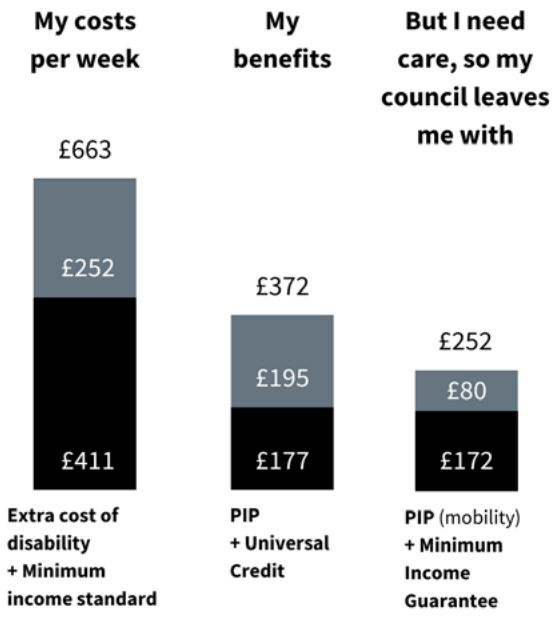
To understand the impact of social care charging, it is essential to consider the financial realities Disabled people face in the UK. Poverty levels have been rising since 2005, disproportionately affecting certain groups, including Disabled people.

Research by the Joseph Rowntree Foundation (JRF)[6] in 2026 found that the poverty rate for Disabled people in 2023/24 was 31%, significantly higher than for non-Disabled people. For working-age adults, the disparity was even more significant. Disabled people were twice as likely to live in poverty, with rates reaching 33%, rising to 34% for those with long-term limiting mental health conditions.

Disabled people face a significantly higher risk of poverty for two key reasons: barriers to employment and the additional costs associated with impairments and health conditions. Despite ongoing efforts to improve employment opportunities, Disabled people continue to experience substantial disadvantage in the labour market. According to government statistics[7], between April and June 2024, only 53% of disabled working-age adults were in employment, compared with 82% of non-disabled working-age adults—a disability employment gap of 29 percentage points.

New evidence continues to show just how stark the financial reality is for Disabled people. Scope's updated Disability Price Tag[8] reveals that in 2024–25, Disabled households needed,

Example weekly budget



Based on a single adult aged 18-25 with no children, living in outer London, receiving the PIP higher rate daily living and mobility allowances.[9]

on average, an additional £1,095 every month simply to achieve the same standard of living as non-Disabled households—an 8% increase on previous years. Even when disability benefits like Personal Independence Payment (PIP) are taken into account, families still face an average monthly shortfall of £630, with extra costs now amounting to an extraordinary 67% of household income.[10] These findings are echoed in academic research, including a major European study showing that Disabled households faced additional weekly costs of £293 in 2013 and £326 in 2016 (in 2020 prices).[11]

> ***The pattern is clear and consistent: Disabled people are forced to shoulder financial pressures far beyond those experienced by the general population.***

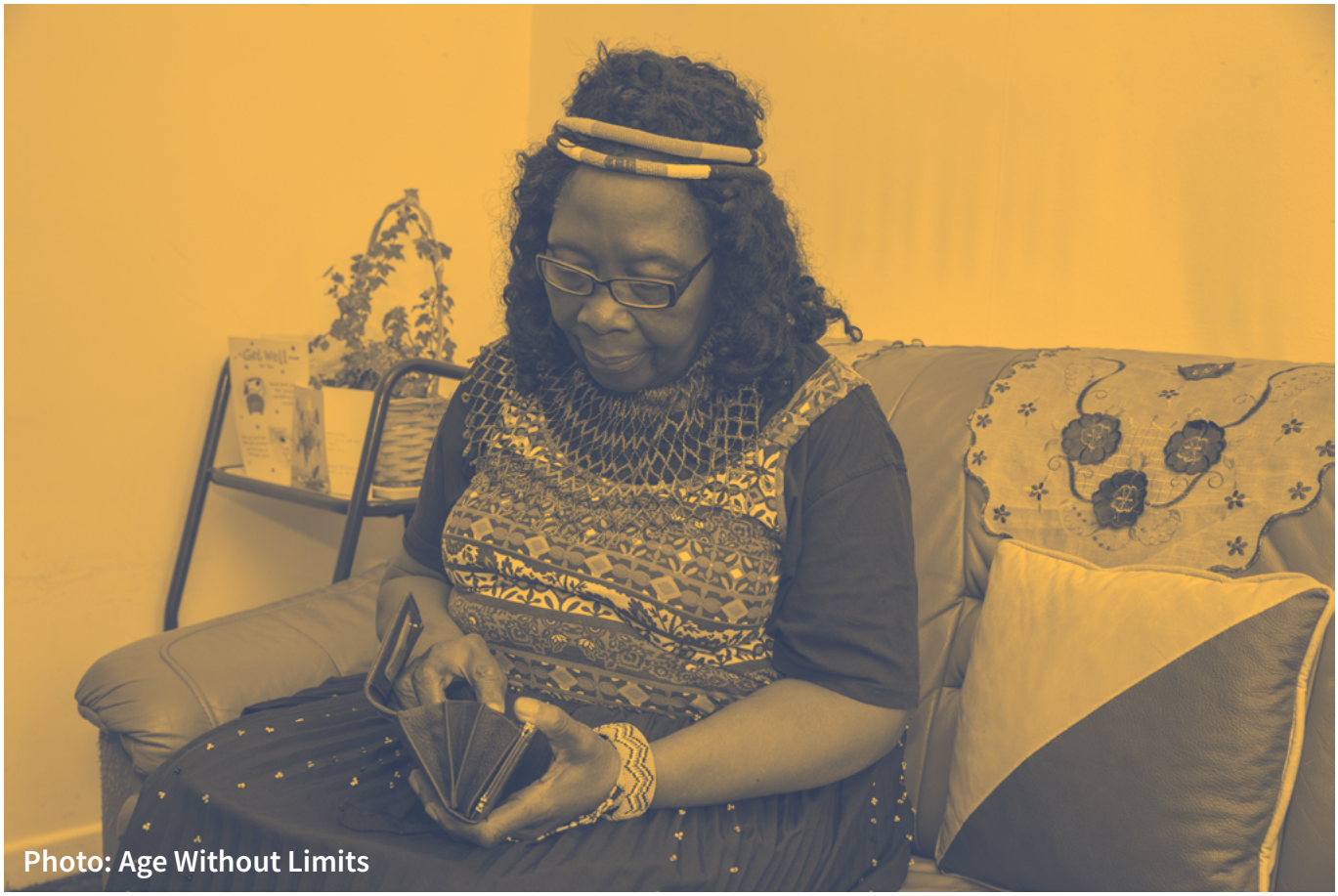


Photo: Age Without Limits

Mencap's latest research[12] reinforces this picture, revealing the breadth and depth of extra costs borne by people with learning difficulties and their families. These are not luxuries. They are the essentials of daily life: adequate food, safe bedding, sensory aids, mobility equipment, therapies, personalised care, and the activities that bring connection, stability, and joy.

For many families, these costs recur more frequently because intensive use means items wear out more quickly, or because behaviours arising from a person's impairment can result in damage or breakage. Higher energy use, limited transport options, and expensive home or vehicle adaptations compound these pressures.

Crucially, some costs arise not from impairments themselves but from system failures, such as NHS provision that is so inadequate that families must pay privately to meet basic needs. Together, this evidence shows a landscape in which Disabled people face profound and unavoidable financial disadvantage, long before they encounter the additional burden of social care charges.

These extra costs include specialist equipment, dietary requirements, higher energy bills, and incontinence products. Limited access to services and shopping options further restricts choice, making it harder for Disabled people to seek lower-cost alternatives. Even essential services such as insurance, travel, and accommodation often incur additional costs for Disabled people.

For many, these expenses are unavoidable and directly linked to their ability to live independently. Unlike discretionary spending, disability-related costs cannot be reduced without severe consequences.

These financial pressures, combined with a social care system that demands contributions from already stretched incomes, leave many Disabled people struggling to afford even the most essential support.

Key issues in social care charging

Unlike the NHS, social care is not free. Even people receiving means-tested benefits are expected to contribute towards the cost of their care. Disability benefits such as Personal Independence Payment and Attendance Allowance are treated as ordinary income, rather than as money intended to meet the extra costs of disability-related needs.

Social care charging creates a complex legal distinction between "health" needs, which are funded by the NHS, and "social care" needs, which can be charged for. **In practice, this means that two people with equally significant care needs can be treated very differently.** Someone with advanced cancer may receive all of their care free through the NHS because their needs are classified as healthcare, while someone with dementia may require similar levels of care but be told their needs fall within the social care system and must therefore pay towards that support.

The boundary between the two is often difficult to understand and can appear arbitrary. What should be a universal right to independent living instead becomes a **penalty for disability and long-term illness**.

> ***"What should be a universal right to independent living instead becomes a penalty for disability and long-term illness.***

In theory, the Care Act allows people who are forced to pay for care out of their disability benefits to keep some of their income if they can demonstrate that they incur additional disability-related costs. This is done through a process known as **Disability-Related Expenditure**.

The result is a confusing and often unfair system that requires Disabled people to navigate complex rules, complete detailed financial assessments, and provide extensive evidence simply to retain income intended to meet the extra costs of disability. In doing so, the system places the greatest burden on those who often have the least time, energy, financial resources, and capacity to navigate it.

What is Disability-Related Expenditure (DRE)?

Disability-Related Expenditure refers to the additional costs Disabled people, older individuals, and those with long-term health conditions incur due to their specific impairments and needs. **These expenses encompass a range of essential items and services**, including increased heating bills, adaptive clothing, incontinence support, specialised dietary needs, and support with household tasks such as cleaning and laundry, or gardening. DRE also covers additional transportation costs, and social activities to promote social inclusion and improve overall wellbeing.

Local authorities are required by law to account for these costs during a financial assessment to determine how much an individual needs to contribute to their care. DRE is designed to ensure that Disabled people are not unfairly disadvantaged when calculating care costs.



How claiming Disability Related Expenditure works

When a local authority assesses a person's finances to determine their contribution to care costs, it must inform the individual about Disability-Related Expenditures and, if necessary, assist in identifying these expenses. The Care and Support Statutory Guidance provides a non-exhaustive list of items that may be claimed under DRE.

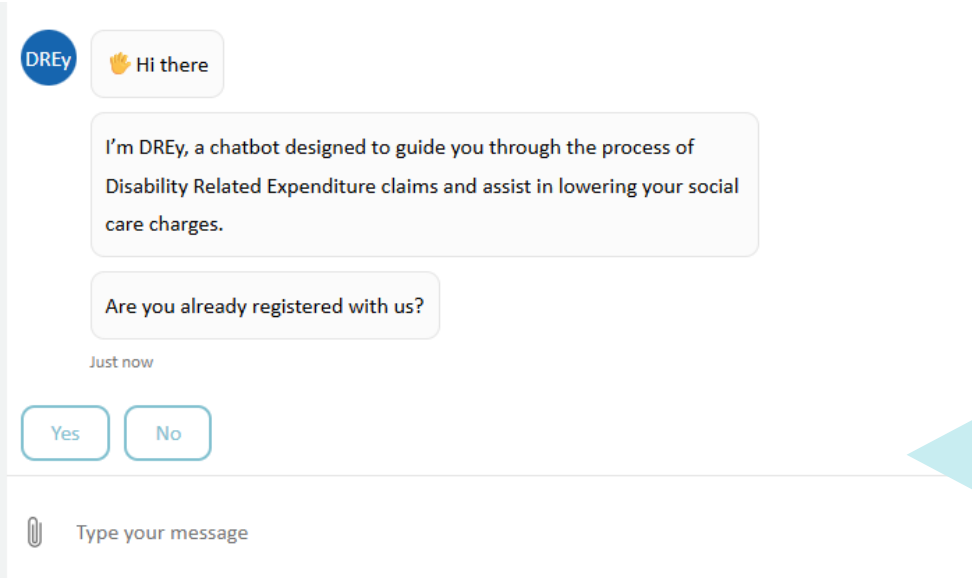
The DRE process closely resembles **filing a tax return**. Individuals must painstakingly identify **every additional cost** associated with their disability, verify that each one qualifies, and then gather evidence to support it. In practice, this means collecting receipts—often from the last 3 months—and demonstrating, **item by item,** that each expense is reasonable and directly related to their impairments. The local authority then goes through the claim with a red pen, deciding **which costs to allow and which to reject**.

This creates a clear double standard. Disability benefits such as Personal Independence Payment (PIP) and Attendance Allowance (AA) are intended to help meet the extra costs of disability, but people who draw on social care can be required to justify how that income is spent in far greater detail. Councils may question whether a cheaper option could have been used, whether a cost is truly necessary, or whether a person should have shopped at Lidl, Tesco or another cheaper retailer instead of Marks & Spencer or John Lewis. This level of scrutiny is intrusive and unfair, and reinforces the reality that **people are being penalised simply because they need social care.**

Key problems uncovered

While supporting grassroots campaigns on social care charging, we noticed that DRE was either not assessed or assessed incorrectly in many locations.

To address these challenges, we developed a **chatbot**[13] designed by Disabled people and carers with lived experience navigating the social care system. The chatbot streamlines the DRE claims process by helping users identify and calculate disability-related expenditures. It provides prompts and examples to help gather supporting evidence, maintains a running total of expenses for clarity, and generates detailed letters and summaries to support claim submissions to local authorities.



The DRE chatbot uses a series of questions to help users gather their evidence, then generates detailed letters and summaries to support submissions to local authorities.

In our support for chatbot users, we have observed practices that constitute **maladministration** and **violate public law duties.** Over the past three years, we have identified several common issues among local authorities.

These include failures to inform individuals about DRE, and inconsistent application of statutory guidance. We have also noted bureaucratic delays, harsh debt-collection practices, threatening letters, and finance officers who demonstrate little or no understanding of social care, the Care Act, or the lived experiences of individuals using the social care system.

For example, a person we supported was required to resubmit all their evidence again, and attend further meetings with both a social worker and a financial officer, despite having already provided the detailed information required.

Bureaucratic barriers:

The lack of clear, accessible information on disability-related expenditure

Many people are unaware of Disability-Related Expenditure (DRE) and how it can help reduce social care charges, as councils often fail to provide and promote this information. When DRE is not adequately explained, financial assessments may be inaccurate, resulting in higher social care charges than necessary. This oversight can lead to greater poverty and hardship for Disabled and older people.

The widespread lack of awareness about DRE affects **nearly everyone we have supported** over the last few years. While some individuals may have heard of DRE, many do not fully understand the range of expenses they can ask the council to consider. This is largely due to inadequate explanations and a lack of accessible information from councils.

> ***"The information about what you can claim is very basic. I seem to remember a form I filled out but of course, I didn't claim for anything very much as it wasn't very clear at all what you could claim for or how.***

To better inform Disabled people, older individuals, and carers about their rights, we launched a campaign to raise awareness of how to claim for Disability Related Expenditure (DRE). Financial assessments are often conducted remotely, without personal interaction, which disadvantages many people. For example, a deaf-blind client we supported didn't receive care plans, a financial assessment, or explanations about DRE in braille, which meant they had no idea or understanding of being charged and how it was calculated. Many receive assessments, calculations, and invoices without being informed about DRE.

Consequently, they are forced to pay a lot more than they should. This lack of clarity and the absence of proactive support force individuals to navigate a complex system alone. A carer explained that *"the problem is knowing where to go to ask for help and knowing that the help is there. Surely we should be told about this when we first get a financial assessment."*

> ***"The officer over the phone last Tuesday was threatening me that if I try and send in all my DRE receipts that I'm currently gathering up, they would charge me more for care… This is causing me to go into mental health burnout."***

Even when claims are submitted, recalculations can take months and are not automatically backdated, causing further financial strain.

For carers, the system can be equally frustrating. *"My conclusion is they don't make allowances unless you complain, which is wrong."* Another remarked on the lack of coordination between departments: *"I sent all my evidence to the Audit team, but they don't appear to communicate with the Financial Assessment team."*

The financial burden from these issues is severe, as explained by a Disabled person drawing on social care. *"First and foremost, I cannot afford it. Then not only does the care charge team not recognise my disability expenses, but on top of that, you want me to pay around £300 more a month."*

These experiences reveal **systemic failures in how local authorities handle DRE and social care charging**: from inaccessible communication and unclear guidance to long delays, missing assessments, and a lack of meaningful support. They also show that this is not a system that can simply be "fixed" with better forms or guidance. At its heart, social care charging operates as a financial penalty on disability, taking money from people who are already in poverty and crisis. That is why we are campaigning to scrap care charges altogether, rather than merely improve the DRE process—so that Disabled people, older people and carers are **no longer forced to fight a hostile bureaucracy** just to hang on to the basic support they need.

> ***"It's like playing a game where only the other side knows the rules."***

When councils charge first and explain later:

Invoices, enforcement letters, and missing assessments

Many individuals who pay social care charges do not receive copies of their financial assessments, leaving them unsure of how their contributions are calculated. Those who receive this information often face complex calculations that are difficult to understand. Instead of clear explanations, they typically receive invoices or enforcement notices demanding payment. This lack of transparency leads to confusion and distress, making it difficult for them to effectively contest any inaccuracies.

A person with autism and a learning disability described the emotional toll of dealing with an inaccessible and confusing financial assessment process. She recounted interactions with an aggressive financial officer: *"I am in tears, overwhelmed, burnt out and haven't been able to volunteer due to it. When I think I'm coming out of it, this leads me back into it."* This sentiment underscores the exhaustion caused by a system that often fails to provide clarity or support.

> ***I'm at my wit's end. They have not given me any copy of a financial assessment; they just sent a bill that I then disputed.***

In many cases, individuals never receive financial assessments. As another person shared: *"I'm at my wits' end. They have not given me any copy of a financial assessment, just sent a bill that I then disputed".* The absence of clear documentation leaves individuals unable to understand or challenge their charges effectively.

Sometimes, DRE claims are **denied without justification**, which violates public law because local councils must be transparent and provide fair, rational reasons when rejecting DRE items.

In one case, the council rejected all 19 new DRE items and reduced two long-standing DRE items that had been accepted for eight years, despite updated evidence showing that the costs had increased. No reasons were given for either decision.

The situation is exacerbated by poor communication and dismissive responses. One individual, Sally, wrote: *"I sent a financial form around two months ago, and it got back with nothing changed. The council has not taken into account my disability expenses."* Sally further expressed confusion over council communication: *"I got this email thread, and I must confess I am wildly confused about what's what. The council has this strategy to give weird and changing names to things without an update. The council has not explained what I need to know either."*

> ***We were never informed about these charges previously. No one ever explained to us that he had to pay any money for his care.***

These accounts demonstrate a pattern of **neglect, poor communication, and systemic dysfunction**. Local authorities fail to provide adequate information, leaving individuals to struggle with unexplained charges, denied claims, and bureaucratic inertia. The consequences of these failures extend far beyond financial distress, impacting mental health, family stability, and overall wellbeing. Addressing these issues is essential to create a system that respects the dignity and rights of those it serves.

Claire Bolderson's qualitative research on social care charging for Disabled adults of working age[14] reinforces this wider pattern. Her study found that charging practices can cause both financial hardship and emotional harm, leaving people feeling devalued, powerless and treated unequally. This reflects the experiences described above. Poor communication, opaque decision-making and dismissive responses do not simply create administrative confusion, they undermine trust, independence and wellbeing. Bolderson's research also found that some people became more dependent on family support or turned down care because they could not afford the charges, reinforcing the central finding of this report that social care charging deepens poverty and damages lives.

Delays in DRE recalculations:

A burdensome and bureaucratic process and its impact on wellbeing

Individuals seeking a recalculated Disability-Related Expenditure (DRE) must first request a financial reassessment. However, in many cases we have supported, receiving an initial response can take months.

Often, the replies are generic rejections, forcing individuals to file formal complaints and navigate the lengthy stages of the complaints process before any recalculation is made. During this drawn-out period, local authorities expect individuals to continue paying their disputed contributions, which can push people into hardship, and in some cases debt. It also takes a heavy toll on their mental health and wellbeing.

One person described the cumulative emotional impact of repeated dismissals and the denial of essential disability-related needs:

> ***"The amount of work and stress caused by the multiple claims, phone calls, etc. has been immense.***

"I can't even count how many times I've been brought to tears after receiving yet another dismissive response from the council. It's heartbreaking when they tell you something that's so fundamental to your disability, something that you rely on every single day, isn't even considered a real need. It feels like they're completely out of touch with your reality, and it's soul-crushing to be met with something so impersonal and cold. It makes you feel like you're not seen, not heard—just another case to push through, rather than a person who deserves understanding and support."

For Katherine, who has a learning difficulty and autism, the process has been particularly distressing. She shared her experience with a financial officer: *"The officer over the phone last Tuesday was threatening me that if I try and send in all my DRE receipts that I'm currently gathering up, they would charge me more for care. She was telling me she can only see up to 2019 of what was agreed and nothing before that… This is causing me to go into mental health burnout."* Such interactions highlight the

intimidating nature of the process, leaving individuals feeling powerless and vulnerable.

Others describe the frustrations of **repeated delays** and **unresponsiveness** from local authorities. After chasing up their DRE reassessment multiple times, one individual wrote: *"I have chased up at least 3 times, but have still heard nothing as yet. Where do we go from here now please?"* The lack of communication creates a sense of being ignored and forgotten, compounding the emotional strain.

Another person we supported, Jemma, waited seven months for a response after submitting 19 DRE items with detailed evidence. Despite this, all items were initially rejected, and it took two years of repeated challenges before the council accepted that more than ten of the items should have been approved.



Photo: Age Without Limits

The excessive bureaucratic demands for documentation and evidence also exacerbate **stress** and impact **physical health**. One person explained, *"It's caused me extreme stress having to gather all the information and answering endless emails, having to send in so much information which has already been submitted. This is impacting my own physical health as I have my own medical conditions."*

The delays also have serious implications for individuals' **financial and emotional wellbeing**. One carer shared their concerns about the impact of unresolved care charges on their dependent: *"I'm extremely worried about E's financial situation as, after this proposed care charge, he will not be able to meet his very basic living costs.*

I'm very worried that if this isn't resolved in his favour, his standard of living will be affected—especially his activities, which are vital for his wellbeing. These activities keep his behaviours stable, but without them, there could be significant impacts."

The threshold for receiving social care support is already high, leaving those who qualify often reliant on carers or advocates to navigate the complex system. However, the demands of the process frequently overwhelm carers, who struggle to find the time or energy to write lengthy complaint letters or chase unresponsive local authorities. Many ultimately **give up fighting for their entitlements**, not because the claims lack merit but because the system discourages persistence.

> ***"It's caused me extreme stress having to gather all the information and answering endless emails, having to send in so much information which has already been submitted. This is impacting my own health.***

These delays and barriers illustrate a **systemic failure** to provide timely, accessible support for those in need. The result is not only deepening financial hardship but also serious harm to people's mental and physical health, placing an unjust burden on some of the most vulnerable individuals and their carers.

This is not a system that can be repaired with minor adjustments or better paperwork. To end this damage, we can't simply streamline a process that penalises disability and pushes people further into poverty and crisis. **We must abolish social care charging altogether.**

Escalating to legal remedies:

A system that forces Disabled people to fight for their rights

As social care charging has become more complex and punitive, Disabled people, older people and carers are increasingly being pushed into formal legal routes to challenge unlawful decisions.

Instead of having their needs met through straightforward, lawful financial assessments, people are having to refer cases to council Monitoring Officers, seek specialist community care solicitors, or escalate complaints to the Local Government and Social Care Ombudsman. This is not a sign of a healthy system; it is evidence of routine breaches of charging regulations, the Care Act 2014, and statutory guidance, leaving people with no option but to turn to legal mechanisms simply to enforce rights they already have in law.

However, access to justice in this area is shrinking. Years of **cuts to legal aid** mean that fewer law firms now undertake community care work, and those that remain are often overwhelmed.

> ***"At every step, they drag their feet as much as they can.***

We have advised several Disabled people we support to seek legal representation, who have then approached four or five different legal aid firms without success. In one case, the individual contacted more than 10 legal aid solicitors, yet every firm said it was unable to take the case because it lacked the capacity.

The result is a **"justice gap"** in which councils can act unlawfully with little fear of effective challenge, while Disabled people are left to navigate intimidating legal processes alone. A system that relies on individuals in crisis finding scarce legal representation to correct routine illegality is not just unsustainable, it is fundamentally unjust.

The scale of social care charging and the case for abolition

Analysis of the Adult Social Care Finance Report, England: 2024 to 2025[15] indicates councils in England received approximately £1.72 billion in client contributions for non-residential long-term adult social care in 2024–25.

The Department of Health and Social Care does not publish a single national total for these charges. Our estimate combines client contributions recorded under Fairer Charging, Direct Payments, Home Care, Supported Living and Other Long-Term Care, while excluding residential and nursing care. Councils do not classify this income consistently: some record most of it under Fairer Charging, while others allocate it to particular support settings. Blank entries or dashes cannot necessarily be treated as evidence that no income was collected. The £1.72 billion figure should therefore be presented as an estimate derived from official data, not as a government-published total.

The data also does not identify where people obtain the money used to pay their charges. It is therefore not possible to calculate how much comes from disability benefits, pensions, earnings or savings. However, non-residential charging is means-tested, and welfare benefits can be included as income in financial assessments. It is reasonable to conclude that a significant proportion is collected from people on low incomes, including many who rely heavily on benefits, but the precise amount cannot be established from the published figure.

For context, gross current expenditure on adult social care in England was approximately **£29.39 billion** in 2024–25[16]. The estimated £1.72 billion collected through non-residential charges was therefore equivalent to about **5.9%** of that expenditure. This is significant income for councils, but a relatively small proportion of national adult social care spending.

The Independent Living Strategy Group's report, Charging for Social Care: A tax on the need for support?[17] used Freedom of Information evidence to examine the costs of administering social care charges. Although the report's financial figures are now seven years old and should not be treated as current, it demonstrated that **councils devote significant staff time and resources** to assessing, collecting, reviewing and enforcing

charges, while also writing off some uncollectible debt. However, it found that charging still generated net income for councils.

Abolition would not, therefore, pay for itself through administrative savings alone. The estimated £1.72 billion is gross contribution income, not the precise amount of replacement funding required. An up-to-date costing would need to consider avoidable administrative savings, transition costs and additional demand from people who currently reduce or refuse support because of charges.

Assessing that additional demand is difficult because the consequences of charging are not systematically tracked. Councils generally record the immediate decision when someone refuses, reduces or stops receiving social care because of the charge. However, Inclusion London's Freedom of Information requests to London councils found that the vast majority do not monitor what happens to those people afterwards. They record the withdrawal from support, but not its consequences.[18]

Therefore, once someone leaves the system, the charging data does not show whether their needs remain unmet, their physical or mental health deteriorates, they become more dependent on unpaid carers, or they later reach a crisis requiring NHS treatment. It also does not capture the effects on carers who may have to provide more support, reduce their working hours or leave employment.



Photo: Disabled and Here

Consequently, the £1.72 billion figure captures only the income received by councils. It does not include the **human cost of people going without support** or the costs displaced onto families, the NHS and other public services. A joined-up health and social care economy cannot assess the impact of its policies if one part of the system records the income, while no one records the consequences. This is particularly important where reduced or withdrawn social care may contribute to needs escalating and people reaching crisis.

The Government's Care and Support Statutory Guidance[19] recognises the importance of preventing people from reaching crisis and reducing emergency hospital admissions. The potential cost when prevention fails is considerable. Department of Health and Social Care figures show that a non-elective long-stay hospital bed day cost an average of **£791 in 2024–25**, equivalent to approximately **£5,537 a week.**[20] Costs vary according to the treatment and type of admission, and this figure does not establish that every admission could have been prevented through social care. It does, however, illustrate the scale of NHS expenditure that can arise when people reach crisis.

Where people reduce or refuse formal care because of charges, greater responsibility may fall on unpaid carers. The Department of Health and Social Care recognises that formal social care can reduce the amount of unpaid care provided, stating: "In the absence of formal care, the amount of unpaid care might increase for some people, impacting their health, wellbeing and employment outcome".[21]

Carers UK's 2026 research highlights the significant impact of caring on employment. Nearly half (47%) of employed carers are considering reducing their working hours or giving up work altogether. The findings also revealed that **"35% of carers who had given up employment said more affordable, accessible, or reliable social care services would have prevented them from reaching a tipping point."**[22] While this does not establish that social care charging itself caused carers to leave employment, it demonstrates the potentially significant labour-market and household costs associated with inadequate or unaffordable social care.

> ***"35% of carers who had given up employment said more affordable, accessible, or reliable social care services would have prevented them from reaching a tipping point.***

Fully funded abolition would also be expected to generate wider economic benefits. Bank of England research[23] indicates that households experiencing financial pressure are more likely to spend additional disposable income rather than save it. Disabled and older people who retain more of their income would be likely to spend much of it on essentials, transport, household costs and participation in community life.

If central government replaced the income lost by councils, social care spending would be maintained while service users would have greater spending power. Much of this additional spending would be likely to flow back into local economies, supporting local businesses and wider economic activity. This should not, however, be presented as creating £1.72 billion of entirely new economic value.

A credible abolition policy must be fully and permanently funded by central government. Funding should replace the net income councils currently retain, meet transition costs and allow for increased demand from people who previously reduced or refused support because of charges. It should reflect differences between local authorities and rise in line with costs and levels of need. Crucially, it must be additional funding so that councils do not respond by tightening eligibility, rationing support or reducing care packages.

The Casey Commission should examine not only the income raised through charging, but also its wider costs across the NHS, mental health services, unpaid care and employment. The absence of national data on these consequences should not be taken as evidence that they do not exist. This is an important evidence gap that government should address. The central question is not whether councils can simply absorb the loss—they cannot. It is whether essential social care should be funded collectively through national taxation or through individual charges imposed on Disabled people because they need support. The evidence presented in this report supports a clear conclusion: non-residential social care charging should be abolished and replaced with sustainable national funding.

Conclusion

Time for change

The evidence in this report is clear: social care charging is not just failing in practice, it is failing by design.

We have heard from people receiving threatening letters for disputed charges, carers pushed to breaking point by debt and bureaucracy, and Disabled people left choosing between rent, food, heating, care and the basic costs of living with impairment. These are not isolated mistakes. They are the predictable consequences of a system that charges people for the support they need to live independently and with dignity, choice, and control.

Some people manage to challenge decisions, but only after months or years of stress, repeated evidence-gathering, complaints and pressure. Many others cannot. They depend on local authorities for essential care, creating a profound power imbalance. This is how silent poverty takes hold: people cut back, withdraw from support, become increasingly reliant on family, stop challenging decisions, or go without care altogether because the system feels impossible to fight.

This cannot be resolved through clearer guidance, administrative changes or minor adjustments. The harm is structural. Care and support are not luxuries; they are fundamental to dignity and independent living. Disabled people, older people and carers should not be pushed into poverty simply because they need support.

Abolition of charges for older and younger people would strengthen financial security and local economies by allowing Disabled and older people to spend more of their income on essentials, support and participation in community life.

It would also help realise the vision set out in this report: that **people should be able to live independently**, maintain relationships, contribute to their communities and live with dignity, choice and control.

Ending charges must be backed by **sufficient, permanent central government funding** to replace the income councils currently receive and meet any increase in demand. Without this guarantee, abolition could be undermined by tighter eligibility, rationed support or reduced care packages. Reform must remove the cost from individuals, not transfer it to other Disabled people, older people, unpaid carers or families.



A National Care Service should be free for everyone who needs support, including working age Disabled people. We must stop requiring people to use welfare benefits or other essential income to pay for the support they need, no matter their age.

Social care charging should be abolished, for everyone.

A National Care Service must guarantee support according to need and be collectively funded. It must make independent living real, so that everyone who needs support has the **choice and control to live a gloriously ordinary life.**

Endnotes

1 Inclusion London, DREy chatbot - Reduce your social care charges today

2 Reclaiming Our Futures Alliance, Independent Living for the Future

3 Inclusion London, The Social Model of Disability

4 United Nations Convention on the Rights of Persons with Disabilities, Article 19 – Living independently and being included in the community

5 Joseph Rowntree Foundation, Disability and poverty

6 Department for Work & Pensions, The employment of disabled people 2024

7 Scope, Disability Price Tag 2025

8 Extra cost of disability is £252 per week for a disabled household, adapted from monthly to weekly, in 2025. Scope, Disability Price Tag 2025

Minimum income standard is £411 per week for a single, working-age adult without children in outer London, excluding rent, in 2025. Trust for London and the Centre for Research in Social Policy, A minimum income standard for London 2025

PIP is £195 per week for higher rate daily living and higher rate mobility.

Department for Work and Pensions, Personal Independence Payment (PIP): How much you'll get - GOV.UK

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22 Bank of England, Staff Working Paper No. 965 Financial concerns and the marginal propensity to consume in Covid times: evidence from UK survey data

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