

Independent Living Strategy Group

Charging for Social Care: A tax on the need for support?



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The Independent Living Strategy Group

The Independent Living Strategy Group is a network of disabled people's organisations and their allies. We exist to protect, promote and ensure the fulfilment of disabled people's rights to independent living in England. We have been meeting and sharing information about all aspects of independent living since 2013.

The group is chaired by Baroness Jane Campbell and includes disabled people who were part of the independent living movement from the 1970s, as well as younger activists, other individuals and organisations concerned with the future of independent living. Through coordinated action we aim to frame debates and shape new agendas, influence emerging policy and legislation and ensure effective implementation of existing law and policy.

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Executive summary

The Independent Living Strategy Group recently carried out a study of local authority charges for social care, exploring in particular whether and to what extent the practice of charging is undermining people's well-being, the primary purpose of social care services as set out in the Care Act 2014. We examined some key features of the way local authorities implement charges and gathered evidence on the impact of charges on disabled people.

Summary of findings

Our study comprised two parts: an online survey of people who had received a community care assessment; and a Freedom of Information request to 152 English local authorities. The survey was open for responses between 19th April and 9th July 2018 and in total we received 604 responses. All 152 local authorities responded to our Freedom of Information request.

Key findings from the survey of disabled people's experiences:

- Four out of ten people said they had experienced a substantial increase in the level of charging over the past 2 years, and of those providing a figure a third said the increase had been over 50%.
 - Just under half (48%) said they had frequently or occasionally used money intended for other household costs such as food and heating to pay for care and support.
 - One in five reported that they had gone into debt by borrowing to pay for care and support. Informal debt was more common, with 52% saying they had relied on family or friends to meet the cost of care and support
 - Just over a third (35%) reported that they had struggled to pay for care and support, falling behind or delaying payments that were due.
 - Three out of four said that they worried about the cost of care and support.
- People are having to find money for care and support from other areas of essential spending: 33% reported that they had reduced spending on housing costs, 43% had reduced the amount they spend on food and 40% reduced what they spent on heating in order to meet the cost of care.
 - The majority of people are critical of the local charging policy in their area, just under two thirds of people viewed their policy as poor or very poor in terms of fairness (64%) and approaching three quarters rated it as poor or very poor in terms of being easy to understand (71%).
 - Amongst other things people spoke about the unfairness of the system, having to challenge the application of local policies, increasing amounts of money that had to be paid, the stress of paying for care and having to rely on family members to pay charges.
 - A 'cliff edge' was identified by people who move from paid employment to a pension income, in that the latter is included in the means test while earned income is not, which can result in significant increases in charges.

Key findings relating to local authorities:

- All but one local authority currently choose to exercise their power to make a charge for social care services to people who need support. The majority make services available to carers free of charge.
- The majority of authorities carried out an equality impact assessment and a range of risks were identified, including a risk to people's well-being and a risk of financial hardship. Risks to the well-being of carers were identified and that people in need would decline help. Local authorities also identified risks to themselves including a loss of income and legal challenges.
- Some, but by no means all, local authorities demonstrated they had a good understanding of the risks associated with charging for social care and had some strategies in place to monitor and mitigate some risks.
- 13% of the 122 local authorities who undertook an equality assessment failed to identify a single risk associated with their charging policy.
- Only 17 local authorities were able to provide a figure for how many ceased receiving or failed to take up services following a financial assessment.
- Charging accounts for around 12% of the total spent on community support. On average local authorities spend around £456,106 on collecting charges (around 9% of the total raised). About 3% is written off as uncollectible.
- There are wide variations across local authorities in terms of the amount raised from charging and how many people are charged.

Conclusion

Local authority eligibility criteria for social care have been significantly tightened in recent years, often resulting in support being limited to the most essential needs. Disabled and older people are therefore being charged for the most basic personal care support that is necessary for day-to-day survival.

Our study concludes that charging for the support disabled people need to go about their daily lives is unfair, counterproductive and undermines the primary purpose of the care and support system that it subsidises. Charging is essentially a mechanism for means-testing social care which makes a small contribution to local authority budgets. However, the effect is all too often to drive disabled people into care poverty, and to create confusion, stress and complexity in an already overly burdened bureaucratic system.

While the purpose of support provided under the Care Act is to protect and enhance a person's well-being, charging undermines this by having a negative impact on people's well-being. It leads to unnecessary restrictions on people's lives, undermines national eligibility criteria and is a major barrier to health and social care integration. Charging for community care services is effectively an unhelpful and unnecessary tax on disability and old age.

Introduction

This report aims to consider the value and impact of charging for community based adult social care support. It does this by examining some key features of the way local authorities implement charges, and by gathering evidence on the impact of charges on disabled people. In particular we explore whether and to what extent the practice of charging is undermining people's well-being, the primary purpose of social care services as set out in the Care Act 2014.

There is a dearth of up-to-date information about the impact of charging for social care. A 2008 survey¹ found evidence of people giving up social care support because they couldn't afford the charge, and almost a third said they didn't feel their disability-related expenditure was taken properly into account in the means-test their Council applied. Local disability organisations have in recent years drawn attention to the difficulties caused by charges for social care.² A Freedom of Information request from the GMB to all local authorities earlier this year found that 78,000 people had had debt management procedures started against them for non-payment of social care charges.³

Understanding what charging is and the policy issues which arise

Local authorities have a duty to arrange support for those with eligible needs, and also have discretion as to whether to charge for the support provided.

Where the local authority chooses to make a charge, this must be done following the Care and Support (Charging and Assessment of Resources) Regulations⁴ and the local authority must also have regard to the Care Act Guidance.⁵ These regulations and guidance require local authorities to discount disability-related expenditure and earned (but not pension) income when carrying out financial assessments, and give them the discretion to include the care component of DLA or PIP and Attendance Allowance in the calculation of a person's income.

Regulations also set out how much savings are to be taken into account and that charges must not reduce people's income below a certain amount (the Minimum Income Guarantee).⁶

Charging disabled people for the care and support they require is both a means-test to ration scarce resources, and a way of raising local authority revenue

The financial assessment is carried out separately from, and after, an assessment and determination of a person's eligible assessed needs for support.

Charging disabled people for the care and support they require is both a means-test to ration scarce resources, and a way of raising local authority revenue. This gives rise to a number of distinct but interlinked questions which need to be separated out to be understood:

1. Is it fair that those who need care or support to live their lives bear the financial consequences, given such support concerns their basic human rights to dignity, to control over their life and to participate in the community?
2. How can a future approach to social care funding support wider policy goals? What approach would best promote social justice, and individual choice and control? What approach would avoid disadvantaging people who rely on family carers, or the carers themselves?
3. Given needs vary across the population and across people's lifetimes, what should the fair balance be between the individual and the state in terms of paying? How do we avoid a situation where those who need care and support are economically disadvantaged?

4. How should care and support be funded – how can money to fund care and support be collected fairly and efficiently? Is applying a means-tested charge to individuals who need support an efficient way of raising funds?
5. If individuals should be expected to contribute towards the cost of meeting their care and support needs, at what point should they have to pay: at the point support is delivered to them, or at an earlier stage in life, prior to having a care and support need, based on their ability to pay?

This report aims to provide information about the current charging system in order to inform the wider debate about the funding of social care. It is also important to set evidence about the impact of charging for social care in the context of the £7bn reduction in funding for social care since 2010. As the Association of Directors of Adult Social Services states, such a significant reduction in funding, at the same time as increasing demand, means that:

Fewer older and disabled people with more complex care and support needs [are] getting less long-term care. This amounts to a redefinition of the relationship between the state and the citizen, with an increasing move towards a highly targeted ‘offer’ in adult social care.⁷

There were two parts to the Independent Living Strategy Group’s examination of the current charging system:

- an online survey of those receiving support; and
- a Freedom of Information request to 152 English local authorities with responsibility for adult social care.

The next section of this report presents the results of the survey and the following one the results of the Freedom of Information requests.

The survey of disabled people needing support

The survey was open for responses between 19th April and 9th July 2018. In total we received 604 responses: 417 from people who made a contribution to the cost their care and support, 125 were from people who made no contribution because they were assessed as not having to pay a contribution, 35 responses were from people who self-funded their own care entirely and a further 27 came from people who said they had been assessed as eligible for council subsidised support but had decided not to take it because of the cost of charges.

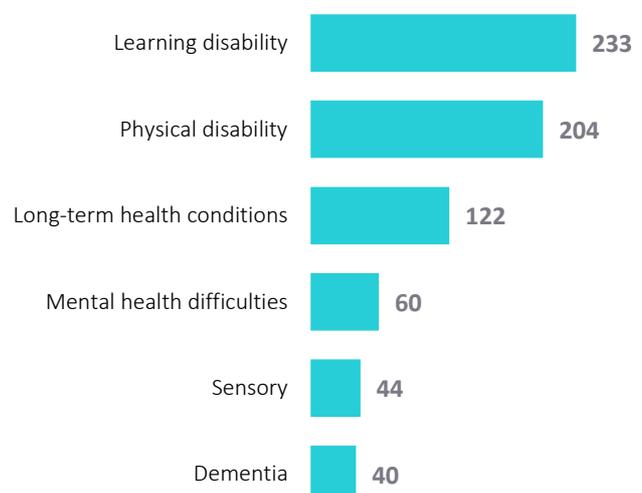
Key findings

- Four out of ten of people said they had experienced a substantial increase in the level of charge over the past 2 years, and of those providing a figure a third said they had experienced an increase of over 50% in the last two years.
- Just under half of the group (48%) said they had frequently or occasionally used money intended for other household costs such as food and heating to pay for care and support
- One in five reported that they had gone into debt by borrowing to pay for care and support. Informal debt was more common, with over half the group (52%) saying they had relied on family or friends to meet the cost of care and support
- Just over a third of the group (35%) reported that they had struggled to pay for care and support falling behind or delaying payments that were due.
- Three quarters of the group (78%) said that they worried about the cost of care and support.
- People are having to find money for care and support from other areas of essential spend: 33% reported that they had reduced spending on housing costs; 43% had reduced the amount they spend on food and heating to meet the cost of care.
- The majority of people are critical of the local charging policy in their area, Just under two thirds of people viewed their policy as poor or very poor in terms of fairness (64%) and approaching three quarters rated it as poor or very poor in terms of being easy to understand (71%).
- Amongst other things people spoke about the unfairness of the system, having to challenge the application of local policies, increasing amounts of money that had to be paid, the stress of paying for care and having to rely on family members to pay charges.
- A 'cliff edge' was identified by people who move from paid employment to a pension income, in that the latter is included in the means test while earned income is not, which can result in significant increases in charges.

For the rest of this section of the report we look at the responses of the 417 people who made a contribution to the cost of their care and support through charges applied by the local authority.

The majority of the group were of working age, and they reported a broad range of reasons for needing support. These are shown in Chart 1.

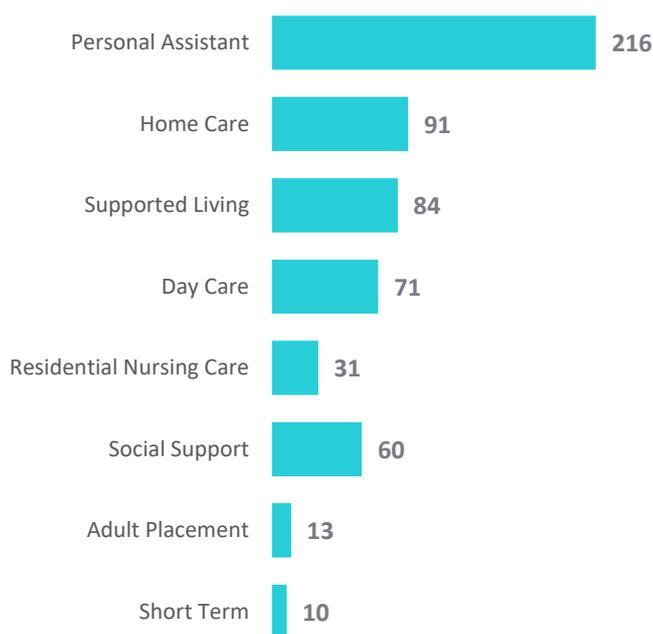
Chart 1: What is the reason you have support?



Note: Throughout the report where responses are shown as percentages the totals do not necessarily add up to 100 as not all people answered all the questions. The percentages are of the total responding to that particular question, and for some questions people could select more than one answer.

The type of support people received is shown in Chart 2. Just over two thirds of the group reported that they received individual support at home or in the community either from a personal assistant or home care service. The remainder said they received other types of support, mainly in group settings.

Chart 2: What type of support do you get from social services?



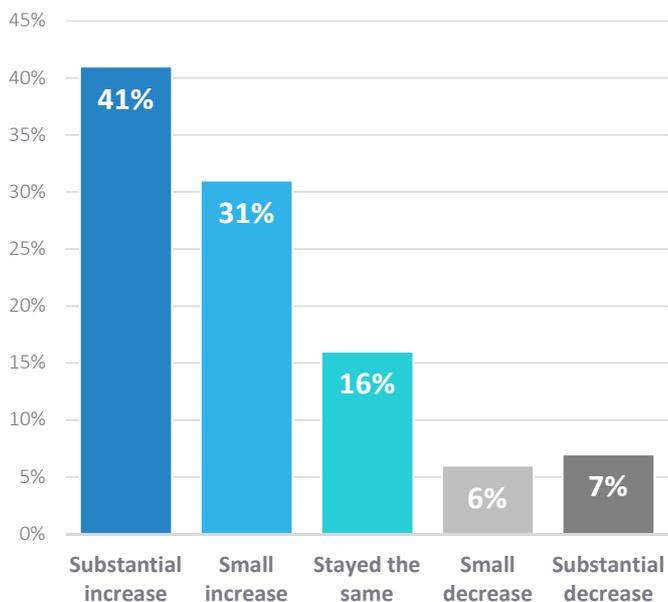
We also asked people if they had experienced a reduction in the level of support they received over the last two years; nearly half of the group (48%) said they had experienced a reduction in the level of support they received.

Changes to charging

Over two thirds (72%) of people said they had experienced an increase in the level of charge over the past 2 years.

Chart 3: Changes to charging over the last two years

Have you experienced a change in the cost of paying for care and support in the last two years?



We also asked people to estimate the percentage increase in the charge they paid. 175 people provided an estimated figure, a third of whom said they had experienced an increase of over 50% in the last two years. A further 17 people reported that they were now being charged for care that was previously free, and the average charge for this group was £65 per week or £3,380 per year.

48%

had experienced a reduction in the level of support they received

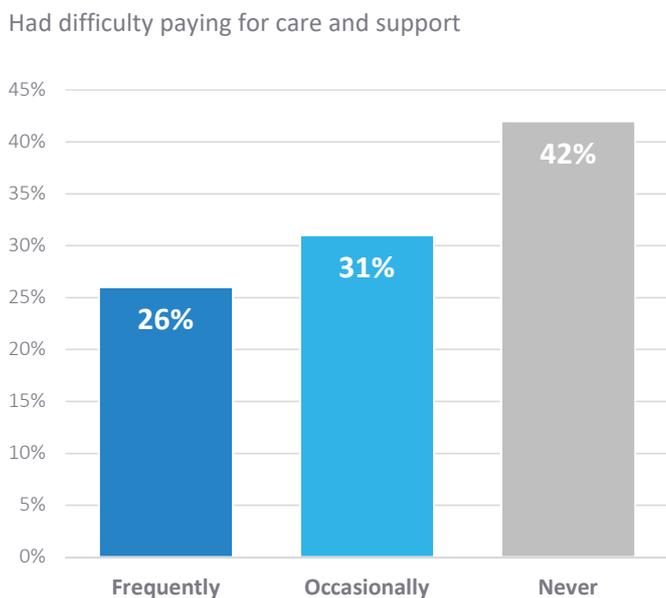
Impact of charging of people’s well-being

Clause 1 (1) of the Care Act 2014 states that “The general duty of a local authority, in exercising [any of their care and support functions], is to promote that individual’s well-being”⁸. Both the Act and Care Act statutory guidance⁹ explains that promoting ‘well-being’ means ensuring care and support is provided in a way which ensures personal dignity, physical and mental health, control over day-to-day life, participation in family life and in work, education, training and recreation.

We asked people a set of questions designed to determine whether charging was having an impact on their well-being, asking them to think about their experience of paying for care and support over the past two years.

Just over a half of the group (57%) said they had frequently or occasionally experienced difficulty paying charges.

Chart 4: Difficulties in paying for care and support.



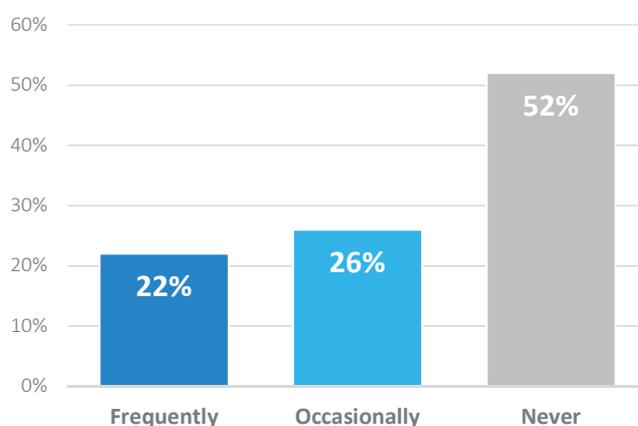
In terms of the types of difficulty people experienced we ask whether they had used money intended for essential household costs (e.g. food, rent, mortgage, heating) to pay for the cost of care and support. Just under half of the group (48%) said they had frequently or occasionally used money intended for other household costs to pay for care and support.

57%

frequently or occasionally experienced difficulty paying charges

Chart 5: Using money intended for essential household costs to pay for the cost of care and support.

Used money intended for essential household costs to pay for the cost of care and support (e.g. food, rent, mortgage, heating)



We asked whether people had savings and whether they had used money from their savings towards the cost of care and support. Just under half the group (48%) said they had savings in excess of £1000, while a third (34%) said they had no savings.

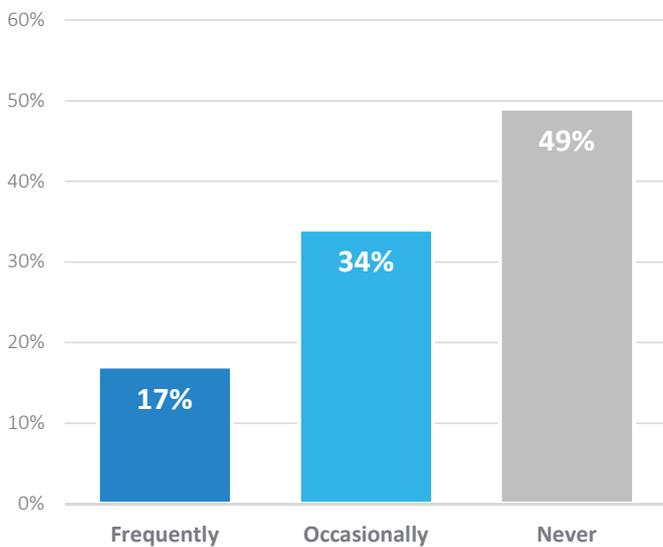
Chart 6: Do you have savings?



Half of the group who had savings said they had used money from their savings to pay for their care and support.

Chart 7: Use of savings to pay for care and support.

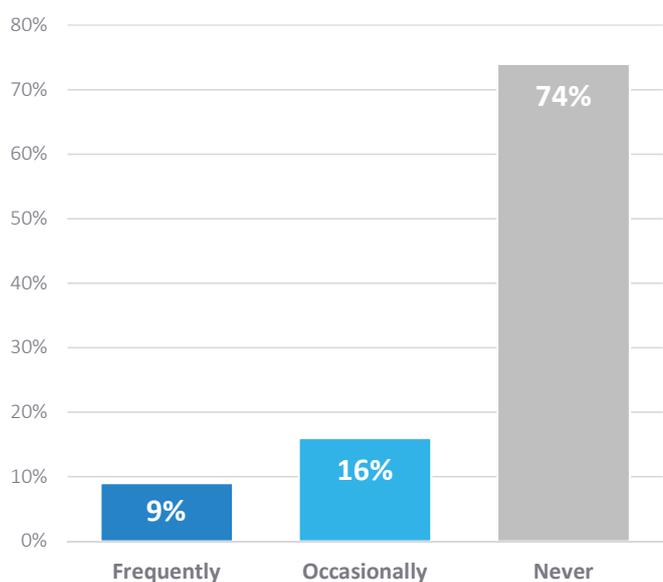
Used money from your savings towards the cost of care and support?



We asked people whether they had gone into debt because of charging; we asked about falling behind with payments for care, and about borrowing from both formal (e.g. banks) and informal (family and friends) sources. One in five reported that they had gone into debt by borrowing from formal sources to pay for care and support.

Chart 8: Debt and paying for care and support – formal borrowing.

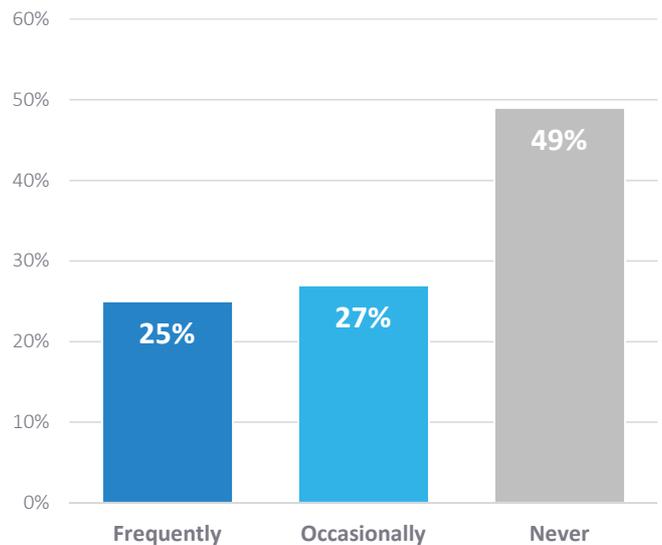
Borrowed, including going overdrawn, to pay for care and support



Informal debt was more common, with half the group saying they had relied on family or friends to meet the cost of care and support. We also asked whether the cost of care had impacted on family relationships or friendships. Just over a third of the group (38%) reported that paying for care had impacted on close relationships.

Chart 9: Debt and paying for support – informal borrowing.

Relied on family and friends to meet the cost of care and support



Just over a third of the group (35%) reported that they had struggled to pay for care and support falling behind or delaying payments that were due.

Chart 10: Overdue payments

Delayed or fallen behind in making payments for care and support

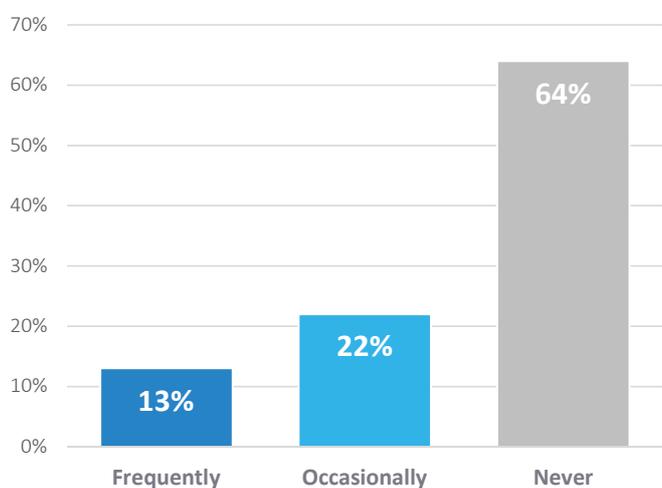


Chart 11: Worrying about the cost of care and support

Worried about the cost of care and support

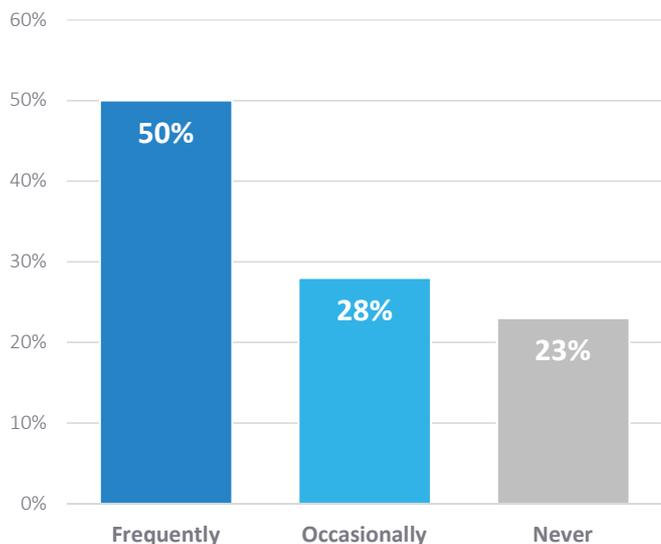


Chart 12: Confusion about payments

Experienced confusion about how much you needed to pay

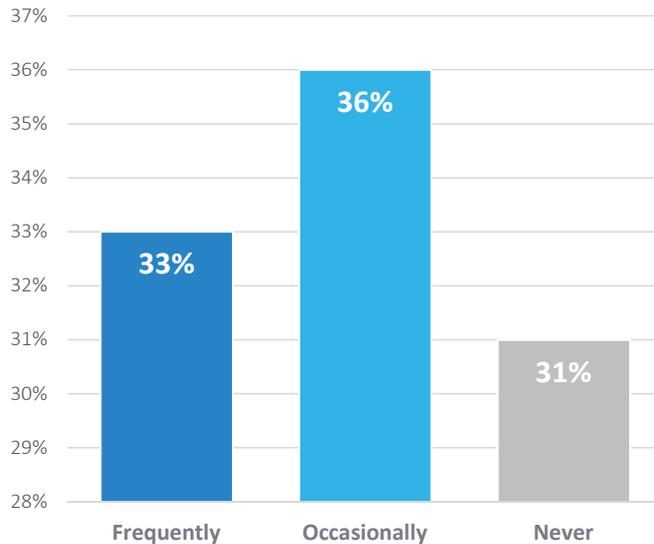
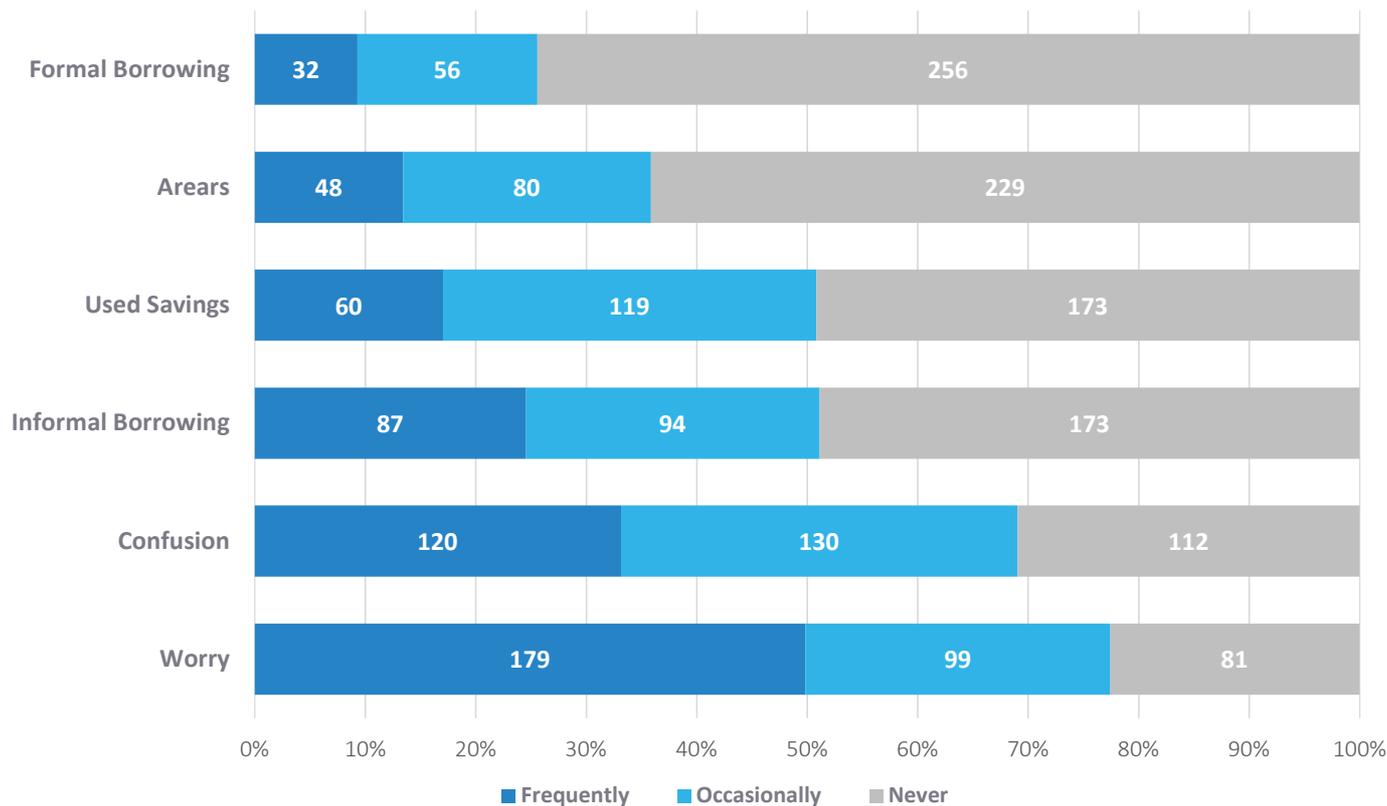


Figure 1: Impact of charging of people’s well-being



Over three quarters of the group (78%) said that they worried about the cost of care and support, while over two thirds reported that they had experienced confusion about how much money they needed to pay.

The impact of charging on all of these aspects of people’s well-being is illustrated above.

We asked people whether they had to reduce other essential spending to meet the cost of care and support in a range of areas associated with well-being. A third reported that they had reduced spending on housing costs, and on work and training.

Four out of 10 had reduced the amount they spend on food (43%) and heating (40%) to meet the cost of care. Half had reduced travel expenditure (52%) and seven out of ten had reduced the amount they spend on leisure to pay for care and support.

Chart 13: Reducing essential spending in order to meet the cost of care and support

Have you had to reduce other essential spending to meet the cost of care and support?

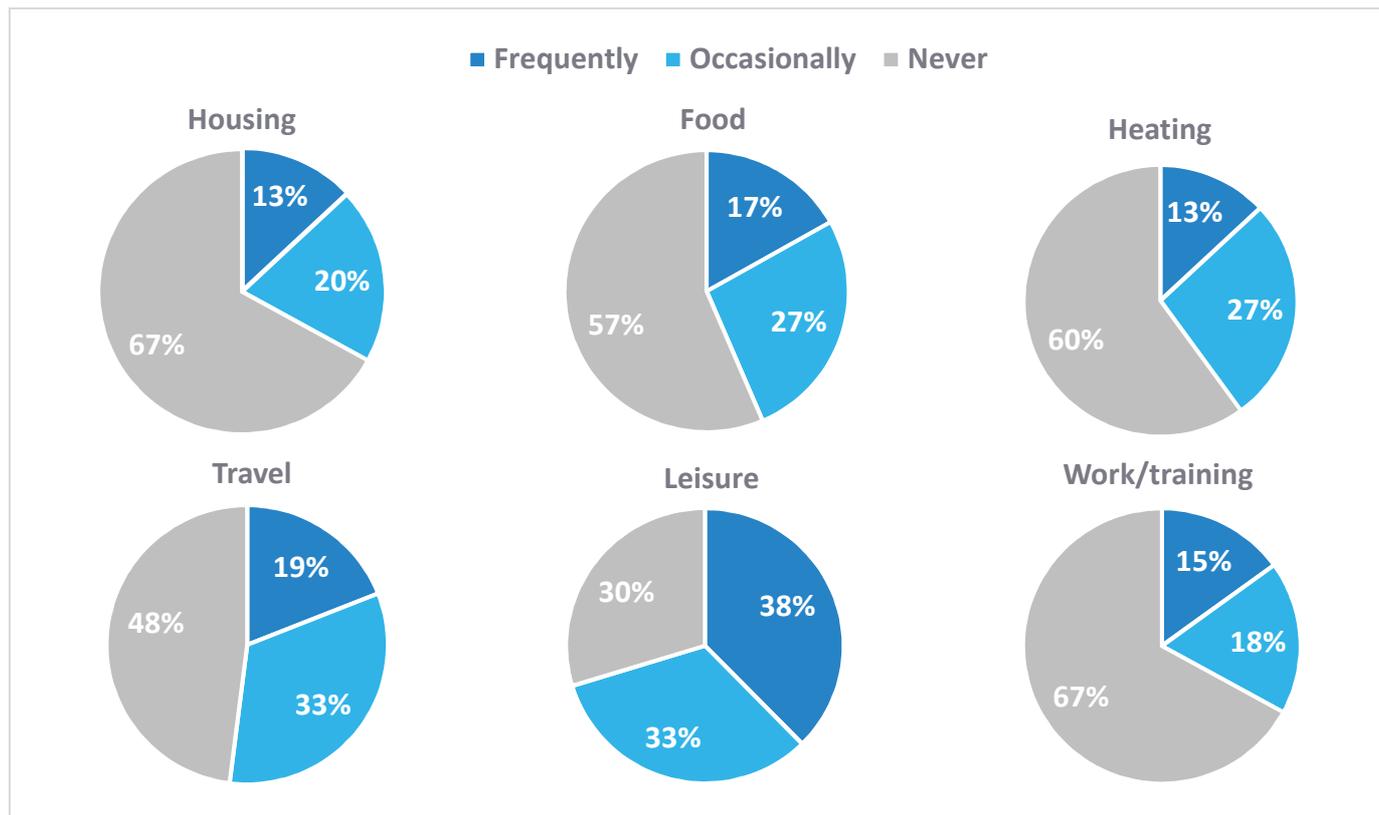
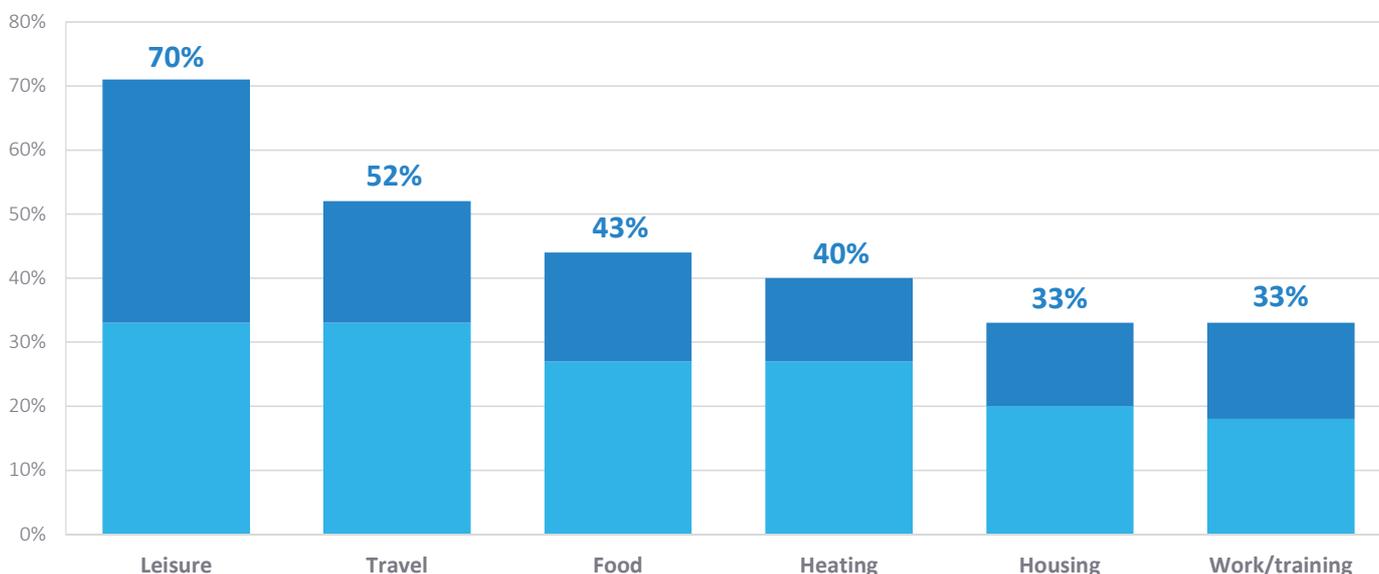


Figure 2: Proportion of people reducing spend in other essential areas to meet the cost of care and support.



What people thought about their council's charging policy

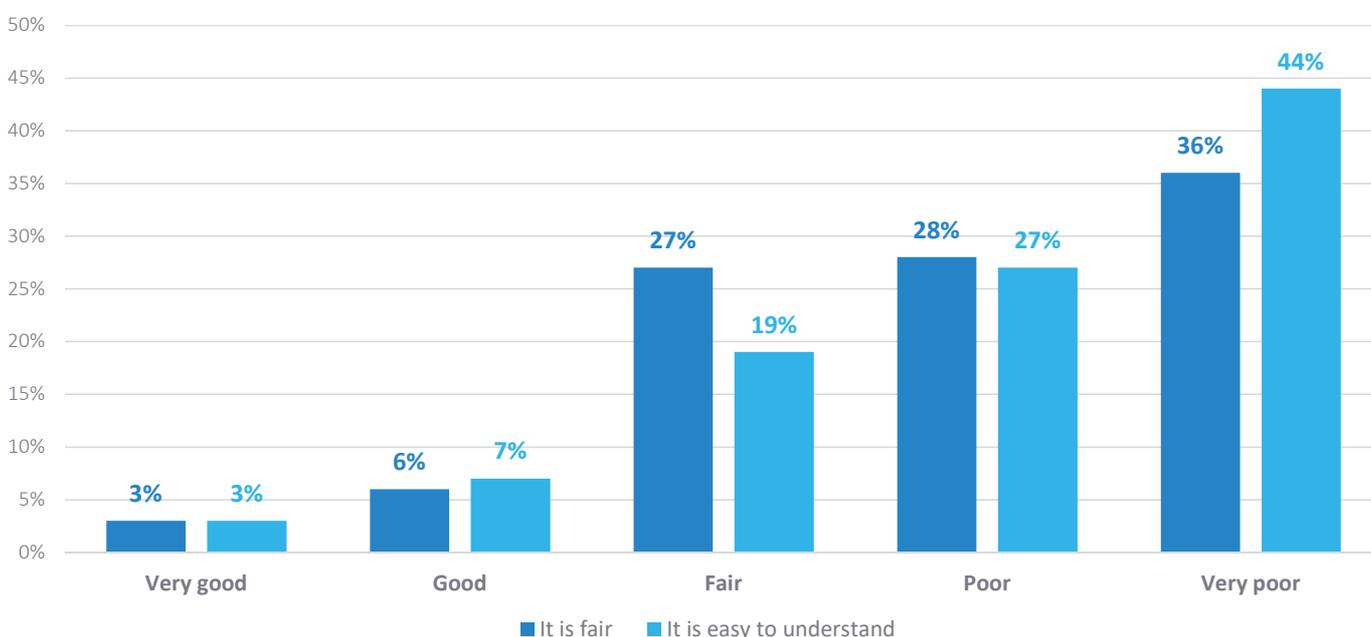
We asked people to describe their experience of their council's charging policy in terms of fairness and transparency. Just under two thirds of people viewed the council charging policy as poor or very poor in terms of fairness (64%) and approaching three quarters viewed the policy as poor or very poor in terms of being easy to understand (71%).

71%

viewed the policy as poor or very poor in terms of being easy to understand

Chart 14: Perceptions of fairness and transparency amongst those being charged

How would you describe your experience of the local authority's approach to charging for care and support?



Unfair, a source of worry and undermining well-being

Finally we asked people whether they had anything else to say about their experience of paying for care and support.

The most frequently mentioned comment related to a feeling that the system of charging was unfair (mentioned by just under a half) – for example, “why should I have to pay for essential care when I have no choice because of my situation”. Others remarked that they felt that “people shouldn’t be penalised for being disabled” and “This is a backdoor tax on disabled people”.

Disability-related expenditure must, according to Care Act regulations and guidance, be discounted in the means-test for support but there seems to be much confusion and variation between authorities as to what should be included. A number of people commented on the onerous nature of the evidence that is required, with for example some being told they had to get evidence provided by a healthcare professional.

Some wrote about how unfair it was that their local authority didn’t give them guidance on what counted as disability-related expenditure – “the council is unfair in not disclosing what we are to claim back as additional disability related expenditure”.

Other respondents reported that their local authority significantly restricted what they could claim and expected them to provide hard-to-get evidence of such expenditure.

People who found that their care charges went up once they retired felt this was particularly unjust and didn't understand why: "I've never been able to get an explanation for why I have to contribute from my pension but didn't from my wages" said one. Others wrote more generally about the "Lack of proper clear information. No one seems to know the rules or be willing to share them with us".

Another source of unfairness identified was the contrast between the way what was defined as social care was treated as compared to what was defined as health care: "Dementia should be recognised as an illness and not seen as a social care need", wrote one respondent. Others reported on how a decision to redefine what had previously been provided as continuing healthcare (funded by the NHS) to social care had a significant impact on their finances.

78%

worried about the cost of care and support

70%

reduced the amount they spend on leisure to pay for care and support

As previously mentioned, over two thirds of respondents had experienced an increase in the charges they had to pay over the last two years and a number wrote about how difficult this was for them and the resulting worry about how they would manage. Some authorities who had previously not taken the DLA/PIP care component/daily living allowance or Attendance Allowance into account had changed their rules and this sometimes led to a significant increase in the charges made. The worry was particularly acute for those who had gone into debt, with one person saying: "I'm thinking of re-mortgaging to pay off my debt – it should never have come to this!".

Even when people didn't go into debt as a result of having to pay a charge for essential support, they could sometimes find the whole system of being financially assessed very worrying, particularly when there were then delays ("the invoice didn't come until November and was a shock!") and disagreements over what they should be charged. One person who challenged what she was charged wrote that "The whole process took a year and caused emotional and mental distress".

Local authorities' policies and practice in relation to charging for social care

We wrote to all 152 English local authorities who have social services responsibilities making a Freedom of Information request, setting out a series of questions relating to their charging arrangements.

We originally wrote to them on the 19th April 2018 and nearly two thirds responded within 20 days. A series of follow up requests resulted in the remainder being received by the 17th July (see Appendix 2).

Not all local authorities determined that they were able or were required to respond to all the questions we asked. Where information was not provided this was generally because the local authority did not hold the information, they viewed the information as commercially sensitive, the information was already in the public domain, or the information would take too long to compile. Interestingly there seemed to be very little consistency from area to area regarding what information was and was not provided, and which information could not be provided for which reason.

A particular gap in information related to how many people failed to take up, or ceased receiving, support following a financial assessment. Only 17 out of the 151 local authorities who charged provided a figure, but it was not at all clear that the information provided was comparable across authorities. The failure of people to get the support they have been assessed as needing – possibly because they feel they cannot afford the charge – is an important issue, not least because people's need may well increase with further consequences for health and social care. We highlight this issue in our conclusions as an area in which more work is required.

100%

of local authorities
responded to our Freedom of
Information request

- All but one local authority currently choose to exercise their power to make a charge for social care services to people who need support. The majority make services available to carers free of charge.
- The majority of local authorities had renewed or introduced their charging policy since the Care Act 2014 and the majority had carried out an equality impact assessment.
- 13% of local authorities (16 of the 122) who undertook an equality impact assessment failed to identify a single risk associated with their charging policy.
- Those who did anticipate risks described a range of concerns associated with their charging policies including a risk to peoples' well-being and a risk of financial hardship. Risks to the well-being of carers were also identified and that people in need would decline help. Local authorities identified risks to themselves including a loss of income and legal challenges.
- Some, but by no means all, local authorities demonstrated they had a good understanding of the risks associated with charging for social care and had some strategies in place to monitor and mitigate some risks.
- The majority of councils undertake assessment for and collection of charges directly, with only a very small number outsourcing the task.
- Income from charging contributes around 12% of the cost of community support. On average local authorities spend just over £44 million on community based services and collect just over £5 million through charging.
- On average local authorities spend around £421,383 on collecting charges (around 8% of the total raised) and a further 3% is written off as uncollectible.

Local authorities enjoy a power but are under no duty to make a charge for the provision of community based adult social care services. However, all except one (London Borough of Hammersmith and Fulham) said they did make a charge. We also asked whether a charge was made to carers for support services provided to them and in this case the majority replied that they do not, with only five replying that they do charge carers for social care support.

When were current charging arrangements put in place?

Councils have long had the power to charge for social care. However current powers came into force with the Care Act 2014 which provides a single legal framework for charging for care and support. We asked local authorities to say when the current charging policy was introduced.

Of the 151 local authorities who have a charging policy in place, 144 gave a date for its introduction. Forty-six indicated that the introduction of their current charging policy predated the 2014 care act but the remaining 98 said their policy had been updated or introduced since the Care Act.

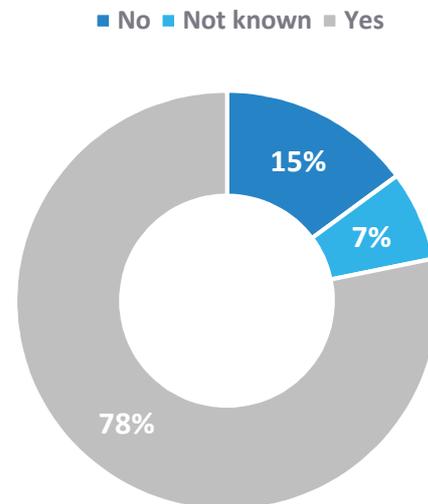
To what extent are local authorities monitoring the impact of their charging policies?

The Care Act statutory guidance covers charging for social care services, providing a set of principles that should be adhered to, and reminds local authorities of their duties in relation to the Equalities Act 2010. In our freedom of information request to local authorities we asked them whether they had undertaken an equality impact assessment prior to introducing the current policy, if so what risks had been identified and how these risks have been monitored since implementation of the policy.

Almost eight out of 10 Authorities said they had undertaken an equality impact assessment when the current policy was introduced.

Of the 22 local authorities who admitted they had not undertaken an assessment, most said they had not been required by law to do so when they had originally implemented their policy.

Figure 3: Was there an equality impact assessment prior to introducing the current policy?



What risks were identified?

Sixteen of the 122 (13%) local authorities who actually undertook an equality assessment failed to identify a single risk associated with their charging policy. Strikingly some local authorities identified risks to themselves rather than to local people needing support In their equality impact assessment. For example, one authority said they had identified “A potential reduction in number of customers receiving the service and from the customer base who are assessed to pay the full charge, therefore a reduction in income to the authority”.

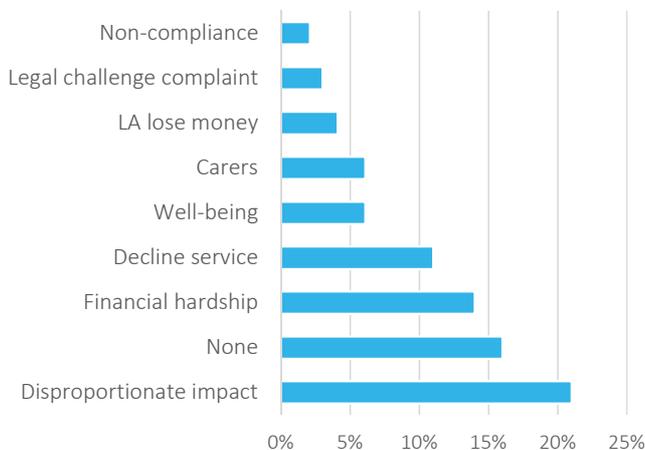
A very small number of local authorities indicated they had amended their policy as a result of the assessment.

We reviewed the risks local authorities had identified in their equality impact assessment and identified a number of common themes emerging. These are set out in Chart 15 below (in descending order of how often mentioned) while Figure 4 indicates how frequently each risk was mentioned.

Chart 15: Risks that local authorities have identified when undertaking equality impact assessments as part of their introduction of charging policies.

Disproportionate impact	The policy may affect social groups differently e.g. only disabled people pay the charge and more women are affected than men, older people are more likely to be affected.
None	Local authority failed to identify any possible risk associated with their policy.
Financial hardship	People being charged could face financial hardship.
Decline service	People in need of care and support may decline or reduce their service because of the cost leaving them vulnerable.
Well-being	Charging has a negative impact on people's well-being.
Carers	There is a knock on effect impacting on the well-being of family carers.
Reduced income for the authority	The net result would be a loss of income to the authority.
Legal challenge complaint	The authority would be subject to challenge and complaint by people objecting to the new policy.
Non-compliance	People would be unwilling, unable or refuse to pay.

Figure 4: Frequency of risks identified in Equality Impact assessments



13%

local authorities who did an equality impact assessment and failed to identify a single risk associated with their charging policy

How have these risks been monitored since implementation of the policy?

Of the 122 local authorities who said they had undertaken an assessment a significant minority (21) either said that they had taken no action to monitor the risks or failed to provide any detail as to how they had done so. Monitoring activity reported by the remainder of the group fell broadly in to two types: reaction to individual circumstances and systemic monitoring.

Responses at an individual level seemed to be focussed on mitigating risk such as individual risk assessments where services had been declined, the application of a waiver where people were not charged, and transitional agreements where fees had increased. Some mitigation was in place at a system level including taking action to publicise disability related expenditure. Some authorities said that the means-test as part of the financial assessment was a way of mitigating risks. One authority said it had been necessary to establish a 'hardship fund'.

Monitoring at a system level included; the monitoring of overall debt levels, service uptake monitoring, periodic case file audit and surveys of people who were charged. However, as mentioned above, only 17 authorities were able to provide a figure for how many people had failed to take up, or had ceased, services following a financial assessment and it was unclear whether the information provided was comparable.

Is charging undertaken directly by the local authority or by a third party organisation on behalf of the council?

The majority of local authorities 91% said they undertook all of the charging process directly, and only a small proportion (9%) had outsourced either the assessment for and/or the collection of charges.

One said they did not know whether an equality impact assessment had been undertaken regarding charging as the function of collecting charges had been outsourced to a third party organisation.

Charging income, costs and numbers charged: the national picture

Our Freedom of Information request asked a number of questions about the money collected by charging for social care. Combining this information with the nationally collected data available in Adult Social Care Activity and Finance report for England 2016-17 we were able to look at the overall national position in relation to funding raised through charging and to compare and contrast charging levels across local authorities of different size.¹⁰

£5m

average collected per authority

Not all local authorities provided responses that we could use but the information available was used to calculate an average figure per person charged or per person receiving support as appropriate. The majority of local authorities (148) provided information about how much money they collected by charging; three areas had yet to close their accounts and so were unable to provide information and one did not make a charge. In total £766,264,115 was collected across the 148 authorities who provided a figure, meaning on average just over five million pounds (£5,177,460) is collected per authority.

From the information in Chart 16 we can see that:

- The average amount spent on community support by local authorities is around £44 million. Of this around £5 million (12%) is recouped through charging.
- The average number of people receiving support is 4,511, and the average number of people subject to charging being 2,293 meaning typically only half of those receiving support pay a charge.
- The average charge per person was £2,243.42
- The average cost of collecting charges was £421,383 just over 8% of the money collected.
- The average amount written off in each local authority as uncollectible was £147,907 or 3% of the money collected.

Chart 16: Summary of local authority responses relating to income from and costs of charging

	Community spend	Charging income	People receiving non-residential support	People charged	Collection cost	Written off
Responses	150	148	151	142	93	140
Excluded responses	1	3	0	9	58	11
Total	£6,701,129,000	£761,348,499	681,207	325,611	£39,188,636	£20,707,023
Average	£44,674,193.33	£5,177,447	4,511	2,293	£421,383	£147,907
Est. national total	£6,745,803,193	£776,781,238	£681,207	£346,248	£63,628,860	£22,334,002

Local variations in the proportion of people who were charged

A figure for both the number of people charged and the number of people receiving non-residential social care services was provided by 141 local authorities. Seven areas said they did not know how many people they had charged.

Not everyone who receives support is subject to charging and, in total, the number of people reported as paying a charge was just over half the number of people said to be receiving services. But as Figure 5 shows, there are significant local variations in the proportion of people reported to be subject to charging, ranging from 13% of people receiving support to 100%.

Local variations in the contribution charging makes to spending on community services

The proportion of money spent on community support that was generated by charging also varied from area to area. With the exception of two outliers the majority of local authorities collected less than a quarter of the money they spent on community services through charges. Eight out of ten collected less than 15% of the money they spent on community services through charges.

Figure 5: The number of people in each local authority who pay a charge for care and support as a percentage of the number of people receiving support in that area.

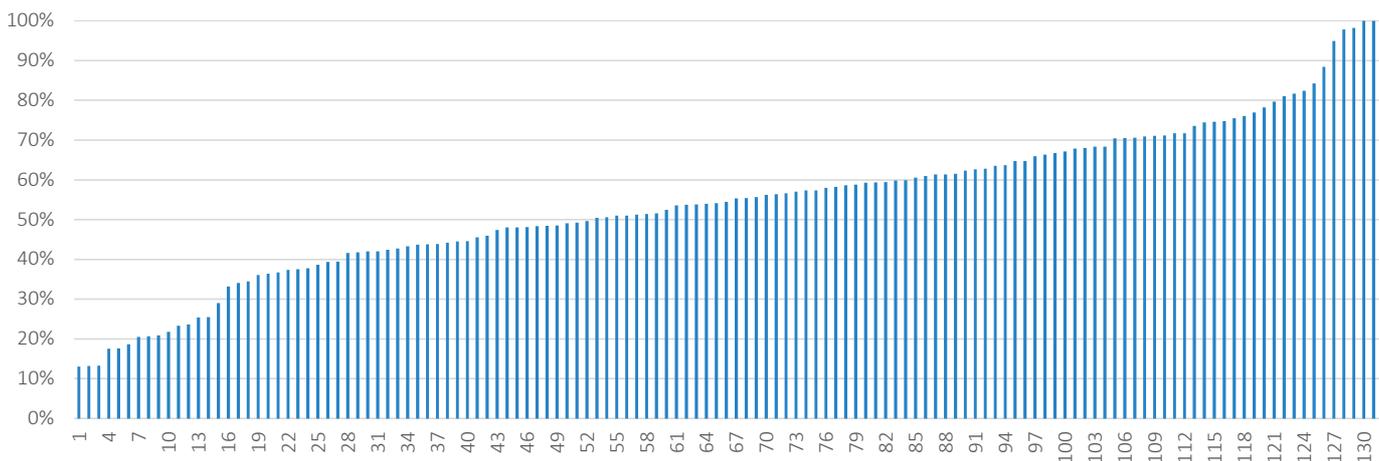
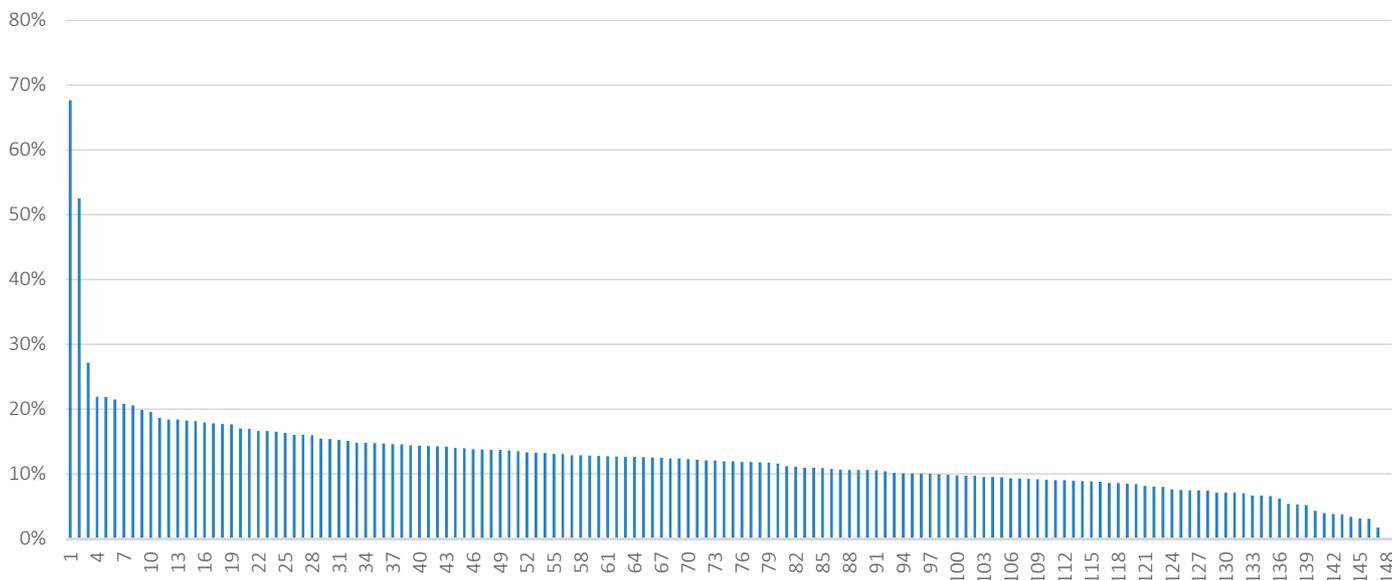


Figure 6: The proportion of money spent on community support that was generated by charging.

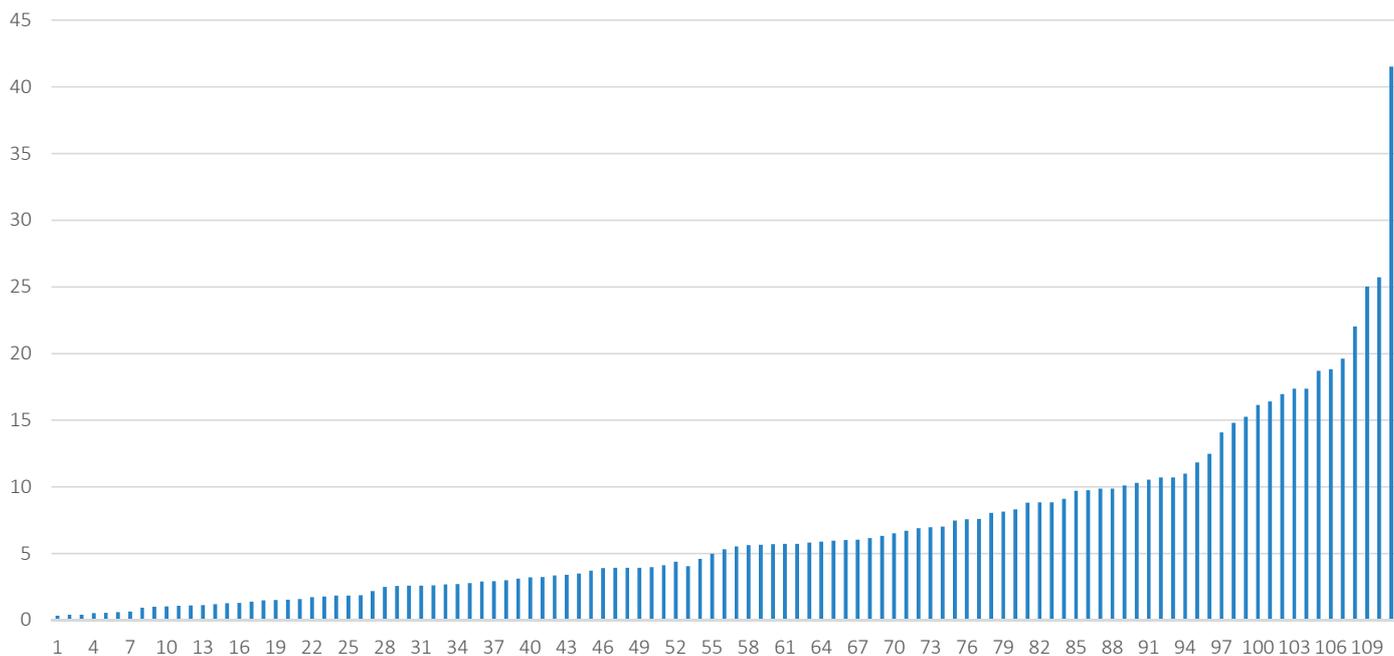


How many formal complaints did the local authority receive relating to charging?

128 local authorities knew and provided information on how many complaints they had received relating to charging for community based support.

Seventeen said they had received no complaints. As Figure 7 shows, the proportion of people making a complaint about their charges varied considerably. All but three areas reported fewer than 25 complaints per 1000 people being charged.

Figure 7: The number of complaints per 1000 people being charged



Conclusion

As a result of the evidence we have gathered, the Independent Living Strategy Group concludes that charging for the essential support disabled people need to go about their daily lives is unfair and counterproductive and undermines the primary purpose of the care and support system that it subsidises.

Local authority eligibility criteria for social care have been significantly tightened in recent years, often resulting in support being limited to the most essential needs. Disabled and older people are therefore being charged for the most basic personal care support that is necessary for day-to-day survival.

As a mechanism of means testing social care, charging raises modest amounts of money, on average around £5 million per local authority which is about 12% of the money spent on community services. However, raising revenue in this way has a profound impact on the individual. The effect is all too often to drive disabled and older people into care poverty, and to create confusion and complexity in an already overly burdened bureaucratic system.

Charging undermines people's social and economic well-being as it creates a risk of care poverty and of being pushed into debt. It leads to unnecessary restrictions on people's lives, causing many people to cut down on other expenditure and driving some into debt. It therefore undermines the well-being principle which is at the heart of the Care Act 2014.

The effect of raising revenue in this way is all too often to drive disabled and older people into care poverty, and to create confusion and complexity in an already overly burdened bureaucratic system.

12%

the contribution charging income makes to the cost of support

Charging for community care services is not only an unhelpful and unnecessary tax on disability and old age, it also creates a barrier to health and social care integration. Moreover, the way in which income is measured creates a 'cliff edge' and injustice for people who move from paid employment to a pension income. The latter is included in the means test while earned income is not, penalising people who have contributed deferred income to provide a pension. This also acts as a disincentive for young disabled people to save towards their future.

Charging for social care undermines the well-being principle at the heart of the Care Act 2014

Charging potentially pushes people out of the system who are eligible and require help and support. Some of the respondents to our survey said that they had ceased, or failed to take up, support because they thought they could not afford the charge. This not only undermines national eligibility criteria when people most in need go without support rather than pay the charge, it is also counterproductive if they return later with higher needs and in crisis needing hospital care. However, this does not seem to be an issue which is commonly or consistently monitored by local authorities.

Our recommendations

The power local authorities have to charge for social care should be removed and funding provided to local authorities to cover the shortfall.

We already have evidence that abolishing charging is a realistic option.

The London Borough of Hammersmith and Fulham abolished charges for social care in 2015, funded by cutting the costs of senior management and public relations activities. Since then the Council has increased funding for social care. As one person benefitting from the policy said: “Social care is a human right. It’s an essential service like education or the NHS. It’s not ethical to charge for it, in effect it’s an extra tax”.¹¹

The NHS’s ‘need, not ability to pay’ principle should be extended to social care and the service should be fully funded as part of a ‘new social contract’ between the citizen and the state (as recommended by the 2018 Darzi review of health and social care).

If, however, charging is not removed a number of safeguards need to be introduced to mitigate against the worst effects of generating income in this manner:

1. Local authorities should review their equality impact assessments of charging in light of the findings of this study, and where a local authority has failed to undertake an equality impact assessment this should be completed as matter of urgency. They should be undertaken in partnership with local disabled people’s organisations. They should include an assessment of the impact on well-being and feature an action plan for monitoring and mitigating the impact of the policy.
2. All local authorities should assess the impact on the individual of levying a charge as part of the financial assessment to determine the level of charge.
3. There is an urgent need to amend and update good practice guidance on what should be included in a financial assessment, particularly in relation to what should be included as disability-related expenditure. This should be done in partnership with disabled people’s organisations.
4. All local authorities should ensure that clear information is provided on how charges are calculated, together with their right to appeal and complain, and information about independent sources of information, advice and advocacy.
5. All local authorities should introduce an ‘early warning’ system for identifying where people are getting into charges-related debt, introduce a ‘breathing space’ before any action is taken, and provide access to support to manage debt.
6. Local authorities should monitor the proportion of people who do not go on to have, or cease having, care following a charge being made or increased.
7. Local authorities should undertake work to better understand the cost and impact of charging for community care. They should publish an annual statement including key details setting out: the total income raised through charging; the average charge levied on each person; the cost of collection; and the numbers of people who failed to take up, or ceased having, support following a charge being made or increased.

Appendix 1: Extract from Care and Support Statutory Guidance ¹²

8.2 Where a local authority arranges care and support to meet a person's needs, it may charge the adult, except where the local authority is required to arrange care and support free of charge. The new framework is intended to make charging fairer and more clearly understood by everyone. The overarching principle is that people should only be required to pay what they can afford. People will be entitled to financial support based on a means-test and some will be entitled to free care. The framework is therefore based on the following principles that local authorities should take into account when making decisions on charging. The principles are that the approach to charging for care and support needs should:

- ensure that people are not charged more than it is reasonably practicable for them to pay
- be comprehensive, to reduce variation in the way people are assessed and charged
- be clear and transparent, so people know what they will be charged
- promote well-being, social inclusion, and support the vision of personalisation, independence, choice and control
- support carers to look after their own health and well-being and to care effectively and safely

- be person-focused, reflecting the variety of care and caring journeys and the variety of options available to meet their needs
- apply the charging rules equally so those with similar needs or services are treated the same and minimise anomalies between different care settings
- encourage and enable those who wish to stay in or take up employment, education or training or plan for the future costs of meeting their needs to do so
- be sustainable for local authorities in the long-term

8.3 Alongside this, local authorities should ensure there is sufficient information and advice available in a suitable format for the person's needs, in line with the Equality Act 2010 (in particular for those with a sensory impairment, with learning disabilities or for whom English is not their first language), to ensure that they or their representative are able to understand any contributions they are asked to make. Local authorities should also make the person or their representative aware of the availability of independent financial information and advice.

Appendix 2: Freedom of Information Requests

We wrote to all 152 local authorities who have social service responsibilities making a Freedom of Information request, setting out a series of questions relating to their charging arrangements.

Nearly two thirds (64%) of authorities responded promptly (within 20 days) acknowledging receipt of the request and indicating they would provide the information. After 22 days we wrote a reminder to local authorities who had failed to respond, this led to a further 16% of authorities responding. We then wrote again after 31 days pursuing the matter and we received further acknowledgements and commitment to respond from another 6%.

Having written three times already and collected responses from the vast majority (86%) of areas we set about the task of securing a response from those who had not yet replied. A fourth letter personally addressed to the directors of non-responding authorities followed by a series of phone calls requesting a response meant that we eventually received information back from all the areas we wrote to.

This means we have been able to compile the data supplied to provide a full and up to date national picture of council practices in relation charging for community based adult social care.

Appendix 3: Members of the Independent Living Strategy Group

Baroness Jane Campbell, Chair	Catherine Hale, Chronic Illness Inclusion Project
Baroness Tanni Grey-Thompson	Mark Harrison, DPAC and ROFA
Baroness Celia Thomas	Chris Hatton
Lyla Adwan-Kamara, Merton Centre for Independent Living	Andrew Lee, People First
Beatrice Barleon, Mencap	Simon Legg, Spinal Injuries Association
Katherine Beard, Independent Lives	Ian Loynes, Spectrum (Southampton CIL)
Sue Bott, Disability Rights UK	Becki Meakin, Shaping Our Lives
Gary Bourlet, Learning Disability England	Jenny Morris
Philipa Bragman, CHANGE	Fleur Perry
Don Brand	Ben Reed, Equal Lives
Steve Broach	Martin Routledge
Kevin Caulfield, Hammersmith and Fulham Campaign Against Cuts	Michelle Scattergood, Breakthrough UK
Ellen Clifford, Inclusion London	Andrew Shipley, Aspire
Neil Crowther	James Taylor, Scope
Dominic Ellison, West of England Centre for Inclusive Living	Philippa Thompson, Sussex Oakleaf
John Evans	Lynne Turnbull, Cheshire Centre for Independent Living
Clenton Farquharson	Sian Vaisey
Clare Gray, Shaw Trust	John Waters, In Control
	Rich Watts
	Jane Young

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- ¹⁰ Adult Social Care Activity and Finance report for England 2016-17
https://files.digital.nhs.uk/pdf/2/m/adult_social_care_activity_and_finance_report.pdf. We included non-residential care services for each local authority, for working age and older people: costs attributed to long term community care included Supported Accommodation, Direct Payments, Home Care, Supported Living.
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The Independent Living Strategy Group exists to protect, promote and ensure the fulfilment of disabled people's rights to independent living in England.

This report was developed by In Control and published by Disability Rights UK on behalf of the Independent Living Strategy Group.

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