



The **costs** of **care**

The impact of the Fairer Charging policy on disabled and older people and their carers in England

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About the Coalition on Charging

The Coalition on Charging is an alliance of 200 national and local organisations that are opposed to charging for essential non-residential social services. We believe these services should be free to everybody who needs them.

The Coalition has a steering group which meets regularly and is made up of the following organisations: Mencap, Scope, Disability Alliance, Age Concern, Help the Aged, British Polio Fellowship, MS Society and Carers UK.

Coalition principles

The Coalition believes it is wrong to charge people for essential community care services and that these services are a fundamental human right, necessary if people are to lead independent lives with dignity and choice. Community care services are as important as education or health services and therefore should be treated in the same way and provided without charge.

The current charging system is unfair and inconsistent. People who are charged sometimes have to economise on essential daily items – their choices may be between having adequate heat, whether to eat or whether to pay for the care they have been assessed as needing. Charging can leave those members of our society, who already face high costs as a result of their impairment, with no choice but to reduce the level of service they receive. Consequently, charging puts people at risk and increases social exclusion.

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■ Summary

In October 2002 local authorities in England began implementing the Government's guidance on charging for care services *Fairer charging for home care and other non-residential social services*ⁱⁱⁱ. To check how the new guidance was impacting on the real lives of disabled and older people, members of the Coalition on Charging invited service users to take part in a survey during the summer of 2003.

Findings from this survey indicate that despite the introduction of new national guidance there are still inconsistencies with charging policies. Not only do service users and carers find it difficult to get the information they need about local authorities' charging policies but charging for essential services continues to have a negative impact on people's personal finances and lifestyles and it remains fundamentally unjust.

The case studies gathered as part of this survey mirror the regular feedback members of the Coalition get from individuals throughout the country who are deeply concerned and anxious about the amount of money they are expected to pay for community care services essential to their daily lives.

"The charges have doubled since last year. I have four dependent children as well as two sick and very dependent parents-in-law. I am the main carer and cannot afford to have any life outside the home."

"The impact of charging to us is that we are unable to cope because we cannot afford to pay for practical help. I feel physically, mentally and emotionally exhausted. I feel angry that I haven't been able to acquire help through social services because of cost... I am saving social services money at the cost to my health and income."

■ Key findings

The key findings from the survey are:

- A majority of service users and carers report a lack of available information from local authorities on changes to charging policies.

- As a result of the new policies a number of people have had to stop or cut back on the services they need.
- A majority of respondents did not find charging policies acted as a barrier to gaining employment but some respondents were deterred from seeking employment because of the impact they perceived it would have on their care package.
- More than half those responding to the questionnaire said current policies had had a negative effect on their income and lifestyle.

■ Recommendations

Fundamentally the Coalition is opposed to charging for essential community services, given the impact this policy has on the lives of disabled and older people, and believes these services should be provided out of general taxation.

However drawing on both the evidence gathered from our survey and the day-to-day contact our members and member organisations have with people's experiences of care charging, the Coalition would like to make the following recommendations to the Government about the current system in place.

A need for consistent monitoring

The Coalition on Charging believes that the following need to be monitored if we are to get a more accurate picture of whether or not charging policies are really becoming fairer:

- The cost of administering charging, both as a sum, and as a percentage of income raised;
- The number of service users and carers refusing or cutting down on services as a result of charging, or asking for charges to be reviewed, both as a figure and as a percentage of service users;
- The number of service users and carers of working age and available for work who feel charges act as a barrier to gaining employment.

A need to place limits on increases

Case studies gathered by our organisations show that local authorities have increased charges over the rate of inflation, possibly as a solution to solving a budget crisis.

The Department of Health should clearly state that any increases in charges should only reflect increases due to inflation, as the income of the vast majority of disabled and older people only increases in line with inflation each year.

Our research shows that higher increases in charges result in disabled and older people being pushed further into povertyⁱⁱⁱ, which is not acceptable.

A need to improve benefit advice services

At the time of a charge assessment, councils must ensure that 'comprehensive' benefit advice is available. The guidance states that councils have a responsibility to maximise the incomes of users, where they would be entitled to receive benefits.

Responses to our questionnaire and callers to Coalition organisations demonstrate that there is considerable room for improving the benefit services offered by local authorities.

When the fairer charging guidance was published the Coalition felt that it was vital that those who were to carry out benefit assessments on behalf of local authorities must be trained correctly on welfare benefit issues, and experience shows there is still the need for improvement in this area.

A need for better management of debt and debt collection agencies

The Coalition pointed out after the publication of the guidance that a major gap existed in the area of management of debt and debt collection agencies. Steering group organisations have received calls from people who have gone into debt as the result of a large increase in their charges and delays in billing.

"Their assessors have little experience and do not advise in detail on disability-related expenditure nor how to recognise and associate expenditure that is disability-related."

The survey findings

For details on how we gathered the evidence please see page 12.

1. Information provided by local authorities

Question: Has your local authority provided sufficient information about changes to charging policies?

Type of respondent	Yes	No	Very little	Don't know
Service users	9	18	4	3
Carers	7	15	0	1
TOTAL	16	33	4	4

Experience of service users

- Of the 34 service users who responded to this question, nine were satisfied with the information provided, but 18 felt the information was unsatisfactory and four felt there was little information available from their local authority on Fairer Charging Policies. Therefore the majority of respondents felt the information provided was insufficient.
- A number of respondents commented that information was sparse, especially on disability-related expenditure. This resulted in confusion amongst service users as to the type of expenditure that would be recognised as disability-related.

"...[the local authority] do not advise in detail on disability-related expenditure, how to recognise and associate expenditure that is disability-related. Most people do not realise what is considered as disability-related expenditure..."

- One respondent commented on the inaccessibility of the information provided by their local authority. They felt their local authority had not been sensitive to the information needs of different client groups.

“We received information but only when pressed and only in an accessible format for people with a learning difficulty when I reported them to the Disability Rights Commission. We fought the charging policy and the council have withdrawn all charges for day services for all client groups.”

Experience of carers

- Of the 24 carers in the survey, 23 responded to this question. Most were not satisfied with the amount of information received from their local authority on Fairer Charging policies. Some respondents commented on the manner in which they received the information.

“Just a phone call informing us of a backdated 200% rise.”

2. Impact on services

Question: Have you had to stop accessing services because of the amount you are charged under Fairer Charging policies?

Type of respondent	Yes	No	Considered	Considerable restrictions	Don't know
Service users	6	19	3	2	3
Carers	4	15	2	0	0
TOTAL	10	34	5	2	3

Experience of service users

- Of the 33 service users who responded to this question the majority had not considered stopping their services due to the amount being charged. Some respondents saw their charge reduced to nil, especially when they had undergone a comprehensive disability-related expenditure assessment.

“... I saw my charges disappear altogether due to full disclosure of all disability-related expenses right down to the cost of special mugs and pro rata cost of charging my electric chair...”

- Six people had decided to stop accessing services and a further three respondents had considered reducing their service.

“I have had to cut my homecare from nine hours per week to three hours.”

“...my wife and I may be about to cut our services. Our care manager has just informed us that our weekly charge has risen from £8.40 to £25.28, an increase of over 200%.”

- Other respondents commented that charge increases have imposed considerable restrictions on the amount of service they can afford.

“[I] have to make sure care is kept to under 10 hours a week.”

Experience of carers

- The majority of carers had not stopped or reduced their services due to charges.

- One respondent did comment that she could not reduce the service regardless of cost because she depended on it.

“I am unable to stop as all services are needed so I have to find the increases!”

- One respondent felt that charges were acting as a barrier to her husband being able to remain in their own home.

“We can't afford the charges. If I can't get help to care for my husband at home he will have to go into a nursing home. I cannot do all he needs by myself any longer. I am now very ill.”

3. Employment

Question: Have changes in the way or amount you are charged affected your ability to enter employment?

Type of respondent	Yes	No	N/a
Service users	8	20	5
Carers	0	15	5
TOTAL	8	35	10

Experience of service users

- The majority of service users did not find charging policies acted as a barrier to gaining employment.
- Some respondents were deterred from seeking employment because of the impact they perceived it would have on their care package.

“The problem is that if you take a job it will trigger a review and a reassessment of hours. A lot of people are not prepared to go through the anxieties of this.”

Experience of carers

- No carers saw charging for community care services as a barrier to gaining employment. The main barrier to entering work for carers was their caring duties.

“I had to give up work since my husband had a stroke.”

“I am unable to work and care.”

4. Quality of life

Question: Have the current policies on charging affected your income and lifestyle?

Type of respondent	Positive effect	Negative effect	Positive and negative aspects	No effect	Don't know
Service users	5	14	4	6	3
Carers	0	14	0	8	0
TOTAL	5	28	4	14	3

Experience of service users

- Fourteen of the 32 service users felt charging had a negative effect on their lives.

“I end up not getting anywhere near as much help as I need because of the cost and problem of my carers having the time available. So I end up struggling and making myself worse.”

- Those who felt it had a positive effect welcomed the introduction of the protected basic level of income (income support + 25% buffer). Most of these people had their charges reduced due to a thorough disability-related expenditure assessment.

“It has reduced the threat of reduced income.”

“I am £17 a week better off.”

Experience of carers

- The majority of carers believe charging has had a negative effect on their lives, with the remaining eight claiming no effect.
- The impact of the charges has caused anxiety and distress, especially when services have had to be reduced. There is also distress when an individual's needs increase, which could result in an increase in charges, as more services are required.

“Unable to afford any care in the home although needed.”

“Since we are both over 70 it is going to make a great difference when my husband needs more care than I can provide.”

About Care Charging and the current guidance

There is no statutory requirement on local authorities to set charges for the services they provide and they do so at their own discretion. Section 17(1) of the Health and Social Security and Social Services Act 1983 states that charges should be “reasonable” and “practicable” for the individual to pay.

The Coalition remains opposed to disabled people being charged for services which are essential and which are not being used as an extra or luxury. It is wrong that disabled people are asked to pay for such services, which simply enable activities that non-disabled people take for granted.

The Audit Commission Report *Charging with Care*^{iv} has shown that care charging is not a useful source of revenue for local authorities as an average of 25 – 40% of revenue raised is swallowed up in administrative costs.

Case study

Jim is a 73-year-old man who was paralysed after an accident at the age of 28. He worked all his life until retiring a few years ago. He lives independently and requires help in his home for up to 14 hours a week. He was charged £12 a week for these services.

Last year, as a result of the guidance, his local authority increased those charges tenfold to £112. Jim lives on Industrial Injuries Benefit and the minimum state pension.

Jim's is not an isolated situation. According to the Government's own statistics there are 8.6 million disabled people in the UK, many of whom rely on welfare benefits as their main source of income. These same people are being charged out of those benefits for the very services they are assessed as needing. Charging for essential community care services is an additional tax on disabled and older people.

Income

When levying a charge, consideration should be given to what impact a charge will have on a person's net income. The guidance states that income must not fall below basic Income Support plus 25%. However, the severe disability premium and Disability Living Allowance (not mobility component) can be taken into account.

The guidance states that any reduction below this level would not be appropriate as this would undermine social care policy more broadly in relation to social inclusion and independence. This provision is important for two reasons: it protects people who are on an income just above Income Support and there is an acknowledgement that people may be on low incomes but may not be in receipt of Income Support such as people with savings above a certain level.

At the time of a charge assessment, councils must ensure that 'comprehensive' benefit advice is available. The guidance states that councils have a responsibility to maximise the incomes of users, where they would be entitled to receive benefits.

Where councils take disability benefits as income when they assess a charge, they are expected to assess the individual's disability-related expenditure. Councils should have specifically consulted on the need to assess disability-related expenditure.

The guidance states that it will not be appropriate to make a charge on disability-related benefits without assessing how reasonable this is to each user.

It is important to note here the significance of *R v Coventry City Council*^v which asserted that it is unlawful for a council to take into account money provided for night time care at a charging assessment.

Capital

Councils are entitled (although not obliged) by the guidance to take into account when assessing a charge the level of savings and other capital of the individual concerned. If the level of capital is in excess of £19,500 then the council can charge the full cost of the service or a lower maximum level if they have one. If a person's income is between £12,000 and £19,500 then councils are entitled to assume a tariff income of £1 per week for each £250 between £12,000 and £19,500.

Employment

To ensure disabled people and their carers (if applicable) are able to enter and progress in employment, the guidance states that earnings are disregarded when a charging assessment is being conducted. This is welcome, but it is important to bear in mind that disabled people are five times more likely to be unemployed than non-disabled people. Therefore, while we clearly welcome this aspect to the guidance, we feel that it only goes a short way towards breaking the clear link that exists between poverty and disability.

When a person stops work perhaps due to their disability worsening then they may have to make a contribution towards care costs, this may have severe consequences for the health of such people as they may stay in work for longer in an attempt to avoid this happening. This situation seems to us to be a particularly harsh anomaly as people are being hit hardest when they have saved which also goes against government policies to encourage such saving.

Conclusion

It is unacceptable to expect people to pay to carry out the most basic personal and everyday activities. Charging is not even a good source of revenue for local authorities, as we have mentioned above, as an estimated 25 – 40% of the money raised by charging

goes on administering the system. What is clear however is the distress which charging policies cause for people who have seen their weekly fees rise.

Essentially, charging is nothing more than a tax on age and disability. Our research clearly demonstrates that charging is further emphasising the long-established links between poverty and disability, and poverty and old age. Consequently these groups are further isolated from activities which are taken for granted by others within society.

■ How we gathered the evidence

The steering group, in consultation with grass roots members of our organisations, devised a short questionnaire covering the main aspects of a disabled person's life, which would be affected by the implementation of the Fairer Charging policy guidance.

This questionnaire was made available via the websites of steering group organisations or sent out to members of these organisations. This took place over a short period during the summer of 2003 to enable the results to be made available as close to the anniversary of the introduction of *Fairer charging for home care and other non-residential social services*.

The data for these findings is based on analysis of the 78 questionnaire responses. Fifty-four of the respondents were service users and 24 were carers. The respondents were from 28 local authorities in England.

References

ⁱDepartment of Health. *Fairer Charging Policies for Home Care and other non-residential Social Services – Guidance for Councils with Social Services Responsibilities*. November 2001.

ⁱⁱ Department of Health and Department of Work and Pensions. *Fairer Charging Policies for Home Care and other non-residential Social Services – Practice Guidance*. August 2002.

ⁱⁱⁱ *The Household Below Average Income (HBAI) statistics 2001/02*

^{iv} Audit Commission. *Charging with Care – How Councils Charge for Home Care*. May 2000.

^v *R v Coventry City Council*. November 2000.

■ Sources of further information and advice

Disability Alliance has produced a publication, *Charges for community care services*, which costs £4 (or £2.50 to a person in receipt of benefit). For an order form, please contact Disability Alliance at the address below or via the website at www.disabilityalliance.org

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Further case studies are available from Coalition on Charging member organisations.