

Charging into poverty?

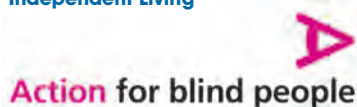
Charges for care services at home and the national debate on adult care reform in England



Challenging charges

June 2008

The Coalition on Charging Membership includes:



Disabled Peoples' Council

Acknowledgements:

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Summary, key findings and recommendations

The Coalition on Charging is a group of disabled people, older people and carers' organisations working together on the issue of charges to use care services. Our members are aware that restricted access to adult social care services and increased charges for the support that is available to remain living at home has had a significant impact on the day to day lives of the people we represent.

Many people fear that the future will bring further unaffordable costs and limitations on the support essential to maintain independence. One respondent to our survey commented that:

'If they make charges to the help that I receive, I shall commit suicide'

This opinion is extreme, but overall responses to our survey demonstrate strong feelings of despair at the current situation and anxiety for the future. Our survey reveals that:

- **80% of individual respondents who no longer use care services say charges played a part in the decision to end using services. A fifth (22%) of people currently using services suggested they would also stop if charges rise.**
- **29% of individual respondents do not feel their essential expenditure (related to impairment/health condition) is taken into account in financial assessments to pay charges.**
- **A third (34%) of individuals believe they have no choice over the services they use.**
- **Nearly three quarters (72%) of individuals and 81% of organisations believe the Government should consider service charges for support at home in adult care reform plans.**

In May 2008 the Government launched a national debate on adult care reform in England. Ministers have three aims for a new care service framework; it must:

- Promote independence, choice and control for everyone who uses the care and support system;
- Ensure everyone can receive the high quality care and support they need, and target government support at those most in need; and
- Be affordable for government, individuals and families in the long-term.

In order to secure its aims, the Government must address the findings of our survey and examine the full impact of charges to use care services on people with care needs and their families.

Current plans suggest reviewing charges outside of broader care reform. Our primary recommendation is that a thorough review of the impact of charges be undertaken from 2008.

Our findings also suggest the need for immediate and/or interim improvements in three other areas:

- the way disability related expenditure is assessed;
- local authority process issues; and
- the contribution care services could make to delivering national policy goals in relation to inclusion, wellbeing, equal citizenship and reducing poverty.

These improvements would deliver affordability to individuals and their families by: ensuring full consideration of essential disability related expenditure in assessments to pay charges; increasing the amounts people are left with after charges; clarifying national guidance on charges; and delivering comprehensive equality impact assessments in local authorities.

'It is good that someone is asking my views about charging me for service which are vital for me. I have a disability with which I was born. Perhaps the Government might consider and reduce the amount of financial support which is poured ... into other areas before taking money from the most vulnerable members of society who are already living in the poverty zone'

Introduction

The Coalition on Charging decided to undertake a snapshot survey of people needing care services and their representative organisations in England on experiences of charges for using services as a result of two issues:

- the lack of data and analysis of the current impact of charges on people's lives; and
- the need to review charging arrangements in the context of the national debate on adult care reform.

Coalition on Charging organisations have become increasingly aware through our members, helplines and previous research of the negative impact local authority charging policies for care and support services at home can have on disabled people, older people and carers.

At the same time as England has witnessed growing numbers of older and disabled people with care needs, social service access has been restricted and increasing charges have been levied on service users, leaving many people likely to experience poverty and social isolation.

"Society is going through huge change – care and support must adapt to meet the challenges this will bring because the current [social care] system is simply not sustainable in the long term. There is no option of a quick fix. Radical change is needed to bring together the range of activities, services and relationship that underpin care and support so that people are clear about what they are entitled to and how and where they can get it.

"Funding is a vital part of this debate, but it is not just about money. It is also a question of individual choice, enabling people to live as independently as possible for as long as possible."

Alan Johnson MP, Secretary of State for Health, May 2008

Set against existing availability of social services, the Wanless Review¹ estimated that demand for informal care would increase 45% by 2026. The increase in care needs results from a growing population of older and disabled people in England.²

But the current trend in social services is of increasing restrictions on access to support. Our report examines the effects of charging, as evidenced by our survey findings, but cannot be seen in isolation from this trend. Fewer people now receive services from local authorities in their own homes than in 1997.

Restricted access and increased charges for support mean that more care is provided directly by people's family and friends.

Whilst it is complicated to draw national conclusions from divergent local authority charging policies, the evidence also suggests that charges are being more heavily levied on fewer recipients.

Delaying use of support services, or being denied access to support through local authority eligibility criteria and increasing charges, can result in additional costs to national and local government.

People enter care homes rather than remaining in their own homes by delaying support until crisis levels which results in higher costs to local authorities. Delayed use of support services also results in higher healthcare needs of disabled and older people and their families (requiring NHS resources).

People leaving work (through being unable to access appropriate support or to care for someone unable to) also require benefits and state pensions.

As the Government develops a green paper on care reform we believe that the 72% of individuals and 81% organisations who responded to our survey calling for consideration of charges should have their views taken into account.

'There is a tremendous negative psychological impact on me when I receive an invoice for just being who I am'

¹'Securing good care for older people' King's Fund, 2006.

² See, for example, National Statistics Online: <http://www.statistics.gov.uk/cci/nugget.asp?ID=6>

An overview of domiciliary care service charges

Background

Since 1948 local authorities have been able to (but don't have to) charge for care and support provided to help people remain living in their own home. Under current legislation local authorities may recover 'such charge (if any) for it as they consider reasonable.' If a person using services satisfies the local authority that his or her means are insufficient, then it should not require the person to 'pay more for it than it appears to them that it is reasonably practicable to pay'.

Local authorities therefore have discretion to decide whether or not to charge, what it is reasonable to charge in general and what it is reasonable to charge a particular individual.

Charging for care and support at home has become more common since the introduction of Community Care reforms in the early 1990s. The pressure on authorities to levy charges is evident from a circular issued in 1994³ which explained the position:

17. ... The Government's view ... has consistently been that users who can pay for such services should be expected to do so taking account of their ability to pay. The White Paper and Policy Guidance also make it clear that ability to pay should not influence decisions on the services to be provided, and the assessment of financial means should therefore follow the care assessment.

18. Authorities are locally accountable for making sensible and constructive use of the discretionary powers they have, in order to prevent avoidable burdens falling on council and national taxpayers.

With more and more local authorities starting to charge for care and

³ LAC (94)1

support services at home during the 1990s it became clear that there were huge variations in what they charged for similar levels of service. A number of reports⁴ raised concerns about charges and called for central guidance on what was 'reasonable'.

At this time charging for domiciliary services was part of the much wider debate about payment for services addressed by the Royal Commission on Long Term Care, set up in 1997. The Royal Commission's main recommendation was that:

'Personal care should be available after an assessment, according to need and paid for from general taxation, the rest should be subject to a co-payment according to means'.

On domiciliary care, the Royal Commission recommended that there should be a national system for charging for practical help (excluding the personal care which would be free) and that this national system should ignore the savings of people using services.

'Not only do charging policies vary hugely, but in some councils it is the poorest members of society who are most in need of care who pay the highest charges. The Government has therefore taken a new power in the Care Standards Act to allow binding statutory guidance to be issued under section 7 of the Local Authority Social Services Act 1970 on discretionary charges for non-residential services.'

Government response to Royal Commission, July 2000

The guidance which accompanied 'Fairer charging for home care and other non-residential services'⁵ came into force in 2003 and stated:

'There is no presumption by the Government that all councils will charge and, where they do decide to charge for services, they also

⁴ Baldwin and Lunt 'Charging Ahead' 1996; Chetwynd and Ritche 'The Cost of Care' 1996.

⁵ LAC (2001)32

retain substantial discretion in the design of charging policies. The guidance sets out a broad framework to help councils ensure that their charging policies are fair and operate consistently with their overall social care objectives.’

‘Fairer Charging’

- 1) Councils are not obliged to charge for care and support services to help people remain in their own home.
- 2) Flat-rate charges are acceptable only in limited circumstances (for instance where they are a substitute for ordinary living costs – such as for meals on wheels or meals at a day centre).
- 3) Net incomes should not be reduced below basic income support levels or the guarantee credit of pension credit, plus a buffer of 25%; ‘basic levels’ of income support includes the personal allowance and all premiums, but it ‘need not include the Severe Disability Premium’.⁶
- 4) Councils should consider and specifically consult on the need to set a maximum charge.
- 5) Where disability benefits are taken into account as income in assessing ability to pay a charge, councils should assess the individual user’s disability-related expenditure.
- 6) Councils should ensure that comprehensive benefits advice is provided to all users at the time of a charge assessment.
- 7) As a minimum, the same savings limits as for residential care charges should be applied (ie £22,250 for 2008-09). Councils are free to operate more generous rules, as with other parts of the guidance.
- 8) ‘To ensure that disabled people and their carers, who wish to do so, are able to enter and progress in work’ the guidance requires earnings (including tax credits) to be disregarded in charge assessments.
- 9) Any savings credit paid under the pension credit arrangements is disregarded.

⁶ Because the buffer is based on benefits which are paid at different rates according to age, it leads to large differences between what younger disabled people and older people are able to keep. A few authorities try to avoid this potential age discrimination by using the more generous pension credit rates for younger people.

Effects of Fairer Charging

Age Concern issued a report on the implementation of the guidance in 2004.⁷ The main findings were:

- 71% of responding authorities set a maximum weekly charge; some charged the full cost no matter how high. The range of the maximum weekly charge was £23.50 to £400.
- Hourly charges varied from £3.50 to £15.50 an hour: 35% did not have any subsidy for hourly charges. For those that did, the subsidy varied from 4% to 72%. Some authorities had a variable hourly charge.
- Most followed the capital limits suggested in the guidance. Ten did not have an upper capital limit and four had a higher limit.
- Most counted the severe disability premium and attendance allowance or disability living allowance (care) as assessable income.
- A minority allowed extra additions or only charged against a percentage of income on top of the sum below which they could not charge (£131.81 at that time for older people).
- 60% undertook individual assessments of disability-related expenditure; 9% ignored part or all of disability benefits instead; 18% gave a standard allowance ranging from £10-£40 a week.

Most striking was a hypothetical case study whereby 65 of the responding local authorities calculated a charge for a person needing ten hours of care and two sessions at day care. The charges varied from £0–£103 per week. The variation was mainly due to the way disability related costs were calculated or whether there was a maximum charge.

More recent surveys in 2006 and 2007 undertaken by Counsel and Care found similar variations in charges.⁸ But whatever the variations, there is a general trend for rates to increase for those who have to pay the full cost or the maximum charge. The 2007 Counsel and Care report found that only 32% of local authorities set a maximum charge, and the highest hourly rate had increased to £17.30 per hour.

A 'Public Finance' survey in 2007 found that English councils were

⁷ Thompson and Mathew 'Fair Enough?' Age Concern, April 2004.

⁸ 'Care Contradictions: Higher Charges Fewer Services', Counsel and Care, 2006 and 2007. Available at: <http://www.counselandcare.org.uk/influence/publications>

proposing to increase their fees for home care by an average of 23%⁹ which supports our survey's finding on above inflation charging increases (see p19).

Postcode lotteries, charging and devolution

Although there have been moves over the last few years which are gradually bringing more uniformity to the charging system in England, the evidence shows that different hourly rates, maximum charges and the way that disability related expenses are taken into account still mean considerable variations. There are still a few local authorities that do not charge at all for care and support in the home in England.¹⁰

The Audit Commission undertook a wide-ranging national survey of home care charges. 'Charging with care' (2000) examined the ways local authorities had developed their policies and drew attention to the postcode lottery of charges and the unfairness of some policies.

Scotland opted to provide personal care free since 2002 for people aged 65 and over although support services such as shopping and domestic cleaning are charged for. When people are charged it is based on advice produced by COSLA.¹¹ This has some similarity to the English means test. However there is no upper capital limit and the amount an individual can be left with after being charged is income support or pension credit plus a buffer of 16.5%. No allowances are made for disability related costs, and earnings can be taken into account.

In Wales a 2003 commitment to phase out charges for home care was dropped in 2006 on the grounds that the plans could not be put in place 'equitably and affordably'. The current guidance for Wales is largely based on the English guidance although the buffer is more generous (35% above income support or pension credit levels) and councils must ensure that **all** service users have a disability expenditure disregard of 10% of the 'basic' level of income support

⁹ Public Finance Magazine, 27 April 2007, accessible at:

http://www.publicfinance.co.uk/features_details.cfm?News_id=30450

¹⁰ Including two London Boroughs (Hammersmith and Fulham and Tower Hamlets).

¹¹ Convention of Scottish Local Authorities guidance on charging policies for non-residential services that enable people to remain in their own home, January 2006

and appropriate guarantee pension credit level. If service users believe they have expenditure above this amount they can apply for a further disregard based on their individual expenditure.¹²

In Northern Ireland home care is free for people aged 75 and over.

Current context

England's growing numbers of older and disabled people is well evidenced.¹³ But growth in the numbers of people with care needs is set against a trend of diminishing access to support services:

- 73% of local authorities in England now only provide support to the people with the very highest levels of assessed needs, compared to 53% in 2005;¹⁴ and
- between 1997 and 2006 homecare recipients fell by 121,000, with a 16% drop 2000-2007 and a 3% drop 2006-07.¹⁵

'Many users are unable to access services...Without access to these services people may remain at home and deteriorate'

Many older and disabled people made ineligible for local authority support, or unable/unwilling to pay charges to use services rely on informal carers. There are 6 million carers in the UK; 1.25 million provide over 50 hours support per week.¹⁶ Providing informal care restricts opportunities. One in five carers has given up or been unable to take up work as a result of care responsibilities.¹⁷ Around 200,000 carers claim Incapacity Benefit, many as a result of developing poor health from caring without the right support.¹⁸

¹² NAFWC 11/07 annex A and para 11.

¹³ See, for example, the Wanless Review 'Securing good care for older people', the King's Fund 2006.

¹⁴ 'The State of Social Care in England' CSCI, 2008. The highest levels of needs, using 'Fair Access to Care Services' criteria are critical and substantial. But some local authorities have reduced support even within the 'substantial' criterion.

¹⁵ 'Community Care Statistics 2007', The NHS Information Centre, May 2008.

¹⁶ ONS from Census 2001.

¹⁷ Equal Opportunities Commission BMRB survey, 2004.

¹⁸ 'Mental Health and the UK Economy', Oxford Economics, published by Unumprovident, March 2007. See also 'In Poor Health Carers' UK, 2004 for findings on carer's ill health.

Census 2001 also shows that there are 97,000 carers under 16. Nearly 5,500 children between 5-7 years of age provide some support; almost 800 of this age group provide 50 or more hours support per week. The impact on education and other life chances is unquantifiable but likely to be considerable and a factor in intergenerational poverty.

At the other end of the spectrum roughly half of informal care is provided by people over 50 years of age. 5.6% of the population aged 65 and older in England and Wales provide care for 20 hours a week or more.¹⁹ This is likely to have a significant impact on health and wellbeing.

There is also a trend of increasing revenue raised by local authorities from a diminishing pool of people able to access support at home. The NHS Information Centre reports on gross and net expenditure by local authorities on care services in England. In 1997 authorities raised £102 million in 'sales, fees and charges' for homecare services – the vast majority of which was from older people. By 2004 this figure had more than doubled to £205 million.²⁰ By 2006 people over 65 years of age were contributing £380 million to the support they receive to remain living in their own homes.²¹ Fewer people paying more is unsustainable.

Denying people access to support (through restricted eligibility criteria or charges that disincentivise accessing services) can also result in additional costs to local and national government.

People may enter care homes rather than remaining in their own homes through not accessing support until experiencing crisis needs. This results in higher costs to local authorities. Delaying using services also results in rising healthcare needs of disabled and older people and their families (requiring NHS resources).

¹⁹ Young, Harriet, Grundy, Emily & Kalogirou, Stamatia 2005. 'Who Cares? Geographic Variation in Unpaid Caregiving in England and Wales: Evidence from the 2001 Census. Population Trends'.

²⁰ £92 million from older people in 1997 and £164 million from older people in 2004. NHS Information Centre 'Finance Statistics of Council Social Services Departments: 1994-95 to 2003-04', 2007.

²¹ CSCI, 'State of Social Care In England, 2006-2007', 2008. Rising local income from charges also comes on top of real terms increases in funding to local authorities from central government.

People also leave work (through being unable to access appropriate support or to care for someone unable to access support) and require central Government expenditure on benefits and pensions.

Whilst the survey which provides the basis of this report was being undertaken, the Government launched the national debate on adult social care reform. Much media coverage of the launch focused on care homes, but it is important that the effect of charges for care and support in people's own homes is fully considered.

Around 1.55 million people in England received community based services in 2006-7 compared to around 250,000 helped with funding in care homes. A majority of the public would prefer to be supported to remain independent in their own home.²² Policy is rightly aimed at helping people remain in their own homes. It is vital to consider ways of achieving a fair and sustainable support system which better facilitates the intention of enabling people to live as independently as possible.

The current policy commitment is to give people a personalised budget, i.e. a Direct Payment or Individual Budget to enable them to have more choice and control over how the money allocated to providing their support is spent. Work is being undertaken by the Department of Health to review Fairer Charging as charges based on hours of service do not fit easily with the more flexible approach that is planned to transform the way care and support is provided through personal budgets. This work is intended to make the necessary changes by April 2009, but is a cost-neutral exercise not intended to make any changes to the amounts people are charged or how people are assessed to pay charges.

The Government also announced in the Independent Living Strategy that the DWP Office for Disability Issues²³ would investigate the combined impact of reforms to benefits, employment support and adult care service charges and the promotion of disability equality. It is unclear how this commitment fits with broader care reform plans, with a green paper due out after the six month national debate on reform (launched in May 2008) has occurred.

²² See, for example, Ipsos-MORI 'The Future: Who Cares?', DRC, EOC and Carers UK, 2006.

²³ 'Independent Living: a cross Government strategy about independent living for disabled people', March 2008. Recommendation 6.5, p59.

Findings of the Coalition on Charging survey

61 individuals and 31 organisations responded to our survey in April and May 2008 which targeted individual people with care needs and organisations primarily representing disabled people, carers and older people in England.

The survey sought statistical and qualitative responses. We believe the responses provide a snapshot of opinion requiring further, more detailed analysis in order to ensure adult care reform plans include the views and needs of people requiring support and their families.²⁴

General information on respondents

- Two thirds (64%) of individual respondents were 50-89 years of age; 18% were 18-49 and 8% were over 90 years of age.
- 75% of individuals currently use and 17% had previously used social services.
- 63% of individual respondents pay charges for using services; 26% do not currently pay.
- A third (31%) of individual respondents had used services for over ten years; a quarter (26%) for 5-10 years; and 24% for 2-5 years.
- 64% of organisations who responded covered local authority areas; 23% described themselves as regional and 7% national.

Key findings

- 80% of the people who no longer used care services said charges played a part in the decision to end using services. A fifth (22%) of people using services suggested they would stop if charges rise.
- 29% of individuals did not feel their essential expenditure (related

²⁴ Due to space not all survey results are provided in this report. Further information on the findings, questions and copies of the surveys are available from the National Centre for Independent Living: policy@ncil.org.uk

to impairment/health condition) had been taken into account in financial assessments to pay charges. Another quarter (23%) believed that only some of their essential costs were considered.

- A third (34%) of individuals described having no choice over the support services they used.
- Three quarters (72%) of individual respondents and 81% of organisations said the Government should consider care service charges in care reform. 59% of individuals and 77% of organisations also believe the Government should consider ending charges.

Other major concerns revealed in the survey were: the postcode lottery (within England and across the UK) of charges; anxiety, anger, and confusion over the current system; and a fear of future charge increases.

We examine the survey responses in detail below using the headings:

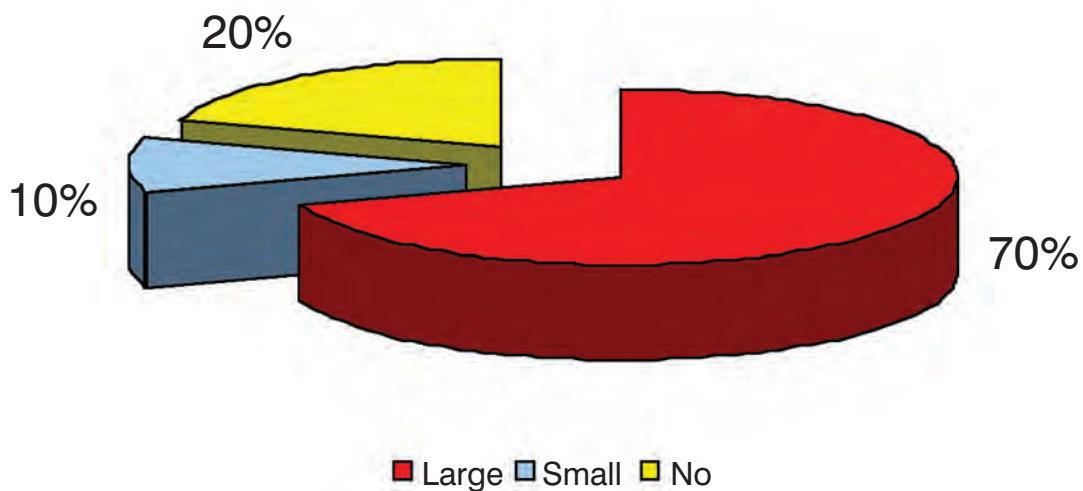
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- 3) Choice, care services and charges
- 4) Charges and Government plans for adult care reform
- 5) Fairer Charging: organisation views
- 6) Concluding individual and organisation comments and suggested improvements (assuming charges are retained)

1) Charges and people stopping/reducing services

Key survey finding: **80% of the people who no longer used care services described charges for accessing support as playing a part in stopping usage.**

We asked respondents who had used care services in the past but no longer did so if charges had played a small, large or no role in their decision to not use services any more. The response was overwhelmingly that charges impacted on people's decisions:

Did paying charges influence your decision not to use services any more?



77% of the organisations which responded also reported people they represented cutting down/stopping services primarily because of having to pay charges.

We also asked whether people would continue accessing support to the same level if charges were increased. We discovered that:

- 22% of respondents using care services said they were likely to reduce or stop receiving services if charges increased.
- 41% of respondents stated that they had no choice but to continue using services as they were essential and could not be reduced.

'The council's figures at March 2008 showed that 62 people had cancelled services since charges increased in September 2007 and 20 of these people had explicitly stated that the increased charges had been the reason'

Of the respondents who said they would reduce or stop using services if charges were increased, many used the space provided to outline the negative impact this would have on their (and their families') lives and general quality of life:

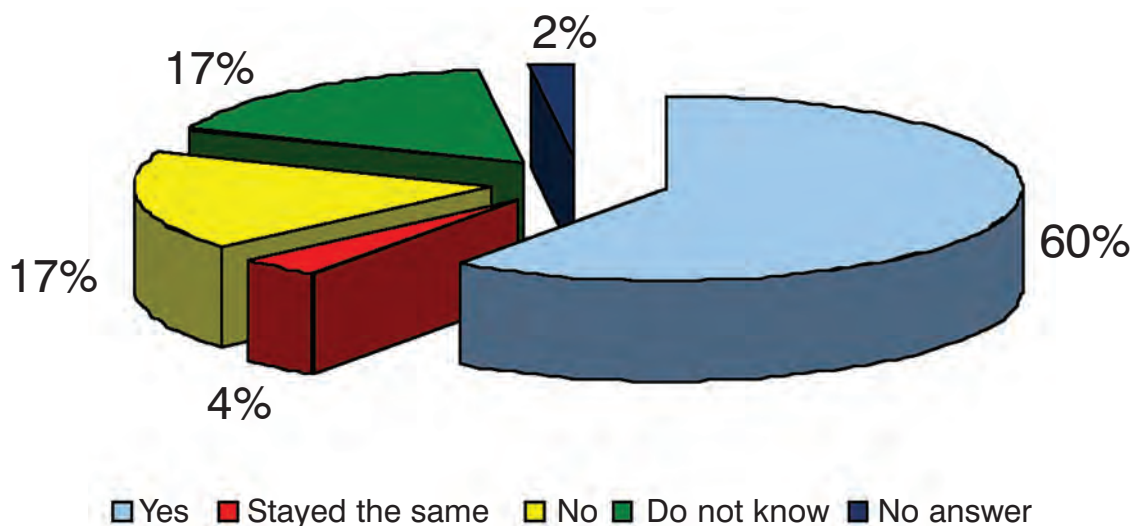
'My mum and dad already have to do too much for me...But I don't have any choice and nor do they. If I stopped having services they would have to do more...I am too reliant on my family already for support...I used to get services about 12 to 14 years ago and things were good then. I got what I needed and I didn't have to pay. Now things have changed and it's made my life and my families life much worse'

'I've just received my new charge amount...it has gone up over 12%, far above the level of inflation, as I believe it has on several, if not all occasions. This increase takes up the whole of the annual increase on my DLA...and at a time when many of the essential costs associated with ill health/disability (such as diet, fuel and transport) are also increasing far beyond inflation'

Part of the rationale behind people's decisions to cut or end using services if faced with increases in charges may be the recent pattern of dramatic charge increases. There is a fear charges will continue to rise at above inflation rates, pricing people out of receiving support.

60% of individual respondents said their charges had risen more than inflation since they had started using services.

Have charges for the services you use gone up more than annual inflation increases?



2) Financial assessments and essential living costs

Key survey finding: **29% of individuals do not feel their essential expenditure (related to impairment/health condition) is taken into account in local authority financial assessments to pay charges to use care services.**

Individuals were largely negative when describing local authority social services financial assessments and taking account of essential costs of living with an impairment/health condition:

- 29% did not feel their needs had been taken into account properly.
- 23% believed that only some costs had been considered.
- 26% felt that all the extra costs had been taken into account.

The majority of organisation responses (58%) also strongly suggested that current financial assessments of people needing support do not take adequate account of people's essential disability or health condition expenses. Just 16% of organisations responded that financial assessments did cover all essential expenditure.

Individuals and organisations used space on the survey to describe the kinds of essential costs they experienced which were not taken into account. Examples of costs not fully considered in assessments given in responses were:

- Heating – the need to keep homes at set temperatures.
- Laundry – additional washing/drying of clothes due to incontinence and/or spilling food and drinks.
- Specialist clothing – such as shoes made to measure.
- Wear and tear on clothes and housing – some partly due to equipment and numbers of people required to provide support.
- Essential dietary requirements – relating to impairment.
- Equipment – such as lifts, hoists, wheelchairs and scooters.
- Repairs, maintenance and replacing essential equipment.
- Internet costs – independently ordering shopping.
- Respite care.
- High costs of accessible transport.

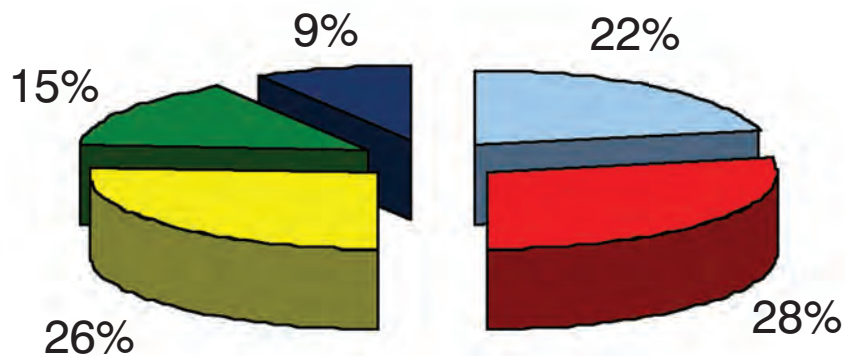
'They acknowledge that a disability causes extra living costs but do not seem to care or sympathise with this issue. Utility bills are always rising and so to food. I eat very little now. They told me that they do take extra costs into account but I could not see how. My special diet and heating is due to medical NEED not preference'

The impact of financial assessments and charges on day to day life

We also surveyed if people using services could afford all the support they needed; opinions of organisations on whether charges were reasonable; the impact on day-to-day living costs of paying charges and (where appropriate) unmet needs as a result of charges.

A fifth (22%) of individual respondents felt they could easily afford the care service charges they paid, but 28% could only afford charges with difficulty and 26% stated that they could not afford the charges for the support they required. 81% of organisations believed charges were unreasonable (whilst just 10% believed they were reasonable).

Can you afford the charges for the services you need?



■ Yes, easily
 ■ Yes, with difficulty
 ■ No, I cannot afford the services I need
■ Do not know
 ■ No answer

Of the people who stated that they could only afford the services with difficulty or could not afford them:

- 44% stated they had cut back on services/other spending a lot.
- 36% had cut back on services/other spending a little.²⁵

²⁵ 16% did not answer or did not know and just 4% said they had not cut back at all.

- 39% of individuals who currently use adult services also said they do not have enough money to pay for day to day needs after paying charges.

People provided examples of what this means in day to day life.

'As a full time wheelchair user my family, husband and I are struggling to do the housework. I am now very limited to go out to socialise - have the indignity of crawling to get dressed, do things around the house '

'Its taken all my independence and choice and control were taken away - I cannot get out of bed feed myself when I want'

Not one organisation expressed the view that the people they represented were able to afford charges to the extent that their quality of life and day to day activities were unaffected. 79% of organisation responses suggested that the people they represented had made cut backs in their personal lives as a result of care service charges. Cut backs included:

- Going out less – not being able to afford transport costs and experiencing social exclusion.
- Stopping education classes.
- Stopping/reducing activities such as swimming, physiotherapy which were beneficial to people's health and wellbeing.
- Food and heating.

One local organisation, which held a focus group with its members to discuss our survey, suggested that:

'Individuals often have to compromise on essential utilities in order to meet care costs. One member described the following: "I had to cut back on my heating and take a calculator to the supermarket so I could make sure I had enough for the carer". Often leisure activities and education opportunities had to be cut back on as paying for care was seen as a priority'

Many respondents who stated they did not have enough money to pay for day to day living activities after paying for charges cited exclusion as a result of having to restrict or end completely social events such as going out with friends, going on holidays and other 'luxuries'.

Examples were even given of:

- Having to stop having hair washed/cut.
- Cutting down on heating and lighting.
- No longer buying Christmas and Birthday presents for family/friends.
- Reducing spending on property/garden maintenance.

Respondents using care services also demonstrated many unmet needs despite accessing support: 20% stated that they had many personal, social and leisure needs that are currently not being met, whilst 43% had some needs that that were currently unmet. A quarter (24%) said all their needs were currently being met.

People stating that many or some of their current personal, social or leisure needs were not being met described the following scenarios:

'I have some help from family including with high food bills for special diet, supplements and with occasional osteopathy treatment (all essential for my health)...I can't have the latter as often as I need...Any 'extras' usually have to be paid for by family...Meanwhile, essential costs like food, gas and electricity...are constantly increasing'

'Heating/food, cleaning...Any social activities including aqua mobility which helped ease my arthritis'

'I have cut back on laundry and housework, but cannot do without personal care and help with meals...I very rarely buy new clothes or shoes'

'I cannot meet with friends...I cannot go swimming to maintain muscle strength...I cannot buy clothing as often as I need...It is not good for self esteem if your clothing is showing extreme wear and tear'

'I need help with personal care every day but I only get a service of 1/2 hour a week - it's an insult. I need someone to accompany me wherever I go...I am an adult in my thirties and I don't want my mum to have to take me everywhere, but I have no choice'

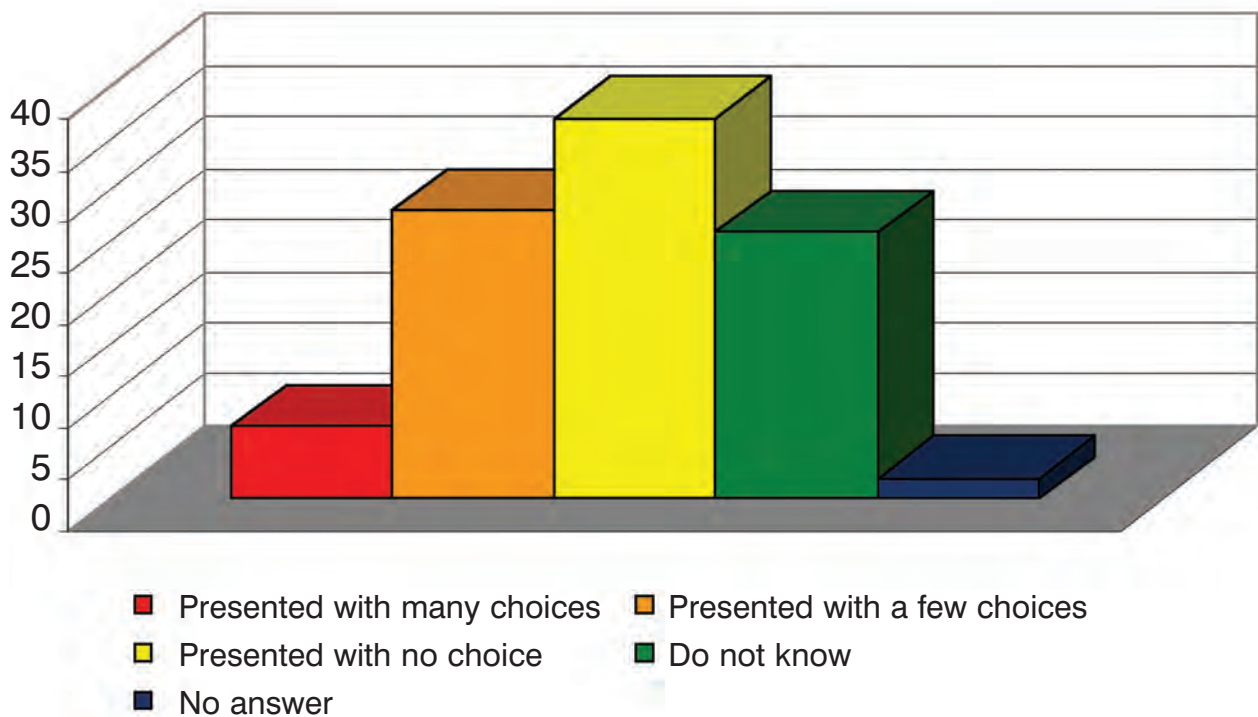
'I only have hours to cover the basics - going to bed, getting up and some cleaning. I also need support sometimes to go to the loo in the middle of the day but I don't get that'

3) Choice, care services and charges

Key survey finding: **A third (34%) of individuals described having no choice over the support services they were paying charges to use.**

Individual respondents described the level of choice offered when assessed for support as poor. A third (34%) described having no choice in the support they received. A quarter (25%) said they had a few choices but just 4% believed they had been presented with many choices.

Choice of care services people are charged to use



Choice, 'user voice' and local changes to service charges

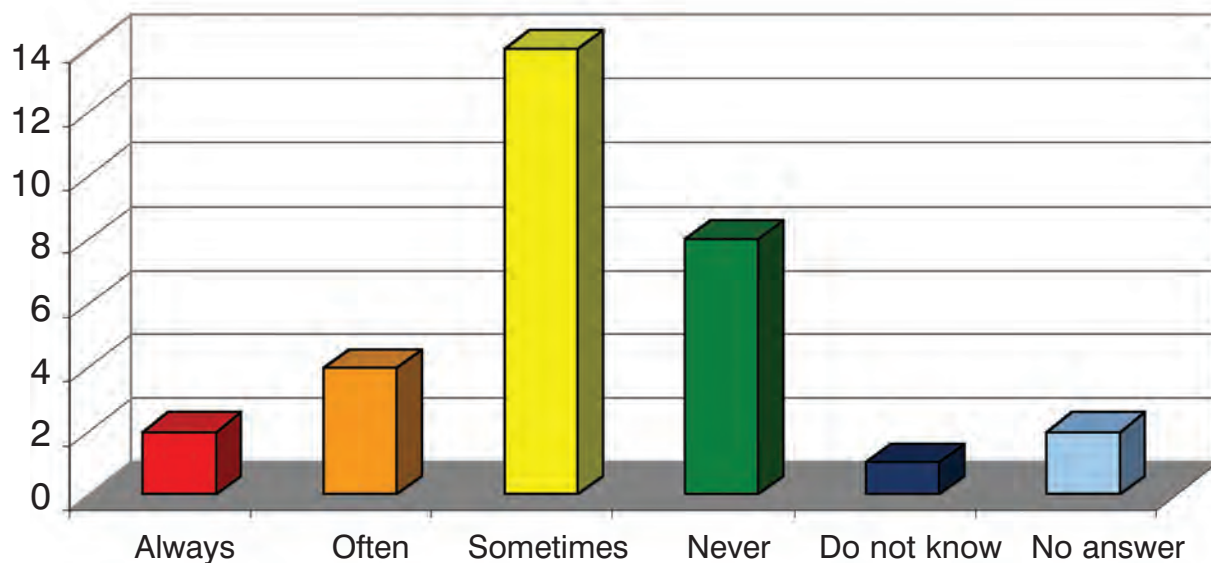
More than half the individual respondents (55%) also demonstrated that they were limited in their ability to exercise choice over their services as they stated that they had **never** been consulted by their local authority about changes for care services charges.

The Disability Discrimination (Amendment) Act (DDA) 2005 obliges public authorities, like local authority social services, to promote disabled people's equality of opportunity and to involve disabled people in policies that affect disabled people. Our survey suggests this is not happening.

'Letter from council informing of charging both insulting and threatening. It caused a lot of upset. Stressful worrying about not having enough money, both for me and my family. Think I should have been asked about it before the decisions were made'

Organisations were also asked whether they believed local authorities consulted/involved the people they represented about changes to charging policies. The majority believed this only occurred sometimes. A significant proportion felt their members were never consulted.

Organisation responses to whether members were consulted by local authorities on changes to care service charges:



Respondents also mentioned that, where their members/the people they represented were 'consulted' it was not always a genuine process of opinions being sought and used to generate action; instead being a tick-box effort to legitimise changes already planned to increase charges. Respondents pointed out that:

'When the policy changed in 2007 it was announced without any consultation whatsoever. When the illegality of this was pointed out 'a consultation' took place. This took the form of a questionnaire with 'loaded' questions and the changes went ahead unaltered'

'Consultation is tokenistic'

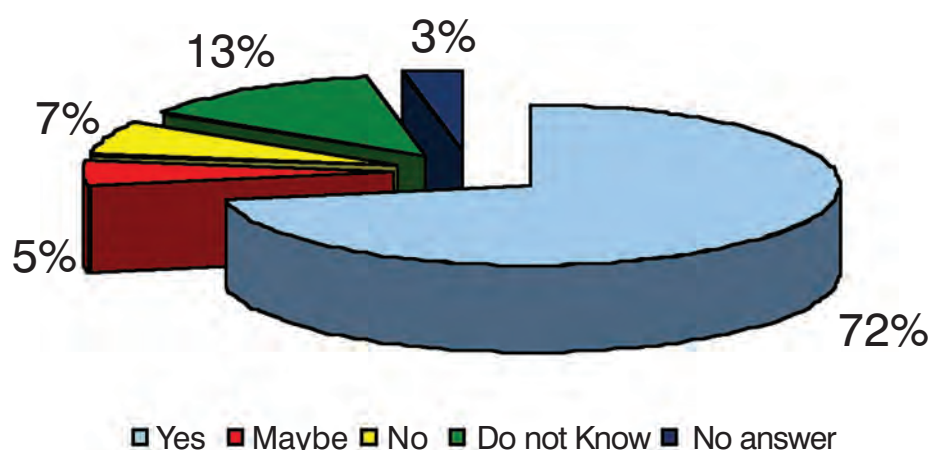
4) Charges and Government plans for adult care reform

Key survey findings: Three quarters (72%) of individual respondents and 81% of organisations believe the Government should consider care service charges in adult care reform plans. 59% of individuals and 77% of organisations also believe the Government should consider ending care service charges.

We asked individuals and organisations whether the Government should consider care service charges in its plans for adult care reform in England:

- Three quarters (72%) of respondents believed that the Government should consider charges.
- 5% also suggested 'maybe' charges should be considered.
- 7% did not believe charges should be considered.

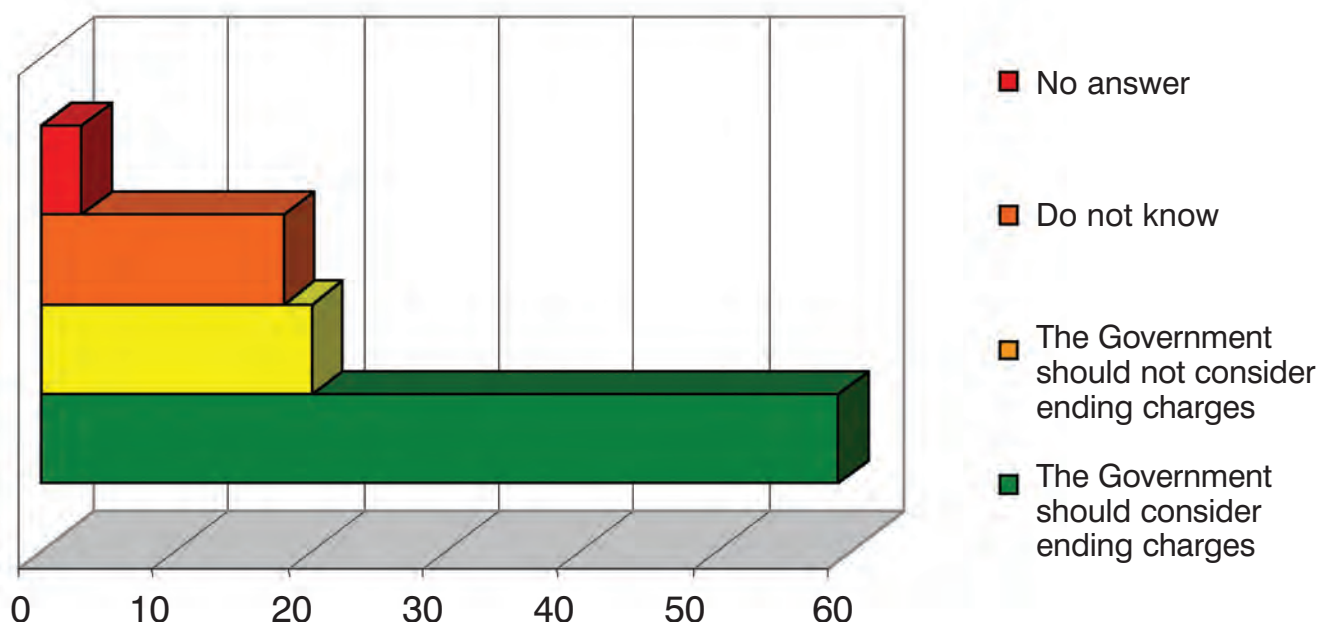
Should the Government consider care service charges in care reform plans: individual responses



Three quarters (77%) of organisations also felt that the Government should consider ending care service charges as an option in broader care reform plans. No organisation believed that care reform plans should not consider charges for using services.

We also asked individuals and organisations whether they believed care reform should consider ending care service charges. Fewer individuals and organisations supported this option, but large majorities backed considering ending charges. 59% of individuals favoured the Government considering ending charges (19% did not). Organisations favoured the Government considering ending charges by 77% to 7%.

Should the Government consider ending care service charges: individual responses



The reasons given by individuals and organisations for their belief that the Government considering charges (or ending charges) were varied but several themes emerged in responses.

Poor understanding of distinction between health and social care and a general lack of understanding of the principles of charging.

'My wife having Alzheimer's makes it really annoying at the unfairness of having to pay for care for this illness. The real problem is the artificial boundary between health care and social care'

'[People] do not understand the arbitrary distinction between health and 'social care' and believe that they had already contributed towards the cost of potential care needs via their National Insurance payments'

Services being paid for through tax and National Insurance contributions was strongly expressed by individuals and organisations.

'I have paid into the NI scheme and paid my taxes all my working life...I do not feel anyone should be forced to pay for help and care they need when they become ill, or grow old which is inevitable'

'Many other Council run services are included within the Council Tax - and so should be social care provision'

The postcode lottery and devolution issues were perceived as iniquitous.

'All councils should charge the same rate'

'If we are going to have a charging system - should be national - and if we are going to have services free at point of need, as in some UK countries - that approach should extend to the UK to promote universal approach'

Charges being discriminatory and poorly administered were also common responses.

'Charging is unfair, intrusive and costly to administer'

'Alan Johnson has recently said that means testing will not end otherwise the poor end up subsidising the rich. What nonsense! Means testing is a very divisive and discriminatory process...To have £22,000 does surely not make one rich!'

Charges having a negative impact on dignity and contributing to

hardship and poverty were consistent themes.

'It is degrading to have to pay for things that are basic human needs'

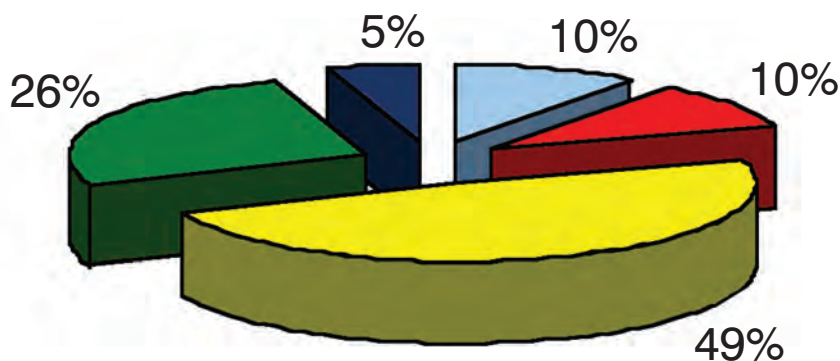
'No non disabled person...would tolerate such an affront to their dignity...I am a general tax payer, council tax payer and I already contribute to society in many ways. Yet as a disabled person I am expected to just keep contributing'

'Most disabled people are experiencing hardship and poverty'

'It is a direct threat to disabled people's dignity, individual choice and independence to charge for social care provision'

Charges having a negative impact on independence, wellbeing and control was also commented on by half (49%) of the individual respondents when we asked about the impact of charges on these central themes of Government care reform plans.

The impact of charges on independence, wellbeing and control: individual responses



■ Positive ■ Neither positive nor negative ■ Negative ■ Do not know ■ No answer

5) Fairer Charging: organisation views

We asked organisations what impact Fairer Charging (see pp9-10) had made to the people they represented. Two thirds (65%) of organisations believed that their local authority had changed its policies after initial alterations brought about by Fairer Charging in 2003.

More than half (55%) of the organisations believed changes to charging policies post 2003 had not been beneficial to the people they represented. Just 7% felt that changes had been beneficial.

Organisations views on the effect of changes to charging policies since Fairer Charging was introduced in 2003 were mixed. One organisation suggested the system had improved through being less complex, whilst others believed the opposite. Examples given included the reduction of individual service plans and the move from daily to hourly charging which increased prices.

'Individual service plans were reduced and many lost or had reduction in service. Domestic and shopping support was withdrawn. Some were told hair washing not included as personal care'

6) Concluding individual and organisation comments and suggested improvements (assuming charges are retained)

We asked individuals and organisations what would be most beneficial to them assuming charges were retained through care reform.

The overwhelming topic suggested for changes to the system by individuals was disregarding Attendance Allowance/Disability Living Allowance as income in assessments for charges. Organisations also suggested disregarding DLA/AA in large numbers.

Other changes suggested by individuals and organisations were:

- Fully assessing costs of living, especially the essential costs experienced by disabled people and their families on bills, equipment and transport.
- Increasing the capital limits thresholds.
- Nationally agreeing care charge limits and subsidies – including subsidised hourly rates (to reduce the postcode lottery effect).

- Better defining boundaries between health and social care (to ensure people are not charged for services which benefit health).

The following quotes were typical responses:

'Reducing the amount they take from Disability Living Allowance and also disregarding Severe Disablement Premium'

'disregarding Disability Living Allowance, and/or taking the full range of disability/health related expenses into account, would be of most benefit'

The following final quote demonstrates the clear need for the impact of charges to be better analysed and addressed in care service reform:

'If they make charges to the help that I receive, I shall commit suicide'

Government agenda and a forward look

The Government launched the start of a national debate on the future of care services in May 2008 and reaffirmed its three requirements of a new framework in England which should:

- Promote independence, choice and control for everyone who uses the care and support system.
- Ensure everyone can receive the high quality care and support they need, and that government support should be targeted at those most in need.
- Be affordable for government, individuals and families in the long-term.

The Coalition on Charging examines these ideas in the context of our survey in more detail below, with a focus on the potential impact of charges for care services on the Government's aims.

Promoting independence, wellbeing, choice and control

Our survey findings show that:

- a third (34%) of individual respondents believe they have no choice in the support they received;
- half (49%) of individual respondents believe charges have a negative impact on independence, wellbeing and control; and
- 39% of individuals who currently use adult services said they do not have enough money after charges to pay for day to day needs.

Charges impact on people's independence, wellbeing and control in terms of whether they access essential support, how much support they use and on the finances left after charges for everyday expenditure.

The day to day experiences of disabled and older people and their families using or needing support from the social care system also has an impact on their human rights. Local authorities have a responsibility

to take financial considerations into account when establishing or altering care service policies. However, there is little evidence to demonstrate how authorities ascertain the impact of changing charging policies on the human rights of people needing support. There is also little evidence of good practice of local authorities meeting equality duty obligations when deciding care policy and charges.

Local authorities have been taken to court for failures to involve disabled people in care service reform. Acknowledging the high needs people must have before local authorities provide support means most care service users are very likely to meet the Government definition of disability set out in the Disability Discrimination Act (DDA). The public sector duty to promote equality of opportunity for disabled people was a commitment of the DDA Amendment Act 2005 and requires all public bodies (including local authorities) to involve disabled people when policies (such as charges for care services) are reviewed/being made.

But more than half the individual respondents (55%) said that they were limited in their ability to exercise choice as they had never been consulted by local authorities about changes for care service charges.

There is a similar gender equality duty which local authorities also routinely fail to consider. Raising charges and reducing recipients of formal service support results in a reliance on many unpaid carers to plug the gap – and carers are predominantly women who reduce/stop working, diminishing gender equality opportunities and increasing the likelihood of pensioner poverty for women.

“When we debate the future of adult social care, we are talking about people's human rights and equality, not just for the person requiring the support, but for those with whom they share their lives... [The care reform debate should decide how] we deliver a support system where people's human rights are enshrined and everyone's life chances equally valued and supported”

Baroness Campbell, Commissioner and Chair of Disability Committee, Equality and Human Rights Commission, 2007

Ensuring support for everyone and prioritisation for people who need most support

Our survey findings show that:

- 80% of the people who no longer use care services say charges played a part in stopping usage. 22% of respondents currently using care services said they were likely to reduce or stop receiving services if charges increased; and
- over half (54%) of individuals currently using services said they could only afford charges with difficulty or could not afford the charges for the support they required; and
- respondents using care services had many unmet needs despite accessing support: 20% had ‘many’ and 43% had ‘some’ unmet personal, social and leisure needs.

Charges for support at home impact on whether people access services and the level of services used.

Public services are essential to tackling disadvantage and there is recognition. The Office of Public Services Reform reported in 2004 that:

“that people do not start off with equal chances in life, so it is essential that specific support is provided for those who are particularly disadvantaged”

Our survey has provided startling evidence of the impact charges for using care services have played on essential day to day activities and needs of disabled people, carers and older people. Ensuring that future support for citizens with needs is provided in a manner which acknowledges their essential expenditure and allows for activities such as buying presents occasionally for family birthdays (for example) is vital. This is particularly important for people with the highest levels of need who are likely to incur the highest levels of care service charges for essential support.

Prioritisation of government resources must support and allow for people with high level of needs to have the same inclusion aspirations as other citizens, in terms of meeting friends and buying essential goods. It should take account of the impact charges for essential support has on exclusion, as evidenced by our survey and other research.

Affordability for individuals, families and government

Our survey findings show that:

- 60% of individual respondents said charges had risen more than inflation since they had started using services;
- 29% of individuals did not feel their needs had been taken into account properly in financial assessments; and
- 39% of individuals who use services said they do not have enough money to pay for day to day needs after paying charges.

The level of charges, failure to adequately recognise essential costs of living and above inflation increases in charges can make essential support unaffordable.

Local authorities have increased charges at above inflation levels – an extreme example being a 35% jump in Kent in 2008. There is also huge disparity between local authorities on how they use their autonomy to raise revenue through charges for care services, generating resentment at ‘postcode lotteries’. In 2003-04 Stockton on Tees, Southwark, Oldham and Newham reported zero income for older people’s domiciliary care, whilst Norfolk raised nearly £7 million and Kent £6.5 million for the same period.

Our survey demonstrated that people cut down on food, decrease utility usage, cannot purchase or maintain essential equipment or household goods and furnishings, and have to deny themselves such ‘luxuries’ as new clothes as a result of care service charges. This is likely to mean they live in poverty. Many of our respondents were older people where there is a commitment to end pensioner poverty.

Genuinely tackling the affordability of care services could also support tackling child poverty. A third of all children living in poverty have at

least one disabled parent. Better social care support and assessments of genuine essential expenditure (including on children's clothes for example) could assist in tackling child poverty.

In examining costs to government of care reform, the impact of charges must be examined fully. A joint report by the All Party Parliamentary Groups on Primary Care and Public Health and Social Care²⁶ concluded, for example, that:

'the level of charges for domiciliary social care...acts as a deterrent from using such services...This often leads to earlier use of more expensive institutional care.'

The potential result of people delaying/deferring accessing support and later moving out of their own homes and into residential care fails public expectations of being supported at home, limits any cost savings to local authorities of not providing support in people's own homes, and undermines Government's Public Service Agreement targets to promote people being supported to live independently in their own home.

'How can the Government drive for inclusion and independence be supported by LA's who are denying that inclusion and independence by withdrawing services essential to that inclusion and independence'

The question of affordability was also raised in a 2006 Ipsos-MORI survey of public attitudes to care and support services which revealed that:

- Half the public supported an increase in tax to fund better social care, while a quarter (25%) oppose such a move; a 2:1 ratio in favour to deliver more/better services.
- 54% of respondents stated they would be prepared to pay more for better services. Higher earners were more likely to agree to pay more: 65% of those earning £30,000 or more, compared with 55% of people earning £17,499 or under.

²⁶ 'Our health, our care, our say', November 2006, p33.

- A third of respondents (32%) said none of the costs of caring should be borne by individuals receiving support or their family/friends.²⁷

These findings suggest that people would be willing to contribute more through general taxation to ensure better support and in order to reduce demands for informal care from family/friends. This issue could be examined in investigating the affordability of any new care framework to individuals, families and the state.

The knock-on effect of charges on later expenditure by local authorities, the NHS and to national and local government in terms of benefits, pensions, measures to tackle poverty, disadvantage and exclusion must also be taken into account in examining affordability issues in care reform.

²⁷ Ipsos-MORI 'The Future: Who Cares?' DRC, EOC, Carers UK, 2006.

Conclusions and Recommendations

The Coalition on Charging survey demonstrates the direct effects of the current charging system for care and support at home on disabled people, carers and older people. We will be contributing this evidence to the debate regarding the future provision and funding of adult care.

We support the Government aim of adult care reform in England: to deliver a new framework which promotes independence, wellbeing, choice and control; delivers quality support to all people with needs; and is affordable to individuals, families and the state. To secure its aim we believe the Government must address the findings of our survey and recommendations of our report.

Our findings suggest the need for immediate and/or interim improvements in four areas:

- 1) analysis of the impact of care service charges;
- 2) the assessment of disability related expenditure;
- 3) local authority process issues; and
- 4) how care services could contribute to national policy goals in relation to inclusion, wellbeing, equal citizenship and reducing poverty.

1) Analysis of the impact of care service charges

Main recommendation: **thorough review of the impact of charges to be undertaken from 2008.**

The responses to our survey show that the impact of charges can profoundly affect the quality of life of people needing support. We believe that, to secure its aim of care reform, the Government must address the findings of our survey and examine the full impact of

charges to use care services on people with care needs and their families. Current plans suggest reviewing charges outside of broader care reform. We believe a thorough review must be undertaken from 2008 to assist in delivering effective reform. Our primary recommendation is that a thorough review of the impact of charges be undertaken from 2008 linking the current Department of Health and planned Office for Disability Issues (DWP) investigations (see p15). The issue of charging must be addressed in the forthcoming green paper on adult care reform.

This review should, as an interim measure, make improvements to the current charging system that could be brought into effect for the period of the next Comprehensive Spending Review.

Our survey showed very strong feelings about the whole of people's pensions being taken into account, which acts as a disincentive to save and clearly discriminates against older people. Although older people can keep whatever savings disregard they may receive in pension credit, this is not a true reward for saving, and indeed the current system can perversely mean that people who saved more can be left (after charging) with less income than people who saved less.

'People who have saved and have even a modest private pension...are being penalised for being sensible when younger'

'Pensions are delayed earnings, these should be disregarded to encourage saving for a pension'

As a result of the feelings expressed in responses to our survey we recommend the review also takes into account:

- the true costs of living across the country and reflects this through increasing the amount of basic income people are left with following charges; and
- concerns about age discrimination due to disregarding earnings but taking occupational pensions (which are deferred earnings) into account, by allowing higher disregards of such pensions than are presently provided.

2) The assessment of disability related expenditure

Main recommendation: **a new agreement on disability related expenditure should be set nationally.**²⁸

The results of our survey demonstrate that disability related expenditure is not assessed properly. It is unacceptable in England in 2008 that disabled and older people and their families have to choose between food and heating and receiving essential support.

Many people find it very hard to understand and price the ‘extra’ costs of disability as it has become part of their norm to pay for items or to have larger bills.

We believe that the Department of Health in partnership with the Office for Disability Issues should establish a national agreement on disability related expenditure. This should be set using evidence on the additional costs of living experienced by disabled people. It should involve older and disabled people and their families.

If an individual believes their essential expenses to be above the national figure, local authorities should have the flexibility to provide a personalised assessment. Assessments must also be flexible enough to reflect increases through the year, for example for utility bills and heating in winter or air conditioning (where essential) in summer.

If local authorities do not approve expenditure costs, responsibility must be on authorities to explain why and to provide comparator estimates (if costs are disputed). Explanations must be provided in writing to people being assessed regarding what costs have been accounted for and what have not.

With the introduction of Personal or Individual Budgets there must be clear mechanisms to establish whether disability related expenditure is included in the budget that the individual is given to cover such costs,

²⁸ This could consider regional differences to reflect costs of living in London and rural transport costs.

or whether they are discounted against the contribution the person has to make towards the total budget.

The Department of Health should also use guidance to improve local authority awareness of essential disability related expenditure.

3) Local authority process issues

Main recommendations: **the Department of Health, under section 7 of the Local Authority Social Services Act 1970, should issue guidance on effective and transparent financial assessments; and local authorities should increase accountability in changes to charges.**

Our survey raised significant concerns about local authority processes in relation to: financial assessments of people needing support; and how policy changes (and increases to charges) were considered and implemented.

Financial Assessments

It is clear from the survey that many people find the financial assessment confusing and have little information about how their charge has been reached. We recommend that people needing care services be able to access completely transparent financial assessments.

Transparency should include people needing support and their families being able to appeal charge increases and having appeals processes explained as a matter of course. Appeals must be guaranteed and be fully accessible. We recommend that the Care Quality Commission²⁹ (CQC) monitor the transparency of local authority financial assessments and appeals processes.

We also recommend that the Department of Health issues guidance outlining that local authorities should make clear to people facing financial assessments (and their families) that partners' income does not have to be disclosed.

²⁹ The Care Quality Commission (CQC) will be the regulator of health and social care services from 2009. The Commission for Social Care Inspection, Healthcare Commission and Mental Health Act Commission will be abolished to form the CQC.

We recommend that the Department of Health clarifies and that the CQC monitors charges for services to ensure no person using a service pays more for that service than the local authority pays to provide it. This could be done, in conjunction with other recommendations, in a timely renewal of Fairer Charging guidance, five years on from its original implementation.

We also recommend that clear guidance is given to local authorities on dealing with overdue bills. Debts resulting from local authority delays should be automatically written off after a nationally agreed timescale (perhaps one month). The CQC should monitor local authority performance in the timely collection of payments to prevent build up of debt forcing service users into hardship and poverty.

Changes to charging policies

Our survey found that some people are hugely adversely affected by changes to charging policies. We recommend better transition planning for changes to charges. People using services should be notified in advance (with a nationally prescribed minimum notification period) of proposed changes to allow them to make plans to meet charge increases. Charging policies should be set for a minimum period (eg three years) to allow people needing support to plan their finances.

We also recommend national annual caps on charge increases to prevent the super-hikes which have led to an average increase of 23% in 2007. Charge increases should be incremental and allow people needing support to manage personal finances well. The CQC should monitor annual charge increases and ensure compliance with national caps.

We recommend, when local authorities propose changes to charging policy, that people needing care services (or likely to need them in the period for which the charges will apply) and their families³⁰ are fully involved in planning changes. This would support the delivery of national commitments to promoting user 'voice' in improving services and 'putting people first' in care services. It would also help local

³⁰ Potentially through new Local Involvement Networks.

authorities meet their Disability Equality Duty obligations. The CQC should monitor how local voice is incorporated into planning care service charges.

Where negative impacts to charge increases that local authorities did not predict can be demonstrated (for example by local people and organisations), we recommend local authorities plan to address these impacts and demonstrate how the evidenced impact has been used to predict effects of further policy changes.

4) Delivering national policy goals in relation to inclusion, wellbeing, equal citizenship and reducing poverty

Main recommendation: **local authorities should undertake comprehensive equality impact assessments on current charging policies.**

The Coalition on Charging is concerned that the current system of charging for adult care services:

- undermines Government commitments to equal citizenship and independent living (especially where charges are levied without meeting obligations to promote equality of opportunity);
- increases the likelihood of disabled and older people living in poverty by failing to consider the evidence on the additional costs of living which disabled people experience;
- prevents delivery of the health and well-being agenda by creating a barrier between local statutory bodies; and
- causes unnecessary demands on healthcare budgets as disabled and older people stop/reduce services due to charges, resulting in poor health experiences and the need for crisis interventions.

Our snapshot survey, and other evidence (including recent legal proceedings³¹), suggests that local authorities are largely ignoring or ignorant of their obligations to promote equality and human rights within social care – or what this means in practice. Most local

³¹ See, for example, *Chavda v Harrow*, March 2008.

authorities set their current charging policies prior to the implementation of the equality impact assessment requirement.

We recommend that the Department of Health, Office for Disability Issues and Equality and Human Rights Commission support local authorities to undertake comprehensive equality impact assessments on their current charging policies in partnership with the Local Government Association and Association of Directors of Adult Social Services.

We also believe that local authorities should more closely analyse proposed changes to charging policy – involving more thorough impact assessment models and local groups of people who need care services (including Local Involvement Networks).

Analysis of predicted effects of changes must be reviewed after implementation to ensure accuracy and to guarantee no adverse side-effects have resulted from changes. Analysis must also consider the impact of changes in the context of equality duty considerations (including Disability and Gender Equality Duty obligations).

Nationally we recommend a more effective monitoring and support role for the Local Government Association, Association of Directors of Adult Social Services, Care Quality Commission and the Department of Health working together to rollout good practice in projecting the effects of changes and also in supporting authorities to improve performance. We recommend that the training programme of the Improvement and Development Agency be extended to local authority staff involved in planning changes to care and charging policy. This training should fully incorporate equality and human rights obligations.

We recommend that the Department of Health and Department of Communities and Local Government work with the Local Government Association and Association of Directors of Adult Social Services to analyse how local authority charging practices are impacting on people's health. Services which assist good health management and maintenance of a health condition should have their charges monitored closely at national level to ensure they do not result in

people reducing use of services and experiencing poorer health and wellbeing. This recommendation would support delivery of national policy direction on early intervention and maintaining wellbeing.

Different budget holders do not often consider how reducing outlay in one area extends it in another. This is particularly true in health and social care where reducing (through increasing charges or restricting eligibility) the numbers of people using care services can lead to crises in people's health and hospitalisation. This is compounded by health and social care services being provided in fragmented systems that put process before people. Disabled and older people, who are the main users of these services, often suffer the consequences of divided provision. Public knowledge differs from the service (and budget) driven model of provision as to what is healthcare and what is social care. This recommendation would ensure national policy direction on early-intervention is delivered in practice and support people's wellbeing.

Charging policies (along with eligibility criteria) across the country are very varied and this can have a major impact on people's freedom of movement around the country – undermining equal citizenship.

Finally, and in the context of required efficiency savings from local authorities, we recommend that the Audit Commission investigate whether local authority charges are cost effective. If the costs of authorities of assessing, reviewing, administering and collecting charges outweighs the revenue they provide then the question of their use must be considered.

Cost implications and final comment

We recognise that some our recommendations may have cost implications. Others are concerned with improving the processes and introducing better guidance. Some require better resource allocation for existing obligations such as equality and human rights legislation – which is not currently understood or observed well. Others may factor in broader care reform plans (workforce training). Some recommendations however require investment.

Our recommendations are also largely based on the current social care framework and may be superseded if there is radical reform of the care system to create a framework fit for the 21st century:³²

“a system that is personalised to individual needs and gives real control to those needing care and their carers; that values the informal care on which our society depends; that gives people who would benefit from it access to care in the home; and that offers us all protection against the costs of care in old age, which can be catastrophic for some families”

Gordon Brown MP, Prime Minister, May 2008

To secure a framework fit for the 21st century and the vision of the Prime Minister, the Coalition on Charging believes the Government must address the findings of our survey and recommendations of our report in adult care reform in England.

³² ‘The Case for Change – Why England needs a new care and support system’, Department of Health, May 2008. Foreword.



When we debate the future of adult social care, we are talking about people's human rights and equality, not just for the person requiring the support, but for those with whom they share their lives... [The care reform debate should decide how] we deliver a support system where people's human rights are enshrined and everyone's life chances equally valued and supported



Baroness Campbell

Commissioner and Chair of Disability Committee,
Equality and Human Rights Commission, 2007



Challenging charges

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