



## **Lothian Centre for Inclusive Living (LCiL)**

### **Response to CEC Health and Social Care Draft Contribution Based Charging Policy Consultation July 2015**

LCiL will use the electronic consultation Summary and Questionnaire to communicate its response to City of Edinburgh Council (CEC). Our organisation, however, encourages everyone to use this document to develop and shape their own response to the local authority.

To respond on line or access more information click

<https://consultationhub.edinburgh.gov.uk/hsc/draft-contribution-based-charging-policy>

In the earlier version of this response document LCiL acknowledged the City of Edinburgh Council's willingness to consult on this very important issue and welcomed the move. Since, however, we have learned, through service users, that the City Council has just increased the maximum charge that people will need to pay towards their care package from £13.50 to £15 per hour (it was £12.50 the previous year). This latest significant 10%+ increase is not only concerning for service users and their organisations but completely undermines the credibility of any consultation attempt on care charges.

We are also disappointed that there has been no communication with our organisation about this latest increase although, despite our diverging views on care charges, we have been willing to work in a positive manner with CEC on this issue. This significant increase in care charges will hit disabled people and people with long term conditions who already face reducing support and care services as well as the negative impacts of the welfare reforms. Yet, although we are one of the main organisations providing support and information to this group in relation to any disability issues, including health and social care and self-directed support, we learned of this impacting policy through the grapevine.

## **Response to Question 1: Do you agree that people who can afford to contribute to the cost of their care should do so?**

- 1.1. As a Disabled People Organisation, LCiL sees the policy of charging people for their care as a breach of Human Rights and as a contributing factor to the unequal society we live in, while fostering exclusion of a particular group from their communities. Through this policy, enabling people to live independent lives with choice and control is not seen as a universal service and therefore living independent lives with choice and control is not considered a universal right, although it is under the UN Convention on the Rights of Disabled People (UNCRPD).
- 1.2. Unlike other services in Edinburgh, e.g. education or culture, whereby the community as a whole contributes towards the costs of services delivered to, or used by, a smaller number of service users, disabled people and people with long term conditions are singled out as a group having to pay for the service they receive (even though many of them will also pay a council tax for services that are less accessible to them). We have seen in our own organisations how care charges discriminate between disabled and non-disabled members of staff. For example: two staff members doing the same job and receiving the same salary have found themselves with very different levels of cash in their pocket at the end of the month. One can use the totality of his income, while the other has to pay care charges so that he is able to work in the first place.
- 1.3. Quoting from the CEC Record of Equality and Rights Impact Assessment 'the argument that charging for non-residential social care is itself an infringement of human rights is plausible but not yet compelling. These arguments do not appear to have been tested in the courts, and we have not identified any case law that rules that charging for social care is itself in breach of human rights, or that the financial assessments that councils undertake to establish how much a person can afford

to pay for their care are flawed on human rights grounds' (p. 5 – item 2 in bottom of text box) we are very concerned that the City of Edinburgh Council takes such a cynical view of the lives of disabled people and people with long term conditions.

- 1.4. Again quoting from the CEC Record of Equality and Rights Impact Assessment 'If social care charges were an infringement of human rights it could be argued to be proportional and justified if the volume of care services currently funded by income from charges were no longer sustainable because the income lost could not be made up from other sources' (p.6 – Item 4 in the text box). We are also very concerned by this statement which legitimise any breach of human rights happening in the first place. On which grounds can CEC state that other sources e.g. council tax, Scottish Government funding, savings in other areas of the Council cannot be made available to ensure that discrimination does not take place? Funding priorities are a relative concept and it would appear that ensuring equal treatment of disabled people and people with long term conditions is not a priority in Edinburgh.

As a city wanting to promote its strong sense of community and citizenship, the City of Edinburgh Council should put its money where its mouth is and stop such a regressive policy.

1.5 No matter what affordability the bottom line is, life often costs more as a disabled person. From higher transport costs, to the cost of an electric wheelchair; from higher energy costs, to a lack of access to affordable home contents insurance, disabled people face extra costs in most areas of their lives so an additional charge for care surely undermines their autonomy further. Governments since 1975 have reconsidered the financial penalties disabled people incur with the introduction of the Mobility Allowance in 1975; however, financial help to assist disabled people to cover these extra costs is getting smaller and more stringent to access as a result of welfare reform which is discussed in more detail below.

**Response to question 7. Do you agree that everyone should have a financial assessment to work out what they can afford to contribute towards their personal budget to meet their care and support needs?**

2. Understanding the associated additional daily living costs of living with an illness or a disability is essential if local authorities are to avoid charging disabled people more than they can afford for social care services. Failure to take Disability Related Expenditure (DRE) into account as part of the financial assessment could result in charging levels which cause financial hardship, emotional stress, and restrict the life opportunities of disabled people and their right to live independently in their community.
  - 2.1. Disability Related Expenditure is not 'exceptional' in that these expenses enable a disabled person to maintain an independent life and pay for the additional costs of living with an impairment or long term condition.
  - 2.2. Leonard Cheshire Disability research shows that disabled people have about 25% extra costs compared to non-disabled people, these costs may relate to but will not be restricted to:
    - additional heating requirements;
    - purchase, maintenance and repair of disability related equipment;
    - specialist dietary requirement;
    - specialist clothing;
    - daily living aids;
    - replacement clothing due to frequently wear and tear;
    - therapies e.g. physiotherapy, massage, pain management or to benefit their mental health;
    - higher transport costs due to inaccessible public transport;
    - help with cleaning and other domestic tasks.

A Scope study found last year that disabled people pay on average £550 per month on extra costs related to their disability.

- 2.3. Ideally, questions about disability related expenditure should be included in the financial assessment form and taken based on an individual's circumstances. This will enable a local authority to decide whether to disregard more of a person's income or capital, over and above any existing disregards, to take account of any disability related expenditure.
- 2.4 Information on financial assessment processes must be made widely available in plain English in a range of accessible formats including for waiving and abating charges (see section on information). This should include details of the processes by which the authority considers such requests.
- 2.5 Where a supported person has difficulty in meeting the approved cost of the service due to their financial circumstances, it is recommended that Councils use their powers to abate or waive charges on a case by case basis.
- 2.6 It is also recommended that thresholds take into account the wider implications of the welfare system. For example, people don't pay any income tax until they have earned eleven thousand pounds or so, yet the threshold for contributions towards care charges is six and a half thousand pounds.
- 2.7 Furthermore the treatment of non-means tested disability benefits such as the care component of DLA (or equivalent daily living component of Personal Independent Payment) as income by local authorities carrying out assessments for discretionary housing payments has recently faced a legal challenge. Amongst the rulings the judge gave was that this was an example of "**indirect discrimination** because it treats disabled applicants and their disability-related income in exactly the same way as it treats others and their non-disability related incomes, giving rise to unfavourable treatment to the disabled applicants". Full details can be read here: <http://www.bailii.org/ew/cases/EWHC/Admin/2015/890.html>
- 2.8 Partners and family members are often providing significant levels of care to the person and, as such should be recognised and

valued as net providers of care, whose contribution provides a significant saving to both health and social care. They should not face additional hardship simply because they care for their spouse or partner, therefore the partners' sole income should not be taken into account within a financial assessment. Where a couple have joint income or capital, only the person's share of this income (no more than 50%) should be taken into account. This is a reasonable approach which takes account of the person's share of household costs. However, this must be applied consistently and have flexibility to set at a lower percentage share.

**Response to Question: Do you have any other comments on the proposed policy?**

**3.1 Health and social care integration:**

Very worrying is the contrast between the right for all Scottish citizens to access health services while at the same time the equivalent right in relation to social care is denied to citizens who happen to be disabled or have a long term condition. This leads to absurd situations. For example:

- A person receiving a thousand of pounds heart operation free of charge, saving his/her life, may have to pay a thousand more from his/her own pocket to ensure that his/her life is worth to live.
- Parents giving birth to a child after serious obstetric complications will not have to pay for this but may have to spend a very large amount of the family income to ensure that their disabled child lives a dignified and more independent life in the future.
- Unfortunately the consultation document does not shed any light on how this discrepancy will be negotiated between health and social care under the new integrated setting. There is no clarity for users of SDS on how this particular issue will work for them.

3.2. We are very disappointed that not only the policy disregards the current discriminatory nature of care charges but potentially plans to increase the number of people being discriminated under that policy. The CEC Record of Equality and Rights Impact

Assessment clearly state that 'there will be an overall increase in the amount that people contribute to the cost of their package. So while many people will pay the same level of charges which they would have paid under the current policies, the number of people who will pay more in charges is likely to be greater than the number of people who will pay less.' (p.8- Age and Disability).

- 3.3. We strongly disagree that the impact of increasing charges of a specific group of citizens, who need social care service to access equal opportunities and live dignified lives, is seen as a 'positive impact' in the CEC Record of Equality and Rights Impact Assessment. 'Maintaining or increasing income from charges required to fund care services at the time of rising demand and reducing resources, recognising the importance of social care services to reducing disadvantage due to frailty in older age, disabilities, and mental health.' (p. 9 – item (4) in the positive impact textbox). We believe that the argument is justifying a dangerous logic whereby any (discriminating in this case) means can be justified as long as it leads to positive outcomes.
- 3.4. Similarly we strongly object to the reason given in the consultation document on why the council charges for care and support. The document states that 'Without money from charging there would be fewer services'. Again this statement is misleading as it conveniently ignores that within overall reduced funding for local authorities, it is their choice and decision to target a particular group of citizens to pay for the service they receive.
- 3.5. In relation to 'how people will know the new way of charging is fair' i.e. 'we will do this by treating people fairly', we would like to point out that fairness is a relative concept. This is well demonstrated by this care charges policy which argues that targeting a specific group of citizens to pay for their services is not unfair, while also arguing that not extending it to more members of that particular group could be unfair.

- 3.6. **Scotland Against the Care Tax Campaign (SACT)** have also recommended that all local authorities should take account of the Social Model of Disability, the UN Convention on the Rights of Persons with Disabilities and any other related principles on the independent of, and social inclusion of, older and disabled people. Charging policies should be seen within this context and should equally seek to promote the independence and social inclusion of service users.
- 3.7. The **welfare reform agenda** is also hitting disabled people and people with long term conditions hard, with the full impact not being felt until 2018. In 2014 the report: *The Cumulative Impact of Welfare Reform on Households in Scotland*
- 3.8. , there is clear evidence that claimants with health problems or disabilities also lose out badly. Reductions in incapacity benefits are estimated to average £2,000 a year, and some of the same people also face big losses in Disability Living Allowance as well as reductions in other benefits. It states Scotland's incapacity claimants can on average expect to lose £1,050 a year from this element of the reforms alone, and working-age DLA claimants can expect to lose an average of £1,530 a year.
- 3.9. Other considerations which the welfare reform system has created and impact on disabled people's ability to pay for care which were highlighted in a recent report issued from the Scottish Government, (*The Welfare Reform Tracking Study*) include:
- Mistakes with transitions between benefits causing gaps in payments – this will no doubt cause problems in financial assessments if there are variations in income throughout the course of the year.
  - Drawn out appeals processes which often results in 6 months or longer. If successful a claimant receives their entitlement backdated to the original date of claim. If this is a substantial amount are people being guaranteed that this income will remain in the claimants pocket without suffering the fate of having the local authority reassess this backdated amount as savings?
  - As the study showed these have impacts on the health and wellbeing of claimants, For example, depression and stress



caused by benefits being wrongly interpreted as personal savings and impact on care package payments if they receive these directly.

**Sources:**

***THE IMPACT OF WELFARE REFORM IN SCOTLAND – TRACKING STUDY Year 1 report to the Scottish Government***

<http://news.scotland.gov.uk/imagelibrary/downloadmedia.ashx?MediaDetailsID=2891&SizeId=-1>

***1st Report, 2015 (Session 4): The Cumulative Impact of Welfare Reform on Households in Scotland:***

<http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/87136.aspx>

<https://www.change.org/p/scottish-parliament-end-non-residential-social-care-charges-for-older-and-disabled-people>

**SANDWELL METROPOLITAN BOROUGH COUNCIL case:**

<http://www.bailii.org/ew/cases/EWHC/Admin/2015/890.html>

**Priced out: ending the financial penalty of disability by 2020, April 2014:**

<http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Priced-out.pdf>

**Scotland against the care tax campaign:**

<http://scotlandagainstthecaretax.org/>

**Disability and the Downturn:**

<https://www.leonardcheshire.org/sites/default/files/Disability%20and%20the%20downturn.pdf>

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