Proposed Bill to abolish charges for nonresidential social care

Page 2: About you

Please provide your name and other contact details. Please provide at least one means of contacting you (address, e-mail or telephone) - e-mail is our preferred option. (NB: you will be given the option shortly to specify whether it is your name or your organisation's name that is to be used, and you may also request anonymity or confidentiality for your response.)

Your name (mandatory)

Name of your organisation (if applicable - otherwise leave blank)

Your Job Title (if applicable - otherwise leave blank)

Contact details (please provide at least one of: email, telephone number, postal address) (mandatory)

Please indicate below whether you are content for your response to be attributed to you by name (either your name or that of your organisation)

I am content for my response to be attributed to me (as an individual)

Page 4: Your comments on the proposal

Q1: Do you support the principle that non-residential social care services should be available free at the point of delivery to those who have been assessed by a relevant professional as requiring them (as is the case within health care)?

Yes

Please explain your answer

1. Do you support the principle that non-residential social care services should be available free at the point of delivery to those who have been assessed by a relevant professional as requiring them (as is the case within health care)? Yes. I receive a direct payment from my local authority which I use to employ personal assistants for 80 hours a week. This should allow me to live a full and active life which I would be denied were this support not in place. The support includes assistance with personal tasks such as washing and dressing, eating, toileting - even help to blow my nose as well as accompanying and assisting me at meetings and social events. However, having to pay a substantial amount of money from the income I receive from benefits, and an occupational pension, negates many of the benefits of this support by restricting the income I have to participate in everyday life. The amount of money I have to pay for this support, which gives me my basic human rights, is calculated through means testing. In my case I am allowed a personal allowance of £137 a week. Any income I have above this amount is subject to a care tax of 70% which is paid to my local authority, Midlothian Council. In my case this amounts to £668 a month. To put this into perspective, the threshold for paying income tax is £10,600 per annum with any personal income above this amount subject to a tax of 20%. The threshold for paying the care tax in Midlothian, in my case, is £7,124 per annum with any personal income above this amount subject to a tax of 70%. The means test I have to undergo takes no account of any disability related expenditure. For

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example, the average family fuel bill is approximately twelve hundred pounds. As I need a warmer temperature than most my bill is nearer two thousand pounds. No account is taken of the cost of maintaining my house whose mortgage I paid off when I stopped working. If I was still paying my mortgage the interest payment would be added to my personal allowance. If I was renting a property that cost would be added to my allowance and any repairs would be paid for by the landlord. Many people would think that I was foolish to pay off my mortgage and should have invested the money; however, disabled people who receive community care support are actively discouraged to save money. In the vast majority of local authorities, as soon as any savings exceed £6,000 every extra £250 is judged to be earning £52 a year. Any savings over £16,500 would mean paying the full cost of my support package. It would seem that a disabled person relying on support to meet their basic needs forfeits their right to save up for a house or for any other major purchase. Care Charging also affects my wife. She cares for me for over 43 hours each week. When I first came out of hospital my wife was working full-time. Adding these hours and the hours providing my day care meant she was working at least 80 hours a week with no days off. This way of life eventually took its toll on her physically but, more importantly it affected her mental health. Diagnosed with depression, she had no choice but to reduce her working week by half. This has meant a positive change to her health and well-being. The downside is the effect on her earnings. She is being financially penalised for providing me with care in two ways: by losing half her pay and by having to subsidise me because of my reduction in income due to care charges. Like me she has had her choices, control, freedom and dignity eroded. As well as affecting the health and finances of the partners of disabled people it can also affect their relationship resulting in a high risk of separation.

Q2. Do you agree that legislation is a necessary and appropriate means of addressing the issues identified?

Yes

Please explain the reasons for your response

Legislation is essential to address the issues resulting from this punitive tax. As it stands, the Scottish Government abdicates responsibility for community care charging to the local authorities with guidance from COSLA. Every year, COSLA publishes guidelines for local authorities on non-domiciliary care charging. Every year, local authorities pick the guidance which best suits their purposes, and their finances, ignoring any guidance which benefits disabled people, their partners/spouses or carers. In 2015 COSLA's guidelines stated that local authorities should take into account disability related expenditure when calculating an individual's personal threshold. Very few, if any, local authorities take this expenditure into account. In England, local authorities have a duty to take disability related expenditure into account. COSLA do not have the right to impose a duty on a local authority, that can only come from the government. In the same guidance, COSLA states that partners/spouses incomes should not be taken into account when calculating the disabled or older people's community care charge but some local authorities do. So, even although the partner/spouse may be providing a substantial amount of care, saving the local authority substantial amounts of money, they are being penalised for having a relationship with someone receiving community care. COSLA and local authorities have no interest in abolishing the care tax, it's a guaranteed income stream that keeps on giving, never mind any power to do so. Only the Scottish Government can do this through legislation.

Q3. The current system has resulted in varying charges in different areas for the same level and quality of service. Do you agree that there should be consistency across Scotland?

Yes

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What do you think the advantages and disadvantages would be?

I stay in a village in Midlothian which is just outside Edinburgh city boundary. As I said earlier, I have 80 hours of support a week and my monthly care tax is £668. • If I moved half a mile north into Edinburgh I would pay £90 less a month. • Moving 3 miles east to East Lothian I would pay £235 less a month. • Moving 15 miles south into The Borders I would pay a staggering £440 less a month. I should add that Midlothian is not at the top of the charging league. In some areas 100% of my income over the threshold would be taken from me to pay my care tax. It would make sense for me to move to another local authority were the care tax is substantially lower than that of Midlothian; however, this would mean leaving the home I have lived in for over 50 years and the support network I have in the area. I would also be putting myself at the mercy of the local authority I moved to as I would have to undergo another assessment of my needs which may result in my support package being reduced. This is too much of a risk for me, or any other disabled person, wishing to move to another local authority.

Q4. Should all social care related services be free at the point of delivery?

Yes

If you answered Yes, please explain your reasons. If you answered No, please explain which services should be excluded, and why. (Please refer to the services set out on page 7 of the consultation document).

If someone has been assessed and a need has been identified for a social care service then, that service should be free.

Q5. What are the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

In 1999 an undetected tumour next to my spine haemorrhaged leaving me paralysed and needing 24 hours care every day. After my discharge from hospital I tried to continue working but it proved to be impossible and I had to retire. I was comforted by the knowledge that, having paid into a pension scheme, I would have an income which, along with disability related benefits, would allow me to lead a decent life rather than merely exist.

This is not the case. As I receive disability related benefits, all the income I receive from my pension is subject to care tax at a rate of 70%. As I said previously, in some local authorities this could be as much as 100%. Successive governments tell us that we should save into a pension fund to ensure a reasonable income upon retirement. This may be true for non-disabled people but for disabled people it is a fallacy. I know of many disabled people who are in employment and do not pay into a pension fund as they know that, when they retire, most, if not all, of their pension will be subject to a care tax which will deprive them of any extra income from their investments.

As for disabled people who need support and are lucky enough to be in employment, they are heavily penalised by the current charging system which subjects them to a tax rate which far exceeds the 45% rate for those who earn more than £150,000 a year. The disabled person will pay the national rate of income tax that their salary warrants. After this, with most local authorities, any income above £145 (£125 threshold plus £20 of their earnings) is subject to their local care tax rate which could range from 0% to 100%. Governments make a lot of noise about getting disabled people into work but where is the incentive if you are financially penalised for doing so?

Q6. What do you think the implications of the proposed Bill are for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

Positive

Please explain your answer. If you answered Negative, please suggest any ways this impact could be minimised or avoided.

There are no negative implications for equality in any proposed Bill to abolish care charges only positive implications. By abolishing charges disabled people will have the same control, choices, freedom and dignity that other members of society are given. Disabled people will be able to contribute to society as much as any non-disabled person could whether it be by financial input or by their involvement in civic life. Disabled people will be able to have a social life instead of a life of isolation.

Q7. Are there any other comments you would wish to make that are relevant to this proposal?

On 5th March 2013, at the Scottish Parliament, the Cabinet Secretary for Health and Wellbeing and Jim Elder-Woodward OBE Convenor of the Scottish Independent Living Coalition joined with Derek Feeley Director General of the NHS in Scotland and Councillor Peter Johnstone CoSLA's spokesperson on Health and Wellbeing to sign a Vision for Independent Living.

http://www.ilis.co.uk/uploads/Vision1.pdf

The Vision sets out that independent living is the right thing to do for disabled people, for public services and for society and indeed, for the economy. It talks about how human rights are at the heart of this agenda and how we need to work together to get this right. The following statements are excerpts from this vision.

- Independent living means "disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life."
- These rights to independent living are enshrined within the United Nations Convention on the Rights of Persons with Disabilities, the Human Rights Act 1998, and the Equality Act 2010.
- It is right for the individual to be free from prejudice and discrimination; and to participate within society as full, and active, equal citizens.
- We will work to make all our outcomes inclusive of independent living principles and practices, so that disabled people can participate in society and lead an ordinary life, on an equal basis to that of other citizens, and be a part of Scotland's future development as a country of equal opportunity and quality of life for all of its citizens.
- Our overall objective is to deliver real choice and control for disabled people in all areas of life, and all parts of Scotland, ensuring their dignity and respect at all times as full, and active, equal citizens of Scotland.

Without abolishing community care charges for disabled and older people this vision will never be truly realised.