

Proposed Bill to abolish charges for non-residential 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)

[REDACTED]

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

Self Directed Support Scotland

Your Job Title (if applicable - otherwise leave blank)

[REDACTED]

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

[REDACTED]

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 my organisation

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

SDSS believes that social care should move from creating dependent clients to sustaining citizenship and empowering disabled and older people to take an active part in the life of their community. We believe that abolishing charges for non-residential community care is an essential step in doing this. Getting the right support to live good lives in the community is about fulfilling the human rights of disabled and older people. Charging for social care forces people in Scotland to trade off the right to have nutritious food or to be warm and secure in their own homes or for help to get out of bed in the morning. Scots law recognises that people should be given the support they need but social care charging threatens this vital response. Having to pay to exercise these basic rights discriminates against disabled and older people. Care Charging has negative impacts on other services such as health. People declining, or not being offered, social care are more at risk of using emergency health or other crisis services. Our evidence suggests that up to 10% of service users decline services because of charges depending on the type of service, the intensity of support and the costs. Any relationship between "health" and "social care" is increasingly well-recognised. Poor social care will lead to poor health. Poor health care will make good social care very hard. The distinction is based on outmoded values and approaches; therefore, charging for one and not the other is an unnecessary barrier for the future of proper Health and Social Care Integration.

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)?

Furthermore, human rights should not be affected by which organisation, NHS or local authority social care, gives you help or support. Disabled people in work are only allowed a £20 disregard before their earnings from work are taken into account. This means that working disabled people who need care and support can pay up to 100% of their already taxed income to the local authority as their contribution towards care costs. Finding employment is hard enough for disabled people but this punitive tax could mean that, after deducting personal expenses, going to work could make them financially worse off. Savers also face a tough time with a banded approach which means that people, below pension age, with savings over £6,000 (£10,000 for those above pension age) are assumed to be making 10% interest on every £250 (£500 for those above pension age) of savings above their capital threshold. Although these kind of interest rates are of course completely fanciful, it is still regarded as income and is therefore subject to Care Tax of up to 100%. Those with savings over £16,000 are currently assumed to be able to pay the full cost of their care. These barriers to working and saving send a clear message that disabled people are not allowed to achieve any aspirations they may have with a life of poverty being the default setting.

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

Through the Community Care and Health (Scotland) Act 2002 the Scottish Government took the power to regulate the practice of care charging. This power, if it were ever implemented, would lead to changes in the existing system and not to the end of care charges.

In practice, it has not been used in 14 years but has merely created the illusion that consensus can solve the current problems; however, COSLA and local authorities have been trying to make the charging system fairer for 14 years without success and, currently, ending care charges completely is not even on their agenda.

COSLA has produced national guidance on the implementation of care charges, but this guidance remains only advisory and local authorities are free to set their own charging policies. It has therefore failed to achieve the consistency sought by the Scottish Government who made a commitment to hold its regulatory power in reserve until the implementation of guidance issued by COSLA in 2002 could be evaluated. That evaluation has never been carried out.

COSLA cannot reform care charging. It has found it impossible in 14 years to introduce consistency in anything to do with care charging. Indeed its diminishing membership means that it now has even less authority to reform care charging than it had in 2002.

Care charging is not simply an easy gain for councils short of money. There are important social consequences that arise from using charging as a disincentive to take up services. These costs may fall on other public bodies which currently councils can ignore.

With respect to the NHS, local authorities, and other public bodies, the cost benefit analysis is difficult to calculate. Joint Integration Boards, however, will need to pay more attention to how these costs interact. Clearly, though, all the costs and benefits are of interest to the Scottish Government.

COSLA's task is to attempt to find a compromise between different councils trying to manage significant financial challenges. No council trusts another not to put their own interests first. Every suggestion of a reform in local government finance is first of all seen as favouring those who put it forward.

In a complicated financial assessment there will always be some winners and losers when changes are proposed. Losing councils tend to block such changes. The Scottish Government will be trying to do the decent thing and also look for a compromise. But, since some councils will lose out, they will already be demanding more in compensation for having to stop years of unfairly taxing disabled people.

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

But if the tax is only reformed and not abolished, then there is a risk of a new round of 'Income Grab' by cash strapped councils at some point in the future. What is to stop them raising the "taper rate", or anything else that is left, to the discretion of the local authorities?

We believe the Scottish Government should not attempt to reform care charging but, instead, abolish it. Any attempt to reform it would simply leave them attracting blame for all the variations and changes that would appear council by council as they found loopholes to apply "Income Maximisation". The political capital needed by the Scottish Government to deal with care charging should not be wasted on reform but used instead to abolish it altogether.

The Scottish Government should do the decent thing, stop haggling over the human rights of disabled people and make councils completely stop care charging. The decision to end care charges for carers was introduced in legislation and this has set a precedent for other action to change care charges. It has also created a 'perverse incentive' for families to mediate services to disabled people via carers for financial reasons, in some instances disempowering the disabled person concerned.

A new law would give the government the moral authority to take firm action and would make it more difficult for a future government to change its mind and reintroduce charges.

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

What do you think the advantages and disadvantages would be?

Councillors and others can give no rational explanation as to why their rates are different from those of neighbouring authorities. In reality, as the agenda for this is driven purely by income maximisation, there is no more profound explanation or social purpose behind these variations. Advantages People will be able to move easily from one part of the country to another to take advantage of informal support or other resources available to them without being affected adversely and creating a level playing field for social care support all over Scotland. It will generate a sense of fairness for people who receive social care services that they are not disadvantaged just because of where they should live. It will save extensively on the resources involved in the creation and maintenance of 32 different charging systems cutting down on local authority bureaucracy. Disadvantages The loss of charging income may mean that some local authorities cut back on social care spending to compensate. Therefore new legislation will need to come with resources to replace lost income; however, savings will be made through ending the bureaucratic and costly systems used to collect charges There are no other disadvantages that we can think of.

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).

Access to all social care services is through an assessment of need using eligibility criteria which focus increasingly on risk assessment. Decisions on which services should be provided tend to be based on what will help a person maintain themselves in the community without coming to any harm. There is a danger that charging selectively for services may lead a person to opt out of that aspect of support thereby undermining the whole care package. If someone is assessed by social care services and a need for meal services is identified and they meet the eligibility criteria, then they should not be charged for this

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service. People with certain long-term conditions currently receive some foods free through the NHS. People with coeliac disease are eligible for free prescriptions for certain foods such as; bread, pasta and breakfast cereals. If food can be provided free through NHS services, surely social care services should follow suit. Charging for community alarms and call services should also be discontinued if an individual is assessed as needing these services and meets the eligibility criteria. These particular services relate directly to those of the NHS. Their primary use is to prevent serious injury, thereby saving the NHS money by reducing the need for hospital admissions. The abolition of community care charges is about disabled/older people's human rights and these rights cannot be diluted.

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?

Disabled people will be able to meet the additional expenditure associated with their disability without waiting for permission from the local authority. These disability related expenses may include such things as above average laundry, transport and heating costs.

Disabled people will be able to make choices about how they spend their income without their local authority interfering. They will be able to save money for the future, for holidays, for unexpected events or for anything else that might come up.

Disabled people with some savings with which they plan to buy a house, save for their retirement - or more likely buy equipment not provided by the state - are also affected. One of our case studies tells how he has had to buy a specialist powered wheelchair with a unique tie-down facility for safely travelling in his vehicle; a wheelchair adapted vehicle – not provided by Motability; an indoor powered wheelchair; a powered arm support and weekly physiotherapy from his savings.

Disabled people in work will be able to keep all the money they earn after national taxes are deducted. At the moment, they could be subject to a care tax of 100% on any earnings above £20. At the same time, more disabled people will be freed from the poverty trap created by charging policies. They will be more incentivised to gain employment if they are able to, reducing reliance on state benefits, paying income tax and National Insurance, increasing their spending power, paying more VAT, and contributing to the local and national economy.

Unpaid carers are also likely to benefit from scrapping charges to disabled people and there will be an equivalent if not greater impact on employment, benefits, tax revenue and spending.

Local Authorities will save significantly on the costs of administering care charges. Any net loss of charging income and additional costs due to increased demand would need to be considered for compensatory intervention by the Scottish Government. There could also be savings in the cost of long term social care support if there is a better take up of low level, preventative, social care services.

Health Boards will save significantly on unplanned admissions, use of A & E departments as crisis centres and delayed discharges. Increased activity, whether through higher disposable income or by virtue of gaining employment, is also likely to have a positive ongoing impact on health, reducing demand on health services generally.

The Scottish Government will have to properly fund social care services in Scotland.

Whilst care charges contribute 3% (or approx. £42.6m) to the cost of social care in Scotland, this 3% can be as much as 100% of disabled people's income after basic housing costs.

Local authorities repeat the fallacy that councils are using the income from charges to invest in more and better services. The reality is something different. Charges are being used to substitute for other ways of raising money. Disabled and older people are being punished because they are dependent on the people

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who charge them for the basic care they need to live a decent life. Our information comes from information published by councils themselves,

Community care charges are a highly inefficient tax that has a number of hidden consequences that are often overlooked in discussions over what it would cost to end. We believe that the actual cash amount raised is only the first part of the calculation. In addition there are the high costs of collection, the cost of emergency care for those who decline preventative services because of the level of charges, and the lost income from those who cannot work.

Over a four year period from 2009 to 2013, the amount of money collected from older and disabled people has risen from £40 million to £51 million, while the number of home care clients has fallen from 66,000 to 61,000. This represents approximately four times the average annual rate of inflation and is an entirely disproportionate burden on those often least able to pay (see <http://scotlandagainstthecaretax.org/index.php/the-issues>).

Our calculations suggest that the actual cost of abolishing care charges is actually less than half of the amount taken off disabled people – only £22 million instead of the £50 million charged to disabled people.

But a second element to the calculation suggests that there might even be a net gain if we take into account the wider changes as a result of abolishing care charges. Taking into account the not unreasonable assumptions that more people will be able to work and will consequently spend more, there could be a net gain of £5 million per year.

COSLA proposes to make partners who provide unpaid support for a disabled person be jointly assessed to pay for care charges, taking their own personal income into account. Many of these people are providing a substantial amount of care to their partners - support that might otherwise have to be resourced by local authorities.

In March 2015 the Scottish Government published a report "Severe Poverty In Scotland" which showed that many disabled people were not only in relative poverty but actually in severe or extreme poverty. Even at these poverty levels, disabled people would be expected to pay care charges. Many simply cannot pay.

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.

Positive

Disabled people will be able to access services that they need to live good lives in the community without having to worry about the financial consequences. They will have the same ability to live in the community as non-disabled people.

Also, disabled people (and also often carers) in receipt of earned income through employment or an occupational pension, will obtain the same value from it as non-disabled people would from the same income. In other words they will not have to pay simply to exercise their basic rights.

Negative

We think of any negative implications for equality.

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?

For many disabled people, community care is needed to eliminate discrimination, promote equality of opportunity and protect human rights. Without it, many disabled people cannot: participate in society on an equal basis to others.

All of the rights protected by the Equality Act, European Convention on Human Rights, in the Human Rights Act and in subsequent human rights conventions, belong to disabled people.

Article 19 of the United Nations Convention on the Rights of Disabled People (UNCRPD) says that states signed up to it must ensure; "disabled people have a right to live in the community, with the support they need and can make choices like other people do".

Charging for care breaches the following instruments that the UK has implemented or is signatory to: UN Convention on the Rights of Disabled People, Equality Act (2010), Human Rights Act (1997), and it is in indirect contravention of the EU Directive on Freedom Movement.

UNCRPD

Art. 7 Disabled children – Families face the same costs and variation (and reduced eligibility) as adults.

Art. 9 Accessibility – Care charges vastly reduce disabled people's incomes and limits their access to goods, services, the local community, sports, etc. Many disabled people have to use what would otherwise be disposable income to cover disability related expenditure (DRE) related to access issues eg for effective mobility equipment, to pay for an accessible holiday or hotel room.

Art. 19 Living independently and being included in the community - Charging changes care and support from a fundamental right to independent living to a commodity that people can choose to pay for. Disabled people cannot choose whether or not they want care – they either NEED it or they don't.

Art. 20 Personal mobility - The earlier point made regarding Accessibility also applies here. Additionally, many people rely on personal assistance for any real mobility. This right is therefore not realised if the Care Tax makes sufficient support unaffordable.

Art. 23 Right to private and family life (HRA art.8) - Charging disabled people who need social care to participate in aspects of private and family life is inconsistent with preserving a right to it.

Indirect contravention of the EU directive on Freedom of Movement - It does not make sense that, as a European citizen, a disabled person living in Scotland has the right to move (to live or work) freely between states, but faces barriers from doing so if they want to move between local authorities to do the same because of the variation in charges from area to area.

Art. 27 and 28 Employment and Adequate Standard of living - Charges can be a disincentive to work if earnings are included in charging assessments. Current COSLA guidance for example recommends that a mere £20 of earnings is disregarded – so you are £20 better off in employment than you would be out of work!

Equality Act (2010) Age Discrimination - People over the age of 65 in Scotland are no longer charged for their personal care and disabled people view this as arbitrary and unequal, discriminating against disabled people of working age simply on the basis of age.

Equality Impact Assessments are currently little more than window dressing. Midlothian's 2011 EIA on increasing care charging notes "lower income families will be impacted by charging policies as a higher percentage of their income will be required to meet charges." But what does it propose to do about this for those already claiming state benefits? – nothing! This is all perfectly legal - councils are not obliged to change their policies to mitigate negative impacts, they simply have to note them.

Social care free at the point of need is as important an infrastructure as health, education, transport and housing, in achieving equalities and human rights.

Enabling disabled people to participate in the economic, social, cultural and civic life of the community does not only allow them the freedom to exercise their human rights, it also benefits society as a whole.

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?

Human Rights and Equality law is untested in this matter and there may be a case for the courts to determine the legality of the way that care charging is implemented throughout Scotland.

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

Research by Scotland Against the Care Tax found that 21% of disabled people, some 14,300, who pay care charges are now in substantial arrears in their Care Tax payments. Of these, almost 5,600 people have so little prospect of being paid that councils have started debt management procedures against them.

Yet in the whole of 2014, only 25 disabled people in just 4 councils were taken to court for non-payment of their Care Tax. Councils know that many disabled people just cannot afford to pay their care charges and after threatening them through debt management procedures, most councils just give up and write off the debt.

As one council said when explaining why they didn't pursue people to court, "This is mainly due to the client group involved (elderly/vulnerable/etc) but also down to simple economics – the low value of the majority of the debts makes court action uneconomic."

There have been claims that since care charging by councils is discretionary and that they all have a waiver system that anyone who has a problem paying can be excused. However councils have admitted to Scotland Against the Care Tax that they do not advertise the waiver process for fear of getting too many applications! A low level of application for waivers does not mean that people are happy to pay or that they can afford to pay. It is more likely that people are simply not told how to apply so that councils can maximise their income at the expense of disabled people.

Case studies.

A Joanne is a disabled woman who has muscular dystrophy and uses an electronic wheelchair. She requires 24/7 support and requires medical assistance including use of a night ventilator. She does not have a car through the Motability scheme, but uses the money as part-owner of a car, for taxi and train fares, as well as the upkeep and running of the car. She also pays privately for a podiatrist to come to the house.

Joanne receives Employment Support Allowance and both mobility and care components of Disability Living Allowance. She is charged £53 per week from her income towards the costs of her care.

B Leon is a young man with a learning difficulty. He lives in a small flat provided by a local housing association in Glasgow. He has experienced some bullying from young people in the street near to where he lives. He needs a range of support in managing his money, keeping his house safe and clean and helping him remain healthy. Leon has been assessed as needing 9 hours per week home care support and receives this from a local voluntary organisation.

Leon receives Employment Support Allowance and both mobility and care components of Disability Living Allowance. He is asked to make a contribution of £35.73 per week towards his support package

C Iman is a physically disabled man in his early 30's. He has a care package which enables him to employ a PA who supported him for 24hrs/week. He also still relies heavily on his parents for additional care and support and gets regular physiotherapy sessions crucial to his health and wellbeing. He works in Human Resources for more than 16 hours per week in a Disabled People's Organisation.

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

Iman receives his salary, tax credits and both mobility and care components of Disability Living Allowance. He is asked to make a contribution of £134.54 per week towards his support package.