

**'What to do about care charging in Scotland?'**  
**SACT Consultation**  
**29th January 2016**  
**Glasgow**

**Total number in attendance: 41**

**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: all agreed that services should be free at the point of delivery.
- Yes: unanimous.
- Should be supported by the whole of community and society.
- If MSPs think it is terrible then why don't they do something about it?
- "Social" care gives the average person the wrong impression.
- What does social care cover?
  - holistic approach
  - to live a normal life
  - flexible to cover change in needs
  - lack of awareness by assessors
  - additional tax on disabled people.
- YES!
- To give extra income.
- As you get older health deteriorates – need more hours – need to pay more – EXTRA DRAIN on personal finances.
- LA doesn't ask how much extra costs you have to pay.
- LA adding in ILF i.e. giving individuals less.
- Without the cost of care tax – money could be life changing!
- SDA have to pay for contribution and respite.
- Often paid off one wage – majority of single people who are disabled.
- Social care in chaos: where did money go from when 'community care' started in 1990s?

- In principle – yes!
- Issue about who is assessing and what money is available.
- A feeling that there is no honesty – just tell us that it is about cutting services and maybe we'll understand – don't disguise cuts as 'personalisation' – changing thresholds.
- Council tax freeze doesn't make sense – has meant that councils have less money for services.
- How 'need' is defined is another issue.
- Whole process should be based on human rights – a rights based approach.
- Decisions not put in writing and signed by a manager.
- People 1<sup>st</sup> had a meeting with finance manager at GCC and she implied that, as she has children, she gets less than disabled people.
- Yes it's hard enough living on benefits without care charges.
- With care charges you get stuck in a vicious circle where you can't afford to work.
- Debt causes stress and more ill health.
- People are turning away support because they are frightened they can't afford it.
- There are things that the clinic can't do and my support worker can't do either but I can't afford to pay a professional to do this as I have no money left.
- Even mandatory treatment that a person may not want is charged for (CPAs).
- I would be happy to pay for things I need if I had the money but I don't and sometimes I don't even get what I need e.g. physio.
- I am fed up being assessed for getting services I need. An assessment is another word for a cut.
- Organisations have to collect the money. This has a bad impact on the support relationship.

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

- Yes: we need a law to enforce it and make it fair across the country.
- Current laws are not being used properly.
- Human rights legislation (Section 8) should encompass care.
  - Right to be treated like everyone else
- Transport not funded
  - affects families
  - young people can't live independently.
- Cost of legal challenge too high!
- Yes!
- Yes! Must be compulsory – councils won't do it.
- Legislation would ensure consistency – but what we want are no charges at all (i.e. in Fife).
- Do we need legislation? SG has the power now to tell LAs what to charge – or not.
- Should it go to the European court?
- Disability law centres would help to establish case law.  
[Experience is that law centres only look at mental health issues].
- Social care is an equality and HR issue – what other area/ protocol characteristics would be treated like this – disabled people are an easy target!
- The Government and LAS won't change things the way they are.
- Government hasn't used its existing powers to end care charges.
- Councils should be allowed to make it up and Government hasn't done anything about it.
- Legislation would mean that everyone is treated the same – hopefully with NO charges.
- A new law would take time when they can do something now!
- How do other European countries do it?
- It would be nice to hear disabled people's voices in the parliament.
- Scottish Parliament should look at the whole picture when making policy – ending care charges needs to work with revising FACS criteria otherwise LAs will just exclude more people from services. It might help social workers to do their jobs!

**3. 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? What do you think the advantages and disadvantages would be?**

- Consistency is about fairness and equality, everyone should be treated the same.
- Glasgow City Council included ILF contributions in the money they receive from care charging in a report to Scottish Government. In doing this they've shown they aren't operating transparently. They should be fair, honest and upfront.
- Disabled people are being penalised by the council's inability to manage their own budgets, this contradicts a Fairer Scotland.
- It's unfair for one area to have higher charges than another.
- We want them to be straight with us, which isn't happening. This leads to mistrust of the local authorities and the whole government system.
- No consistency between social work teams or across councils.
- Blanket charges don't take account of people's different costs.
- Quality varies between councils.
- Huge impact on families as the cost is unaffordable so carers have to stop work in order to care for family members.
- Need consistent quality and charges at assessment.
- Quality checking essential.
- Every penny has to be accounted for when being assessed.
- Charges should be the same wherever you are.
- Possible difference in additional costs due to travel i.e. Glasgow/ Highlands.
- Allocating hours can vary from LA to LA.
- Hourly rates are different from individual PAs and LA support – not budgeting for the difference.
- Not allowing presently for inflation – PAs need pay increase.
- Freezing PA salary?? FEAR!
- Some PAs can go across a boundary and get an increase/ decrease in pay.
- Working for LA advantages – have pension schemes etc.

- Not use top rate to bring wages up as fear – may freeze to bring wage down.
- Consistency should be – no charges!
- Working group (COSLA) been working at this for 14 years – disabled people not part of this – walked out.
- Only way to ensure consistency is not charge at all – even setting a certain level consistently means that there would winners and losers.
- Possibly research social care generally and how it's funded.
- Duplication of effort to campaign/ change things.
- New applicants for supported housing – can't pay support charges and so can't get accommodation plus care providers can't fill houses and may go out of business.
- Of course! It should be free for all.
- In isolated areas things cost more which isn't fair.
- People have to think about where (LA) to live on the basis of whether they can afford care charges.
- We don't want care services getting cut to pay the care charge shortfall.
- Differences cause problems and confusion for everyone including politicians.

### **Key Point**

Yes: we agree there should be consistency across Scotland. If there continue to be care charges they should be the same and fair across the country.

**4. Should all social care related services be free at the point of delivery? If you answered Yes, please explain your reasons. If you answered No, please explain which services should be excluded, and why.**

- People have paid enough into the system over the years so should be getting free social care just as they get free healthcare from the NHS.

- If people are assessed as needing things such as day centres and it's part of their care package, they have no choice but to contribute to that.
- It's all part of you having a life. Getting meals, transport and support is the difference between having a life or not.
- It's part of your welfare. It's short-sighted and dishonest to distinguish between medical and social care when it comes to charging. If people aren't looked after properly they might end up being admitted into hospital and put a strain on the NHS or other services. It's common sense.
- If assessed and wanted then it should be free.
- Community alarms are being refused because of cost in some cases.
- Should be covered (alarms) stops people going into care.
- Pay for food – not delivery.
- Shopping – therapeutic – important to look at the whole service  
HOLISTIC = meeting people is more than just keeping people fed!
- Disabled people shouldn't have to pay the cost – universal entitlement.
- YES!
- Not having the service means that you can't have a normal life – this is an equality and HR issue.
- Basic human right to be able to get a bath etc.
- Disabled people only group in Scotland who are having tax rises!
- This is a tax – and not a contribution (it implies it's given willingly – it's not).
- We DPOs would be better running support services as we don't have such huge overheads.
- Get people onto option 2 (SDS) as this would be much cheaper but people feel bullied.
- If it's free then people will take up service – charges mean that people are at risk – not getting care they need.
- Disabled people do not take more than they need!
- A lot of time and resources are wasted gate-keeping.
- You generally have to pay for food but if food costs more because of disability the difference should be paid.

- Sometimes mental health is crucial to well-being so food is more important than just nourishment.
- Not offering some charged for services free can cost much more when people get sick because they chose not to use them because of charges.
- Spend to save – getting people back to health might mean they can go back to work and contribute.
- If you are assessed as needing help then it should be free.
- Community alarm - £12 per month. A person tried to cancel because it was unsuitable but had to jump through hoops to get rid of it. LAs need to be a bit more professional if selling products and services commercially to vulnerable people.
- An effective alarm system can save the NHS money in the long term as it can prevent serious harm/ injury.
- Because social care isn't free occasionally families can make decisions that a person shouldn't get what they need as it might affect the inheritance pot.

### **Key Point**

Yes: they should be free, as it ensures people can stay in their own home, have a good quality of life and prevents hospital admissions.

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

- You have to find some of that money yourself. It's deducted from what you get in your support package so if it wasn't it could be used to fund more hours.
- People aren't aware of how much care tax is being deducted from their packages.
- It would help our lives considerably and could go into more hours for us.
- Care tax is quite hidden. At the moment care packages are at a minimum and only life and limb needs are considered so people only get the very basic support they need to get by. If people have

more money and hours then agencies have more scope to provide holistic services.

- It could also mean a higher hourly rate for PAs and less of a balancing act between choosing more hours and a lower hourly or a cheaper agency.
- Likely council tax would increase.
- Would save considerable money to enable people to do other things in their life.
  - more choice
  - improve quality of life
  - enable respite for carers
- Would remove social workers from their life!
- Enable people to repair their house.
- More independence.
- Still the cheaper option – is it that much to find?
- Is there a point where there is a financial cut off and individuals are faced with RESIDENTIAL CARE FEAR.
- People worry about ending up in care.
- Councils have to be open about the formula they use in calculating costs of hourly rates.
- If not paying care tax, could have holiday.
- Lack of security for next year.
- I could visit my mum.
- Job security for PAs.
- LAs could save money because people will have their needs met – so healthier and happier they spend less time in hospital etc.
- If people are in control they use less money as funds are used flexibly.
- Some people not taking packages due to charges.
- Stimulate the economy through disabled people spending their money to buy equipment and purchase other services.
- Disabled people may be able to work if they had support and participate in civic life – contribution!
- Free social care levels the playing field so disabled people can do more – live a full life, an ordinary life, address some of the impact of welfare reforms – mitigation.

- Social care providers are fed up feeling like debt collectors. People avoid staff because of charges. In a mental health services this could leave the person vulnerable if avoiding staff.
- I'd have a better social life. I could have a holiday. – to Skye! – to Tenerife!
- I just want what I need and the ability to pay for physio or other things I think I need. Because my condition won't improve I am assessed as not needing physio but it really helps me so if I had the money I'd pay for it!
- I wouldn't have to fundraise for the things I need!
- We would have a better relationship with the person we support. It would be more relaxed and positive with a clear separation of duties.

### **Key Point**

More money in your pocket means a better quality of life.

### **6. What do you think the implications of the proposed Bill are for equality? (Positive/Negative/No significant implications/Undecided). Please explain your answer. If you answered Negative, please suggest any ways this impact could be minimised or avoided**

- There are inequalities between areas and ending care tax or making care charging consistent would end the current postcode lottery.
- There can be a high rate in one area and a low rate in another, even in neighbouring authorities. This means people are limited in whether they can afford to move to a different area and so restricts where they can live.
- People in the Borders pay £400 less in care tax - surely that's discrimination.
- It would be more equal for families and carers as they would be able to continue working which has many benefits (e.g. mental health, income etc.) in and of itself. However, there is also no

incentive for disabled people to work in paid jobs: as soon as they earn more money it's taken from them.

- You pay council tax your whole life, your family pays it and you aren't getting much of a service from that.
- We pay council tax for children to go to school even if we don't have children ourselves. So care tax discriminates against disabled people as we are the only group who have to pay for our own services in addition to the general council tax we already pay.
- It's downright dishonest - double taxation.
- Social care is an essential service.
- It could enhance people's human rights if care tax were abolished.
- As a taxpayer we don't have a choice between what services are paid for with tax.
- The general public have got to see what their money is being spent on to be willing to pay more council tax. They've got to see the money going towards essential frontline services, so there has to be more transparency.
- The extra money could go towards things like going on holiday and having the support from PAs to do so, which isn't possible just now.
- Will enable disabled people to live the same life as the rest of the population.
  - reduce poverty
  - whole family face additional costs
  - reduce mental health pressures on disabled people and carers
  - ability to participate in society
  - more choice
  - more disposable income
  - more choice of places to live.
- If health care is consistent across Scotland then why is social care not consistent?
- No transparency of care package charging.
- Same costs throughout the country would be more equal.
- Would close the gap between disabled and non-disabled.
  - Equality of health/ physical/ mental well-being provision.

- People who are not active – health deteriorates and cost more in future.
- Socialising – laugh and joke therapeutic.
- Palliative care – needs joining up – assessments need more flexibility in what service / support on offer – (should be up to the individual).
- This ( care charges) is basically unfair and unjust as disabled people suffer cuts disproportionately.
- Disabled people don't start with a level playing field so it is unfair to charge people just to be the same as older people.
- This is an equality and human rights issue.
- People are living in fear – afraid to 'rock the boat' and change their current support package.
- You want to earn the same as other people but you don't always because of extra costs and care charges coming off your income.
- Don't look at the chair or the person pushing the chair LAs, look at me! Talk to me!
- Unfair to charge disabled people for support to try to live ordinary lives.
- There is already plenty of free universal stuff – prescriptions, university fees, NHS but we charge disabled people for essential care?
- Why are essential welfare benefits taken into account as income? They are not. They are to pay for the additional cost of disability.
- The ways things are is unequal!
- Some support services such as Access to Work are not charges for as they are provided by or paid for by the local authority.

### **Key Point**

Without care charges, disabled people and their families would have more equal lives and more choices.

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

- It's something that needs to be put right over a long period of time. They're saying things they've always said (i.e. excuses) but they always find the money for what they need.
- I don't remember when social care wasn't considered as an essential service - I was never consulted on that decision.
- Some disabled people and the majority of the general public don't know that disabled people pay for social care services so there has to be more awareness.
- The media portrays disabled people as scroungers who get everything for free. There's huge media bias.
- Social workers need to be trained and fully aware of changes – clued up!
- Fear that after all consultation this just gets lost and ignored!
- Social care commission.
- Assessment is about risk/ perceived risk – not needed.
- Possible that scrapping charges could save money overall by stimulating the economy.
- Less likely to use health services if social care was free:
  - possibly able to work
  - learn
  - look for work
  - contribute to family
  - contribute to community.
- Preventative.
- Free social care levels the playing field for disabled people who are not starting from the same baseline as others. They already have less access to the world.
- Campaign and communications needed to muster support.
- Who speaks up for people who can't speak up for themselves?
- Everyone should have an advocate or someone who has no financial interest to speak up for them.
- There is no science behind needs assessments. They are totally arbitrary in terms of working out what hours aren't personal care.

- People will now look at services as respite because under the new carers legislation respite will be free. This could set the rights of people with learning difficulties back 20 years!
- Equality – walk in my shoes for a day then charge me for care!
- People are terrified and too shy to ask for help they really need!

## **Care charging scenario**

### ***Former Serviceman***

Awarded 80% War Disablement Pension in recognition of the severity of the injuries received whilst serving his country. It is recognised by the medical board that these injuries will continue and his overall condition will deteriorate as a result. This includes both physical and mental health. This is the highest award given.

This is to cover not only care which he will need but also the extra costs of his needs. i.e. heating, food, clothing, laundry etc. It also covers the cost of medical care which the NHS is unable to provide

There is a statutory £10 disregard only when assessing his care needs.

It is a disgrace that any local authority should take this War Disablement Pension from someone who gave the best years of his life in defending his country. A person who gave his health, and future, unquestioningly.

### ***Wife who is his full time unpaid carer***

In receipt of middle rate care DLA.

This is to cover the extra costs of sight loss. This does NOT include personal care.

It covers the costs of assistants, escorts when leaving home environment. Costs of travel with assistance for shopping, leisure, and social events.

If this money is included as household income when assessing the cared for person's care needs it has the potential to prevent the carer from going out.

It was awarded to the carer for her own disability and no award should ever be used to cover another person's care costs.