

Campaign for Independent Living in Lewisham



**'SHAPING THE FUTURE OF
CARE TOGETHER' RESPONSE OF
CAMPAIGN FOR INDEPENDENT
LIVING (CILL)**

NOVEMBER 2009

'SHAPING THE FUTURE OF CARE TOGETHER'

Response of Campaign for Independent Living in Lewisham (CILL)

Set out below is the Big Care Questionnaire. Our responses to the questions are printed in RED.

1 The Vision for the future

The Government has suggested six key things that everyone should expect from a National Care Service and want your views on them.

- **Prevention Services**

You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse.

- **National Assessment**

Wherever you live in England, you will have the same right to have your care and support needs assessed in the same way and you will have a right to have the same proportion of your costs paid for.

- **A joined-up service**

All the services you need will work together smoothly, particularly when your needs are assessed. You will only need to have one assessment of your needs to access a whole range of care and support services.

- **Information and advice**

If you need care and support, or are preparing for it, you will find it easy to get information about who can help you, what care and support you can expect, and how quickly you can get it.

- **Personalised care and support**

Your care and support will be designed and delivered around your individual needs. As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate.

- **Fair funding**

Everyone who qualifies for care and support from the state will get some help meeting the cost of their care and support needs. Your money will be spent wisely to fund a care and support system that is fair and sustainable.

1a) Is there anything missing from this list?

- **The various funding options relate to basic level care and support but what is that? Different impairment groups may have very different needs but may well see their needs as 'basic level'. As well as national assessment we need a national definition or guidance of what basic level care and support is or what it should achieve. Without it the concept is purely**

subjective and Campaign for Independent Living in Lewisham (CILL) fears may well be very narrowly focused on personal care. If that does become the interpretation some people (for example those with learning disabilities or mental health issues) may be left unsupported. Unless there is consensus, rather than local interpretation, CILL fears we may well slide into yet another postcode lottery based around local authority budgets and value judgements of individual local social care professionals.

- Information and advice are certainly needed but alongside them is a crucial need for advocacy. Many people who come into the care and support system are disempowered and have never been allowed to exercise choice and control in their own lives. Advocacy allows each person to work through what is right for them and to communicate those needs. Simply signposting them to relevant services can all too easily become control dressed up as choice.
- Overall the stated objective is to create a service that is fair, simple and affordable but surely it must also be equitable and non discriminatory. To make any system truly fair, simple and affordable there would be no means testing and that quite obviously will not happen given the options. As for being affordable the danger is it becomes focused on what budget holders can afford and not on meeting the needs of service users in a satisfactory way.

1b) How should this work?

- To achieve this vision, many different professionals and sectors will need to be involved and work together as joint partners. CILL believes a national system will need a national body to implement a unified system. Service provision could well be delegated to local level, and focused on local need.

2 Making the vision a reality

We think that to deliver this vision three main changes are required to the care and support system.

- **More joined-up working** between health, housing, social care and benefits systems.
- **A wider range of care and support services** so people have a greater range of services to choose from.
- **Better quality and innovation.** Staff must have the right training and skills, and services should be based on the best and most recent information about what works well in providing care.

2a) Do you agree?

- Yes

2b) What would this look like in practice?

- A Care and Support body to set standards, co-ordinate the service, share good practice, foster partnership working, ensure confidentiality of information and have budgetary control of the money going in to the system. CILL's understanding from the evaluation of the Individual Budget pilot sites is that it was difficult to get different budget resources allocated into one funding stream so giving responsibility to one body overcomes that barrier. We would also like to see a mandatory requirement around the involvement of and service provision from user led organisations, who have considerable knowledge and skills around the issues. Although this is advocated by the Government sadly few local authorities have actually got beyond consultation.

2c) What are the barriers to making this happen?

- Current providers will not want to relinquish their control and in the present economic climate any increase to the cost of public services will not be welcome. However if we are to have a national care service that runs alongside the NHS it is no good tinkering with the systems we already have – the reality is that they have failed – we must have a national body with care and support as its only focus.

3 Funding care and support in the future

We will achieve this vision by making better use of taxpayers money so funding is focused on people who can benefit from it and need it most. But the money in the system at the moment won't pay for all of everyone's care in the future.

In deciding how to fund care and support, there are some very difficult decisions to make.

Funding options

We have therefore proposed three options for funding a National Care Service.

(i) **Partnership:** The responsibility for paying for care and support would be shared between the Government and the person who has care and support needs. The Government provides between a quarter and a third of the cost of care and support, more for people on a low income. Today's 65 year olds will need care and support costing on average £30,000.

The Partnership system would work for adults of all ages. Under this system we expect many people born with a care and support need to qualify for free care, as they do under the current system. Those working age adults who do not qualify for free care (those who are better off) would have the same offer around funding as people over 65.

(ii) Insurance: The same as Partnership but the Government could help people prepare to meet the costs that they would have to pay for themselves through an insurance-based approach. As well as providing people with between a third and a quarter of the cost of care and support, the Government would make it easier to take out insurance to cover care and support costs if they want it. It is estimated that the cost of insurance could be around £20,000 to £25,000.

The insurance part of the second option would be likely to be less relevant to people who have been born with a care and support need, since people cannot insure against the risk of something that has already happened. However, many people born with a care and support need are likely to qualify for free care under the Partnership element of the system.

(iii) Comprehensive: Everyone over retirement age who can afford it would pay into a state insurance scheme, so that everyone who needs care and support will receive it free. It is estimated that the cost of being in the system could be between £17,000 and £20,000.

The Comprehensive system would be for people over retirement age, but we would also look at having a free care and support system for people of working age alongside this.

We have ruled out a system based on tax funding, because it would put a large burden of paying for care and support on people who are working. Given demographic changes, there will be an increasing pressure on a shrinking proportion of working age people. In 2007, the number of people aged over 65 became greater than the number of people under 18 for the first time. Because the majority of people benefiting from a reformed care and support system will be pensioners, it is fairer to think about more targeted ways of bringing in extra funding, rather than placing a lot of the burden of the system on people of working age.

Disabled people of working age

At the moment, people who are disabled when they are born, or who become disabled during their working lives, are likely to have lower incomes and so will struggle to meet the cost of their care and support. In the future more disabled people will be working, but those who are on low incomes will have their care and support provided by the state.

What about accommodation costs?

It is important to note that these options consider only the cost of people's care and support. People entering a care home would have to pay for their accommodation costs, such as the costs of food and lodging. This is because the state would not pay for people to buy their food or pay their mortgage or rent if they were living at home.

Of course, the state will always have a role in supporting people who cannot afford these costs.

3a) Which of the three funding options do you prefer and why?

- Until we know what we are agreeing to in terms of 'basic level' support it is almost impossible to answer this question. There is also very little detail with regard to younger disabled adults. The notion that we all get free care and support already so we'll just continue with the system we have is so misleading it's offensive. All disabled people are means tested, have to justify how they spend their income and most contribute to the cost of their care and support so that their income is reduced to income support level plus a small 'buffer'.

Those who have worked and managed to accumulate reasonably small savings either have to self-fund so they get no assistance or, if they are below the savings threshold may have to pay a tariff. Those who have worked and receive either a private or occupational pension have that taken from them and are reduced to income support plus 'buffer'. The current system for disabled people is a disincentive to work, save or contribute to a pension.

While CILL welcomes the recent announcement that Disability Living Allowance (DLA) is to be maintained the truth is that most local authorities already take this into account as assessable income when calculating a disabled person's charges and the individual has to justify any extra costs relating to their disability. Yet the original purpose of DLA was to meet those extra costs not to pay for social care. The current system is not working for individuals, carers or local authorities – that's why eligibility criteria are being used to ration care and if we are not careful local interpretations of 'basic' will again result in rationing of services.

All 3 options present difficulties:

- Partnership – While it is welcoming to see that everyone will get some financial help, CILL suspects more means testing will be required and that's exactly what we do not want. Apart from anything else, the cost of administering financial assessments swallows up much of the revenues collected. Also, those older people who need a lot of expensive care and support will still be faced with the prospect of using up all of their life savings and selling their homes. As for younger disabled people it suggests that the current system continues but it is not working and in reality reduces disabled people to poverty.
- Insurance – Obviously it will not work for disabled people but CILL can also see that it may not be affordable to many if what you have to pay in starts being 'loaded' because of other pre-existing conditions – high blood pressure, smoking, obesity, family history etc.
- Comprehensive – This system offers free care and support to all so you will not have to use all your savings but although you can defer payment until after your death those with relatively small savings or a property feel it's unfair to expect them to pay in the region of £20,000 when they may not

have used anything like this and it doesn't matter whether you are very wealthy or just have modest savings everyone pays the same. The reality is that many, many older people will not use anything like this. Also we fear that some will reduce their assets prior to retirement to avoid paying in to the system. The comprehensive system will certainly be better for those relatively few older people who go on to have very high care and support costs but many will see this as another attack against those who work and save.

- There is no detail about younger disabled adults but if a free system is proposed then again that is welcome although CILL suspects something along the lines of the 'free' system we already have or in other words no incentive to save or secure a pension and even more means testing, Any new system needs to include an increased savings threshold and disregard DLA from assessable income so that it can be used by the individual for what it was originally intended – the extra costs incurred such as heating, special diets, clothing or travel costs to name a few. Currently earnings are disregarded for charges but private and occupational pensions are not, yet surely they are little more than deferred earnings so should be. All of these measures would help disabled people to have greater income and more life chances but there is nothing in the Green Paper to suggest that we will get anything much different to what we already have.
- All three options are unfair to people who have planned to be self supporting in retirement. Taking away Attendance Allowance will substantially reduce their income and unless eligibility criteria improve then those who do not qualify for basic support will have less income to meet their needs.
- The whole point of last year's Big Care Debate was to find out what we wanted. Well we wanted a care service funded through taxation – yet this option is dismissed and we cannot discuss it. At the Debate stakeholder events most people felt that the state should provide care and support for old and disabled people from its resources eg national insurance and universal progressive taxation and should be based on need and not means tested. Many people mistakenly believe this is already the case. The division between health and social care was created by the welfare reforms of the 1940s but has always been artificial because it is the health condition that causes the care and support need - so if the NHS is free at the point of need why isn't care and support? We had hoped that the Green Paper would at least attempt to rectify this longstanding injustice. It does not. Moreover the argument, against taxation, put forward in the Green Paper does not take into account the tax that is paid by older, retired people and disabled people. If more disabled people will be working in the future we think it reasonable that their care and support is funded through taxation. From what we can see the proposals do little to help those who have worked, saved and try to take responsibility for their lives and nothing at all for those disabled people who have never been able to work. All that these proposals

do is to further the worst aspects of 'welfarism' - they nurture dependency, penalise work, savings and pensions, and condemn all younger disabled people to economic hardship reducing opportunities.

Surely a small increase in taxation, ringfenced for care and support, where those who earn more pay in more but where everyone benefits would be a way forward. The proposals around joined-up working and single assessment are likely to reduce some of the costs of administering the system. There is also the issue of possibly using a small percentage from NHS budgets as preventative services and personalised care are likely to reduce demand on the NHS.

CILL does not believe that it is a question of affordability rather it is a question of political will. There always seems to be money for other causes, illegal wars, bailing out banks, cutting VAT, car scrapping incentives and more, but not for the welfare of two of its most disadvantaged groups. We suspect its because these groups are largely voiceless with little power but the measure of a humane society is how it cares for its most vulnerable members.

A national or local system

We believe that the care and support system should be fair and universal. But we also need to ensure that the system is flexible enough to respond to local circumstances and encourage innovative approaches. There could be two different approaches to how the system works – either a part national part local system or a fully national system. The two approaches have different implications for the way money is raised and distributed around England.

3b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

- While CILL understands the argument for part local part national involvement unless money and service provision are separated the postcode lottery we have at the moment is likely to continue. The inbuilt conflict of interest in allowing assessment of need to be carried out by the purseholder will continue.

The funding for basic care, whatever we decide that is, should be decided nationally to national standards. The need for a national service highlights surely that care and support is a national issue and how that is funded deserves a national lead and responsibility.

Conclusion

CILL welcomes the formation of a National Care Service.

While we broadly agree with the vision we believe that there must be an agreed national definition of basic level care and support if we are to really understand what the service will provide and to avoid more postcode lotter-

ies of service provision.

We would also like to see information and advice expanded to include advocacy.

As to the overall objectives of being fair, simple and affordable they are subjective. An end to means testing would we believe be a better way of ensuring fairness and simplicity.

We are also concerned that affordability of services will take precedence over needs being met in a suitable way. They also need to include equity and non-discriminatory.

To achieve the vision we see a national body bringing together all the professionals and sectors needed with service provision managed locally.

In practice we would like to see a Care and Support body to set standards, co-ordinate the service, share good practice, foster partnership working, ensure confidentiality of information and have budgetary control of the money going in to the system. At a local level we believe user led organisations have knowledge and skills that are important for service provision and must be used.

Barriers to this will include a reluctance by present agencies to give up control and concerns around the cost involved to public spending. However we need a national body focused purely on care and support and what we have now is not working.

We have major concerns around all 3 funding options:

Partnership – For older people while we welcome the idea that everyone gets some help, the reality is that those who need a lot of expensive care and support will still lose all their savings and property. For disabled people it implies that we already get free care and support, which for most is untrue, and seeks to continue the present system which is not working.

Insurance - Clearly it will not work for disabled people but if what you have to pay in starts being 'loaded' because of other pre-existing conditions – high blood pressure, smoking, obesity, family history etc. it will not be affordable to many.

Comprehensive – The fact that all older people will get free basic care and support sounds attractive but firstly we don't really know what that means, secondly all older people with savings or property will have to pay in the region of £20,000 although many will not need anything like that level of care – so those who work and save are penalised, and thirdly there is no detail about how a free system for younger disabled adults would work.

Last year's Big Care Debate highlighted that most people want a service funded through taxation. We argue that this is the fairest and simplest system – free services at the point of need without means testing, no discrimination and prejudice against those who have worked and saved and an end to the artificial divide between health and social care. It is no use dismissing this as unaffordable the issue is whether there is the political will to do it.

Any new system for younger disabled people is, we believe, unlikely to be

completely free but we suspect will include means testing. If so we say that savings thresholds must be raised, private and occupational pensions disregarded as deferred earnings and DLA to be taken out of assessable income so that disabled people can use it for its original purpose – to help with the hidden extra costs of living with a disability.

All three options are unfair to people who have planned to be self supporting in retirement and taking away Attendance Allowance will substantially reduce their income.

There is a conflict of interest in allowing assessment of need to be carried out by the purseholder and unless funding and service provision are separated the postcode lottery we have at the moment is likely to continue. That is why we say that the funding for basic care, whatever we decide that is, should be decided nationally to national standards. The need for a national service highlights surely that care and support is a national issue and how that is funded deserves a national lead and responsibility.

The issues around funding care and support are complex and while the vision of a National Care Service is to be applauded the funding options will not support any system that can be described as running alongside the NHS and any comparison is misleading.