

Your Feedback on The Big Care Debate...

Re: CVS Hounslow Health & Social Care Voluntary Sector Forum on Tuesday 29 September 2009 at Isleworth Public Hall.

On Tuesday 29th September 2009, CVS Hounslow in partnership with Parents In Touch and the Hounslow LINK held the 2nd Health and Social Care Voluntary Sector Forum at Isleworth Public Hall. The theme for the meeting was on the Big Care Debate.

Shaping the Future of Care Together spells out a vision to build a National Care Service that is fair, simple and affordable for all adults in England. It sets out the options for service reform, and how the new system could be organised and paid for. At the forum, we considered the 3 main government consultation questions on what the new system would like and how it should be funded. This feedback report captures the summary of the points participants raised at the meeting in response to each of the questions, and this is your chance to add anything else that we may have missed.

Summary

In some parts, we had more questions than answers in response to the Government's proposals. This is an indication that, overall, the proposals set out are not clear and specific enough. We think we understood the big picture, but we need more information on the details and how it will work in practise and whether there will be effective checks.

We are concerned about the little focus carer's issues received and how their needs and aspirations would be reflected in the design of the new National Care Service. The forum were strongly in favour of having a Care Ombudsman.

We are also concerned that accommodation costs are not included in the cost of funding for the new system. Specialist accommodation costs are very high and would need to be included in any government proposal to support people to stay in the community. **End.**

Full Feedback

Responses to Question/Topic 1 – Approach

The Government wants to... build a National Care Service that is fair, simple and affordable. The Government thinks that in this new system there are six things that you should be able to expect: Prevention services, national assessment (ending post code lottery), a joined up service, information and advice, personalised care and support and fair funding.

Government question: a) Is there anything missing from this approach?

You said...

1. There needs to be an effective way of monitoring the system to ensure that it is meeting its aims and objectives and there is quality assurance. The forum strongly supported the idea of creating an ombudsman.
2. Access to aids and adaptations is just as important as access to care.
3. It is important you get services when you start to need them, instead of being put on a list until you get worse. What guarantees are there on the speed of response to changing individual needs?
4. Information should be offered in different formats such as easy read, different languages, tape etc. There are significant unclaimed benefits currently. The forms are far too complex. How will this be dealt with in a new system?
5. Advice options should include one to one support by independent organisations using advocacy and disability mentors.
6. Services need to be delivered at community level, including an accessible appeals process. It is important to raise awareness of the services that are available and that there is outreach work alongside this.
7. Fair funding is a good idea in principle. The outcomes specified by the government need to be more detailed and specific especially for under 65s so that people are clear about what the benefits are and what it will mean for them in their everyday lives.

8. The government's proposals state that, in the new system, services will be personalised, however, there is NO mention of carer's needs and support in the 6 elements at all.

Government question: b) How should this work?

You said...

1. If services are to be joined up, then budgets and funding must be joined up too.
2. There should be more service user involvement and users should be on best practice boards.
3. We should receive care within a reasonable time frame such as one month after assessment.

Responses to Question/Topic 2 – The vision

The Government thinks... that, in order to make the vision of a National Care Service a reality, there are three key challenges we will need to make to the care and support system. We need: More joined up service working, a wider range of care and support services and better quality and innovation.

Government question: a) Do you agree with this?

You said...

1. Joined-up working needs to start at point of access to care (i.e. whilst still in hospital). What support will there be then?
2. If a wider range of care and support services is to be delivered, won't this make coordination even more difficult than it is now? Who co-ordinates?
3. The range of current services and benefits is confusing. Won't a wider range be even more confusing?
4. There are no clear defined roles between the NHS and National Care Service in the new system.
5. Commissioning needs to have sufficient flexibility to awards contracts to innovative projects that have some element of risk.

Government question: b) What would this look like in practice?

You said...

1. Who updates and checks the information? This is not clear in the proposals.
2. How will confidentiality be maintained? This is not sufficiently explained.
3. Joined-up working will never be achieved unless you eliminate the gulf between NHS and Social Care and merge their funding streams.

Government question: c) What are the barriers to making this happen?

You said...

1. Current trends in social care (contracted-out services and independent commissioning) are good for innovation, but unfortunately the same trends can work against good training and good information.
2. Bed-blocking is the largest current barrier and needs to be dealt with under any new system.
3. There are artificial geographic boundaries between neighbouring local authorities and primary care trusts. What is the intention around making reciprocal arrangements work?
4. We need to learn the lessons from Children's Services – the Lamb Inquiry has recognised the inherent conflicts and will be removing assessment and monitoring from the organisation charged with commissioning, provision and delivery (the local authorities).
5. Human selfishness and lack of putting other people first including those less fortunate than us.
6. How do you maintain the value of the investment and insurance scheme? What guarantees are there?

Responses to Question/Topic 3 – The Cost of Care

The Government think...that there are three ways in which care and support could be funded in the future. It is important to note that these options consider only the cost of people's care and support and **do not include accommodation costs** including cost of food and lodging. There are three funding options.

Partnership – This option means that the responsibility for paying for care 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 low income.

Insurance – This option is the same as the Partnership option 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 between a quarter and a third of the cost of care and support, the Government would make it easier for people to take out insurance to cover care and support costs.

Comprehensive - This option means that everyone over retirement age could afford it would pay into a state insurance scheme, meaning that everyone who needs care and support would receive it free. This option would mainly work for people under retirement age – there would need to be transition arrangements for people who have already retired.

Government question: a) Which of these options do you prefer, and why?

You said...

1. What is National Insurance for? Does it not cover care?
2. For the insurance options, we are told of the cost (premium) attached, but the benefits are not stated. What's in the insurance clauses/fine print?
3. Who underwrites the insurance?
4. What guarantee is there that the benefits envisioned will actually be delivered, as much as 30 years later?
5. We are not sure we can trust the government sufficiently, to pay over large capital sums now for insurance and trust that the benefits might not be reduced later over the next 20 or 30 years, by the time we need the Care. For example,

pensions have been downgraded by the government at the same time as National Insurance contributions have steadily increased.

6. The government is perceived as having a poor record of delivering what they promise, so entering into this 'insurance' contract and paying in advance seems very risky indeed, compared to investing the money ourselves.
7. People who pay for insurance will expect accommodation costs to be included in the 'policy'.
8. Current unpaid carers save the government £billions. Do these proposals have sufficient scope for increased expectations? Is the aim to replace the carers?
9. The current system works for some – will it remain the same for them? Will there be transition arrangements?
10. The Green Paper talks about increasing choice, but many people see the withdrawal of Attendance Allowance (AA) and Disability Living Allowance (DLA) as reducing choice, since these benefits are spent at the discretion of the recipients now.
11. How can the Green Paper promise that an equivalent level of care will be provided for people who currently receive AA/DLA, without even knowing how we spend the benefit now?
12. The figures don't seem to add up. If people buy into the Insurance option, it would cost them £25,000. If the Comprehensive option is introduced everybody would be required to pay £17,000-£20,000. How can this be? Compulsory or voluntary the insurance policy is providing the same level of cover to the individual so why is the premium so different?
13. Similarly I'm told my average care costs will be £30,000 and the Partnership model will fund a quarter to a third of that. If I have to contribute 75% of the costs I will have to find £22,500, so why would £25,000 be attractive?

Government question: b) Should local government say how much money people get.....or should national government decide?

You said...

1. Both options depend on effective ring-fencing of the monies. We are all aware that many current announcements of 'additional funding' do not reach the supposed recipients.

2. If local, will this not retain or recreate the current postcode lottery? High cost, low incidence conditions will be badly served if local providers cannot access more specialised regional or national provision. If local, pathways to national provision must still exist.
3. National decisions would cut out a tier of bureaucracy within every single local authority.
4. If national, decisions can be challenged more simply and this would help create a more responsive service.

Government prompt: a) Accommodation costs are not included

1. Accommodation in care home can cost £850 per week. Why isn't accommodation included? It's a very significant cost and needs to be included. Specifically, proper preventative care quality cannot be delivered without including accommodation cost.
2. If accommodation costs are not being met, how would those on a very low income pay for those?

Government prompt: b) Should disability benefits be included?

1. We believe that disability benefits should NOT be included in any new proposal. We believe that disability benefits should be included in any new proposal. People do not want to spend their DLA on care costs. Even if this funding would not be lost, people didn't want DLA combined with care money. DLA should be separate. This is a big concern for all of us. This policy should be reconsidered
2. It is essential that Carers Allowance, which depends on the awarding of DLA or AA to the person receiving care, is retained for those less than 65 years of age who have to give up work to care. Carers need to be able to collect enough national insurance credits to still qualify for a full pension at retirement age.
3. DLA and AA are Benefits and are awarded by the Department of Work and Pensions to agreed National criteria. If one or other or both were to be subsumed into Local Authority funding they must be ring-fenced, and subject to National criteria, otherwise they will become subject to a postcode lottery.

You're additional and/or general comments...

1. No indication is given in the government document, *Shaping the Future of Care Together*, as to what 'basic needs' would consist of.
2. There is a paperwork burden for people with Learning Difficulties. We need clear messages so that we can communicate this more effectively to those we aim to support.
3. The Government paper refers to free care, but we are all paying for this through the tax system.
4. What are the plans to include disabled people at strategic decision-making level?
5. For people with life-long conditions their families have been involved in their care from birth. Family carer status needs to be recognised for as long as both parties agree to it.
6. It really does not make sense to have separate children's and adults' provision. It is highly unsettling for everything in your life to change at age 18 or 19 and you have to get to know a whole new team and system. Transition needs to be much smoother, with an aim of being seamless.

End of full feedback summary.