

Care Support Independence

# Care and Support Conference 19 February 2010

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# **Care and Support Conference**

19 February 2010

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## 1. Introduction

On 19 February 2010 the Secretary of State for Health, the Rt. Hon. Andy Burnham MP, invited key stakeholders from the Care and Support Alliance as well as a number of other organisations, including representatives of political parties to attend the *Care and Support Conference*.

The Central Office of Information (COI) facilitated the event, and has produced this report on behalf of the Department of Health (DH).

This report is summary of the event and will be distributed to all those who attended as a record of the discussions that took place.

## 2. Background

In July 2009, the Government published the Green Paper *Shaping the Future of Care Together*. This Green Paper was built on a long period of engagement that took place throughout 2008, during which the need for reform of the care and support system was debated.

Shaping the Future of Care Together set out the Government's proposals for meeting these challenges, through building a new National Care Service (NCS) that is fair, simple and affordable for all adults in England. The publication of Shaping the Future of Care Together also marked the beginning of the Big Care Debate, a wide ranging consultation on the proposed reforms, which ran from 14 July to 13 November 2009.

Although the formal consultation has now ended, the debate on the future of the care and support system has continued.

## 3. The Secretary of State's Challenge

Following a letter to *The Times* by members of the Care and Support Alliance calling for a serious and mature debate on care and support reform, the Secretary of State convened the *Care and Support Conference*. Against this backdrop, the Secretary of State's purpose in convening the *Care and Support Conference* was to give key stakeholders from the Care and Support Alliance and a number of other organisations<sup>1</sup>, including representatives of political parties an opportunity to debate key questions raised by responses to the consultation. In doing so, they were invited to present politicians from across all political parties with their views on where the debate has reached, on how to move forward, and on building a lasting consensus on the reform of the care and support system.

In inviting participants to attend the conference, the Secretary of State welcomed the fact that the *Big Care Debate* has stimulated a significant increase in the attention given to and support for radical reform of the care and support system in England. He also took the opportunity to offer delegates a summary of the issues emerging from the analysis of responses to the *Big Care Debate* consultation, noting what he believed to be three broad areas of consensus around:

<sup>&</sup>lt;sup>1</sup> A full list of attendees can be found in the appendix at the end of this document.

- 1. The principle of national entitlements to replace the current lottery of local eligibility rules.
- 2. The aim of personalisation giving individuals and families maximum control of the care and support they receive, and providing support in the form of direct payments where these are wanted.
- 3. The need for care and support to be funded through a relationship of shared responsibility between the individual and the state.

The Secretary of State also pointed out that the *Big Care Debate* has highlighted a number of difficult choices that must be addressed if the proposed reforms are to be successfully implemented. He summarised these questions as follows:

- 1. To what extent should we reform disability benefits for older people into a single care and support system?
- 2. How can we move care and support to be more preventative, so that people can get help earlier to prevent falls, slow down any physical problems and enable them to live well and independently in their own homes for longer?
- 3. How can we make health and social care provision more integrated?
- 4. If we accept the need for individuals to contribute to the costs of care and support care as well as the state, should the contribution be compulsory or voluntary?

It was these questions that the Secretary of State asked participants at the *Care and Support Conference* to address. His hope was to produce at the end of the event a document outlining the key areas of consensus and any other areas where it was agreed that more work was required.

### 3.1. Event structure

The event was chaired by Dame Denise Platt. Joining the Secretary of State on the panel were Phil Hope MP, Minister of State for Care Services, Norman Lamb MP, Liberal Democrat Shadow Health Secretary, and David Behan, Director General for Social Care from the Department of Health.

The day opened with a short welcome from the Secretary of State, in which he restated his summary of both the areas of consensus and the challenges that have emerged from the *Big Care Debate* consultation. This welcome was followed with an address from Norman Lamb, who emphasised the need to move this debate away from political point scoring and to retain the focus on the needs of care service users and their families.

Following these short addresses, David Behan gave participants a more in-depth summary of the consultation process and of the key questions and issues for debate. The Secretary of State then restated his aspiration that participants use the day to work towards a statement of agreement on these questions and issues.

Participants then took part in two table discussion sessions, in six small groups. A facilitator was attached to each group to guide participants through the key areas for discussion and to capture their views.

During these discussions they explored the following key questions:

1. The Vision for a National Care Service

- a. Do you still agree with the Vision for a National Care Service?
- b. Do you agree that the following are the remaining challenges? Are there any specific points around the issues?
  - Prevention
  - Integration
  - Role of the family/carers
  - Role of National/Local
  - Benefit reform
- 2. Funding a National Care Service
  - a. Which funding model or combination of models best delivers our vision of a National Care Service?
  - b. What are the general trade offs in this solution? Where should the balance be for;
    - Individual choice to contribute?
    - Predictability of cost?
    - Peace of mind?
    - Universal coverage?

Following each discussion session a spokesperson from each table provided feedback on what had been agreed. These key points were summarised in a draft document which participants agreed at the end of the event. This document can be found in section six, below.

Phil Hope and the Secretary of State closed the day by thanking everyone for their contribution.



## 4. The Vision for a National Care Service

During the first discussion session, participants gave their views on the Vision for a NCS overall. They also explored the challenges that had been outlined by the Secretary of State in convening the event, and gave their views on how these might be addressed.

## 4.1. The picture overall

Participants expressed strong support for the Vision of a NCS as outlined in the Green Paper. A number of elements of the Vision were singled out as particularly positive:

1. The **far reaching and radical nature of the reforms**, with participants particularly stressing the value of a reform to the system overall rather than merely how care is paid for.

"The system needs to work, the choices offered need to be realistic. The White Paper should be a true reform of social care, not just the funding part."

2. The perceived **strength of a national system**, in particular in removing the risk of a "postcode lottery" in terms of people's entitlements and their ability to access care services.

"We think national entitlement is a huge step forward."

3. Increased **mobility for care users** through the portability implied in the proposed national assessment system.

"Portability is absolutely key."

4. The increased **fairness**, **clarity and simplicity** that a national system implies. Participants were particularly keen to highlight the difficulties that people encounter trying to navigate the current system, particularly in terms of what is or is not paid for, and how to access services.

"Service users want fairness, equity and transparency, across different geographical areas. So having a national system is critical."

A system that works is vital, but also that is simple and easy to use."

5. The importance of learning from existing good practice was emphasised.

"Evidence from Isle of Wight and West Wittering shows that it can work."

Some participants also highlighted areas where they felt the Vision could benefit from an even more ambitious approach. Others suggested particular pieces of work they believed would be beneficial in making the Vision an effective reality:

 The need to establish strong public buy in to the proposals, with the caution that significant work will be required to achieve widespread acceptance of the requirement to contribute through the system to care costs, especially among those who currently assume that care and support is funded from taxation like the NHS.

Presenting a NCS in terms of citizens sharing responsibility across the community rather than as consumers receiving care was seen as one way to ensure that people understood and accepted what they were contributing to.

"People actually support a contributory model as long as they are clear about what they're contributing to."

For several participants, the increased flexibility implied by talking about a national care *system* rather than *service* would be beneficial. Others also highlighted the vital importance of achieving buy-in from health services.

2. The need to **tackle perceptions that the Green Paper is only aimed at older people**. This point was raised in particular by those representing disability organisations, who were concerned that the reforms may not improve understanding and public buy-in to the need to provide support for younger adults alongside the elderly.

*"What worries us at the Autistic Society is an over-focus on younger disabled people. Don't forget, these will become older disabled people."* 

3. The **lack of integration between adult and children's care services**. The importance of ensuring that care users could move seamlessly from child to adult services was highlighted, with some participants arguing in favour of a NCS for all *people* rather than for all adults.

"A national care service for all ages is what we hear people are looking for. There is an inter-generational aspect to care and support."

4. A need for **further transparency in the system**, with some participants advocating a more explicit focus on the planning needed to make the system work well.

"We need another 'p' in the Vision – Planned – so that people know what to expect at a point of crisis."

For many, this need for clarity is particularly strong when thinking about the different needs of different groups, for example younger compared to older care users.

### 4.2. The remaining challenges

After considering the Vision overall, participants then focused on a range of key issues arising from responses to the *Big Care Debate* consultation, which have been identified for further development in the Government's forthcoming White Paper:

- 1. Prevention
- 2. Integration
- 3. Carers, community and the family
- 4. Role of national/local
- 5. Benefits reform

The key issues raised during these discussions are outlined below.

### 4.2.1. Prevention

Participants were firmly supportive of the focus on prevention in the Vision for a NCS. They strongly agreed that effective prevention services can bring great benefits to care users, and can also create very significant cost savings.

"Prevention – it's the holy grail."

A number of areas were discussed where further consideration or clarity around prevention services would be seen as beneficial:

- 1. Further clarity on the **definition of prevention** included in the Green Paper. For example, there was uncertainty about whether leisure services might be covered. An explicit focus on the question of what it is we are trying to prevent was seen as likely to be helpful here.
- 2. Building on this point, the importance of ensuring intervention at lower levels of need, as it is at the lower levels that prevention services are most effective in keeping people healthy and well, and where they can deliver the greatest cost savings. Some participants suggested that delivering this might require some restructuring at the local level, for example Local Service Partnerships could band together around care for all older people, rather than focusing on provision for critical need when it arises
- 3. The need to **support providers in building capacity**. Some participants suggested that significant modifications may be required to the existing Fair Access to Care Services (FACS) allocation system in order to ensure it was creating effective incentives for organisations to provide prevention services.

Others suggested that payment by results within the NHS can prevent the transfer of acute budgets towards the creation of more capacity for prevention. The question of whether the NHS would ultimately be required to support prevention services was raised here, with some debate about the relative benefits of a mandatory requirement as opposed to a system of incentives.

- 4. The benefits of a **national prevention strategy**, both in terms of laying down effective definitions of prevention and also in ensuring that more capacity could be created through more effective interaction between NHS and social care systems.
- 5. The need to tackle a **lack of understanding and conviction among the general public** about the value and effectiveness of prevention service provision. It was suggested that a communications campaign to provide the public with evidence about the benefits of prevention would be beneficial in gaining their buy-in.

### 4.2.2. Integration

Participants unanimously agreed with the Green Paper's call for greater and more effective integration of services. A desire was expressed to understand more about how the Government was intending to work up the proposals around integration, and some participants cautioned that there would be risks for the integration agenda in creating a new, free-standing service.

Key points arising from these discussions were:

 The critical importance of ensuring better integration between health and social care services, particularly but not exclusively in the area of prevention. Participants strongly argued that it should not stop there, and that a truly integrated system of care and support would require participation from all relevant Local Authority services as well as a wide range of private and third sector bodies.

"Partnerships between [our charity], service providers and housing organisations are working."

2. The need to ensure that the **creation of a holistic system** remains the priority. Some concerns were expressed that the creation of a new care service 'institution' might detract from this aim. The effectiveness of national strategies in this area was highlighted, as they can provide user focused frameworks around which services from broad range of providers can be clustered.

"People are not looking for a service, but support in living their lives. People don't think of [this] as separate services."

*"With the Stroke Strategy, multi disciplinary teams show it's working. The key worker system with responsibility model works."* 

3. Building on the above point, the retention of an **explicit focus on individual's needs** as the core driver for creating an integrated system built around and capable of responding to the changing needs of the individual. It was noted that those in need of support cannot be expected to understand complex structural or definitional barriers between health and social care provision.

"Where dementia is concerned, partnerships are crucial between health and social services, to avoid the eternal debate about what's classed as health and what is social care. We need clarity and joining up to address this critical issue."

4. The need for a clearer understanding about **how integration would work behind the scenes,** across government, particularly in terms of an all encompassing social contract between central government and the population.

"How will a National Care Service tie in with other policy areas – this all needs to explicitly link with them."

"The Vision is trying to re-negotiate the social contract, so this needs to be a cross government issue. It's about how we live and everything needs to be built in."

#### 4.2.3. Carers, communities and the family

Participants strongly agreed with the Green Paper's focus on carers, communities and family, and supported the focus on the workforce in the Vision for a NCS, both in terms of formal and informal care provision. A care system that "works for employment" was called for, particularly in terms of the development of a clear career path and an attainment framework for carers.

Key points arising from these discussions were:

1. The need for a still more **explicit focus on quality** in the workforce. There was agreement that the Government must "fill this gap" before moving forward with realising the Vision. Careful consideration of exactly what the workforce would be

expected to deliver was recommended in particular, in order to allow for effective planning of services.

"Nothing much has been said about the staff delivering the service – critical to achieving the Vision – this is a gap that needs to be filled moving forward."

*"I'm concerned about the workforce. Do we have enough community nursing to deliver this, especially where those with specialist needs are concerned?"* 

2. The value of a focus on increased and more flexible **training and development** of the workforce as a core part of the Vision for a NCS.

"We should be designing a care system that works for employment, not just around the individual but getting carers in work, and ensuring training and support is critical. We need specialist NVQs and so on..."

3. The need to provide **long term help and guidance** to family and community carers was emphasised, particularly where people with specialist needs are concerned.

"Don't forget, the dependency ratio keeps changing. People with serious conditions are living longer and placing longer term demand on their carers."

4. The benefits of making a **clear statement about the value placed on the workforce**, particularly when considering the entitlement of informal carers and care users to benefits.

*"Informal care needs to be strengthened, and the benefits system needs to recognise this. Get more support to those who are caring, and help them."* 

5. A desire for a greater focus on **providing for the care needs of younger adults**, particularly in terms of the care and support provided by family members and the local community.

#### 4.2.4. Role of national / local

Participants recognised the significant difficulties inherent in establishing a good balance between national consistency and local responsiveness. There was significant debate about how this balance would best be struck, with little clear consensus emerging.

Key points raised during discussions were:

1. The value of the **principle of national consistency** in tackling endemic unfairness in the current system and ensuring greater clarity, transparency and trust.

"Key to this is trust. If I am paying in, what happens to my money? Currently there is a lack of transparency, there is complexity, and there is a lack of consistency."

2. The need to maintain the **ability of local providers to respond to local needs**, particularly in relation to the aim of building personalised services around the needs of the individual. For many, the involvement of care users and carers in the design of care provision at the local level will be vital in realising this aim.

"Local policy people know what local people want."

3. The possibility of a solution based on the **separation of assessment and entitlement from provision**. It was acknowledged that significant work will be required on the details of implementation. It was suggested that this would allow people certainty in terms of their entitlements, as well as giving them the ability to move round the country more easily, while also allowing the delivery of services to be tailored to local need.

#### 4.2.5. Benefits reform

Participants in general felt that the question of benefits and benefits reform was the least well considered issue in the Green Paper and the ensuing consultation. Many suggested that a commission or working group should be established to consider this question in significantly more detail.

However, participants noted that consensus in this area may be very difficult to achieve, given the breadth of the benefits question and the number of different groups that could be affected. It was suggested that political leadership and a clear decision from the Government would be required.

Several participants expressed support for the principle of harmonising and unifying the benefits system around care and support, although a number of provisos and cautionary notes were attached:

 Given the widespread popularity and reliance on benefits like Attendance Allowance (AA), a desire for work to be carried out to ensure that changes to the current benefits system would not cause people to lose current entitlements or cover. The need for relevant information to explain what the changes would mean to people was highlighted here, in particular where trade-offs between different benefit models are concerned.

"Can we devise a new system that keeps AA features but also is integrated into a wider care package?"

2. Alongside support for a simplified system, there was concern that **benefits which are currently universal could be lost** behind a new means tested system or due to re-categorisation of need as part of the implementation of a NCS. This was seen as a particular worry for those who currently receive AA but do not qualify for the top categories under FACS and who could therefore lose entitlement.

"Why not bring it together as a single entitlement. But would need to take care with this to make sure people weren't disadvantaged."

3. The need to preserve the **principle that benefits like AA and Independent Living Allowance are for living costs** rather than care costs. Participants noted that particular attention would be needed to ensure that a NCS was flexible enough to maintain benefits designed to help people with their wider living costs, and that the universal nature of these benefits must not be threatened.

"It's not just a benefit for care needs but for additional life costs."

"We agree that if the system can be made to work, in principle AA could be integrated."

- 4. The **difficulty of building a single system** that provides for all adults, given that younger disabled people and older people often have markedly different needs. Some participants believed that a wholesale reform of the adult benefit systems in line with the creation of a NCS might be required.
- 5. The importance of building a **benefits system that recognises and rewards those who provide informal care** to members of their family and local community.

"Capacity around informal care needs to be strengthened, and the benefits system needs to recognise this. Get more support to those who are caring, and help them."



## 5. Funding a National Care Service

During the second discussion session participants explored a range of issues around funding a NCS. These discussions were grouped around a number of key themes arising from responses to the *Big Care Debate* consultation:

- 1. Individual choice to contribute
- 2. Predictability of cost
- 3. Peace of mind
- 4. Universal coverage

A summary of the issues raised during these discussions is provided below.

### 5.1. Individual choice

The following key issues were raised in discussions around individual choice:

- 1. For some participants, offering people a choice over whether or not to buy in to the care system was a risk. In particular, it was noted that:
  - a. Given current low levels of awareness and understanding of the care system and how it is funded, significant awareness work and incentives would be required to ensure that enough people paid into the system.

"How do you incentivise when people are willing to take risks with their care?"

b. Certain groups in society, notably younger people, would be disproportionately less likely to pay into a voluntary system, potentially creating significant longer term inequalities.

"Very few young people buy pensions. For care and support this would be a crisis waiting to happen, the majority of people don't think it will happen to them. So you'd really need to incentivise it, through tax breaks, employer schemes, performance related pay and so on."

- c. Without such far reaching awareness raising work and a system of effective incentives to encourage people to buy in to the system, the Insurance model could leave significant numbers of people without adequate coverage.
- d. This situation would be politically challenging at both the local and national government level. Participants stressed that it would be very difficult to provide retrospective support to those who had not bought insurance, as people would be even less likely to feel it was worth it in the future.
- e. For participants representing disability and other groups concerned with younger adults, the notion of a choice about whether to buy into the system is an anomaly.

*"For older people it's one thing, at least ageing is predictable. But with the onset of Motor Neurone Disease or with a stroke, this question doesn't make sense, because how could you predict that and make the right choice?"* 

- For the vast majority of participants, the key focus around individual choice in a NCS should be on the importance of providing carers and care users with a good choice of high quality services, rather than focusing on a choice of systems. A number of key points were raised here:
  - a. In terms of the choice between funding options, participants stated almost unanimously that the people and groups they represent – once they understand that care is not already paid for by tax or National Insurance contributions – believe that only a compulsory system would be able to deliver this range of options.

"[Ideally] you decide how to use [funding] as you want, for example to support the family unit. Personal care is too narrow a definition; it might not just be about buying services."

- b. Several participants suggested that within a compulsory system, there would still be room to offer people flexibility and individual choice. In particular, it was suggested that people could be offered the option of topping-up their care contribution, which is seen as working well in the areas of health and education
- 3. Participants were clear that in a compulsory system, it would be very important to offer the broadest possible range of **choice in the ways that people would pay** into the system.
  - a. It was noted that any system of payments must be flexible enough to change with people's changing circumstances. This might include giving people the possibility to take a payment holiday from their regular contributions, or the chance to pay off the full amount at any time.
  - b. Several participants also suggested that the option for people to pay into the system during their working life should be introduced as soon as possible.
  - c. Participants also stressed that the range of payment options would need to be very clearly explained to people, to ensure that they were making the appropriate choices. The provision of effective and easily accessible information, advice and guidance on these choices was also seen as crucial.
  - d. Many participants highlighted the importance of supporting the choice to care within a compulsory system. They stressed that there must not be any perverse incentive against providing family care, and that allowing people to make at least some of their contributions in kind in the form of providing informal care within the family or community would help to alleviate this risk.

"Need to ensure that different ways to contribute are recognised, not just financial ones. Formal recognition is needed from the system. What a person has to do in order to give the care, for example giving up work, needs to be compensated."

## 5.2. Predictability of cost

Predictability of cost was seen as a vital element of a NCS, in terms of the costs to be met by individuals, service providers and the state. As outlined below, predictability is also seen as strongly linked to peace of mind.

For the vast majority of participants, **a compulsory funding system would offer the best balance of predictability** across these groups.

- 1. The key problem attributed to **the Partnership model is that it does not allow for predictability of cost**, particularly to the service user. This was also seen as markedly unfair, as under this system those with the highest levels of need would continue to pay the most, with no theoretical upper limit to their costs.
- 2. Similar concerns were raised around predictability of cost with the Insurance **model**. In particular, participants were worried that people's ability to choose whether or not to pay into the system would be hampered by the impossibility of predicting in advance what care costs will be. For many, this makes the notion of choice inherent in the insurance model misleading.
- 3. Of the options under discussion, the **Comprehensive model was seen as** offering the greatest predictability of cost as it is the closest to a notion of universal entitlement. For many, the ideal system would be a fully integrated entitlement to health and social care, especially for disabled people of working age. While it was recognised that this is unlikely to be achieved unless care and support is funded from general taxation, the comprehensive model was seen as offering many of the same benefits.

"The gold standard for our members would be a national system embracing both health and social care, integrated entitlement is best. And second most popular was comprehensive – consistent, clear, easy to understand."

- 4. Participants were concerned that even in the comprehensive system **uncertainty around accommodation costs** would prevent true predictability of cost.
  - a. It was suggested that more clarity is needed to ensure people are aware that they remain responsible for their own accommodation costs
  - b. Participants also proposed that the provision of very clear guidance on what accommodation costs might be in a range of different situations would give people at least some ability to predict their likely costs

### 5.3. Peace of mind

Participants agreed strongly that providing people with peace of mind should be a core aim of a NCS. For the majority of participants, **the comprehensive model was seen as most likely to achieve this.** 

The following key issues were raised in the discussion around peace of mind:

- 1. The key criteria suggested for choosing between the options are:
  - a. The relative clarity of the system
  - b. People's ability to understand it
  - c. People's ability to trust it

d. Its 'visible'; ability to meet people's diverse needs.

Of those under discussion, the **comprehensive model was seen as the** simplest, the easiest to understand and navigate and the most likely to be able to effectively meet a broad range of needs

"Fairness + trust + clarity + feeling real needs are met = peace of mind."

2. A particular perceived benefit of a comprehensive system in terms of peace of mind was the fact that it **pools risk across the population**. In particular, this was seen as important where those with low incomes are concerned, as this group would be least likely to be able to meet the demands of a partnership system, and would be least likely to pay into a voluntary insurance system.

*"If you know your care is covered, a big risk is reduced as you know you will be able to meet costs and can leave something to children etc."* 

It was also noted that the pooled risk nature of the comprehensive system would give greatest peace of mind to the growing number of people living longer with higher care needs, as they would know that their costs would be covered.

"We know those with big care needs is growing, costs are too, so we need a system that ensures peace of mind – pooling risk allows this."

3. However, some participants noted that work would be needed to ensure that people felt they could trust the comprehensive system, as it does not automatically provide clarity on where a person's contributions are going. Concern was expressed that if people felt their contributions were "disappearing into a black hole", they would lose much of the peace of mind that a compulsory system would otherwise offer.

#### "The person's 'pot' must be simple to understand."

A centralised and clearly ring-fenced financial resource was suggested, into which people's contributions flowed and from which they could one day draw down the support they needed. This was seen as likely to help people feel secure that their money was being used in the right way and that the proper level of resource would be available to them if they needed it.

4. In order to ensure the highest level of buy-in and understanding of the comprehensive system, participants also stressed the need for a clear statement on the balance between entitlement and individual responsibility in the system. In particular, it was suggested that people should be encouraged to understand that they are investing in their future care provision.

"We need to be clearer about responsibilities."

5. However, participants were again concerned that people's peace of mind could be threatened by uncertainty over accommodation costs. As outlined above, participants felt that if accommodation costs are not to be covered by the care and support system, any guidance and support that could be offered on likely accommodation costs in a range of scenarios would be welcomed.

### 5.4. Universal coverage

Participants raised the following key issues in their discussion around universal coverage:

1. There was a strong feeling that only a system based on the principle of universal coverage would be able to **balance individual choice**, **predictability of cost and peace of mind**, in particular where those on lower incomes and those with the highest level of need are concerned. The principle of universality was also seen as likely to achieve greater buy-in from the population.

"None of us have an allergic reaction to compulsory, but universality is a better way of presenting it."

2. Universal coverage was also seen as the easiest principle for people to understand and buy into, especially as it is the most similar to the NHS system.

"There is broad public support for a framework like the NHS and the comprehensive model is similar – if those are linked – people will be supportive and sympathetic."

It was also noted that a system of universal coverage would be the easiest to integrate effectively with the NHS.

- 3. Participants also pointed out that as well as meaning coverage for all people, a clear statement would be required over the meaning of universal coverage in terms of the range of care and support costs that would be met by the system. In particular, strong support was expressed for a system that contributes towards meeting care costs at lower levels of need, including some leisure and recreational activities not traditionally seen as part of a care system.
- 4. Many participants, in particular those representing disabled adults of working age, regretted that the option of going the whole way to universal entitlement in the form of general taxation option was not under discussion.
- 5. Indeed, it was also noted that even under a comprehensive model, universal coverage does not necessarily mean that there is only one system for everyone. Participants stressed that different cohorts in the population have markedly different needs, different ability to pay, and would be likely to have different levels of acceptance of the requirement to contribute individually to a comprehensive system. Even where a comprehensive model was chosen for older people, who make up the bulk of those with care needs, participants were supportive of the idea that disabled people of working age might still be supported out of general taxation, which was seen as a far more sustainable system for this group.

"For the older generation who have lots of housing assets I think a comprehensive model would work, but not for the younger generation – needs to be more sustainable. Younger people need a more sustainable solution."

"[Our members] said they want a system that allows young disabled people to work."

6. Many participants suggested that in order to achieve the greatest level of public buy-in to a compulsory system, a phased introduction would be helpful.

- a. For some, a model that was initially voluntary but which led down a clearly defined path to compulsion was seen as likely to be effective.
- b. Others suggested a model based on growing levels of compulsion. This might begin with an opt-out model, leading to a full requirement for people to pay in.
- c. Others proposed that different levels of compulsion might be levelled at different groups in the population. According to this model it was suggested that older people could be compelled to pay into the system while those still working could be given a greater level of freedom to choose, at least in the short term.

"We need different options for those still working and those retired."



## 6. The Conference Statement

During the final plenary session of the day, the whole conference produced a summary statement of the key messages that they wished to send to politicians on the future of care and support in England. We have reproduced this statement in full as a summary of the final discussion and agreement.

#### **Care and Support Conference**

Key voices in the care and support world came together and discussed the key issues facing the care and support system, to give their views to national and local politicians.

It was a helpful, broad ranging, high level discussion that helped to build consensus towards a White Paper. This report summarises views given by attendees at the conference and was agreed by delegates at the final session as a summary to provide to politicians.

#### Consensus around the Vision...

There was consensus around the Vision for the National Care Service

- 1. A national care service, where individuals make a contribution in partnership with the state
- 2. A system which enables assessments of need to be portable across the country, but delivered locally with local government in the lead
- 3. A personalised system, giving individuals and families maximum control of the care and support they get
- 4. A priority for preventative care and early support
- 5. A joined-up service where all the services that you need will work together smoothly. This includes better joined up working between health, housing, social care and the disability benefits systems
- 6. Clear information and advice so people can understand and find their way through the care and support system, including disability benefits and health

#### But we also agreed...

In addition to this Vision reform also needed to

- 1. Give more emphasis to the vital role that carers, families and communities make to the system
- 2. Give more emphasis to the importance of including adults of working age, ensuring this part of the system is fully funded and better managing transition from childhood to adulthood
- 3. Recognise that workforce planning and development are critical to the quality of care and support
- 4. A wider range of high quality services to support people to experience personalised services
- 5. Give people more detail on delivery, including winners and losers, and no perverse incentives

- 6. Be clear whether it is a national system or service
- 7. Not be isolated from other services e.g. housing, leisure, transport
- 8. Support people as citizens, not passive recipients
- 9. Promote opportunities for better integration between disability benefits and the social care system
- 10. Recognise that a good care and support system will not only deliver quality care for the individual and their family but will also provide an infrastructure to support employers and increase wealth

#### There was concern over the possible reform of disability benefits

- 1. Everyone acknowledged that such benefits provide valuable support to a wide range of people, for a range of disability-related costs. It was agreed that existing or potential recipients should not lose out
- 2. People were fearful that reforming disability benefits would impact on their quality of life and independence
- 3. Any reform needs to capture the strengths of the current benefits system, including universality

#### Comprehensive is the emerging consensus

- 1. On balance, the majority view is in support of a comprehensive system, with a variety of ways to pay the contribution
- 2. An element of compulsion was supported, whether soft or hard
- 3. Universality and fairness is important and we need to consider people's ability to make a contribution (progressive, not a flat rate)
- 4. The contribution of carers needs to be taken into account and recognised in the payment options
- 5. Any system needs to be simple and understandable
- 6. There needs to be clarity over what you receive in return for your contribution
- 7. On balance the majority view was to reject the Green Paper options of 'Partnership' and 'Insurance'
- 8. Any change may need to be phased in over a period of time, recognising affordability
- 9. Any system needs to work for future generations as well as the immediate cohort
- 10. The conference regretted that the option of general taxation had not been explored

## 7. Appendix: Event Attendees

Imelda Redmond - Carers UK Chief Executive Des Kelly - National Care Forum Executive Director Martin Green - English Community Care Association Chief Executive Michelle Mitchell - Age Concern & Help the Aged Charity Director Lynne Berry - WRVS Chief Executive Ciaran Devane - Macmillan Cancer Support Chief Executive Sue Bott National - Centre for Independent Living Director Carole Cochrane - Princess Royal Trust for Carers Chief Executive Dame Philippa Russell - Standing Commission on Carers Chair Matt Davies - Department for Work & Pensions David Oliver - Department of Health National Clinical Director for Older People Alistair Burns - Department of Health National Clinical Director for Dementia Anthea Cox - Learning Disability Coalition Director Nicola Kay - HM Treasury Senior Policy Adviser, Health Team Richard Harries - Communities & Local Government Deputy Director (Council Tax) Councillor David Rogers - LGA Chair of Community Wellbeing Board Benet Middleton - National Autistic Society Director of Communications and Regional Development Baroness Thornton - Government Spokesperson for Health Ruth Sutherland - Alzheimer's Society Interim Chief Executive Sue Brown - Sense Head of Campaigns and Public Policy Cara Brown - Resolution Foundation External Affairs Manager Sarah Wellard - Grandparents Plus Policy and Research Manager John Kell - MND Association Acting Head of Policy Graham Barker - The Stroke Association Public Affairs and Policy Manager Lesley Rimmer - UKHCA Chief Executive Stephen Burke - Counsel and Care Chief Executive Nick Starling - ABI Director of General Insurance & Health Joe Farrington-Douglas - NHS Confederation Senior Policy Manager Melanie Henwood - MS Society Chair of Advisory Group for Independent Living Anne Roberts - Crossroads Care Chief Executive Julie Jones - SCIE Chief Executive Judy Downey - Relatives and Residents Association Chair / Acting Chief Executive

Jenny Owen - ADASS President Mark Goldring - Mencap Chief Executive Norman Lamb - MP Liberal Democrats Richard Humphries - The Kings Fund Senior Fellow, Social Care Steve Winyard - RNIB Head of Policy and Campaigns Guy Parckar - Leonard Cheshire Disability Public Policy Manager Laura Courtney - Every Disabled Child Matters Campaign Director Val Buxton - Parkinson's Disease Society Director of Policy, Campaigns & Information Peter Challis - UNISON National Officer, Local Government Geraldine Cunningham - Royal College of Nursing Head of Learning and Development, RCN Institute Winston McKenzie - UK Independence Party Dan Beety - Sue Ryder Care Head of External Communications Andy Burnham - Secretary of State, Dept of Health Phil Hope - Minister for Care Services, Dept of Health

David Behan - Department of Health

Shaun Gallagher - Department of Health

Sally Warren - Department of Health

Catherine Davies - Department of Health

Richard Simper - Department of Health

Elspeth Henderson - Department of Health (event organiser)

Alex Szyjanowicz - Department of Health (event organiser)

Edward Gilbert - Department of Health (event organiser)

Dame Denise Platt - MC / Lead Facilitator

Brian Parry - COI (facilitator)

Tom Wormald - COI (facilitator)

Anna Brocklehurst - COI (facilitator)

Nick Wilson - COI (facilitator)

Jo Hudek - COI (facilitator)

Mark Pragnall - COI (facilitator)

Andrew Forth - PS to Norman Lamb MP

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