

Minutes Joint APPG on Reform of Care and Support 26Oct2010 FINAL

Joint APPG on Reform of Care and Support

All Party Parliamentary Groups on Social Care; Ageing and Older People; Carers; Dementia; Disability; Housing and Care for Older People.

Tuesday 26 October 17:15-18:45

House of Commons, Committee Room 14

Contributors to the meeting: Lord Best (in chair, APPG on Housing and Care for Older People), Barbara Keeley MP (Social Care), Penny Mordaunt MP (Ageing and Older People), Baroness Pitkeathley (Carers), Hazel Blears MP (Dementia), Baroness Campbell of Surbiton (Disability), Dr Hywel Francis MP, Lord Haskins, Baroness Howarth of Breckland, Baroness Howe, Margot James MP, Sarah Newton MP, Malcolm Wicks MP.

Apologies: Lord Jack Ashley of Stoke, Peter Bottomley MP, Baroness Greengross, Anne McGuire MP

Speaker: Andrew Dilnot, Chair of Commission on Funding of Care and Support

Welcome and Introduction

Lord Best opened the meeting with a brief overview of the work by the Coalition Government and the Labour Government on reform of social care and support, and set the demographic context to illustrate the need for reform of care and support.

Whilst there will be a growing need for care and support, mainly due to the growth in the number of older people, there have been warnings that growing demand and cuts to local authority budgets could lead to a shortfall in social care spending of as much as 40%.

Andrew Dilnot

The Commission is formed by **Andrew Dilnot** (Chair), Dame Jo Williams and Lord Norman Walker. It is supported by a secretariat of 10 people.

It was set up by Government as an independent body to make recommendations on how we can achieve an affordable and

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sustainable funding system for care and support, for all adults in England, both in the home and other settings.

It will also be looking at funding in the context of broader support for older people and other users of care services. The Commission will report on its findings to Government by end of July 2011.

In its first months, the Commission has been making submissions to the Spending Review and planning for the year ahead. The Commissioners expanded the criteria set by the Coalition Government by which they will assess future options for the funding of care and support, and these criteria are now on their website.

The criteria are:

- **Sustainable and resilient:** ensuring the costs to the state are sustainable in the long-term, and the care and support system is able to respond to demographic, economic, political, and societal change
- **Fairness:** for individuals, families, carers and wider society
- **Choice:** offering an affordable choice to individuals, carers and families across a range of care settings, and helping people to prepare and plan for their future
- **Value for Money:** securing the highest quality care outcomes with the available resources
- **Ease of use and understanding:** making the system as clear and simple as possible for people, supporting people to take responsibility for their future well-being (transparency)

The Commission is guided by two overarching principles that should underpin any future system of care and support:

- **Promote the well-being of individuals and families:** enabling people to maintain their dignity, protecting those in the most vulnerable circumstances, and helping everyone to participate in the wider community.
- **Recognise and value the contributions of everyone involved in care and support,** including individuals; unpaid carers and families; volunteers and professional carers; private, public and charitable sector organisations; tax-payers and wider society.

The Commission is gathering evidence. So far they've found that the quality of data provision is extremely poor.

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Later this year there will be a formal call for evidence. The Commission is trying to ask questions that will help them directly in their work. The Commission will also be holding 'deliberative exercises'.

For more information about the work of the Commission on Funding of Care and Support, go to:

<http://carecommission.dh.gov.uk/>

Email: carecommission@dh.gov.uk.

Contributions from APPG Chairs, Officers and Members The key points for each APPG are listed in the appendix.

Barbara Keeley MP (APPG Social Care):

- The Labour Party supports a co-payment system scheme with funding free at the point of use. One way to deliver this would be a 10% levy on the estate.
- The Commission needs to build a relationship with informal carers (family carers) who have the biggest stake in this work.
- Some of the measures that the Commission will recommend will be long-term; will the Commission also be proposing interim measures?

Andrew Dilnot reassured Ms Keeley that implementation was part of the Commission's terms of reference, so they will be looking at short-term and long-term measures.

Baroness Pitkeathley (APPG Carers):

- Carers need to be enabled to keep paid employment in combination with their caring responsibilities.
- With the removal of the ringfencing of grants, what safeguards will be in place to ensure that the Central Government funding for social care will indeed be spent on the people who need it. There is evidence that Primary Care Trusts used respite care grants for other purposes.
- It is vital that the new system is transparent and easy to use.

Baroness Campbell of Surbiton (APPG Disability):

Baroness Campbell highlighted the exclusion of disabled people from society.

- This is not just about 'social care' but about support for people's independence and human rights which goes far beyond social

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care needs. Would the Commission align their findings with the Right to Control legislation and its roll-out?

- Any care and support strategy must be portable so that people can move across boundaries or from one care setting to another.
- The work of the Commission must be underpinned by the principles of equality and human rights. Carers and cared-for people have a right to live autonomous lives, fit for purpose and with equality.
- We see care and support as intrinsic to human dignity, and therefore it should be free at the point of use.

Andrew Dilnot commented that autonomy, individual control and dignity were absolutely fundamental to their work, and that the Commission was having discussions with the Equality and Human Rights Commission. He recognised the issues around portability and said that they would have to see how the agendas for localism and equality would merge – as there was a potential conflict. He would be grateful for suggestions how to address portability.

Malcolm Wicks MP warned the Commission not to seek solutions that are bureaucratic in its use, and instead find approaches that are practical; Mr Wicks suggested a social insurance system. It was vital to put ‘quality’ at the heart of the recommendations.

Andrew Dilnot responded that we’re all in this together. Quality is part of the ‘value for money’ criterion: delivering the highest level of quality of care with the available resources.

Hazel Blears MP (APPG on Dementia):

- It is vital that the Commission’s recommendations are implemented speedily.
 - There is currently unfairness amongst different conditions, for instance people with dementia have their needs identified as ‘social care needs’ and are therefore means-tested for social care, whereas people with mental health issues with similar needs may receive this care from the NHS, and thus for free.
- Ms Blears supported a shared payment model which was fair and pays for quality care. She also called for investment in the development and maintenance of community-based resources.

Andrew Dilnot recognised that the boundaries between NHS and Social Care were fuzzy, and highlighted arthritis as another

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example. He called on Parliamentarians to support a speedy implementation during their scrutiny of the recommendations.

Dr Hywel Francis MP (Chair of the Joint Committee on Human Rights) endorsed Baroness Campbell's comments. There can't be any conflict between localism and equality. Localism is about process, whereas equality and human rights is about policy and principles and should trump localism.

Andrew Dilnot responded that there is a high degree of variety in assessments and delivery across the country which people were very uncomfortable with. If we allow local variation, then people in the same situation may face different outcomes depending on where they live. The challenge is how to avoid that from happening.

Penny Mordaunt MP (APPG on Ageing and Older People) called for quality and quantity to be factored into the Commission's work. Demographic changes are not just about more people growing older, but throws up different challenges, for instance there are more older people living with HIV, as illustrated by a report of the Terence Higgins Trust. Ms Mordaunt deplored the silo-mentality of authorities which makes it difficult for people to move from one care setting to another. She asked the Commission what evidence exists that the current system does not meet the needs; whether the Commission would consider innovative options (for example, selling the house to the council and renting it back); and what work they are doing with the Law Commission.

Andrew Dilnot said that they were working with the Law Commission; the Commission has found that local authority spending hasn't gone up with increased demand and the question is why? Efficiency savings can't be the only reason. The Commission is starting from a blank sheet of paper and was considering all options.

Lord Best concluded the contributions from the APPG Chairs by highlighting the need for a joined-up approach between housing, social care and health. Significant savings could be made through suitable housing, which makes it likely that people will not need residential care until much later and be discharged from hospital sooner. The lack of housing for families is partly due to the low dynamics in the housing market. With accessible and affordable

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housing, older people might be encouraged to move houses, thus freeing up their houses for the new generation with their families.

Emily Thornberry MP introduced herself as the Labour Shadow Health Minister with responsibility for social care. She congratulated the APPGs on pulling together the excellent meeting. She hoped that she would benefit from the knowledge and experience of many of the people present at the meeting.

Geoff Fimister (RNIB) called on the Commission to consider the different dimensions of support for disabled people, including housing benefit, disability benefit. He stressed the need for a preventative infrastructure.

Toby Constable (National Federation for Occupational Business) asked where the labour for social care is going to come from as many care-workers are approaching their retirement age.

Margot James MP (Vice-chair of the APPG on Older People and Housing) suggested improvements to the quality of care through putting in place a career and pay structure (as the minimum wage has become the norm rather than a starting point for growth) and agreed standards for quality. Ms James drew attention to the dearth of care home placements and suggested making leasehold accommodation available so that older people in care might be able to leave this accommodation to their children as an asset.

Baroness Howe deplored the imbalance of money going to those with dementia and physical needs. Lady Howe queried about the role of the corporate sector in encouraging carers, for instance through flexible working hours.

Baroness Howarth of Breckland expressed her concerns about the ability of the voluntary sector to provide services, as many organisations are now struggling in the current fiscal climate.

Madeleine Starr (Carers UK) proposed a corporate model, with a mix of public, private and voluntary providers, as seen elsewhere in Europe.

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A **representative from Independent Age** stressed the need for information and advocacy to enable people to navigate their way through the system.

Elizabeth Feltoe (Age UK) asked Mr Dilnot to elaborate on the gap in evidence, particularly the quantitative evidence about the lack of resources and the lack of services to meet needs.

Sam Walker spoke of her personal experience of looking after her father who has dementia, and the failure of social services and health services to help her father. She said that she'd first-hand experience of the broken system.

Trish Davies (Heritage Care) urged the Commission to consider the growing group of older people with learning disabilities. Heritage Care, a voluntary care provider, is finding that councils try to move older people with learning disabilities from their communities into older people's homes in order to cut costs.

Andrew Dilnot talked about the challenges of the labour force and what limited tools they might have to influence the labour force. He commented that the older population was growing wealthier with more assets, and the Commission would consider this in their funding models. There were still many unknowns that would help their considerations, for instance what is the duration of stays in residential care, and how is it distributed across age bands.

Lord Haskins asked how the Commission is going to help the politicians making the right decisions about the new social care and support system.

John Graham (Hanover Housing Association) said that it was obvious that the demographics would mean that there is not enough money from government sources to fund elderly care in the future. However many older people are asset-rich but income poor. Will the commission be looking at various financial models?

Sarah Newton MP spoke of her constituency which is a remote rural community. Care services are usually designed for people living in metropolitan areas, and do not meet the needs of her constituents. She called for improved outcomes for people in rural communities.

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Marije Davidson (RADAR) asked how the Commission would involve disabled people, older people and carers before the call for evidence, in order to make sure that they would ask questions that are helpful.

Philippa Russell (Chair of the Standing Commission on Carers) drew attention to self-funders, both older people and parents, who often don't receive information, advice or support of any kind. Ms Russell urged the Commission to make sure that they included all adults from very young, including families.

Adrian Whyatt (Autistic Rights Movement and other organisations) talked about Article 4.3 of the UN Convention on the Rights of Disabled People which requires governments to involve disabled people in the planning and development of policies and services. Mr Whyatt called for the current hierarchy of impairments to be addressed, and urged the Commission and Parliamentarians to bring this to a conclusion as there have been many commissions, but now is the time to see action and results.

An **unnamed representative** stressed the need for a honest debate. Expectations have been raised, but funding hasn't followed. She called for a vision of where we want to be, but there was a need for the sector to be clear of where we stand. We want quality of care, but how is it funded? There are currently services being funded that do not meet people's needs.

Andrew Dilnot stated that Ms Newton's experience illustrates why people are in favour of local variation, which can mean that there is optimal provision across the country. With regards to engagement, he explained that they are in contact with a large range of stakeholder organizations, and that the first meeting of our external reference group would be quite soon. Mr Dilnot also invited everybody to submit contributions. He agreed that it was important to start early, and that means people need to fully understand the system. Mr Dilnot agreed that the Commission should consider the role of the private sector, alongside the voluntary and the public sector. He remarked that the challenge is to find a balance between values and economics. Where should the money come from? He was determined that the Commission would see this through to the establishment of a sustainable care and support system.

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Lord Best thanked **Andrew Dilnot**, the chairs of the other APPGs and the observers, and closed the meeting.

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Key points of the APPGs.

APPG on Housing and Care for Older people

1. Alongside social care and health, housing represents the equally important but often neglected third leg of the stool, without which the whole stool will collapse. It must be acknowledged as an equal partner with effective joint working and commissioning encouraged between all three agencies to ensure better and more integrated care for all older people, their families and carers.
2. Good quality and appropriate housing plays an essential role in supporting older people to maintain independence, choice and control over their lives, and with that, access to timely repairs and adaptations to ensure that older people can stay in their own home for longer.
3. Universal access to information and advice on care and housing options must be better promoted in order to empower older people to stay in control and raise any concerns or complaints they may have about the quality, cost or level of support they receive.
4. There is urgent need for radical reform of the care system. Any new funding method recommended by the commission must ensure the development of a fairer and more equitable care and support system that is fully integrated across the traditional boundaries of 'health', 'social care' and 'housing'. The impact of poor quality housing and lengthy waiting lists for repairs and adaptations on pressurised social care budgets and costly acute healthcare must be better recognised and form a central part of the discussions carried out by the commission.

APPG on Ageing and Older People

1. How the Dilnot Commission is working with the Law Commission to ensure that no funding proposals discount options put forward by the Law Commission.
2. Whether the Commission has found evidence that the current system does not meet the growing needs of the older population.

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3. To what extent the Commission is considering the current proposals for new ways of funding social care, (ie, the options that various people have put forward on Partnership, ILC model, etc), or whether they are thinking up new options that haven't previously been considered.

APPG on Carers

1. The care and support system relies on carers and without more investment families will be put under increasing pressure, meaning that fewer carers will be able to juggle work and care
2. Concerns about how families are going to manage in the short term whilst reforms are developed
3. The importance of transparency in the offer that families get from the system to ensure they can plan care

APPG on Dementia

1. Many thousands of people with dementia are currently paying substantial amounts for care, which has been described by Alzheimer's Society as a 'dementia tax'
2. Not only are people paying substantial amounts for care, the care that people with dementia receive is often of poor quality.
3. The Commission in its search for a long term settlement on who pays for care should not lose sight of the need to secure good quality care. If the government is to convince people to make a contribution to the costs of care, there will need to be significant improvements in access and quality.

APPG on Disability

1. Social care must be directed towards giving disabled people autonomy and personal control over their lives.
2. The denial of portable care and support is a flagrant contravention of disabled people's human rights, in particular the rights to found a family, freedom of movement, work and education (as in the UN Convention on the Rights of People with Disabilities).
3. Moral values (solidarity, dignity) must be given equal weight to economic issues in the consideration of the funding system.