

Shaping the Future of Care Together

**Disability Alliance response
(R64) to the Department of
Health Green Paper on adult
social care reform in England**

November 2009

**Disability
alliance**

Breaking the link between poverty and disability

Contents

Executive summary	3
About Disability Alliance	4
Our mission statement	4
Our members	4
Developing our response	5
Consulting our members and the general public	5
Input to Government stakeholder groups	5
Background to reform	6
The 1997 commitment	6
Actions to date	6
Government aims of reform 2009	7
The Green Paper: radical – but too green	9
A National Care Service	9
A single ‘needs assessment’ across England	9
Standardised access	9
The Prevention Agenda: meeting lower level needs	10
Personalisation	11
Challenges within the Green Paper	11
Detail	11
Eligibility	12
Benefits	12
Funding models	13
Case studies	13
Questions on the green paper: results of our survey	14
Who responded to the questions	14
Aspects of a National Care Service	14
Delivering a fair, simple and affordable care service	15
Quality	17
Funding	18
Attendance Allowance and other national funds	19
Who should decide the funding people receive	24
Local flexibilities in resources allocated to individuals	25
Affordability	25
Disability benefits and ‘income’	26
DA recommendations on ‘Shaping the Future of Care Together’	27
Appendix One: The DA survey	28
Appendix Two: DA members’ questions to Care Service Minister	30

Executive summary

Disability Alliance believes that Government plans for care reform hold much potential, but that the absence of detailed information to support the proposals has severely damaged the significant, positive elements of reform. This lack of detail has led to many disabled people fearing the loss of support and resources at a time of significant financial insecurity across the country.

The Government must work in genuine partnership with disability organisations and examine the full impact of reform. DA particularly opposes plans to integrate Attendance Allowance or other national, non means-tested disability benefits into council social service funding. We believe proposals to integrate Attendance Allowance and DLA for people over the age of 65 into local authority funding would undermine the Government's objectives of a fair, simple and affordable National Care Service and could heighten the likelihood of disabled people living in poverty.

We agree with the Prime Minister that big, bold visions in care service reform are essential. However, we believe in an even bolder vision than the Green Paper presents. We support a universal, tax-funded care service for disabled and older people and their families. We believe our view represents that of the vast majority of UK citizens and our members.

We believe that a bold, new National Care Service should:

- Be provided on the same terms as the NHS with universal entitlements to support and free at the point of delivery – as supported by the vast majority (over two thirds) of our members and by the general public. We believe the Government should consider ending care service charges in developing the White Paper – or provide, with detailed analysis, why this is not an affordable option.
- Not be part-funded by disability benefits paid to people to help meet the extra costs of living with an impairment/health condition. Our members and other respondents opposed the integration of Attendance Allowance and other national benefits into care service funding at an astonishing margin (93% against, with just 3% in favour).
- Contribute to tackling poverty and should not leave more people at risk of poverty by removing disability benefits. We believe that the new national, standardised assessments for care should include new financial assessments to ascertain whether older and disabled people can genuinely afford to contribute towards care. Financial assessments should fully include outgoings and be independent from local authorities. Assessments should be monitored by the Care Quality Commission.
- Receive the level of investment required, as highlighted by stakeholders for almost a decade, to ensure support is available to adequately meet the needs of disabled and older people and their families – including 'lower level' needs.
- Be underpinned by equality and human rights. This means ensuring disabled people, older people and their families are supported to participate fully as equal citizens. It also requires services to help tackle the current over-reliance on informal care.

About Disability Alliance

Disability Alliance was formed in 1974 and registered as a charity in 1977 with the purposes of publicising and eliminating the poverty experienced by disabled people in the UK. We are a well-established national voluntary organisation.

Our mission statement

Disability Alliance believes it is unacceptable that disabled people in the UK live in poverty. We are committed to breaking the link between poverty and disability. We provide disabled people and their advisers with information about entitlements and work closely with government to improve disability benefits to reflect the costs of living disabled people and their families experience.

We fulfil our aims by:

- Interpreting and translating complex benefits, tax credits legislation and guidance into accessible, easy to understand information for a wide range of audiences, including disabled people, their families, carers and advisers, MPs, journalists and policy workers;
- Engaging with Government and briefing relevant officials about the impact of policy proposals on the lives and income levels of disabled people;
- Lobbying for positive changes to the welfare system to improve the lives of disabled people, often in partnership with other disability organisations;
- Undertaking research into the income needs of disabled people;
- Fostering co-operation between organisations concerned with disabled people's equality and poverty. We currently chair the Get Fair Coalition, the Coalition on Charging and are an active member of the Disability Benefits Consortium;
- Providing information to disabled people and their advisers on benefit entitlements that help tackle poverty; and
- Campaigning at national level for better support for the higher costs of living disabled people experience.

Our members

We are a membership body, with 300 member organisations in a range of sectors.

Our membership and networks give us access to a vast wealth of expertise and experience of needing and using care and support services, including benefits. We have member organisations at national, regional and local level. Our members provide advice, information and/or advocacy for disabled people and their carers. Our members vary from small self-help groups to welfare rights organisations, local government offices and large national organisations and charities. Our members include Mencap, Leonard Cheshire Disability, RNIB, Radar, the National Association for Colitis and Crohns Disease, the DIAL network, over twenty local Citizens Advice Bureaux and several Law Centres.

A list of our current members can be found on our website: www.disabilityalliance.org

Developing our response

Consulting our members and the general public

Disability Alliance sought to involve our members¹ in developing our response to 'Shaping the Future of Care Together'. Around a third of our members have been involved in the development of our response. Many of our members will respond as individual organisations in addition to contributing to our response.

We also enabled the general public to contribute to our response through a 'members+' approach which included online and direct communications work which has enabled us to access the views of the broader public.

In developing this response we have:

- provided up to date Government documents on the green paper and associated information, including on the 'Big Care Debate';
- run an online survey on care reform based on the questions set out in the green paper (which about 187 unique respondents completed, including about 13% of our members²);
- worked in partnership with some specific members to develop joint responses and share information;
- provided members with an opportunity to put questions on the green paper to the Care Services Minister;
- dedicated space in our members' newsletter to the Green Paper with an opportunity to ask the Care Services Minister, Phil Hope MP, questions; and
- directly corresponded with our members on the green paper to maximise opportunities to inform our response.

Input to Government stakeholder groups

To represent our members' interests and ensure we were well informed on all green paper developments and Government plans we also:

- attended meetings with Ministers/officials to discuss the issues involved (eight times during the consultation period); and
- helped organise a joint meeting of the Disability Benefits Consortium, Coalition on Charging and other organisations with DWP, Treasury and Department of Health officials.

Our Board have also discussed the issue of care reform and contributed to the development of our response.

For further information on the development of the DA response please contact: ncoyle@disabilityalliance.org

¹ DA has almost 300 members at November 2009 and many are directly involved in working with people needing care and support from local authorities and national government.

² We corresponded directly with most of our members who completed the survey. however some online surveys were completed by self-reported members which may not reflect actual membership.

Background to reform

Disability Alliance (DA) supports reform of care services. The 'safety net' approach of the 1940s model of social care is simply unfit for purpose in the UK of the 21st century. The current care service framework is broken and fails to meet the needs of hundreds of thousands of families.

DA is not alone in recognising this concern. Many disability, anti-poverty and equality organisations have been championing the case for reform, based on the needs of modern UK families. As more families have been let down by the current framework, the case for change has grown.

Care service representatives, including the Association of Directors of Adult Social Services, the Local Government Association, trade unions representing the care workforce, and the care regulator have all called for reform of service provision. The Commission for Social Care Commission described care services as 'struggling' in 2006³.

Academics and think-tanks have also contributed to the debate on reforming care. A major contribution was made by The King's Fund (Wanless) 'Securing Good Care for Older People' in 2006 for instance. This report, whilst seen as a future-focused document by many, also centred on the under-funding of services for older people.

The 1997 commitment

The Government came to power in 1997 with a commitment to tackling the community care system which the Labour Party described as being 'in tatters'⁴. Once in Government, a Royal Commission on long-term care was appointed which reported in 1999⁵. The Royal Commission suggested three issues relevant to the care debate of 2009:

- that taking no action was not an option (in 1999);
- that the UK faced no demographic time-bomb; and
- that free personal care be made available for older people.

Had greater action been taken at an earlier date, the costs of reform may not have escalated to the levels the Government has suggested the UK will now face in two decades.

Actions to date

However, DA does not suggest nothing has been done. This Government has invested record sums in care services – with service budgets growing significantly since 1997 in real terms⁶.

³ CSCI 'The state of care services in England' 2006. The CSCI was subsumed by the broader health and social care inspectorate, the Care Quality Commission, in April 2009.

⁴ Labour Party Manifesto, 'New Labour: Because Britain Deserves Better', 1997.

⁵ TSO 'With respect to old age: long term care - rights and responsibilities' 1999.

⁶ 'Securing good care for older people' The King's Fund 2006 estimated, using Department of Health figures that spending on older people alone had risen from roughly £5 billion to almost £8 billion between 1997 and 2005 for example.

The Government has also introduced specific policies to transform care services, including 'Putting People First' 2007 which is delivering a cultural shift in care services towards empowering the people who need support.

The Government did introduce other care reform plans in the 'Independence, Well-being and Choice' 2005 Green Paper and 'Our Health, Our Care Our Say' 2006 White Paper – both of which received considerable stakeholder support.

In 2008 the Government also led the 'national debate' on care reform which ran from May to November and contributed to the production of the latest Green Paper, 'Shaping the Future of Care Together', published in July 2009.

But the delays to reform have shifted some of the focus on why we need a new care and support system. Many of the former public debates focused on what kind of support people needed to enable them to participate as active citizens – in work and in families for instance. Debates have also focused on how to deliver the services that would meet those needs and ensure citizens were able to contribute. This area of the debate was particularly prominent in the 'outcomes' approach to services suggested in the previous Green and White Papers.

However, the current debate focuses primarily on service funding – and terminology has crept in suggesting that older people, in particular, are viewed as a 'burden' which we, as a country, cannot afford to fund. This is despite the UK being the sixth wealthiest nation in the world⁷.

Government aims of reform 2009

Despite the unfortunately pessimistic approach of the current general debate on why we need to reform care and support for adults in England, the aims of the Green Paper are welcomed by Disability Alliance.

The main three themes of 'Shaping the Future of Care Together' are that the Government seeks a new care service framework which is:

- Fair;
- Simple; and
- Affordable.

DA supports a system based on these three principles, especially a new care service framework which is affordable to disabled people of all ages. Our mission is to break the link between poverty and disabled people and their families. We currently believe care services can contribute to the likelihood of disabled people – including older disabled people – and their families living in poverty.

We also believe care service charges create net costs to the public purse. Costs to the state are incurred through the administration costs of means-testing, and through charges for services resulting in people not using the support they require⁸. Unmet

⁷ UK was the 6th richest nation by GDP according to the World Bank and IMF in 2008.

⁸ See, for example of charges resulting in reduced support, Audit Commission 'Charging with Care?' 2000 and Age Concern 'Fair Enough?' 2004.

needs as a result of charges lead to people developing avoidable higher social and healthcare costs which must be met through public resources at a later date.

DA chairs the Coalition on Charging⁹ which has highlighted the risk of not monitoring the impact of care service charges in 'Charging into Poverty?' in June 2008.

The main findings of the Coalition are provided below to demonstrate the need for a new care service framework to be made affordable to people using services.

- Nearly three quarters (72%) of individuals and 81% of organisations believed the Government should consider care service charges for support at home in adult care reform plans;
- Care services are not a choice, but an essential part of living for the people who use them. But a third (34%) of individuals said they had no choice over the services they used;
- 80% of the people who no longer used care services said charges played a part in the decision to end using services (despite the essential nature of the support needed);
- A fifth (22%) of people using services suggested they would also stop being able to access support if charges rose; and
- 29% of individual service users did not feel their essential expenditure (related to impairment/health condition) was taken into account when they were assessed to pay charges¹⁰.

In the research that provided the background to the Coalition report, over three quarters (77%) of the organisations that responded felt that the Government should consider ending care service charges as an option in care reform plans.

The Coalition on Charging was assured in the House of Lords in 2008 that the Government would address the concerns raised in 'Charging into Poverty?' in the Green Paper. The Coalition has now been assured that the White Paper will address charges for care services.

DA welcomes an early involvement of the Coalition in developing the White Paper proposals. We look forward to seeing in detail how the Government intends to tackle the current inadequacies in care service charging policies in the White Paper – using the findings and recommendations of the Coalition on Charging. We believe this would help tackle the poverty that some disabled and older people and their families experience.

There are two further supporting themes of the Green Paper: universalism and personalisation. DA welcomes both these approaches to service provision. As demonstrated below, our members support a system that is personalised around people's needs, but standardised across the country to ensure it is perceived as fair and equitable.

⁹ The Coalition on Charging is 21 disabled people, older people and carers' organisations and seeks fairer care service charges. The Coalition will be responding to the Green Paper in its own right.

¹⁰ Coalition on Charging, 'Charging into Poverty?' 2008.

The Green Paper: radical – but too green

The Green Paper was published later than the Government planned. A general election is due by June 2010. The Government's Draft Legislative Programme (published June 2009) covers the timetable to the election and allows no time in parliament for a Care Reform Bill. Implementation of legislation is not likely to occur for until 2013, leaving many disabled and older people facing an uncertain future as local authorities restrict access to care and support further until final Government plans are put into practice.

However, DA welcomed the publication of the Green Paper, as we believe the debate on the future of care and support is critical to each and every UK citizen. The future of care concerns us all; to meet the current needs of disabled and older people and their families' and to ensure we plan to meet the needs of future generations with a growing population of older and disabled people¹¹.

We also welcomed specific aspects of the Green Paper, including:

A National Care Service

We welcome the radical idea of a new, National Care Service which rivals the NHS, not for cost, but for quality and through being underpinned by a rights and entitlements approach to support as in healthcare currently – and as distinctly different to the Poor Law approach of the present social service framework.

A single 'needs assessment' across England

This approach would enable disabled people to move from one local authority to another without being reassessed – potentially delivering 'portability' of care packages for people moving for education, work or to be nearer families for instance.

Standardised access

DA believes that, in order to deliver a fair, simple and affordable service, the National Care Service must ensure people with similar needs receive support across England, rather than subject to differing local access criteria. The Green Paper states that:

'The Government would also set, at a national level, the level of need at which someone becomes eligible for state funding. This would mean that anyone who had this level of need would be eligible for some support, wherever they go in England'.

This is a radical approach and builds on the Government's earlier attempt to deliver equitable access to support through Fair Access to Care Services (FACS). FACS has had the unintended result of almost three quarters of English local authorities

¹¹ The King's Fund Wanless report 'Securing good care for older people' 2006 estimated that 'In the next 20 years, the number of people aged 85 and over in England is set to increase by two-thirds, compared with a 10 per cent growth in the overall population' for example. Older people are more likely to have health conditions/impairments. There are also more disabled people across the general population following medical advances and other societal changes.

restricting access to only people with the highest levels of needs¹² rather than establishing what level of support each 'tier' of people should receive with needs assessed as being 'low', 'moderate', 'substantial' and 'critical'.

People are increasingly aware of different levels of support being available in different towns, regions and countries of the UK. These 'postcode lotteries' create an impression of unfairness and complexity for those living in areas with more restricted care service access.

DA welcomes the Green Paper acknowledgement that access to support must be set at the national level and hopes the Government will bring forward legislation to this effect at the earliest opportunity.

The Prevention Agenda: meeting lower level needs

As was the case with the 'Independence, Well-Being and Choice' Green Paper, and 'Our Health Our Care Our Say' White Paper, 'Shaping the Future of Care Together' emphasises the need for preventative services and supporting more people with lower needs. DA welcomes an approach that prevents people's care needs being compounded before support is provided.

One of the reasons many people have such deep dissatisfaction with the current care service framework for adults in England, is that it supports too few people. Access to support has been ratcheted up by local authorities. Three quarters (73%) of local authorities in England only provide support to people with the highest levels of needs (critical and substantial using Fair Access to Care Services criteria) – leaving the vast majority of people with low or moderate needs without council support. This has happened over a short time span¹³, and despite increased central government investment.

Extending care and support to reach more people with low and moderate needs is essential for an effective National Care Service if it is to be perceived as fair. Currently, many disabled people feel the way their needs are assessed is unfair. An example of this perceived unfairness is the many visually impaired people or people with fluctuating conditions that do not meet the substantial needs criteria. Extending care and support services to all people with lower level needs will help rebuild public support.

Reaching people with low and moderate needs will also result in a more cost-effective care system – making it 'affordable' to use the Green Paper terminology. Some people enter care homes rather than remaining in their own homes because they are not able to access support until their support needs reach crisis level. This can result in higher costs to local authorities. Delaying using services also results in rising healthcare needs of disabled and older people and their families (requiring NHS resources) as evidenced by the Audit Commission and DWP¹⁴.

¹² CSCI, 'The state of social care in England' 2009.

¹³ In 2005 just over half (53%) of councils only supported the top two FACS bands.

¹⁴ See 'Fully equipped :assisting independence Audit commission update' Audit Commission, 2002 and 'Better outcomes, lower costs' Office for Disability Issues, DWP, 2007 for evidence on the cost-savings of supporting people with lower level needs.

Cost savings are also possible from reducing demands for informal care. Many older and disabled people are rendered ineligible for local authority support and are forced to rely on informal carers to meet their low level care needs. There are over 6 million carers in the UK; some 1.25 million carers provide more than 50 hours support per week¹⁵. Providing informal care restricts opportunities to work. One in five carers has given up or been unable to take up work as a result of care responsibilities¹⁶. And around 200,000 carers claim Incapacity Benefit, many as a result of developing poor health from caring without the right support¹⁷.

Providing a preventative system, with standardised access criteria across the country will help deliver a system that meets the Government's aims of fairness, simplicity and affordability.

Personalisation

DA also welcomes the continued emphasis on providing support to older and disabled people through a personalised approach, including the rollout of Individual or Personal Budgets. The implementation of 'Putting People First' has seen the numbers of people managing their own support more than triple with the Department of Health currently estimating close to 100,000 budget holders. DA believes that it is positive to continue the emphasis on empowerment and user-control.

DA believes that individual management of support must be implemented carefully, with appropriate support and advocacy for people where needed. We also believe that local authorities must ensure workforce needs are met in this area – and support budget holders to meet their obligations as employers.

Challenges within the Green Paper

DA is very concerned that much of the positive nature of the Green Paper aims and broader provisions has failed to capture expert stakeholder attention. The areas we welcome are covered above in brief; we would have liked to have spent more time examining how these ideas would work in practice and the positive contribution they might make to reducing disability-related poverty.

Detail

However we, our members and other stakeholders have had to focus on other areas due to the lack of detail provided in the Green Paper – and the unwillingness of the Department of Health in particular to provide background evidence and supporting materials for generalisations and statements made in the Green Paper.

The Government announced that, to address partners' concerns on the lack of information to support the green paper, the Department of Health would publish a further 'technical note' to provide evidence and background data for the Government's plans. This was being headlined by Care Service Minister Phil Hope on the evening of

¹⁵ ONS, from Census 2001.

¹⁶ Equal Opportunities Commission, BMRB survey, 2004.

¹⁷ 'Mental Health and the UK Economy', Oxford Economics, published by Unumprovident, March 2007. See also 'In Poor Health' Carers UK, 2004 for further evidence on carer's ill health.

27th October 2009¹⁸ but by the morning of 2nd November 2009 it was announced that the technical note would not be published as promised and that ‘partners’ who are being asked to ‘co-develop’ the Government’s plans would now have to wait till 2010 for the full technical note to be provided – potentially after the White Paper is published. This is incredibly disappointing and an unsatisfactory way for the Government – or any organization – to work with partners. A genuine consultation would have shared the full information – as would a Government confident in its plans and the way they have been developed.

We believe the failure to provide a genuinely participative environment for consultation, with shared and transparent costings and evidence, represents an unacceptable disregard for the impact the consultation has had. This is particularly the case for some disabled people who believe their financial situation will be considerably altered by Government plans¹⁹.

The Government amended the Disability Discrimination Act in 2005 to include a duty on public authorities (like national government departments) to promote disability equality. This Disability Equality Duty must be complied with by the Department of Health as it develops the White Paper – involving disabled people and their representative organisations in developing care policies which are effective. DA is not confident that the failure of the Department of Health to share information which has shaped the Green Paper would meet the Equality Duty obligations, and certainly not its spirit.

DA also raised the issue of how human rights would be respected (in particular regarding dignity) under a new care system with the Care Services Minister in August and were promised an answer by the Department of Health which has not been delivered at the end of the consultation period. This lack of response for a legitimate concern is very disappointing. DA recognises the impact poor care services and the current system’s failures have on disabled people, older people and carers’ human rights and expects the National Care Service to be an exemplar in ensuring people’s rights are met²⁰.

Key data missing from the Green Paper includes:

Eligibility: At what level eligibility for support will be set under the proposed National Care Service. DA recognises that this may depend on funding but the Green Paper should have provided an indication of what level of care needs the Government believes support should be made available, if its overarching aims and policies are to be realised. DA hopes this will be set at a low level and expects this to be the Government’s ambition if a truly preventative system is to be delivered.

Benefits: Which disability benefits are already being or will be considered for ‘integration’ in local authority budgets. The Government was asked to specify in the

¹⁸ Phil Hope MP, at the joint meeting of various All Party Parliamentary Groups including Disability, Age, Dementia, Carers and Equality. Committee Room 9, Houses of Parliament.

¹⁹ Almost 22,000 people have signed the 10 Downing Street online petition to retain DLA and AA viewable at: <http://petitions.number10.gov.uk/AttendanceA/>

²⁰ For a fuller explanation of human rights and social care see ‘From Safety Net to Springboard’ EHRG, 2008.

House of Lords, in the DA Newsletter and in parliamentary meetings without further information being made available on exactly which disability benefits had been considered for integration.

Data on statements surrounding the targeting of benefits would also have been useful. The Green Paper suggests that some people who use Attendance Allowance are well-off:

‘Attendance Allowance is not means-tested, so people get it regardless of how well-off they are’²¹.

The inference that some people do not need AA but claim it is a previously unidentified problem. Even the latest research for the House of Commons Work and Pensions Select Committee suggested that, far from being over-used by well-off recipients, AA is not paid to many older disabled people who would benefit from the resource it was intended to provide (in terms of tackling their poverty). The Committee also outlined their belief that AA should be provided based on the DLA model of the additional ‘care’ and ‘mobility’ costs of living being met – i.e. suggesting that AA should be paid at higher levels and to greater numbers of older people²². We provide further information on our concerns over the Green Paper suggestions on the targeting of AA below (pp20-23 in particular).

Funding models: The detailed breakdown of funding for the proposed models and how the Government reached its estimates. It is unknown whether the Government’s plans reflect the recent spike in births in the UK or the rising retirement age in estimating whether the working age population can ‘afford’ to fund a more appropriate care service for example. It is also unknown whether the plans have taken into account the loss of informal carers from the workforce. Carers are predominantly women between 45 and 64 years of age and the current system requires many to reduce or stop working to provide support to family members (see p11 for further information on high demand for informal carers and the impact on carers’ employment options). A more supportive care service framework would facilitate care for older and disabled people and allow people who would otherwise have become carers to be maintained in the workforce, contributing to the system through National Insurance and income tax.

Case studies: Linked to eligibility, benefits and funding is the need for the Government to explain who would have their circumstances improved by the proposed new care and support system. The consultation would have benefitted from examples of how the Government envisaged people would be better supported under a National Care Service.

²¹ Department of Health ‘Shaping the Future of Care Together’ 2009, p102.

²² House of Commons Work and Pensions Committee ‘Tackling Pensioner Poverty’ fifth report of session 2008-2009, August 2009.

Questions on the green paper: results of our survey

The following statistics and analysis is taken from the responses we received to the questions from the Green Paper and our supplementary questions put directly to our members – and to the general public through our online survey.

Our figures are provided based on responses to questions. If respondents skipped a question this is not represented in the figures, but where this was a significant number of respondents the figure is provided below the statistical breakdown.

We believe that, in answering any questions, the responses from experts should be respected and weighted to reflect their proximity to the issues involved. We hope that the Government will respect the views of all respondents – especially concerning the aspirations for how services should be provided. But we also hope the Government will acknowledge the difference between a member of the public, with no experience of care services or how best they might be provided, with the experiences of people closer to the current system. Our members – and the respondents to our survey – fall into the latter category and answers reflect knowledge of current challenges as well as existing good practice.

Who responded to the questions

The responses we received to our survey were mostly from people needing support (75%) and carers/family members of people needing support (20%). We received a lower response rate from people providing other assistance (eg formal care service staff) to people with care and support needs (5%). However, roughly 13% of individual respondents did not answer this question.

Responses received from our membership differ, with a slightly larger proportion of organisations involved in providing care and support – independently or as local authorities – completing the survey.

Aspects of a National Care Service

We asked respondents to select as many issues from the list in the Green Paper that they thought were important if a new care service is to be created that is fair, simple and affordable. They are listed below in order of preference from our responses:

- **Personalised care** (managed as far as possible by the person needing support) was significantly supported at a rate far higher (90%) than other aspects of services suggested in the green paper.
- **Information and advice** – 70% agreed this was essential in a new National Care Service.
- **Fair funding**²³ – 63%.
- **Joined-up services** – 60%. Many respondents also commented that a lack of joined-up working in the current system had been a significant barrier to fairness, simplicity and affordability.
- **Prevention services** – 56%.
- **A national assessment across England** – 49%.

²³ Defined in our survey as people only paying for care if they can afford it.

Delivering a fair, simple and affordable care service

We also asked respondents what (if anything) in their experience had prevented a 'fair, simple and affordable' care system. This was designed to draw-out detail on the choices to the previous question and help the Government identify barriers to tackle in developing the White Paper and more concrete plans for a National Care Service based on the principles of fairness, simplicity and affordability.

This question elicited many answers of various natures, but significant numbers of people cited the following as important issues that the Government should consider.

Funding: for services (by far the most common answer). One DA member representing a local authority suggested that 'budget constraints' were the single biggest issue and another that it was 'Lack of Government funding' for example. Some respondents broke this down further and suggested areas where national resources had been mis-prioritised, including on MPs' expenses and Iraq. This was perhaps natural in the current climate, although the importance attached to quality support and care to citizens with needs was perceived to have been too low. This low prioritisation has led to the funding gap that exists which the Government is now attempting to address.

Eligibility: the second most common theme in answering this question surrounded eligibility for support. This is closely connected to the issue of funding as, with growing demands and expectations from users and rising internal and provider costs, many local authorities have used 'limited resources' as a rationale for restricting who is eligible for care services. Some respondents provided further information on this issue and highlighted the need for a broader understanding of the negative impact cuts to care services can have on other areas of Government funding, especially the NHS. One comment was that:

'clients with mild to moderate support/care needs have been neglected and have had to wait for their needs to become substantial or critical...support earlier would prevent substantial decline in...health, and would also save the government money'.

Bureaucracy: assessments and means-testing were perceived as 'bureaucracy' (used entirely pejoratively). This included comments like: "a tick box mentality" to delivering support which prevented a truly fair or personalized care and support system being delivered.

The tick-boxing may relate to other issues raised, such as the two respondents who commented that there was a "lack of staff" and thus speed of work (because fewer people were responsible for more work) had taken priority over the quality of support offered. Others suggested "poor staff wages" and "burnout" in social service departments had prevented the delivery of a fair, simple and affordable system.

However, the vast majority of comments on staffing levels suggested that there were "too many managers" with a perception of an inverse relationship between the numbers (and salaries) of senior staff compared to the numbers of people supported by formal services.

One DA member stated, relating to bureaucracy: ‘there is a lot of paperwork just to get 2 hrs per week direct payments’.

Inter-agency communications: were also highlighted by many respondents. Typical comments included: ‘too many different departments unable to work together’ and ‘agencies don’t talk to each other’. This particularly included health and social care co-operation, but some specified mental health services and social care as an area of especial concern.

Relationship with services: one theme of respondents concerned the nature of individuals’ relationship with services; and comments which best define this suggested: ‘not being listened to’ or ‘putting people into boxes’ as the main reason behind the current unfair, complex and unaffordable system.

This is a major issue for disabled people who have felt traditionally disempowered by public services. This balance of power should shift with personalisation and greater user-involvement. But the Green Paper has been published and the full consultation period completed without the full background papers and information being provided – and with a lower focus on the outcomes sought for people needing support than in previous consultations on care reform. Restricted access to Government plans and a focus on cost as opposed to outcomes may suggest a slower culture change than people who need services and the general public seek and should expect. At local level, involvement of disabled and older people in care changes by councils has also often been poor. This restricts how speedily and effectively a genuine culture change in care provision can be implemented²⁴.

DA is particularly concerned that people who feel that their local services have not been able to meet their needs or listened to their views will feel even more marginalised if the Government passes funding for current national benefits (like AA or DLA for people over 65 years of age) to councils to administer. There has been a very strong demonstration of the support for the benefits paid to meet disabled people’s higher living costs during the Green Paper consultation. Refusal to acknowledge these legitimate concerns and reflect them in reform will undermine disabled people’s confidence in a National Care Service from the outset.

Postcode lottery: several members and other respondents also cited the postcode lottery as a major problem. One DA member highlighted the problem of ‘local areas being able to operate their own systems’ through a lack of coherent care law²⁵ and an over-reliance at national level in using guidance to deliver national aims when firmer law is required. DA agrees. We know many organisations of the Coalition on Charging share the view that guidance has allowed too much flexibility and not enough national scrutiny of compliance with respect to care service charges for instance.

A different DA member also highlighted the issue of charging guidance stating that one problem in delivering a fair, simple and affordable system was: ‘People and

²⁴ See, for example, B v Cornwall County Council 2009 for evidence of illegality in not providing genuine ‘engagement’ of service users in setting care policy and charges.

²⁵ DA is aware that the Law Commission is looking at codifying care law in one statute currently.

agencies failing to understand, and in some cases apply, funding criteria, often leading to overcharging’.

DA hopes the Government will fully address this issue in the white paper. We believe that standardised assessments procedures for accessing care should include a full and independent analysis of disability related expenditure.

Leonard Cheshire Disability reported that of respondents to their national disability survey in 2009 that:

50% of respondents living in poverty and needing social care support are paying towards their social care

DA believes this is unacceptable and that local authority assessments of disabled and older people’s finances must be made more thorough. We believe local authorities should, as a minimum, be inspected by the Care Quality Commission on their assessment processes including financial assessments.

No change required? That there were no problems with the current framework was suggested by just two respondents saying that the current system was ‘fine’. This was less than the three who suggested that ‘Government’ was directly responsible for the current system’s unfair, complex and unaffordable nature.

Quality

We also asked people what was needed to deliver quality care services, which give people choice and work across government agencies. This question received considerably fewer answers than others, but responses included:

- Removing profit incentives in care services, to ensure people’s needs are the prime concern of care providers. One DA member put this as:

‘Take away the business/for-profit side so that the care of the individual is at the centre rather than the profit of the business’.

- Ensuring benefit take-up was also cited by DA members. One member suggested that ensuring people receive the payments they are entitled to would enable disabled people to:

‘choose what services they require and how they spend their disability money to best suit their own individual needs’.

- ‘Joined-up thinking’ was also cited by many respondents – for the same reasons as failures in this area have led to barriers in delivering a fair, simple and affordable care service as highlighted above.
- Other organisations suggested a cross-agency approach to delivering support would raise quality. For example, one DA member suggested that to deliver quality for people needing support required:

'Multi-disciplinary locality teams comprising of health professionals, social care professionals, occupational therapists and voluntary sector organisations'.

- Increasing staff levels was also suggested by a few respondents. This is particularly important if we move towards a National Care Service that can support people with low or moderate needs who are currently excluded from most council provided services. Greater staff numbers is also relevant if large numbers of current disability benefits recipients are transferred into local authority administered support.
- Training for all staff was also cited by respondents as essential in delivering a quality care and support service.

Funding

On funding, we offered our respondents all five of the Green Paper options and asked people which of the models they thought would be most suitable for England.

The answers were (using the order and Green Paper titles for the funding models):

- 'Pay for Yourself' – 0%; not one respondent backed this option.
- 'Partnership' – 16%.
- 'Insurance' – 10%.
- 'Comprehensive' – 10%; a far lower figure than the Government has suggested respondents have opted for in Department of Health initial consultation work.
- 'Tax-funded' – 64%; this option was ruled out by the Government but two-thirds of our respondents supported this model of care provided free at the point of delivery based on need.

Around thirty respondents selected none of the options suggested. However, very few suggestions were made in the 'Other' category. One DA member suggested that the current system was sustainable. Others suggested that 'higher taxes for those on higher earnings' was the means to fund a fairer, simpler and affordable care framework.

DA is very concerned that, in almost every survey or study, the general public routinely and overwhelmingly supports a system of care service funding that the Government lacks the will to implement.

For example, the question of affordability was asked in a 2006 Ipsos-MORI survey of public attitudes on care and support services which revealed that:

- Half the public supported an increase in tax to fund better social care, while a quarter (25%) oppose such a move; a 2:1 ratio in favour of delivering more/better services.
- 54% of respondents stated they would be prepared to pay more
- for better services.
- Higher earners were more likely to agree to pay more: 65% of those earning £30,000 or more, compared with 55% of people earning £17,499 or under.

- A third of respondents (32%) said none of the costs of caring should be borne by individuals receiving support or their family/friends²⁶.

These findings – and other evidence – suggest that most people are willing to contribute more through general taxation to ensure better support and in order to reduce demands for informal care from family/friends. However, in introducing a Green Paper on funding care services in a new, fair and affordable system the Government has not fully examined the free care model despite overwhelming public support for such an approach.

When the Prime Minister spoke at the Labour Party conference 2009 he mentioned care reform issues and stated that:

“And so I urge you, as the poet said, dream not small dreams because they cannot change the world. Dream big dreams and then watch our country soar.”

DA agrees with the Prime Minister that big, bold visions for the future of care and support are essential. However, we have a bigger, bolder vision and support a universal, tax-funded care service for disabled and older people and their families. We believe our view represents that of the vast majority of UK citizens and our members.

Any alternative system which includes charges to use support will:

- Be expensive to implement and administer. We hope the Government will publish the costings for the means-testing of each of the models with the White Paper or in the full technical note in 2010. The potential funding models not ruled out by Government would introduce significantly more people to means-testing. The option of compulsory contributions from all people over retirement age would require means-testing every person reaching retirement age. Proposals to ‘integrate disability benefits’ to local authority funding would also significant numbers of disabled and older people receiving DLA and Attendance Allowance into means-tested services at considerable expense.
- Sustain barriers between health and social care that work to the detriment of meeting disabled and older people’s needs.
- Reduce the likelihood of people using essential support services (if the fear is that costs will be charged).
- Potentially penalise people for developing illness/impairment.
- Undermine broader Government policy on tackling poverty, reducing inequality, promoting independent living and delivering social inclusion.

Attendance Allowance and other national funds

Because of the nature of our members, we specifically asked whether Attendance Allowance, and other national funds, should be included in funding given to councils to distribute. The answers were very clear:

²⁶ Ipsos-MORI ‘The Future: Who Cares?’ 2006 for the Disability Rights Commission, Equal Opportunities Commission and Carers UK, 2006.

- No – 93%
- Maybe – 3%
- Yes – 3%
- Not sure/don't know – 1%

Just two respondents failed to answer this question. An overwhelming majority did not believe councils were the appropriate distribution agent for current national benefits. This is a very clear request that nationally administered benefits should not be 'integrated' into local authority funding.

DA members include several local authorities, but DA members did not support the integration of AA in councils' care service funding. Nor did any member suggest 'maybe' this was a positive step forward.

One DA member described how the suggested impact of 'diverting disability benefits would be devastating'. DA supports the position of our members and believes there is a strong case for retaining DLA and AA as national, non means-tested benefits.

There are understandable concerns based on our members' experience about passing responsibility to councils:

- Current high criteria for accessing support;
- Means-testing for local service support;
- Perceived bureaucracy;
- Restrictions on independence through council services compared with national benefits; and
- Many of our members and other respondents cited the conflict of interest inherent in local authorities being responsible for assessing for care, decisions on resource allocation for care, and provision of care.

For these reasons – and others – disabled people fear the integration of disability benefits' resources to local authority social service funding.

Some of the reasons for the strong views revealed in our survey are summarized below.

DLA/AA are paid to disabled people to meet their higher living costs. There is ample evidence of the additional costs of living disabled people experience. This includes international research for the DWP in 2008²⁷ which concluded that:

'There is little disagreement with the idea that disability imposes extra costs on individuals and their households, above and beyond the often negative effect on the individual's earnings.'

The Government acknowledges that disabled people are at an economic disadvantage compared with other citizens, in terms of having diminished access to

²⁷ DWP Research Report 542 'Review of international evidence on the cost of disability' 2008. See also Joseph Rowntree Foundation 'Disabled people's costs of living: more than you would think' 2004.

educational and employment opportunities and additional expenditure required through impairment.

Overall, nearly three-quarters of all AA and DLA care component recipients state they have seven or more conditions/impairments²⁸. DLA and AA benefits were introduced to meet the higher costs associated with living with impairments/long-term health conditions.

The White Paper that introduced DLA stated quite clearly that it was for:

‘better coverage of assistance with the extra costs of being disabled’²⁹.

This is not the same as purely ‘social care’ needs – and is part of the reason why the payments provided by DLA/AA have never been high enough to pay for a professional care service.

DA is very concerned that the Government is considering using AA funding – and DLA funding for people receiving it who are over 65 years of age – without recognizing the background to why the benefits were introduced or how they are used.

We believe the Government must examine the use of these essential benefits before further considering them for integration in care service funding. It is unlikely, for example, that many people’s needs that are currently funded by AA or DLA would be met by local authority ‘care’ services. This includes all disabled people who use disability benefits to help with:

- attending hospital/medical appointments
- paying for prescriptions
- going to the shops
- doing housework
- responding to official correspondence (eg from councils or banks)
- higher heating and water bills that result from health conditions/impairments
- paying for internet access to aid participation/communication.

These issues must be addressed before a White Paper is published³⁰ and detail provided on what the Government means by ‘an equivalent level of support’ in the Green Paper for anyone whose benefits are changed through reform.

Disabled people do not misuse DLA/AA. There is little evidence on how DLA and AA are utilized by recipients. This does not mean benefits are misused. The benefits were introduced to help compensate for disabled people’s extra costs of living and the benefits have been absorbed into daily spending.

²⁸ ISER, ‘Disability benefits and paying for care’ 2008.

²⁹ Department for Social Security, 1990.

³⁰ In a full Equalities Impact Assessment which must examine care policy implications for older people, disabled people and gender equality in particular.

What is evidenced is that without DLA/AA many disabled people would be forced to rely on informal care to an even higher degree than currently. The ISER 2008 working paper on the issue suggested that:

‘A transfer of resources from social security benefits to the social services system...would...reduce resources delivered to disabled people who have a partner or other family member to care for them’.

DA believes the current system’s over-reliance on informal care is unsustainable (as emphasised on p11) and that further demand for informal support risks diminishing the working age population further.

DLA/AA provide independence, choice and control to a greater extent than Direct Payments/Individual Budgets. Connected to how people use benefits to meet their needs are the rules on how benefits can be used compared with the limitations in using funds provided by councils. Disabled people cannot use social service ‘personal budgets’ (or direct payments) as freely as they can use DLA/AA.

DLA/AA act as ultimate individual budgets; providing disabled people with a fund from which needs can be met in the manner most suitable to the individual recipient. If they were to be ‘integrated’ into local authority budgets, with recipients transferring across for an ‘equivalent level of support’ this freedom to meet needs independently would be diminished. Local authority funding – were it to be available as a payment to an individual³¹ – comes with far greater limitations on usage.

Through initiatives like ‘Putting People First’ and the Independent Living Strategy, the Government is attempting to ensure more disabled people are given greater control of their lives – including through managing public resources to meet needs. But the ISER concluded in 2008 that:

‘A transfer of funds from social security to local authority budgets could work against the trend towards greater flexibility and independence.’³²

DLA and AA also act as ‘passports’ to other, or higher, benefits. People who receive AA or DLA are more likely to access other forms of support. Removing AA or DLA will impact on how people access other support – or any support. The Government must make clear how take-up of other benefits and access to other support will be impacted by proposals it develops for the White Paper in 2010.

Disabled people using DLA/AA need the benefit and are not ‘wealthy’. The Green Paper suggests that AA in particular is ‘not well targeted’ and benefits people who do not need it.

But 40% of all AA and DLA care component recipients would live below the DWP poverty threshold if disability benefits were removed³³.

³¹ Out of 1.8 million local authority adult social care recipients in England in 2009, only around 100,000 receive Direct Payments compared to 1.5 million AA recipients.

³² ISER, ‘Disability benefits and paying for care’ 2008.

³³ Ibid. Poverty threshold being 60% of median income.

Consistent research also shows that more people should receive DLA/AA than currently do (to help tackle poverty and to meet people's support needs better)³⁴.

The evidence suggests that, without DLA/AA, disabled people will be at greater risk of poverty and increased social isolation (through reduced finance and support and lack of ability to participate):

- 29% of pensioners in households with one or more disabled adults who were not in receipt of disability benefits (like AA) lived in poverty, compared to 11% receiving a disability benefit³⁵.

Disability benefits are already considered as income by councils in implementing charges for using care services. Whilst local authorities contribute 54% of the costs of formal care services to older people in their own homes, it is estimated that AA contributes 16%. The severe disability premium contributes a further 16%³⁶. DA is concerned that this existing contributions to care service funding from AA and other disability benefits is not recognised and that Government plans may not have accounted for this existing contribution.

Connected to this issue is the problem of transferring a non means-tested benefit to means-tested services provided by councils. Means-testing reduces service/benefit take-up. This does not mean needs disappear, but that people 'muddle on' without support until crisis point. DA does not believe people should fear public services or their potential costs; nor is it in the broader interests of 'UK plc' to rely on informal care to meet disabled people's needs; and nor is it cost-effective to only provide state support when crisis point is reached (as highlighted on p11).

Transferring all Attendance Allowance recipients into local authority service would require 1.5 million people to be means-tested at considerable expense. Anyone who would have qualified for AA but could be routed through social services will also require means-testing – with the increase in costs to the system and the decrease in likelihood of seeking or accessing support that this incurs.

Accessing support. The ISER reported in 2008 that: 'a high proportion of [DLA/AA] claimants seem not to be receiving any care'³⁷. But disabled people with lower level needs who can currently access DLA/AA are denied access to council-run social services across England by local eligibility criteria.

People fear this situation would be perpetuated under a National Care Service which ended AA or DLA for people over the age of 65; that the current entitlement to funds to help would be lost as people would not qualify for local authority support.

Transparency and appeals. People also highlighted the differences in accessing support through national, non-means-tested benefits compared with local authority

³⁴ See, for example, the August 2009 report of the Work and Pensions Select Committee 'Tackling Pensioner Poverty'.

³⁵ 'Disabled people's costs of living' Joseph Rowntree Foundation and Disability Alliance 2004.

³⁶ Hancock et al 'Paying for Long Term Care for Older People in the UK' 2007. The remaining 14% was contributed by recipients.

³⁷ Institute for Economic and Social Research 'Disability benefits and paying for care' 2008.

social services. Whilst the DLA and AA claim-forms are notoriously lengthy, there are clear rules and case law to help decide who qualifies and firmer processes for adjudicating disputes. This is not the case with council care services.

DA seeks further information on how disabled people might be able to appeal decisions under a National Care Service and how the equivalent of DLA/AA tribunals would be funded. Current appeal rates are high (and more than half are successful) and the perceived likelihood is that appeals would rise under a new framework, certainly in the short-term. This is likely to require considerable investment and the process and funding of this appeals system need to be clarified by Government.

Who should decide the funding people receive

We asked our members and the public who should decide how much money is given to people to pay for their care. Responses to this question were split, but provide a picture of a lack of confidence in local authorities' abilities to undertake this task well:

- Councils – 2%
- National government – 21%
- Independent national body – 38%
- Individual people needing support and their family/carers – 39%

The reasons people felt strongly about councils not having this power was linked to other areas covered above but also include statements like this from a DA member:

‘council’s are self-interested in maintaining the smallest possible budget’.

A further comment from one DA member highlighted the current problem of councils not assessing disabled people’s outgoings well enough:

‘Means testing is always flawed because it only takes into account what comes in, not what goes out’.

Fewer of our members than general respondents suggested the national government should have this responsibility. One that did, representing a local authority, also suggested a proviso that:

‘If funding is given to councils, this might be a cash limited sum that may not represent the true present or future needs of the local population’.

Supporting comments for an independent national body (which was specifically opposed by just one respondent) included ‘in order to avoid self-interest’ and the need for ‘stability’ in care service funding – citing the existing flux in local authority budgets as dependent on political control of the council and the potential for this to continue even at national level without an independent arbiter.

Respondents suggesting that individuals and their family/carers were best placed to decide how much was needed to meet their needs suggested that assessment processes were not able to reflect people’s circumstances well enough. One DA member put it that resources should be allocated through:

‘an assessment process that better reflects people’s needs and how their disability costs them more money’.

We have highlighted some of the problems with current estimates of disabled people’s costs of living and the limitations of current local authority assessments of Disability Related Expenditure above (see p8). Our members seem to understand this issue well.

DA believes that the White Paper – and its supporting Equality Impact Assessment – must breakdown how many people who would not qualify for ‘care’ from councils but who have higher costs of living that are currently met through AA/DLA. The White Paper must also set out how many people who could have qualified for AA but are not yet already receiving it (i.e. those who have not claimed or will not be able to claim if AA is integrated into social service funding).

Local flexibilities in resources allocated to individuals

To help decide the resources people receive in a National Care Service, we also asked if local issues should be taken into account when deciding how much funding people get to pay for their care (and gave the examples of travel costs and local wages). The answers were that:

- 53% agreed or thought local issues maybe should be taken into account.
- 5% didn’t know.
- And 42% said local issues should not be taken into account.

This suggests that whilst many people (53%) can see some need for more localism in the amounts people receive to meet their needs, the confidence in local authorities to decide this issue was very low (2% in responding to the previous question). This suggests the need for a more independent body to assess any localism in resource allocation.

This finding is reflected in other surveys conducted for the Green Paper by Radar and the Independent Living Fund.

Affordability

We also asked respondents if they paid for care services or represented someone who pays to tell us what could make care more affordable. Many respondents did not answer this question, but some of the themes in responses to this question were:

- Raising the thresholds before people are required to pay for care services. One DA member suggested that: ‘Not charging when people’s income is just above the Income Support applicable amount’ would make the system more affordable. DA supports raising the threshold before charges for care are applicable – to at least the Wales levels of Income Support plus 35%.
- Speed of assessments was also cited by respondents as helping make support more affordable. Reasons included: ‘Having aids and assistance as soon as needs occur would...prevent health from declining and therefore reduce the size of any package of care required in the long term (and therefore the cost)’. This also relates to

ensuring a new National Care Service provides low level support to people and does not wait for higher needs.

- Assessing people's legitimate and essential outgoings better was also suggested by respondents. Currently local authorities do not always assess disabled people's 'Disability Related Expenditure' well. One DA member commented that: 'When assessing income be more realistic about outgoings'.

Disability benefits and 'income'

Finally, we asked if people's disability benefits should be taken into account as 'income' when people are assessed to pay for care. This issue affects many disabled and older people. The responses were significantly balanced against disability benefits being considered income:

- 9% said they should definitely or perhaps be considered income.
- 2% said they didn't know or were unsure.
- 90% said no, disability benefits should definitely not be taken into account as income when assessing people for care charges³⁸.

We believe that this high proportion opposed to disability benefits being included as income is due to the understanding our members have of why disabled people receive these benefits; i.e. to address higher costs of living and more restricted life chances/opportunities (to learn and earn for instance).

One of our local authority members reported that:

'Care provision in the community is never likely to provide for all of a persons care needs so the extra money will usually be needed for top up help'.

Very few (three) DA members definitely supported the inclusion of disability benefits as income in means-testing for care services.

DA recommends the removal of disability benefits from consideration as income in assessments for care service charges. We believe this would prevent local authorities from pushing disabled and older people into poverty as is currently occurring.

³⁸ Figures are rounded to the nearest decimal place, hence the 101% total respondents to this question.

DA recommendations on ‘Shaping the Future of Care Together’

We agree with the Prime Minister that big, bold visions in care service reform are essential. However, we believe in a bolder vision than the Green Paper presents.

We support a universal, tax-funded care service for disabled and older people and their families. We believe our view represents that of the vast majority of UK citizens and our members.

We believe that the Government must work in genuine partnership with disability organisations and examine the full impact of reform. We welcome the opportunity to contribute to Government proposals and the development of the White Paper.

We oppose plans to integrate Attendance Allowance or other national, non means-tested disability benefits into council social service funding. We believe proposals to integrate Attendance Allowance and DLA for people over the age of 65 into local authority funding would undermine the Government’s objectives of a fair, simple and affordable National Care Service and could heighten the likelihood of disabled people living in poverty.

We believe that a bold, new National Care Service should:

- Be provided on the same terms as the NHS with universal entitlements to support and free at the point of delivery – as supported by the vast majority (over two thirds) of our members and by the general public. We believe the Government should consider ending care service charges in developing the White Paper – or provide, with detailed analysis, why this is not an affordable option.
- Not be part-funded by disability benefits paid to people to help meet the extra costs of living with an impairment/health condition. Our members and other respondents opposed the integration of Attendance Allowance and other national benefits into care service funding at an astonishing margin (93% against, with just 3% in favour).
- Contribute to tackling poverty and should not leave more people at risk of poverty by removing disability benefits. We believe that the new national, standardised assessments for care should include new financial assessments to ascertain whether older and disabled people can genuinely afford to contribute towards care. Financial assessments should fully include outgoings and be independent from local authorities. Assessments should be monitored by the Care Quality Commission.
- Receive the level of investment required, as highlighted by stakeholders for almost a decade, to ensure support is available to adequately meet the needs of disabled and older people and their families – including ‘lower level’ needs.
- Be underpinned by equality and human rights. This means ensuring disabled people, older people and their families are supported to participate fully as equal citizens. It also requires services to help tackle the current over-reliance on informal care.

Appendix One: The DA survey

Shaping the Future of Care Together

1. Name

2. Email

3. How do care services affect you?

- I am someone who needs care and support
- I am a carer for a family member/friend
- I work for a care service provider
- I provide advice/assistance to someone who needs care

Other (please specify)

4. Organisation

5. Are you a member of Disability Alliance? Yes/No

6. Please select as many issues from the following list that you think are important to create a new care service which is fair, simple and affordable:

- Prevention services to avoid ill health/accidents
- A standard needs assessment process across England
- Joined-up services between health, social care, councils and other agencies
- Information and advice services
- Personalised care (managed as far as possible by the person needing support)
- People only pay for care if they can afford it

Other (please specify)

7. In your experience, what (if anything) has prevented a 'fair, simple and affordable' care system?

8. What is needed to deliver quality care services, which give people choice and work across government agencies?

9. Which of the following models (pick one only) of care funding do you think is most suitable for England?

- Everyone pays for themselves (no Government funding)
- Everyone gets a bit of Government funding
- People buy insurance to pay for care (and get a bit of Government funding)
- All people over 65 years of age pay towards care (whether using services or not) if they can afford it?
- The Government pays for all care services

Other (please specify)

10. Should Attendance Allowance, or other national funds, be included in funding given to councils to distribute?

- Yes
- Maybe
- Not sure/don't know
- No

11. Who should decide how much money is given to people to pay for their care?

- Councils
- National government
- Independent national body
- Individual people needing support and their family/carers

Please explain your answer in more detail:

12. Should local issues be taken into account when deciding how much funding people get to pay for their care, eg travel costs, local wages?

- Yes
- Maybe
- Don't know
- No

13. If you pay for care services or represent someone who pays please tell us what could make care more affordable for you/the person you represent?

14. Should people's disability benefits be taken into account as 'income' when people are assessed to pay for care?

- Yes, definitely
- Yes, perhaps
- Don't know/unsure
- No, perhaps not
- No, definitely not

15. Can we contact you about your answers/our campaigns/future offers? Yes/No

Appendix Two: DA members' questions to Care Service Minister

Below is a version of the text of the questions DA put to Care Service Minister, Phil Hope MP on behalf of our members. Ten questions were submitted in August and the nine answers received by 13th November 2009 are provided below.

Minister for Care Services answers your questions

Eligibility

Q The National Care Service will introduce one level of needs at which people will receive support from English councils. This is welcome. At what standardised level of need do you expect people to be able to access support across England?

Phil Hope says: The aim of these proposals is to extend care and support services beyond the current 'Fair Access to Care Services' criteria.

In the Green Paper, the principle is that eligibility criteria and the proportion of care and support costs met should be decided nationally. We believe this is fairer and more transparent than the current system.

The new assessment process we propose in the Green Paper will consider all of a person's individual circumstances to tailor the care and support they receive. But it will only be developed after the basics of the new system have been agreed.

Means-testing

Q How will you ensure that eligibility criteria and means-testing will not prevent people from accessing care and support who could currently qualify for disability benefits?

Phil Hope says: With the Green Paper we want to create the first National Care Service to give a better deal for everyone in this country.

We have said in the Green Paper that we want to consider integrating social care funding and some disability benefit funding. But we will only do this if we are certain the new system can better support the needs of older and disabled people.

People receiving any of the relevant benefits at the time of reform would continue to receive an equivalent level of support and protection under a new and better care and support system. In the future, everyone with high needs, and people who are on low incomes with lower levels of need who do not currently qualify for social care services, will be entitled to funding from the new care and support system.

Benefits

Q The Green Paper mentions AA specifically. Which other disability benefits are being considered for integration in local authority social service budgets?

[DA originally received no answer to this question, despite an extension to our deadline to allow the Department of Health to produce a response. We had to publish the following text in our October newsletter.]

Phil Hope says: We are working on answers to all of the Disability Alliance's questions and apologies we haven't been able to so far. We are keen to hear the views of all members so please do go to www.careandsupport.direct.gov.uk so you can have your say and we will come back to you soon.

On Tuesday 10th November DA received the following response to this question:

No decisions have been taken on which benefits will be included in any future system. However, on 22 October 2009 the Secretary of State for Health clarified the Government's position with regard to benefits and the proposals set out in the Green Paper. The Government has ruled out any incorporation of Disability Living Allowance for the under-65s into the new National Care Service.

The reason for this is that, while there will be increases in the numbers of disabled people of working age who need care, the majority of the people needing care in the future will be older people. Therefore, we think there may be a case for bringing together certain disability benefits which are directed at older people, such as Attendance Allowance, within social care funding if we are to create a new care and support system which is able to support all who will need care in the future.

Whatever the outcome of the consultation, people receiving any of the relevant benefits at the time of reform will receive an equivalent level of support and protection under a new and better care and support system.

In addition, we want to ensure that the new system builds on the advantages of the current disability benefits – where everyone can have a cash budget to spend on the services they want.

Independence

Q Can you explain how and why removing disability benefits such as AA from the benefits system and placing them within the care framework would improve opportunities for disabled and older people to remain independent; and how will you prevent local allocation of care resources reducing the assistance disability benefits now provide?

Phil Hope says: We know that disability benefits are popular because they don't depend on where you live, they provide cash to meet care needs and people often use them to help them stay well for longer. Those are the elements we would keep in the new system.

Whatever changes we make, we want to make sure that people would still get an equivalent level of support and protection, under a new and better care and support system.

The current social care and disability benefits systems have developed in isolation from each other. Because of that they are fragmented and can be complex to understand, access and navigate. This can lead to inconsistent and unfair outcomes. Bringing them together helps tackle this, under a new and better National Care Service.

Personal budgets

Q Some councils have put restrictions on how people use Personal Budgets/Direct Payments. Placing AA – or other benefits – in the hands of councils could mean limitations on how people are able to use resources to meet their needs. How do you believe transferring benefits to social service budgets will promote independence, choice and control?

Phil Hope says: The proposals in the Green Paper are not about administering benefits through local authorities. Any changes to the funding arrangements would mean the old elements ceasing to exist in their current form, creating a new National Care Service allowing the greatest public support to go to those who will benefit from it most.

If the public decides that bringing some disability benefits and the social care system together is the right approach, anyone receiving the relevant benefits at the time of its reform would continue to receive an equivalent level of support and protection.

UK-wide reform

Q If Attendance Allowance and DLA are paid through councils what will happen to knock on benefits such as Carer's Allowance or Carers and Disability Premiums etc; and – as the Green paper is applicable to England only – will the Government take a blanket approach and remove AA or other disability benefits across the UK?

Phil Hope says: If the arrangements for disability benefits changed, we would have to carefully consider how to maintain the links to any associated benefits. This does not mean fewer people would be eligible for other benefits, only that the way people qualify for them would change.

The Green Paper covers England only. Any changes to the disability benefits system would affect the devolved administrations in Scotland and Wales, and Northern Ireland may also choose to adopt the new system. We will work with all three devolved administrations to reach a joint conclusion on how to create the best possible outcomes for everyone.

Fluctuating needs

Q The Green Paper talks about a single national assessment of care needs. Assessment processes in the current care and benefits system do not reflect the changing circumstances of people with chronic fluctuating conditions. How will you ensure that the new assessment takes into account fluctuating needs?

Phil Hope says: I'm afraid I can't answer your question – yet! I am clear that the new National Care Service should provide personalised care, tailored to people's individual needs, including people with chronic conditions. But creating the new assessment process will only happen once the basic principles of the new system have been agreed.

Dignity, choice and control

Q Our service users are expressing concerns that the Care Component of DLA will be used to fund social care. They see it as a threat against their freedom of choice and independence. One told us: "My DLA benefit is crucial in helping me maintain a life of dignity". How can you reassure our service users?

Phil Hope says: We are working on answers to all of the Disability Alliance's questions and apologies we haven't been able to so far. We are keen to hear the views of all members so please do go to www.careandsupport.direct.gov.uk so you can have your say and we will come back to you soon.

[NB: At the close of the consultation period no answer was received to this question.]

Consistency

Q The CSCI reported that local authorities were not planning well to meet the personalisation agenda. Currently, the services available are dependent upon where you live. And current services are not flexible in meeting people's needs, eg people with ME needing complementary therapies. How will you ensure consistency alongside personal/flexible support in the National Care Service; and how will the Government help meet the costs of the new model of service delivery?

Phil Hope says: We are working on this right now. Every local authority is working towards the goal of making personal budgets the norm in providing care and support, and the Government has invested £520 million in the Social Care Reform Grant to help them do this.

In the Green Paper, whatever funding approach the public decides on, local authorities will continue to play a central role in giving people personalised care and support services. We want this to be at the heart of the National Care Service. We are asking people for their views on the balance to be struck between national consistency and local flexibility and innovation.

In terms of meeting the costs, we think there are three options for funding a National Care Service and want to know what you think. Please go to www.careandsupport.direct.gov.uk to tell us which one you would choose.

Free care

Most people believe care services are free. When they discover care is not free, they believe it should be. Why has a free funding model been ruled out; and what precedent does it set if only people using public services pay for them?

Phil Hope says: Care is not free, and never has been. It is paid for by individuals either directly or in taxes. We've looked at funding care services out of taxes and the figures just don't add up. At the moment, there are 4 working age people for every one retired. By 2050, this will be 2 working age people for everyone retired. When you consider the care costs of our ageing population, the burden of tax would just be too great for working age people. So we do need a new partnership between individuals and the state.

It is vital that everybody gets involved in this consultation to have their say on how the new care and support system should work. Please visit our website www.careandsupport.direct.gov.uk to join in the Big Care Debate and help us shape the future of care together.

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