REFRESHING THE NATIONAL CARERS STRATEGY

Call for Evidence

The previous Government’s national Carers Strategy – Carers at the heart of 21\textsuperscript{st} century families and communities\textsuperscript{1} – was published in June 2008. It set out a vision that by 2018:

‘carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.’

Ministers and the Standing Commission on Carers\textsuperscript{2} believe that the vision in the Carers Strategy holds good. As part of the process for informing the Spending Review\textsuperscript{3}, the Government must prioritise its actions for the next four years to ensure maximum value for money in the context of the current economic climate and the Government’s top priority of reducing the national deficit.

The Government is therefore ‘refreshing’ the Carers Strategy with a view to producing, before the end of this year, a clear plan of action for 2011 to 2015. This will set out the key activities upon which the Government – working in partnership with Local Authorities, the NHS, employers, the voluntary sector, local communities and carers – can focus from April 2011 onwards, within the context of the ‘Big Society’ and the capacity of the community to support and empower people. The Government is not seeking to re-write the Carers Strategy.

The Government is keen to seek your views now on the key priorities – supported wherever possible by evidence of good practice – on what will have the greatest impact on improving carers’ lives in the next four years. The deadline for responses is 20 September 2010.

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\textsuperscript{1} Available to download at: \url{http://collections.europarchive.org/tna/20100509080731/http://dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH_085345}

\textsuperscript{2} The Standing Commission on Carers is an independent advisory body, providing expert advice to Ministers and the Carers Strategy Cross-Government Programme Board on progress in delivering the strategic vision of the national Carers Strategy.

\textsuperscript{3} For more information about the Spending Review see \url{http://www.hm-treasury.gov.uk/press_10_10.htm}
The Government appreciates that this is a tight timescale but it is a necessary one if the Government is to help inform decisions in the light of the Spending Review and influence planning by Local Authorities, the NHS and others for April 2011 onwards.

**This document is for you to use to give your views.** It sets out the main ambitions of the previous Government’s Carers Strategy, and asks what you believe are the **top priorities** on which we should focus in the next four years, and what **evidence** (including, where relevant, personal experience of what has worked well and proved most cost-effective) you can detail to support those assertions.

**Some important points to note:**

1. The Government recognises that the issue of carers’ benefits is important and will consider this area separately under plans to simplify and modernise the benefit system. In this call for evidence, we are interested to hear about support other than cash benefits that would help to improve carers’ lives.
2. The consultation on the extension to the right to request flexible working for all, referred to in the Coalition Government’s Agreement, is separate to this call for evidence and will be launched by the Department for Business, Innovation & Skills (BIS) later in the year.
3. The Commission on the funding of care and support has recently been established to make recommendations to the Government on how to achieve an affordable and sustainable funding system for care and support, for all adults in England. The Commission will consider evidence from stakeholders including carers as part of its work and will set out how it will engage on this issue shortly.
4. When submitting views on priorities, please be mindful that the present position with public finances makes it likely that there will need to be ‘trade-offs’ in order to determine the highest priorities.
5. The Carers Strategy relates to health, social care, education and training in England, to benefits in Great Britain and to employment in the United Kingdom.

The outcomes identified for 2018 (as set out in the strategic vision of the Carers Strategy) are:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.
- Carers will be able to have a life of their own alongside their caring role.
- Carers will be supported so that they are not forced into financial hardship by their caring role.
- Carers will be supported to stay mentally and physically well and treated with dignity.
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes.
Each of those outcomes is very important but the Government is seeking evidence on what actions are most likely to deliver them. **In your view, what are the priorities to focus on in the next four years?**

**Coalition Government’s Agreement**

The Coalition Government’s Agreement\(^4\) recognises the importance of carers to families and communities and sets out that the Government will look to provide support to carers particularly through:

- extending the roll-out of personal budgets to give people and their carers more control and purchasing power;
- using direct payments to carers and better community based provision to improve access to respite care;
- extending the right to request flexible working to all employees, consulting with business on how best to do so; and
- establishing a commission for long-term care which will consider how to ensure responsible and sustainable funding for long-term care.

**NB:** The points from the Coalition Government’s Agreement are included for background purposes only. We are not seeking views from stakeholders on the Coalition Government’s Agreement.

**How the Government is distributing this document and collecting views**

This call for evidence will build on the extensive consultation with carers undertaken by the previous Government in developing the Carers Strategy and all the evidence contained in it. The Government encourages all organisations responding to this call for evidence to seek and reflect the views of carers about priorities.

The following people and organisations are being asked to disseminate this document through their networks:

- Local Authority Chief Executives
- NHS Chief Executives
- Directors of Adult Social Services and Children’s Services
- Association of Directors of Adult Social Services and Association of Directors of Children’s Services – Carers Reference Group
- NHS Confederation
- Local Government Association
- Government departments
- Voluntary sector (including Carers UK, Crossroads Care, The Princess Royal Trust for Carers, Alzheimer’s Society, Age UK, Mencap, Rethink, Macmillan, Disability Alliance, Counsel and Care, The Children’s Society, National Young

\(^4\) Available to download at [www.cabinetoffice.gov.uk/media/409088/pfg_coalition.pdf](http://www.cabinetoffice.gov.uk/media/409088/pfg_coalition.pdf)
Carers Coalition, RADAR – The Disability Network, Disabled Parents Network, Council for Disabled Children, National Children’s Bureau, Barnardo’s, Contact a Family, National Black Carers & Carers Workers Network, The Afiya Trust and others)

- Care Quality Commission
- Equality and Human Rights Commission
- Employers for Carers
- Confederation of British Industry
- Federation of Small Businesses
- Employers Engineering Federation
- Institute of Directors
- British Chambers of Commerce
- Trades Union Congress
- UNISON
- Centre for International Research on Care, Labour and Equalities (Leeds University)
- Personal Social Services Research Unit

It is also available to download at the Department of Health website at: http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117249

Please forward this document to others who you think may wish to respond.

Summary of key milestones

- 20 September 2010 – deadline for responses to this call for evidence
- September - October 2010 – analysis of evidence received (involving Standing Commission on Carers)
- Autumn 2010 – publication of plan for 2011-2015 (after the outcome of the Spending Review is known)

If you wish to respond

Please complete the tables on pages 5-12 and either email your response to carersevidence@dh.gsi.gov.uk or post it to:

Carers Evidence
Carers Strategy Team, Department of Health
Area 116, First Floor
Wellington House
133-155 Waterloo Road
London SE1 8UG
Your contact details

<table>
<thead>
<tr>
<th>Name of organisation / individual</th>
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| Julie Stansfield CEO of In Control | Address: In Control Support Centre  
Carillon House  
Chapel Lane  
Wythall  
West Midlands  
B47 6JX  
Tel. no.:01564 821 650  
Email: Julie.stansfield@in-control.org.uk |

Freedom of Information

The Department of Health will manage the information you provide in response to this call for evidence in accordance with its Information Charter.

Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may be published in a summary of responses to this call for evidence and passed on, in summary form, to other Government departments.
Are you happy for your response, in summary form, to be passed by the Department of Health to other Government departments?
Yes

Are you happy for your response to be published in a summary of responses?
Yes

Are you responding:
- on behalf of an organisation X

Equality Impact Assessment

An Equality Impact Assessment was conducted for the Carers Strategy when it was published in 2008. It is available at:


Around 6 million people in the UK spend a significant proportion of their life providing unpaid support to family or friends. This can involve caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. The 2001 Census showed that, in England, there were 4.83 million carers (one in ten of the population), and two-thirds of carers of working age combine paid work and care. 58% of carers are women and over-65s account for around a third of all carers providing more than 50 hours of care a week. The Census also indicated that there were approximately 139,000 young carers in England.

The Government recognises that carers are not a homogenous group. Their caring role may develop gradually or it may be thrust upon them unexpectedly or suddenly. Although many carers are family members, others may be friends or neighbours providing a range of practical and emotional support. Demographic change and social mobility mean that many carers may live at a distance from the person to whom they provide support.

A growing number of carers (in particular parents of adult children with a learning disability or long-term condition) may be ‘lifetime carers’, with many carers providing support well into their later years. There are also inter-generational ‘sandwich carers’ (with multiple caring responsibilities) and carers who are themselves disabled. In addition, significant numbers of carers do not identify themselves as such (for example, cultural concepts of caring are not universally shared throughout communities in Britain).

Of the organisations listed on page 3 to which we are sending this call for evidence, the following will be particularly relevant in helping us to make sure, by disseminating through their networks, that it reaches as many carers as possible:

- The Afiya Trust
The Government will undertake a further Equality Impact Assessment in the autumn alongside the preparation of this action plan.
Your views on priorities (by outcome of the strategic vision of the 2008 Carers Strategy)

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<td><strong>Outcome of 2008 Carers Strategy:</strong> “Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.”</td>
<td><strong>The evidence presented here has been gathered over a number of years using In Controls evaluation framework.</strong></td>
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This is a critical requirement, but it needs to be seen in the following light.

1. We are concerned that the phrasing of this particular statement does not reflect the paradigm shift needed to bring personalisation. It remains too focused on an outmoded view of ‘services’ and on the implicit premise that the family (‘carer’) has some sort of ultimate responsibility through their ‘caring role. Our view is that the person in need of support and the family supporting them are interdependent, and both are (or should be) part of a wider community-based system of support. Services should be designed to strengthen and support this system, building on what individuals and families want and need locally to make communities a good place to live for all concerned.

2. We prefer the term ‘families’ to ‘carers.’ Firstly because of the fact that many people we have spoken to do not wish to be defined exclusively in terms of their ‘caring’ role. And secondly because personalisation requires us to think broadly about family, friends, and the wider community – giving care and being caring is something...
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<td>which applies to all, and using the term 'carers' exclusively for family members who have a particular emotional tie narrows it unhelpfully. Our view is that the move to personalisation is a fundamental one, which is essentially <strong>a shift in culture and in relationships</strong>. We need to get the language and thought-processes right in order to then change what we do in the way that is needed.</td>
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<td><strong>There is a big task in changing the attitudes</strong> from “the government should support vulnerable people” to “disabled people do NOT belong to the government and they should have the right to access support that gives them opportunities to an ordinary life”. This shift is as big for the parental nature of services as it is to the dependency culture many disabled people and older people have been entrenched in. All systems work on the basis of functionality of diagnosis and thus there is a perverse incentive for families to state they are abandoning their loved one in order to gain resources. The support systems in turn for carers place a ‘plaster’ on this inept system by offering them spa sessions, or courses on how to look after their back when lifting. Most carers we know would say that if they were left to resolve the situation for themselves that they would find a better way and we have many examples of when this has happened.</td>
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<td>The system needs to change to <strong>whole life</strong> outcomes and place some responsibility back into the hands of people. People accept</td>
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Views on priorities | Supporting evidence (including value for money)
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the expectation that if someone is disabled they do not work, if they are older they have nothing more to give. Our society is engrained in negative and low expectations of people with support needs. There are some movements in this change of culture but it’s slow and the current systems in place do not help the change but hinder it. The recent example of people using their personal budget to pay for sex services focused on the usage of public money – but no one was outraged that people were interfering in someone’s private life. The issue should be as simple as enabling someone to meet an overall broad outcome as long as it’s legal.

3. Of course family members should be respected as experts in the particular needs of their loved-ones. They haven’t always been respected in this way, and this is something that we have campaigned to change. Formal systems of ‘assessment’ and review need to change to recognise and accommodate this, and professional staff need to approach these tasks with this in mind.

4. It is certainly the case that families need integrated and personalised services as part of this fundamental shift. What this means in practice is not yet widely understood. In essence, each service needs to flex to the perspective of the family using it, and have the capacity to meet particular issues about access, language and culture; services also need to be in a position to appreciate and **make use of people’s Real Wealth** - the particular ‘gifts’ or ‘assets’ which
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<td>a family brings; whilst helping them find ways to meet their needs/address ‘deficits.’ It is critical that we allow people to spend their personal budgets in a flexible way, allowing families the freedom to spend the money in a creative way to meet the broader outcomes.</td>
<td>For example, Karen’s daughter, kate was awarded a direct payment for respite. The local authority was happy to spend £500 per week for a specialised residential unit but not £300 per week so Kate could go on holiday with her extended family. The latter would have given Karen a more relaxing break, as she is less worried about whether Kate is OK and happy and it allows Kate to develop other natural networks. The local authority did eventually agree to this after an appeal but these examples are happening too often.</td>
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<td>5. <strong>Money + knowledge = power</strong> and we need to give people real images of what is possible. The best example that we have see of this is through the <strong>Partners in Policymaking</strong> programme and network, through which families are able to explore alternative ways which do not lead to the individual being dependent on government support.</td>
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<td>If families are to feel “in Control” of their role as a carer this takes both the money to access the right support and the knowledge to action it. We know from “self funders” that money alone does not solve the issue they need the images of what is possible and they need to hear this from others in the same situation – not a national carers newsletter. To gain both, personal budgets are essential but more critically there is the need to be able to use this money more flexibly. There are far too many examples of very sensible plans being refused due it not being a traditional way of spending the money, and yet the plans have made economic sense and would enable the person to have a higher quality of life.</td>
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**Outcome of 2008 Carers Strategy:** “Carers will be able to have a life of their own alongside their caring role.”

This is a critical requirement, not only for the success of the carers’ strategy, but also of Putting People First and the government’s wider aim to create a ‘Big Society.’ No-one can or should be expected to give of their best if their whole life is devoted to one activity or to caring for one person. Such an approach creates the conditions for discontent, resentment and narrow inward-focused family situations which see no-one thrive.

The more challenging issue is how we find the **tools to create open, responsive, resourceful communities**

When asking family carers about their experiences of personal budgets:

- 44% of family carers reported an improved quality of life.
- 34% reported an improved leisure and social life.
- 57% reported increased choice and control over their life.
- 49% reported improved relationships with the person they care for.
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<td>where families find that the onset of disability, ill-health or old age is welcomed and embraced, and where they are not expected to ‘take on the burden of care.’</td>
<td>55 % reported improved relationships in other significant relationships</td>
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<td>In Control’s experience suggests that this can only come about through a process to strengthen and empower citizens and families. This is already happening through programmes such as Partners in Policymaking and All Together Better which seek to create citizen- and family-leaders, networks of people with the knowledge, skills and confidence to take a leadership role in their own communities (geographic and otherwise) to push for genuinely personalised solutions to the difficulties we face together. These programmes need to take place in parallel with work with those elected representatives and professional staff responsible for community leadership and for the commissioning of health and social care to bring about change at all levels in the system at the same time.</td>
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**Outcome of 2008 Carers Strategy:** “Carers will be supported so that they are not forced into financial hardship by their caring role.”

*NB. In this exercise, we are particularly interested in support other than cash benefits.*

This is another critical requirement.

We need to analyse what it is that forces families into financial difficulty. By far the most important cause is of course loss of paid employment, which occurs when someone takes on a ‘caring’ role. Hence we need to identify measures to help people stay in work, in those situations where a family member comes to need additional support as a result of disability, ill-health or old age. These measures fall into a number of categories:

1) Legislative and other measures to encourage employers to make special allowances for employees’ caring responsibilities.
2) Flexible welfare benefits that allow people to stay in work part-time where this is necessary, without

When In control asked family carers about their experience of personal budgets.

55% of family carers reported that their financial situation had improved since the allocation of a personal budget to the person they care for. (4% report a worsening, mainly associated with changes to local authority means testing/charging arrangements)

A small number 15% reported improved opportunities to undertake paid work. A significant number of responders indicated they were over retirement age.
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| significant loss of income.  
3) Measures that encourage flexible, responsive and safe community supports/services, so that people can leave a loved one for periods of time, without worry.  
These measures need to be underpinned by an effort to **change social attitudes, so that the norm becomes ‘the whole community cares’** rather than the daughter/wife/son/husband cares.  
We very much look forward to the announcement of the measures that accompany the right to extend flexible working for all, later in the year. |
Views on priorities | Supporting evidence (including value for money)
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Outcome of 2008 Carers Strategy: “Carers will be supported to stay mentally and physically well and treated with dignity.”

This is yet another critical requirement. Families with caring responsibility will stay well if certain conditions prevail:

- Ill-health, disability and old age are regarded as normal aspects of the cycle of life, with no stigma attached to them – or to those supporting family in these situations.
- **Communities are the main source of support** for people who are in need of extra help. Universal services’ are flexible, accessible and welcoming for all.
- **Specialist health and social care services** are available to provide advice and extra support (for both the person supported and for those providing the support), when and where needed. These services have sufficient funding to do the job and are **flexible, accessible and responsive to all**.

When In control asked family carers about their experience of personal budgets.

61% of family members said that the support they had to continue caring and remain well had improved since their family member had been allocated a personal budget. Only 3% reported a decline.

59% of family members reported an improvement in their general health and wellbeing.
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<td>This is another critical requirement. It is not acceptable that children and young people should be expected to forgo a normal childhood and education to take on the role of ‘young carers’ except in limited and clearly defined situations, and where it is clear that this is what is in the best interest of the child.</td>
<td>There is clear evidence about the positive use of personal budgets in ways which sustain and improve the quality of lives for parents and siblings. Families often speak of this as the first and most important outcome for them; “we have our family back”, “it now feels like brothers and sisters” and not “him/her and them”. Personal budgets used positively will promote and sustain...</td>
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<td>best interests of all concerned.</td>
<td>relationships within families, will value the voice of the carer alongside the child or young person and will, in the long term sustain life long relationships more proactively than our current approach of prescribe and service.</td>
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<td>The solution to these difficult situations is in the hands of local people and local communities, supported by adequately funded children and family services, which focus upon the <strong>strengths and needs of whole families</strong> – adults and children; and which work with schools, colleges and youth and community services and other ‘universal services.’</td>
<td>Although personal budgets can bring with them more work for families, their impact outweighs this; families feel more relaxed as they are able to trust and have confidence in the support their son or daughter is receiving, they know what is happening and can plan for instances of ill health for the child or carers.</td>
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<td>All together, personal budgets for the child and an approach which values the voice of the parent carer as an expert, will improve the quality of life for all in the family group.</td>
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