



Report of the Standing Commission on Carers

2007 to 2009

**Carers at the heart of 21st century families and communities
– work in progress**

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 national Carers Strategy. The Department of Health provides the secretariat to the Commission and has funded the publication and distribution of this report.

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Foreword by Dame Philippa Russell DBE, Chair of the Standing Commission on Carers

It is both a privilege and a pleasure to introduce the first Annual Report of the Standing Commission on Carers. The publication in June 2008 of the national Carers Strategy, *Carers at the heart of 21st-century families and communities*, was underpinned by a new vision that 'by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities'. The creation of the Standing Commission on Carers similarly acknowledges both the challenges of meeting demographic change and the aspirations of carers and those they support for maximum independence, choice and control of their own lives.

I have been privileged to be Chair of the Standing Commission in its interim phase and to be reappointed as Chair as we move to our new appointed status. The Standing Commission has an important role to play if we are to attain our long-term ambition of raising the profile of carers and valuing their unique contribution to family, community and society. In order to achieve this goal, we must recognise both the challenges and the opportunities, short and longer-term, in delivering the 10-year Carers Strategy.

The next decade will see significant change, in terms of both the demography and the economy, and with regard to carers' own lives and expectations. The creation of the Standing Commission on Carers in 2007 complements and reinforces the *Putting People First* cross-sector concordat, emphasising the importance of co-production, co-delivery and co-evaluation in developing a care and support system that values and builds upon the aspirations and the expertise of both carers and those they support.

Carers themselves have a key role to play in the transformation of adult social care, and the Standing Commission aspires to provide an independent and authoritative policy forum in which to take forward the challenge of providing timely, personalised and high-quality care and support. Our ambition is to ensure that carers and those they support have the best possible health and wellbeing, are active partners in the development of local and national policy, and can participate fully in family, community and society. To achieve this goal, we in turn will need active partnerships with commissioners and providers across the public, independent and third sectors. We look forward to our next phase of work and the active partnership that is essential to fulfilling the key objectives set out in the Carers Strategy.

The Standing Commission has given carers a voice at the heart of government and we must use that opportunity well over the next decade in terms of scrutinising (and supporting) the delivery of the short and longer-term outcomes set out in the Carers Strategy. We are one year on from the Strategy's publication and we are beginning to make good progress to deliver on its commitments. This report is an important part of that process and I hope it will be read not just by those organisations that represent or advocate on behalf of carers' interests, but also by carers themselves.

Dame Philippa Russell DBE
Chair of the Standing Commission on Carers
October 2009

1. Introduction

Standing Commission on Carers

The Department of Health established the Standing Commission on Carers (hereinafter referred to as 'the Commission') in December 2007 at the request of the Prime Minister. It is an independent advisory body, providing expert advice to ministers and the Carers Strategy Cross-Government Programme Board on progress in delivering the national Carers Strategy. The Prime Minister invited Dame Philippa Russell to chair this first phase of the Commission, whose members included carers and representatives drawn from a wide range of public and third sector organisations.

This annual report concludes the first stage of the Commission's work (December 2007 to June 2009). The report is structured firstly to highlight progress to date against each of the main themes of the strategic vision (as set out in the national Carers Strategy), and secondly to signpost future challenges and opportunities. It also contains recommended actions and suggestions for the Government, delivery partners and the next phase of the Commission. The main recommendations are indicated in **bold**.

The next phase of the Commission follows an exercise to appoint the chair and members in accordance with guidance from the Office of the Commissioner for Public Appointments. The membership of the Commission for this next phase of its work was announced in September 2009.¹

National Carers Strategy

Published in June 2008, *Carers at the heart of 21st-century families and communities*² is a 10-year cross-government strategy. It aims to ensure that carers have increased choice and control, and are empowered to have a life outside caring. The strategy sets out short-term commitments that are being delivered from 2008 to 2011 and identifies longer-term priorities for 2011 onwards.

The strategic vision

The Government is working with delivery partners to implement the short-term commitments, as a first step towards achieving the Strategy's longer-term vision:

'Our vision is 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.'

The Government worked closely with the Commission in developing this vision.

¹ Standing Commission on Carers website: www.dh.gov.uk/ab/SCOC/index.htm

² www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

The outcomes identified for 2018 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 Matters³ outcomes.

Facts and figures

The 2001 Census reports that there were 5.67 million carers in Great Britain (around 5.2 million carers in England and Wales⁴ and almost 500,000 in Scotland⁵). Of these:

- 58% of carers were women, 42% were men; and
- 68% of carers provided care for up to 19 hours a week, 11% for 20–49 hours and 21% for 50 or more hours.

The Government's strategy *Building a society for all ages*,⁶ designed to help Britain prepare for an ageing society, states that over-65s account for around a third of all those carers providing more than 50 hours of care a week.

According to Carers UK:

'In the 45–59 age group in Britain, 16% of all men (over 900,000 men) and 23% of all women (over 1.3 million women) are carers. Well over a third of women in this age group, and about half of men, hold managerial, professional or technical positions... Among carers in this age group, 25% of men (224,000) and 29% of women (384,000) provide 20+ hours of care a week, with 119,000 men and 164,500 women providing 20+ hours of care on top of their paid duties.'⁷

In a Written Parliamentary Answer on 21 July 2009, Jonathan Shaw, Minister of State for Disabled People (Department for Work and Pensions (DWP)), stated that 417,800 carers in England were at that time in receipt of Carer's Allowance.⁸

3 www.everychildmatters.gov.uk/

4 2001 Census data on carers in England and Wales available at:

www.statistics.gov.uk/StatBase/ssdataset.asp?vlnk=7545&Pos=&ColRank=2&Rank=256

5 Census data on carers in Scotland available at: www.scrol.gov.uk/scrol/common/home.jsp

6 Online version available at: www.hmg.gov.uk/buildingasocietyforallages/download.aspx

7 Yeandle, S et al (2007) Carers, Employment and Services Report Series, London: Carers UK

8 www.theyworkforyou.com/wrans/?id=2009-07-21c.289161.h&s=number+of+carers#g289161.r0

2. Progress towards the strategic vision

'The vision is right and what we are trying to do is right. But the timing is difficult – it is a period of massive change and we have got to hold on to the vision. The Commission must not lose sight of this.'

Lina Patel

Chair of the National Black Carers and Carers Workers Network, and member of the first phase of the Standing Commission on Carers

A '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'

The Carers Strategy recognised that there will always be a need for care and support in this country, and that the forecast change in demographics will see the demand for care grow further. To deliver this outcome, carers need a range of services – whether provided from the Government or the independent and third sectors – which are sensitive to the needs and aspirations of people from all sectors and groups within society, and reflect local diversity and communities.

As highlighted in Putting People First without putting carers second,⁹ carers have had to fight over many years to gain some recognition as 'partners in care', and too often they are still left with all of the responsibility but none of the support for or acknowledgement of the role they perform. One carer said, at a consultation event for the Carers Strategy, 'Professionals offer what is available – they don't ask what I need.' The challenge is for the agencies responsible for providing care and support to work effectively together and in active partnership with carers and families in a manner that delivers the vision through carers feeling that the services are 'on their side'.

Carers UK and the University of Leeds have highlighted¹⁰ that longer-term carers, many of whom have much experience of accessing and using services to support them and the person they care for, feel that they become genuinely 'expert' in knowing how to be a carer effectively in their particular set of circumstances. They develop new skills such as advocacy, time management, contingency planning and expertise in a particular illness or condition. Many are concerned that their expert and intimate knowledge of the person they care for is dismissed, ignored or rejected, reflecting the need to treat them as 'equal partners' in the delivery of the overall care package.

⁹ Online version available at: www.carers.org/professionals/health/health-and-wellbeing,808,PP.html

¹⁰ *Stages and Transitions in the Experience of Caring*, online version available at:

www.carersuk.org/Policyandpractice/Research/CarersEmploymentandServices/1201172368

Case study

Centre 404 is based in Islington, London and was founded in 1951 by parents of children with learning difficulties. For over 50 years, it has been a highly successful parent-led organisation providing support, information and advocacy to parents and carers.

With funding from a range of sources including the Big Lottery, Islington and Camden Adult Social Services and previously the Children's Fund, Centre 404's Family Support Service works in partnership with organisations in several other sectors to support carers. Its many activities include allowing carers to meet councillors each month, helping carers to understand their rights and the availability of services and providing complementary therapies for family carers (funded from the Islington Carers' Grant). In addition, its Family Carers Reference Group has made major contributions to the Learning Disability Partnership Board, culminating with the review in 2008 of the Partnership Board and its proceedings.

Centre 404 is an excellent example of third sector support and partnership working and will continue to seek to provide quality services by supporting those with learning difficulties – and their families – to get their voices and views heard.

www.centre404.org.uk

Progress to date, opportunities and challenges

Supporting carers to become expert partners in care and developing a network of champions

- A1 The Commission welcomes the reference to the Carers Strategy in the NHS Constitution¹¹ (published in January 2009) and the recognition of the need to treat carers as expert care partners. As part of the Government's legal duty to keep the Constitution under review, carers will be consulted on its scope, impact and effectiveness. **The next phase of the Commission will wish to take a close interest in the outcome of such consultation.**
- A2 Many carers often take on caring responsibilities at short notice, with very little (if any) preparation for their new role. Their first concern is to acquire confidence in the job of caring. Only then will they find the time and energy to pursue the other generic aspects of caring.

¹¹ Online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093419

- A3 The national Caring with Confidence training programme,¹² established in 2008, has been widely welcomed. The programme comprises two different types of training module – both face-to-face training and distance learning – and provides a wide range of generic information for all carers, focusing on developing their confidence and skills in their caring roles. Modules tailored to support those caring for people with specific conditions will soon be ready.
- A4 Caring with Confidence is expected to reach full capacity in late 2009. However, this is not as soon as was originally planned and the Commission hopes that Caring with Confidence can now move forward without further slippage.
- A5 It is important that the two different types of training module are run in tandem, so that new carers can have a choice about how they access the information they need.
- A6 The Commission notes that existing training had been mapped as part of the development of the Caring with Confidence programme, and that the Department of Health has made clear to local authorities and primary care trusts (PCTs) that Caring with Confidence should be an additional resource for carers and not a replacement for existing training. The Commission welcomes this clarification.
- A7 The third sector has a long and successful track record in supporting carers to be confident in their caring roles. For example, Carers UK's Equal Partners project¹³ provided carers from all parts of the UK with the facts, skills and back-up needed to achieve change locally. It helped carers to be a part of local decision-making with social care and NHS professionals, and also worked to improve the running of services, such as breaks, transport and leisure, for carers and those for whom they care. The National Black Carers and Carers Workers Network also provides invaluable support to reduce the health inequalities of carers in black and minority ethnic communities. Research such as *Beyond We Care – Putting Black Carers in the Picture*,¹⁴ highlights the causes of disadvantage and isolation for carers and identifies potential solutions.
- A8 The work of Partners in Policymaking¹⁵ to build alliances and provide training for disabled adults and parents of disabled children has been well received by participants. These courses are extremely helpful in supporting carers and people with various disabilities to develop a range of skills to support effective partnership working with service providers, contribute to local policy development and also pursue wider training and employment opportunities for themselves.

12 www.caringwithconfidence.net/

13 www.carersuk.org/Newsandcampaigns/Howtocampaign/EqualPartners

14 Report published 2008 by Afiya Trust for the National Black Carers and Carers Workers Network

15 www.partnersinpolicymaking.co.uk/

- A9 The Department of Health is supporting the development of a new national course All Together Better¹⁶ by Partners in Policymaking, which will identify, train, support and sustain a network of carers' champions for the Carers Strategy. The Commission also welcomes the Department of Health's interest in building on the Dignity in Care Champions Network to enable Dignity Champions to become powerful local advocates for the Carers Strategy. **Over the next 12 months, the Department of Health should build on the good work of Partners in Policymaking, the Equal Partners project, the National Black Carers and Carers Workers Network and others, and work with the Dignity in Care Champions Network to identify champions to support delivery of the Carers Strategy locally.**
- A10 **There should also be development of further capacity regarding training courses at a local level so that carers can participate effectively in a wider range of activities including inspection teams, Local Involvement Networks (LINKs), local strategic partnerships and the development and review of local area agreements.**
- A11 At a national level, the Department of Health has made grants to Carers UK, The Princess Royal Trust for Carers, Crossroads, the Afiya Trust and Partners in Policymaking to help build capacity and to support their work in delivering the Carers Strategy. In some areas of the country, however, third sector organisations are finding it difficult to access local funding for their existing services. Third sector capacity to support carers to become expert strategic partners and active participants in their local communities should therefore be reviewed as part of the wider agenda to transform social care. **In addition, it would be helpful if the next phase of the Commission could have an early discussion with the Department of Health, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) on the impact of the transformation agenda on the continuing viability of third sector organisations, given the important role they play in developing, designing and delivering innovative services and support for carers at local and national level.**
- A12 **ADASS and the LGA should consider how best to ensure that transformation and partnership work are achieving the desired outcomes at local levels and whether there are any associated resource issues.**

National information resource for carers

- A13 The provision of accurate and timely information is vital for carers so that they can make informed choices and confidently support the people for whom they care. It is prioritised within *Putting People First*¹⁷ as a first step towards self-directed care, independence and choice. Carers Direct– the 'one-stop-shop' information service for carers, the web component of which is hosted on the

16 Online version available at: www.careline.org.uk/upload/public/attachments/2/iC%20Altogether%20Better%20app-pack-d%20NEW%20print.pdf

17 Online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

NHS Choices website¹⁸ – was launched earlier this year and is an extremely useful resource. It promises to be even more effective once an online community of carers has been well established, giving carers the opportunity to share their knowledge, experiences and best practice.

- A14 Carers will not necessarily think of turning to *NHS Choices* as a first point of contact. The marketing strategy for Carers Direct – which is in development – will be important in ensuring the success of the service and it should be supported with sufficient funds. In addition, local and national voluntary organisations should be encouraged to develop a positive partnership with Carers Direct and to signpost carers to it. Effective partnerships with national and local information and advice services will be vital. Both Caring with Confidence and Carers Direct should seek to create positive partnerships with the third sector and the next phase of the Commission around further development of both programmes in order to address the diversity and complexity of carers' needs (for example, on accessibility for black and minority ethnic communities of carers).

The development of local information services

- A15 The advent of Carers Direct does not mean that there is no longer a place for local information services for carers. Concerns have been expressed that local authorities will reduce investment in local information services now that Carers Direct has been established. However, Carers Direct in itself is insufficient to meet the full range of carers' needs for both local and national information. Local information services (and specialist national information services) will remain highly relevant in providing effective and vital face-to-face support for carers and the people for whom they care. PCTs and local authorities should ensure ongoing support and sustainable funding for these local services through their local strategic partnerships and local area agreements.
- A16 The NHS also has a significant role to play in signposting carers to relevant sources of information and support and in providing them with clinical information and advice, particularly around the time of diagnosis, on discharge from hospital and in transition to different services so that carers can feel confident in their caring role.
- A17 With the emphasis within the personalisation agenda on co-production, the provision of high-quality information and advice for all carers will be vital. Support for self-funders is also an emerging issue. Many self-funders lack basic information about the support that is available to them locally and, in some cases, they have difficulty obtaining an assessment of their care needs. Some families are investing very large sums of money in services, equipment and adaptations without reliable advice on the appropriateness or quality of their purchases. With the number of self-funders likely to increase, provision of appropriate information and advice (a 'core offer' in effect similar to that offered through *Aiming High for Disabled Children: Better support for families*¹⁹) will be vital.

¹⁸ www.nhs.uk/Carersdirect/

¹⁹ www.dcsf.gov.uk/everychildmatters/resources-and-practice/IG00222/

Information sharing on the health of the person being cared for and supported

'Carers often have a deep insight into the condition of the person they are caring for, especially for a fluctuating condition such as a mental illness. They need to be treated by professionals as "Partners in Care". Too often patient confidentiality is used as a reason for excluding carers, leading to poorer outcomes for all and sadly on occasions putting the person and their carers at risk.'

Paul Jenkins

Chief Executive of Rethink and member of the Standing Commission on Carers

A18 The lack of information sharing with carers, particularly in mental health services, is a continuing issue of concern. As indicated in the Carers Strategy, many carers are very knowledgeable about the condition of the person they support and it is important that healthcare professionals recognise this expertise and that appropriate information is shared. The insight of carers into the condition of the person they are caring for can often facilitate an effective earlier intervention and avoid the person reaching a crisis point. While the Commission recognises that a patient's decision not to share information can only be set aside in the very specific circumstances provided in the NHS Confidentiality Code of Practice,²⁰ patient confidentiality is often used as a reason for not sharing information with carers. This can be detrimental to the care of the patient, and in some circumstances may put carers and the family at risk.

A19 In some instances, there seems to be a reluctance to identify ways of sharing information without breaching patient confidentiality, yet more empowerment and enablement of carers as key players in the health and wellbeing of those they support could improve the lives of all concerned and improve the quality of healthcare. This issue needs to be addressed in professional training. In addition, in mental health services the preparation of advance directives, when patients are well, could help to ensure that information sharing with carers and families does not break down when a patient has a period of mental illness. The National Carers Strategy envisages carers being recognised as expert care partners (a good example of which was the Partners in Care campaign, which aimed to improve communication between psychiatrists, carer and patient, and with leaflets on confidentiality and carers produced by the Royal College of Psychiatrists and The Princess Royal Trust for Carers²¹). Yet this ambition will be impossible to achieve without appropriate information exchange and mutual trust and respect between carers and the relevant professionals and managers.

²⁰ www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

²¹ Online version available at: www.rcpsych.ac.uk/systempages/gsearch.aspx?cx=001100616363437152483%3aidnurf1yavs&cof=FORID%3a9&q=partners+in+care+campaign

A20 Better ways of sharing relevant patient information with carers with consent should be addressed as part of the work of the national demonstrator sites on better NHS support for carers²² and given a priority in the development of *New Horizons*,²³ the new strategy for mental health.

Access to integrated and personalised services

A21 People are living longer, meaning that more people need care and support and need it for a longer period, and more children and young people are surviving with complex health conditions. Expectations have changed – people want more choice and services that are flexible and personalised to their individual needs. It is important that support services are planned and provided in the context of the family and wider support network (where appropriate) and that the support needed for the carer, the family and the person for whom they care reflects both individual needs and aspirations and achieves consensus about the best way forward.

A22 Carers are particularly concerned that information, advice and practical support tend to be crisis-driven, without a proper recognition of the importance of earlier and prompt identification, intervention and support from the outset of the 'carer's journey'. The absence of appropriate early identification and intervention can lead to significant deterioration in carers' health and wellbeing, as well as increased costs in care when the carer is no longer able to care.

A23 Carers and the people for whom they care will benefit from more integrated planning across agencies and between different arms of the NHS, housing and other parts of local government, and more flexibility about what care is provided. Care provision should be tailored to what is needed rather than delivered through block contracts that have been traditionally provided in many areas. The development of commissioning skills should assist this shift.

A24 Housing and transport are important aspects of building adequate support for individuals, carers and their families, and there is a need for joint working and the engagement of a wider range of services than health and social care. This was recognised in *Putting People First*:

'Ultimately every locality should seek to have a single community-based support system focused on the health and wellbeing of the local population, binding together local government, primary care, community-based health provision, public health, social care and the wider issues of housing, employment, benefits, advice and education/training. This will not require structural changes, but organisations coming together to re-design local systems around the needs of citizens.'²⁴

22 Announced by the Minister for Care Services on 15 July 2009

23 www.dh.gov.uk/en/Healthcare/Mentalhealth/NewHorizons/index.htm

24 *Putting People First*, page 2, online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

A25 The Commission notes that integrated approaches (including bringing in transport and similar issues) are also referred to in the Ageing Strategy – *Building a society for all ages*, including an outline of the LinkAge Plus approach:

‘Over a two-year period, eight LinkAge Plus pilots have provided joined-up services to older people through an initial point of contact, including benefits, care, health, transport, home security and adaptations. Delivery is tailored to local circumstances and needs, for example through one-stop centres in Tower Hamlets, mobile Village Agents in rural areas of Gloucestershire and First Contact approach in Nottinghamshire where front-line staff are trained in a variety of services...LinkAge Plus has increased the use of effective, low-cost preventative services. Evaluation will be published in July 2009, showing a strong business case for the joined-up approach. ...[A]ll pilot local authorities have seen the benefits of LinkAge Plus and have committed funding to continue the services.’²⁵

A26 In its first phase, the Commission has not had an opportunity to discuss these aspects in any detail. The next phase of the Commission might wish to consider how these pilots have benefited carers.

A27 *High Quality Care For All*, Lord Darzi’s final report of the *Next Stage Review*²⁶ (published in June 2008) set out proposals to improve the quality of care provided by the NHS for patients, families and their carers. The Commission is pleased that the review acknowledged that delivering the right support for carers and families is central to delivering high-quality care for patients.

A28 The Commission notes that there has been good progress²⁷ towards delivering Lord Darzi’s vision in certain areas, including:

- the opening of 50 new GP health centres (integrating services in primary care); and
- nine million patients with long-term conditions now have personal care plans with care organised around their individual needs.

A29 Improvements across the NHS are set out in each NHS region’s local vision. For example, the NHS in Solihull identified a need to improve the experience of patients who are in the early stages of dementia and those caring for them. An extra £50,000 has been allocated to develop peer support, improve advice and information and expand outreach support services to prevent crises. People with dementia and their carers have given positive feedback about the support provided. The Commission hopes, though, that there can be further recognition across the NHS of local solutions that support carers in the drive to personalise and integrate services for individuals.

²⁵ *Building a society for all ages*, page 43, online version available at: www.hmg.gov.uk/buildingasocietyforallages.aspx

²⁶ Online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

²⁷ *High Quality Care for All: Our journey so far* (published June 2009), online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101670

- A30 Many carers are concerned about the regulation of and standards for care and support services. The Government's No Secrets consultation²⁸ has clearly identified a need for a more empowering safeguarding system that offers person-centred safeguarding and risk management within an increasingly personalised care and support system. In its next phase, the Commission will wish to explore positive practice in balancing safeguarding and risk management with self-directed care and a changing and more diverse workforce in social care.
- A31 In the light of demographic change, the Commission should consider further how best to meet the particular needs of older carers. Not only is the population of older people increasing, but they have higher expectations of active lives in their local communities and high-quality and personalised support as required. The issues here are many and varied, including carers' own health, lack of private transport, increased isolation because of poor public transport links in rural areas, the need for help with physical household and gardening tasks, families who may be widely dispersed, reliance on strong community support for tasks (such as shopping), higher bills due to the caring (including increased use of heat and water), basic hygiene equipment, increased risk of impoverishment, broken sleep and poor diet.
- A32 Interim findings from the Partnerships for Older People Projects (POPPs)²⁹ have demonstrated the value of prevention and early intervention services for older people and their carers that improve their health, wellbeing and independence. During its next phase the Commission may wish to consider the development and use of prevention and early intervention services for carers of all ages and their implications for carers (in particular the investment in prevention and early intervention through local authority-led partnerships).
- A33 Many carers take on a caring role for the first time when a relative is discharged from hospital with a major, often long-term, health problem or disability. Although the majority of such people will be older, an increasing number of younger disabled people are now leaving hospital with complex disabilities or health conditions. In both cases, proactive policies of re-ablement and well-integrated health and social care are crucial to support them in the community. **The next phase of the Commission should also maintain a close watch on the implementation of the Carers Strategy to ensure that carers of both younger and older disabled people receive appropriate information, advice and support around hospital discharge and that community services are age appropriate and reflect personal preferences and lifestyles.**
- A34 The recently published Green Paper, *Shaping the Future of Care Together*,³⁰ will encourage a wider national debate about system change and the nature and future funding of care and support. It will, it is hoped, in the longer term ensure

28 Report available at: www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_102764

29 www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/DH_080122

30 Online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102338

a better understanding of the whole system, identifying both the drivers for integration of health and social care and enabling the development of practical solutions. Within the wider debate about reforming the care and support system, the Green Paper recognises that ‘family and friends will play a vital role in caring for people who need care and support.’ But it also acknowledges ‘the importance of achieving a healthy balance between their caring role and a fulfilling life outside caring... We recognise this and believe that we should support people who care for others. We need to ensure that their caring responsibilities are not so great that they harm their wellbeing.’³¹ **The next phase of the Commission will wish to contribute to the debate from the carers’ perspective and within the wider context of the transformation of social care and NHS reforms, to ensure that mechanisms for future funding arrangements fully reflect and respond to the critical role of carers within the health and social care system.**

A35 The Office for Disability Issues launched a consultation³² on The Right to Control in June 2009 to ask disabled people how to make choice and control a reality in their lives. This is an important opportunity for disabled people, third sector organisations, public bodies, commissioners, service providers and families to give their views on the best way to deliver the right to control. The next phase of the Commission may wish to seek early discussion of the outcome of the consultation with DWP.

A36 In the shorter term the Commission welcomes the publication of a good practice guide on commissioning³³ for both health and social care by a consortium of stakeholder bodies (The Princess Royal Trust for Carers, Crossroads, Carers UK, the National Black Carers and Carers Workers Network, ADASS, the LGA, the NHS Confederation and the Improvement and Development Agency for local government (I&DeA)). **The Department of Health should support the guide’s wide dissemination.**

Funding for breaks

A37 The Commission welcomes the Department of Health’s allocation to PCTs of £150 million over two years to provide an improved range of short break options for carers, and the continuing allocation of the Carers’ Grant to local authorities. While the Commission recognises that the removal of ring-fencing is a key part of supporting PCTs and local authorities to determine how they use resources in the light of local priorities, it has concerns that this approach may result in a lack of transparency and inhibit the ability to ensure local accountability to carers and communities on how the money is being used. There is evidence that, in some areas, these new resources have not been sufficiently identified and therefore the development of the joint plans between health and social care identified in the NHS operating framework has not happened.³⁴

31 <http://careandsupport.direct.gov.uk/greenpaper/the-green-paper-and-supporting-documents>

32 Online version available at: www.officefordisability.gov.uk/working/right-to-control.php

33 Online version available at: www.idea.gov.uk/idk/core/page.do?pagelD=13255730

34 NHS Operating Framework – online version available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445

A38 The Commission understands that the Department of Health decided to put new resources into PCT baseline allocations to encourage the NHS to recognise the value of supporting carers in terms of improved cost-effectiveness in service provision and improved health outcomes for both carers and the people they support. Investment by PCTs in breaks for carers is an essential precursor to this and is therefore an important early litmus test of changing attitudes in the NHS towards carers. It is highly desirable for the next phase of the Commission to maintain an interest in this area. **The Commission should work with both the Department of Health and the NHS to gather evidence of how the new resources have been spent and on the cost-benefits and improved health outcomes of supporting carers in their caring roles, including the provision of breaks.**

A39 **The Commission also recommends that in the next planning round for the NHS Operating Framework (2011/12 onwards), health ministers should consider according support for carers a higher status, building on the higher profile for carers in the 2009/10–2010/11 period.** Without such status, the Commission fears that the NHS will not invest appropriately in supporting carers and that the successful delivery of the outcomes for carers set out in the Carers Strategy vision will be jeopardised.

Role of the regulators

A40 The recently established Care Quality Commission (CQC) will hold PCT and council commissioners to account for the outcomes being delivered for people, but does not performance-manage either PCTs or councils. However, the CQC expects increasingly to gather evidence of performance directly from local groups that know about how service users and carers are faring in any particular area, for example, through discussions with LINKs groups and carers' groups.

A41 The Commission hopes that the CQC will consider ways in which it can build on the Commission for Social Care Inspection (CSCI)'s performance assessment framework – in which the value and importance of support for carers is well recognised – to explore how the NHS and local authorities plan to meet the requirement in the NHS Operating Framework for 2009/10.

A42 The Commission understands that the CQC will be considering carers' issues alongside other suggestions for special review topics for 2010/11 and that it will consult on the list in due course. The Commission is reassured that the CQC acknowledges the importance of carers within the wider personalisation agenda and hopes that it can provide a focus on better integration between health and adult social care.

A43 Last autumn, Ofsted looked at provision for young carers in eight local authorities. The report on the survey findings *Supporting young carers – identifying, assessing and meeting the needs of young carers and their families*,³⁵ which was published in June 2009, indicated that:

³⁵ Online version available at: www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Documents-by-type/Thematic-reports/Supporting-young-carers

- Councils were identifying fewer young carers than might be expected – identification of young carers in families with substance misuse and mental health problems was a particular challenge.
- Services working with ill or disabled parents (and not identifying young carers) were consistently failing to take account of their needs and views during assessments.
- Resources for local young carers' projects were not always secure and sustainable.
- At a strategic level, action to deliver better integrated, whole-family working across adult and children's services was still work in progress.

A44 Ofsted's findings about the challenges and gaps in support are much in line with those set out in the Carers Strategy, and the Commission recognises that the Government has an extensive range of actions underway to address them. Ofsted's evidence, however, is helpful in reinforcing the messages in the strategy on the need for ongoing service development to ensure all families with young carers receive the support they need.

B 'Carers will be able to have a life of their own alongside their caring role'

'The quality of professional care offered to the person being cared for fundamentally affects the quality of life for their carer. It is not easy to disentangle their two lives. Only when professional care is good can the carer achieve that peace of mind to have a life of their own.'

Barbara Pointon

Member of the Standing Commission on Carers, Ambassador for the Alzheimer's Society and Ambassador for Admiral Nursing

Putting People First outlined the framework for everyone, including carers, to have improved choice and control over their own lives and the lives of those they support. Building on this, the Carers Strategy recognised that carers should have the opportunity to participate in activities outside their caring role. They should be free to have an identity that is separate from that of those they support and avoid the social exclusion that may result from having no life outside caring.

The personalisation agenda is relevant here, as well as issues such as adequacy of replacement care and the provision of breaks. If carers can choose to pursue work, training, education and leisure interests, whilst confident that the person for whom they care continues to receive high-quality support, they will be more able to fulfil their potential and achieve their wider ambitions in life.

Case study

A project run by the Carers' Resource in Harrogate (a network member of The Princess Royal Trust for Carers), entitled Changing Lives, focuses on carers' leisure, learning and employment. It encourages and helps carers to achieve their own aspirations for learning and wellbeing outside their caring role. Carers are supported at their own pace, with Carers' Resource staff helping them to build confidence and make new opportunities available and accessible.

The courses are tailor-made for carers and take place at times and places that are suitable to them. From computer skills and interview techniques to confidence building and individual interests, the project has increased the confidence of hundreds of carers and helped them to acquire new skills and regain their sense of self.

These carers' achievements will help shape their futures, underlining how much they have to offer outside their role as a carer.

www.carersresource.org

Progress to date, opportunities and challenges

Personalisation

- B1 Adult social care is undergoing a major transformation that should significantly improve the range and quality of care and support services and put people more in control of their lives. Social care professionals are helping people who use services and want more personalised support to determine how it can best be provided. Lord Darzi's review recognised that the relationship between health, social care and wider community services will be integral to the creation of a truly personalised care system. It is important that carers are closely involved in this transformation.
- B2 The wider use of personal budgets has the potential to enable carers and the people for whom they care to design care and support services that maximise choice, and support the whole family to achieve and retain independence and employment. The combination of self-directed care and personal budgets should greatly improve the quality of support available to service users, so that carers can remain in or return to employment and enjoy a life outside caring if that is what they wish. If they wish to continue in their caring role, it should be possible for them to have access to a wider range of support. (Personal health budgets are considered further at paragraphs D15 and D16.)

- B3 The reports *Putting People First without putting carers second* and *Putting People First and Supporting Carers – some key messages for local leaderships*,³⁶ are good examples of how the debate on personalisation and carers is being taken forward in a positive way. They recognise that personalisation is the driving force for the transformation of adult social care, and that increasing numbers of family members, neighbours, friends and the local community will become involved in providing care and support. The reports underline how carers as well as the people for whom they care must be at the heart of this culture shift.
- B4 Personalisation is relevant to all publicly-funded services and support, and the objective is to enable people to have the most accessible and supportive arrangements in place for use at any time, and a carer's role is a prime example. However, the concept of personalisation and the vision of a transformation of adult social care set out in *Putting People First* are still in the early stages and the language that is used to describe personalisation can sometimes contain a large amount of jargon, which people can find confusing.
- B5 Frontline staff, service users and carers often struggle to understand both the concept of personalisation and the different ways in which people can be supported. The language should be simplified and clear messages provided about the benefits of personalisation for both service user and carer.
- B6 The Department of Health is currently developing a communications strategy to support the personalisation agenda. More effective communications will be key to tackling widespread misunderstandings about personalisation.

Carers' assessments

- B7 The quality of carers' assessments is very variable. Many carers are still unaware that they can request a carer's assessment in their own right. Carers also express concern at the multiple and often duplicated assessments frequently carried out in order to prove the eligibility for services of the person for whom they care. Evidence from the Individual Budgets pilot projects³⁷ shows the increased satisfaction of both carers and those they support when carers have been fully and appropriately involved in the assessment arrangements preceding agreement on an individual budget. The development of the Common Assessment Framework for Adults,³⁸ together with the increased involvement of carers as active partners in local strategic thinking and commissioning, should help to avoid duplication in assessments.

36 Online version available at: www.adass.org.uk/images/stories/PPF%20carers%20final%20document.pdf

37 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095420

38 www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/DH_089947

Breaks

B8 Planned, regular short breaks are widely recognised as being a high priority for carers to improve the quality of life for both themselves and those they support. Carers have made it clear that they will not take breaks if the replacement care on offer is inadequate. As stated elsewhere in this report, the Department of Health has recognised this priority and provided funding to PCTs for carers' short breaks, as well as this being one of the categories of Carers Strategy demonstrator sites. The local and national evaluations of the demonstrator sites will need to establish how the impact of breaks is measured in terms of outcomes for carers.

C 'Carers will be supported so that they are not forced into financial hardship by their caring role'

'Our research shows that a substantial number of carers are in debt and struggle with essential household bills such as food shopping and heating. Help for those carers most in need must be the priority in any government review.'

Don Brereton

Chair of Carers UK and member of the Standing Commission on Carers

Carers often find they have to give up work in order to provide the care needed by the person they support. This is often a step taken reluctantly, with financial consequences which are frequently very damaging for the families concerned. Even when the caring role ends, many carers find it difficult to return to work.

While the benefits system can provide a safety net, the most reliable and sustainable means of ensuring that carers can enjoy a reasonable level of income is that they, where possible, combine paid employment with their caring role.

The Work and Pensions Select Committee's inquiry on valuing and supporting carers³⁹ recognised the strong relationship between increased hours of caring per week and living in poverty. It supported the right for carers to request flexible working hours and made recommendations to increase the amount that carers can earn before they lose their Carer's Allowance.

The Carers Strategy highlighted how society, as well as the person cared for, benefits greatly from the care that family and friends provide. A key goal is to consider the groups most at risk and explore what should be done to protect them.

³⁹ Online version available at: www.publications.parliament.uk/pa/cm200809/cmselect/cmworpen/105/10502.htm

Case study

The Action for Carers and Employment (ACE) Partnership, led by Carers UK, has developed an integrated approach, engaging with individuals and employers to address barriers facing carers who want to work. Funded by the European Social Fund's EQUAL Community Initiative Programme, ACE delivery partners have included City & Guilds, local authorities and carers' organisations and comprised multiple projects to raise awareness, test mechanisms and develop services that enable carers to enter, remain in or return to employment.⁴⁰

For example, Surrey County Council, through Action for Carers (Surrey) – part of The Princess Royal Trust for Carers network – initially offered carer awareness training for employers, Jobcentre Plus and local and health authority staff, re-engagement training and job search skills, and a City & Guilds *Learning for Living* pilot. It has since built on this work with activities such as promoting flexible employment policies and practices, which enable carers to balance work and care, through a training programme for local employers. ACE Surrey was successful in accessing continuation funding and is now part of a mainstream service offering impartial information and advice to carers or former carers who are considering a return to learning or work.

www.carersnet.org.uk/actionforcarers/afc.html
www.carersuk.org

Progress to date, opportunities and challenges

Income and benefits

- C1 The outcome of the Government's decision last year to review the structure of the benefits available to carers in the context of longer-term benefit reform and the fundamental review of the care and support system was met with widespread disappointment and anger by carers and carers' groups. Income is the key issue for many carers, and remaining in employment can be essential to maintaining income and ensuring the health and wellbeing of the family. Combined public sector support is often insufficient to provide the financial support that many families need when they do not have other sources of income. Despite carers' prioritisation of income as a key issue in improving their health and wellbeing, the Carers Strategy did not identify any quick solutions to the urgent need to improve benefits (and thereby income) for carers.
- C2 Many carers were in financial difficulty before the recession because of their caring responsibilities, and the impact of the recession on carers who lose their

⁴⁰ Source: Action for Carers and Employment: impact of the ACE partnership 2002–2007. Online version available at: www.carersuk.org/Professionals/OrderPublications/Researchreportsbooks/4030/EWS4030ImpactoftheACEpartnership2002-07.pdf

jobs or are on low incomes is a significant matter of concern. Equally, carers of pensionable age experience financial hardship as their savings reduce rapidly, often linked to costs for domiciliary care. If the carer's partner enters a care home, their income, which would otherwise go towards paying for household bills, also diminishes, and the partner's pension is diverted to pay for the care home. This leaves many older carers with seriously restricted resources for their own standard of living and also their own future care.

- C3 It is therefore important and urgent that the income of carers is reviewed. **DWP is strongly encouraged to set out its timetable for welfare reform and in particular its plans to review carers' benefits. The next phase of the Commission should seek further discussions with DWP on welfare reform and press for a timetable for reform to be established.**
- C4 **In addition, there should be proactive marketing of the benefits currently available to carers to reduce inequalities in access to financial support.** Many carers including those from black and minority ethnic communities are not sufficiently aware of the benefits that might be available to them or where to seek help. Local government has an important role to play in this respect as carers can receive valuable support – such as welfare advice – from many parts of a council, not just adult care services.
- C5 The Carers Direct website and helpline will be useful tools to aid navigation through the benefits system although, as previously stated, the existence of this information service now needs to be widely communicated by government and across carers' networks.
- C6 The new National Insurance credits for parents and carers that will be introduced from April 2010, replacing and building upon existing Home Responsibilities Protection arrangements, should lead to more carers qualifying for more support. DWP estimates that the greatest gain for carers is likely to come from State Second Pension credits and that approximately 240,000 people may accrue State Second Pension entitlement as a result of the new carer's credit, with approximately 160,000 people possibly qualifying for an increased basic State Pension. However, this will not resolve the wider deficiencies in respect of carers' benefits and support for carers who continue to care or become carers after pension age.

Employment and flexible working

- C7 DWP ministers have recently reconfirmed the commitments made in the Carers Strategy to invest up to £38 million in supporting carers to remain in or return to employment. However, there does need to be a much stronger emphasis placed on employment opportunities for carers in the workplace. The forum recently established by Carers UK, Employers for Carers,⁴¹ provides practical advice to employers on carer-friendly policy and practice and promotes the business benefits of supporting carers. It is welcome that a number of government departments have agreed in principle to sign a memorandum of understanding (MoU) with Employers for Carers.

41 www.employersforcarers.org/Home

- C8 Jobcentre Plus has made good progress in a number of areas – including recruiting specialist regional Care Partnership Managers to be responsible for improving information on local carer support for staff and customers – and despite the economic downturn all commitments will be in place by December 2009. It is important, given the economic downturn, that this work remains on track.
- C9 The Work and Families Act 2006 extended the right to carers of adults to request flexible working from April 2007 with a duty on the employer to consider such requests seriously. The Commission encourages the new Department for Business, Innovation and Skills (BIS) to reaffirm the undertaking made by the Department for Business, Enterprise and Regulatory Reform to consider extending this to all carers once the impact of the current extension has been evaluated. The Commission would like to see the Government set out a timetable for this review. A review of the requirement that an employee can only claim for flexible working once they have worked for their employer for 26 weeks would also be welcome.
- C10 The Commission also encourages BIS and the Government Equalities Office (GEO) to ensure that their awareness-raising campaign on flexible working has maximum impact. The Commission welcomes the GEO's undertaking to consider how the recession is affecting particular groups – including carers – in society. The next phase of the Commission will wish to consider inviting GEO to discuss this at an early stage.

Training

- C11 As well as supporting carers to remain in work it is important that carers who wish to return to work are supported to do so. The Commission recognises the pressures of supporting carers to find work alongside many others in the current economic climate but hopes that Jobcentre Plus will still recognise carers as a priority for support.
- C12 In its inquiry on valuing and supporting carers, the Work and Pensions Select Committee noted the apparent contradiction that carers who wished to enter training or education potentially lose their Carer's Allowance, and recommended that the Government should consider lifting this rule, as it prevents carers from seeking to develop new skills and moving back into work. The next phase of the Commission will wish to keep this issue in view.
- C13 The *New Opportunities* White Paper⁴² (published in January 2009) announced the Government's commitment to pilot a new training allowance for those with caring responsibilities wanting to return to work. Pilots will run in the north-east and south-west of England in 2009/10 as part of national trials of skills accounts. The pilots are intended to help make training more affordable for carers who have to make a financial contribution because they are not on income-based benefits. Skills accounts will join carers up to a broader package of ongoing support which includes personalised information on skills provision, funding for courses and any additional financial support and careers advice.

⁴² Online version available at: www.cabinetoffice.gov.uk/newsroom/news_releases/2009/090113_newopportunities.aspx

Diversity of carers and equality

- C14 Carers are not a homogeneous group and it would be helpful to develop a better understanding of their diversity and differing needs for support. Although many carers are family members, others may be friends or neighbours providing a range of practical and emotional support. Additionally, demographic change and social mobility mean that many carers may live at a distance from the person to whom they provide support (for example, adult children supporting elderly parents who may not live in the same locality and who are registered with a different GP).
- C15 The Commission welcomes the focus in *Building a society for all ages* on the changing role of grandparents, including their role as carers for their grandchildren and as a sandwich generation caring for both children and much older relatives. 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 care and support well into their later years. Without recognition and support, multiple caring roles may have adverse effects upon carers' income, health and emotional wellbeing. The next phase of the Commission will wish to keep this in view.
- C16 Some carers from black and minority ethnic communities may experience particular difficulties in identifying and using services, and it can be difficult to identify and reach carers living in deprived areas, both rural and urban, and those with fluctuating caring responsibilities, such as those caring for people with mental health problems. Young carers may also be reluctant to seek help because of anxieties about the possible impact on family relationships.
- C17 To reflect on this in more detail, the next phase of the Commission should consider establishing a sub-group or thematic discussion on diversity and equality, in particular on its correlation with the financial hardship of carers.
- C18 The Commission supports the Equality Bill, which will offer carers protection from discrimination in access to goods and services because of their association with older or disabled people, making it easier for carers to get the support they need at work or when using health or other services. **The Commission's aspiration is that carers should be fully included within all forthcoming equalities legislation and thereby protected from discrimination. The next phase of the Commission will wish to contribute to discussions around carers' issues within the emerging equalities agenda.**

C19 Indeed, the Equality Bill and the Government's intentions to include carers will have wide implications for carers' health and wellbeing – for example, through the availability of appropriate replacement care and a willingness to provide care and support services to enable a carer to enter and sustain employment. During the passage of the Equality Bill, GEO should seek to ensure that the needs of carers are fully acknowledged at every stage and the risk of discrimination and disadvantage because of their caring roles is both recognised and addressed.

D 'Carers will be supported to stay mentally and physically well and treated with dignity'

'Carers are tired of being told that they are doing a wonderful job! They are often consulted – which is good – but then not shown where their feedback and advice has been acted upon.'

Jill Pay

Member of the Standing Commission on Carers, Carers' Training Co-ordinator, Princess Royal Trust Camden Carers' Centre and member of London Carers' Advisory Group

It is widely acknowledged that those who provide long hours of care are much more likely to be in poor health themselves. Nearly 21% of carers providing more than 50 hours of care report that they are not in good health, compared with only 11% of the population. They should be supported both in their own right and in their role as carers. They should not, as one carer at a Carers Strategy consultation meeting stated, have to 'postpone their health' if they are a carer.

The Carers Strategy stated that every carer should be supported so that caring does not adversely affect their health. Health and social care professionals should recognise that caring can place physical and mental stress on the carer, who may need services and support specifically directed at their own health needs.

Case study

The Princess Royal Trust for Carers and the Royal College of General Practitioners (RCGP) have developed an action guide for GPs and their teams to use to help them to support carers.

The guide builds on examples of best practice taking place throughout the country. For example, the Carers Development Worker (Primary and Community Care) project at The Princess Royal Trust Worthing & District Carers Liaison Service⁴³ has seen a dramatic increase in the number of carers identified by GP practices. The project identifies a link person in each GP practice, provides carer awareness training for all GP staff and promotes healthy living practices at carers' events.

The Bennetts End Surgery in Hemel Hempstead is a good example of supporting carers in general practice. It has a well-established carers/patient participation group, provides a regular carers' clinic, is involved in a carers' break brokerage pilot and is working with the RCGP to deliver the first workshop for the National Education Programme for GPs and primary care staff. The workshop will help GPs and primary care teams to support carers by making them aware of their own health needs, supporting them emotionally and practically and providing useful information.

www.carers.org/professionals/health/articles/carers-in-practice-rcgp,1792,PR.html

www.besteam.co.uk

Progress to date, opportunities and challenges

Training and awareness-raising for GPs and key workers

- D1 Improving the identification and awareness of carers by those in primary care is a key challenge. It is widely recognised – by the Government, the RCGP, third sector organisations and carers themselves – that GPs and other professionals who come into contact with carers should be able to support them effectively.
- D2 In light of concerns about raising the profile of carers across primary care, it is a welcome development that The Princess Royal Trust for Carers and the RCGP have developed *Supporting Carers: an action guide for general practitioners and their teams*,⁴⁴ which will be distributed to every GP practice in the country. Funded by the Department of Health, the RCGP has also developed a training programme for GPs, based on the guide, to help them better understand and

⁴³ www.carerswsx.org.uk

⁴⁴ Online version available at: <http://static.carers.org/files/prtc-introductory-section-3660.pdf>

respond to carers' needs. This programme will be piloted in six workshops across England in September and October 2009 and will be independently evaluated.

- D3 **Links should be made between the pilot workshops for GPs (funded by the Department of Health) to increase awareness of carers' issues and the guidance on young carers being developed for GPs by The Children's Society (funded by the Department for Children, Schools and Families (DCSF)).**
- D4 In June 2009, the British Medical Association's (BMA's) Committee on Community Care published an updated version of its guide *Working with carers: guidelines for good practice*.⁴⁵ The guidelines cover carers' rights, identification of carers, needs of carers, how doctors can help and support carers and the provision of sources of further information to doctors and carers. The guidelines are available to both members and non-members of the BMA, and were featured in an article in *BMA News*, a magazine delivered weekly to BMA members.
- D5 In addition, the Commission welcomes the Department of Health's funding of Skills for Care and Skills for Health to develop a range of training and awareness-raising modules to suit the training needs of different groups of key workers. It is hoped that these modules will become embedded in formal qualifications and continuing professional development.

Improving and maintaining the health and wellbeing of carers

- D6 In July 2009, the Department of Health announced the locations of 25 demonstrator sites which will cover health and wellbeing checks for carers, how the NHS can better support carers and breaks for carers. Commencing in autumn 2009, the sites will work with a wide range of local stakeholders and involve carers in planning, delivering and monitoring the services provided. The sites will seek to develop and evaluate good practice on ways to better support carers, including improving the health of carers – and those for whom they care – and gather evidence of cost-effectiveness.⁴⁶
- D7 The Commission welcomes the introduction of the NHS Health Check programme, which PCTs are beginning to roll out from 2009/10. At full roll-out, expected in 2012/13, all 40–74 year olds will be invited for an NHS Health Check every five years. The purpose of the check is to identify a person's risk of coronary heart disease, stroke, diabetes and kidney disease, for this risk to be communicated in a way that the individual understands and for that risk to be managed by appropriate follow-up. The aim of the programme will help ensure a greater focus on the prevention of disease and, it is hoped, will help people – including carers – to stay well for longer.

⁴⁵ www.bma.org.uk/healthcare_policy/community_care/Workingwithcarers.jsp

⁴⁶ Details of the sites can be found at: www.dh.gov.uk/en/SocialCare/Carers/DH_094301

- D8 Bereavement support – when the caring ends – is also important, particularly as long-term carers often experience delayed bereavement shock. In this situation, carers can become vulnerable to serious illness and increased risk of morbidity. GPs should seek to monitor carers' health to try to reduce these risks.
- D9 Given the essential role that carers perform in society and the reliance placed upon them not just by those they support but also by the Government, it is vital to protect their health and wellbeing as part of wider public health initiatives. The Commission welcomes the Department of Health's intention to develop a module of support for carers as part of the resources to meet the challenges of a swine flu pandemic. However, the Commission understands that, at present, there is no intention to prioritise carers (including those who care for people with complex needs) for flu vaccinations. **The Commission believes that the Government should consider prioritising flu vaccinations to carers with significant and complex caring responsibilities, which would help to reduce the risk of them falling ill at times when their care is needed most.**

Information sharing – carers' own health

- D10 In carrying out what are often highly intensive caring roles, carers will frequently place their own health at risk – for example, neglecting to visit their GP or attend regular health checks because of problems in providing cover for a friend or relative, or in getting appointments at convenient times. Innovations around carers could radically improve their quality of life, and in particular their own health. The demonstrator sites on improving the health and wellbeing of carers could help here, with one objective of the sites being that procedures are developed which could provide links to health services or, where appropriate, refer to other agencies (of which information sharing will be an important element).
- D11 **Making good use of technology is critical in this area and the Commission believes that the NHS Care Records Service Programme Board should further explore whether better use can be made of the carers' information held on record, to improve information sharing about carers' health.** In particular, this could help the growing number of carers who are caring at a distance.

Tackling stigma – substance misuse and mental health problems

- D12 The Commission welcomes the recognition – in the Government's drugs strategy⁴⁷ and the National Treatment Agency for Substance Misuse's guide *Supporting and involving carers: A guide for commissioners and providers*⁴⁸ – of the need to improve the support of carers with substance misuse problems.
- D13 Many of those caring for people with mental health problems or who misuse drugs or alcohol still encounter stigma, and they can be reluctant to seek help or utilise the resources of carers' centres and other support services. Young carers may be particularly reluctant to disclose a relative's substance misuse

⁴⁷ *Drugs: protecting families and communities*, HM Government, 2008

⁴⁸ www.nta.nhs.uk/areas/users_and_carers/publications/supporting_and_involving_carers_10.08.pdf

or mental health problem because of the possibility of stigma and associated bullying by their peers and the fear of social exclusion.

- D14 A survey conducted by Rethink in early 2009 found that 60% of carers who responded reported that they had personally experienced stigma. Linked to this, Rethink, MIND, Mental Health Media and the Institute of Psychiatry conducted an anti-stigma campaign, *Time to Change*,⁴⁹ funded by the Big Lottery and Comic Relief and building on evidence from Scotland, New Zealand and Australia. The Commission hopes that this will mark the beginning of a change in attitudes towards mental illness, which has such a negative impact on the experience of carers and service users. The campaign is due to run for three years and, over this period, the next phase of the Commission will wish to keep in view its impact and effectiveness.

Personal health budgets

- D15 *High Quality Care for All* made a commitment to pilot personal health budgets as part of its overall aim to create an NHS that is more responsive to people who use services and their families and carers. The NHS is already able to set up notional budgets, or budgets held by a third party such as an independent user trust on the individual's behalf. There are also draft provisions in the Health Bill, currently before Parliament, to allow the piloting of direct payments for health care as part of the overall programme.
- D16 Personal health budgets could meet a range of health and wellbeing needs, including therapies, personal care, purchase of equipment, lifestyle advice and self-management courses. The policy framework set out for personal health budgets indicates how the Department of Health expects the implementation of personal health budgets to take into account the needs of carers. The Commission accepts that personal health budgets will not be the answer for everyone – including carers – but believes they do have great potential to help some people to receive the NHS care that is right for them.

E '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'

'We must take a much more rounded and whole-family approach. The strategy now needs to start delivering outcomes both for carers and those they care for.'

Anne Roberts

Chief Executive of Crossroads Care and member of the Standing Commission on Carers

⁴⁹ www.time-to-change.org.uk/what-were-doing/our-campaign/about-the-campaign

The precise number of children and young people who are caring regularly for a family member is not known. The 2001 Census indicated that there were some 139,000 children and young people under 18 in England and 175,000 in the UK providing some care to family, friends or neighbours. The majority care for up to 19 hours per week.

The Carers Strategy noted that many young carers value the contribution they are able to make within their families and that caring can be a positive experience – enhancing independence and strengthening family ties. Extensive or inappropriate caring roles, however, can harm children’s ability to attend and achieve at school and make them more vulnerable to negative experiences such as bullying, as well as making the transition to adulthood more difficult.

There is anecdotal evidence that not all young carers wish to be formally identified as such. Identifying young carers can be a significant challenge because of fear of intervention and stigmatisation by peers. It can be very difficult if schools, in trying to support young carers, inappropriately expose their status to others. Sensitive support from school staff which takes account of the young person’s wish for privacy can do much to allay young carers’ concerns. However, in some cases, it may be more appropriate if some elements of the support provided are delivered off the school site to ensure privacy and confidentiality.

Young carers should have the opportunity to experience life in the same way as their contemporaries. To ensure this, effective support – at an early stage – for families and the person being cared for has to be a priority, with assessments taking account of the need to protect children from inappropriate caring, and families having a greater say in the shaping of the services around them. As recognised in Aiming high for children, ‘Preventing poor outcomes from arising in the first place benefits children, young people and families directly. In addition, failure to prevent problems impacts not only on the family but also on society more widely...’⁵⁰

Case study 1

As part of the DCSF’s Family Pathfinder programme, Sunderland City Council is running a project to examine how to improve support for young carers and their families. The Council is targeting families from wards with the highest levels of deprivation and in particular ‘hidden young carers’, making it easier for them to access support. This addressed the barriers that might otherwise have prevented the support from adult social services from being fully effective.

Early lessons now emerging from the project’s work include the importance of adult and children’s services working together more cohesively and effectively, of building trust and recognition amongst young carers and their families that non-judgemental support is available, and having good planning and communication from the start.

www.sunderland.gov.uk

⁵⁰ *Aiming high for children: supporting families*, HM Treasury and Department for Education and Skills, 2007

Case study 2

With funding from DCSF, The Children's Society with The Princess Royal Trust for Carers is delivering a programme of work to help raise awareness and build knowledge and skills in supporting young carers and their families. This includes offering intensive training in whole-family working in relation to young carers to selected councils across the English regions, including Wandsworth Council. The work has comprised reviewing the area's existing policies and strategies, dedicated training days, a conference focused on improving knowledge on what works in relation to support for young carers and their families, and 'education twilight sessions' to raise awareness and extend skills in supporting young carers within schools. As a result of this work, plans are now in place to:

- fund a development project worker post for young carers;
- develop guidance for schools on the identification and co-ordination of support for young carers within the locality; and
- develop and distribute an information sheet for GPs' surgeries and clinics.

One hundred school noticeboard packs were disseminated as well as 250 education leaflets, 60 GP packs and 10 DVDs (*Listening to Young Carers*) for use in further training. The partnership is creating a comprehensive list of organisations and key contacts providing support for young carers which will be inserted in the Wandsworth Council directory. It is also delivering further twilight training to two areas to further raise awareness.

www.wandsworth.gov.uk
www.childrenssociety.org.uk
www.carers.org

Progress to date, opportunities and challenges

Family Pathfinders, Think Family and supporting young carers

- E1 The work of the third sector and DCSF has given young carers a higher profile in the media than they have had before. This welcome trend needs to be encouraged and maintained.
- E2 The Commission welcomes the six Extended Family Pathfinders for young carers which have been set up by DCSF for young carers (see case study 1 above). The Pathfinders are testing how support can be better joined up around families with young carers so that they are protected from or supported out of inappropriate caring roles.

- E3 Schools are young people's natural communities and their role is vital in ensuring young carers' health and emotional wellbeing. A new programme of work to increase support and guidance on young carers in schools is now being made available via the National Healthy Schools Programme. Implementation will take place until March 2011.
- E4 It is hoped that this work will help reduce the stigma which can sometimes surround illness and caring and which too often discourages young carers from coming forward for the help they may need. The Commission welcomes this positive development which should help to ensure that the particular support needs of young carers are recognised and better addressed.
- E5 Ensuring interventions are appropriate is a significant challenge for service providers. Child protection and safeguarding issues need to be taken into account and it is important that sensitive and appropriate ways of working with families are further developed. Workshops involving adult mental health services, drugs teams and the voluntary sector are planned as part of the Family Pathfinder programme, and broader work under the Government's *Think Family* banner will help in this area.
- E6 The development of the Common Assessment Framework for Adults should also benefit young carers. DCSF's Family Pathfinders are looking at ways to assess the whole family when working with families with complex needs. Projects are using the Common Assessment Framework for children and young people in a family-focused way to ensure that family strengths and wider support needs are taken into account in the development and provision of services.
- E7 Over the next two years, best practice from existing young carers' projects and other forms of targeted support will be collated and action taken to embed the learning across all local targeted services and extended schools. From this autumn, a tailored programme of capacity and knowledge-building on young carers will also be developed for GPs and health staff.
- E8 DCSF is developing methods to help to identify and assess young carers at an early stage and its challenge will be to identify them in a sensitive manner and one that does not reinforce the potential stigma of young carers. **The next phase of the Commission will wish to keep a watching brief on this work as it develops.**
- E9 **The issue of the identification of and support for young carers in families that self-fund support for the adult concerned (where the young carer may have no contact with any professional agency) needs to be further considered. This could be supported by building up broader awareness about young carers through children's centres, GPs and schools. The next phase of the Commission should consider establishing a sub-group or thematic discussion on this area.**

- E10 The *Think Family*⁵¹ initiatives are designed to ensure that adult services working with ill or disabled parents consider as early as possible the needs of dependent children in the family, including those who are or could become young carers. The Government is offering all local authorities additional funding to support them in joining up services around vulnerable families, including those with young carers.
- E11 Transition to adult health and social care services can be a difficult time for families adjusting to different cultures, attitudes and expectations. Families are still expected to fit in with the system, rather than have the system moulded to their needs. Often, caring is not static and many carers will go through a number of transitions as their needs – and those of the person they support – change over time.
- E12 The *Think Family* approach, which takes an holistic view of support needs, is therefore particularly important at different transition points: in ensuring continued access to educational support, in aiding the transition to adult care services, and in ensuring effective support for carers who are part of the sandwich generation and when caring responsibilities end.
- E13 This is complemented by the Transition Support Programme⁵² for disabled young people within *Aiming High for Disabled Children*. One of the key issues identified in *Aiming High* was that more work was needed to improve and co-ordinate services for disabled young people in their transition to adult life. To address this, the Transition Support Programme was established to raise the standards of transition in all local areas. **The Commission hopes that the Transition Support team can continue to engage with and exchange good practice in transition to help build capacity and maintain its partnership with regional advisers, DCSF and the Department of Health to improve transition practice. In particular, the Commission hopes that PCTs and local authorities can ensure that the benefits of the National Transition Support team's work are sustainable beyond the *Aiming High* lifecycle, in acknowledgement of the challenges facing many carers as well as young disabled people during the transition from children's to adult social care services and support.**
- E14 Many young carers will continue to have a caring role as they move into adult life. Concerns have been raised about the barriers they face when wanting to move on to college, university or other education and training opportunities. Support for adults who have been young carers should also be considered, as the impact of caring is often not recognised until later in their lives. It is welcome that there are plans to introduce, over the next two years, more general awareness-raising about caring and the broader issues it raises.

51 *Think Family: Improving the life chances of families at risk*, Cabinet Office (2007), online version available at: www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/think_families/think_family_life_chances_report.pdf

52 www.transitionsupportprogramme.org.uk/

Development of a Memorandum of Understanding on young carers by ADASS / ADCS

- E15 ADASS and the Association of Directors of Children's Services are developing an MoU on 'working together to better support young carers' as part of their joint commitment to take forward implementation of the Carers Strategy as it relates to young carers. This work is linked to the commitment in *Putting People First* that the provision of adult social care should take account of the need to sustain family units to avoid children having to take on inappropriate caring roles. It will build on feedback from young carers and the important work by The Children's Society on the *Key Principles of Practice* and the *Whole Family Pathway*. It is also intended to take account of the findings of the CSCI report *Supporting disabled parents: A family or a fragmented approach?* (February 2009) and the more recent report by Ofsted (June 2009) referenced above.
- E16 The Commission welcomes this development. It provides a good opportunity to enhance joint working between adult care and children's services on information, assessment and provision of personalised support. This work should contribute significantly to the overarching goal of protecting young carers from excessive and inappropriate caring roles. The next phase of the Commission will therefore wish to keep in view the extent to which this MoU is adopted by local authorities.

3. Developing the evidence base

'This Government has put carers and carers' rights on the agenda in a way that no other Government has ever done before. The Commission has a role to play in making sure carers remain "visible" and that rights for carers remain on the political agenda. It cannot and does not pretend to know it all, and must continue to take positive action to remain in touch with carers.'

'The next phase of the Commission can play a role in "mapping gaps" in service provision and find out more about the experience of carers. It must make sure the Carers Strategy delivers real outcomes for carers. It needs to be proactive in exploring and extracting carers' experiences.'

John Hannett

General Secretary, Union of Shop, Distributive and Allied Workers and member of the first phase of the Standing Commission on Carers

The first phase of the Commission

- 3.1 Over the course of 11 meetings, the Commission has held wide-ranging discussions about the development and implementation of the Carers Strategy with the Prime Minister, the Secretary of State for Health, the Minister for Disabled People, the Ministers for Care Services and the Carers Strategy Task Force chairs.
- 3.2 The Commission has also discussed the *Next Stage Review* with Lord Darzi, and personalisation (and how it relates to carers) with the Department of Health's *Putting People First* implementation team. It has also held discussions with the teams developing *Caring with Confidence*, *Carers Direct*, the Green Paper on care and support and the proposals on welfare reform. A summary of these discussions can be found on the Commission's website.⁵³
- 3.3 The Commission's role has been strengthened and enriched through the experience, expertise and networks of its members. The chair and members have taken many opportunities to meet carers, commissioners and service providers and to attend and speak at conferences, including the nine regional events on the Carers Strategy organised by the Department of Health in 2008. The chair has also visited carers' centres and made links with a wide range of key stakeholders and delivery partners in all sectors.

⁵³ www.dh.gov.uk/ab/SCOC/index.htm

- 3.4 To enable it to perform its scrutiny role effectively, the next phase of the Commission will wish to continue to maximise the breadth of its members' range of networks and to engage with carers and other stakeholders as much as possible to gather sound qualitative and quantitative evidence and examples of emerging good practice.

Census – 2001 and 2011

- 3.5 The inclusion of a question about carers in the 2001 Census provided vital data to help inform the Carers Strategy; for example, allowing comparisons between caring and poor health, between the different socioeconomic positions of carers providing different levels of care and support, and between carers across black and minority ethnic communities.
- 3.6 However, notwithstanding information from the 2001 Census, there is concern at the lack of a broader range of basic up-to-date information on carers (their overall numbers, how many are in employment and details of their caring role as well as characteristics such as their age, gender, ethnicity, disability and health status). It is welcome, therefore, that a question on carers is included in recommendations to Parliament for the 2011 Census. This will provide a 10-year comparison with the 2001 data and should assist with future policy formulation and the targeting of resources to better support carers.

Existing and future research

- 3.7 The surveys and research commissioned by Carers UK⁵⁴ provide an invaluable evidence base by which to measure trends in carers' attitudes and the evolving challenges they face. The findings of its Carers, Employment and Services study conducted in 2006/07 by the University of Leeds, are based on almost 2,000 responses to a national survey targeting carers of working age, and 134 face-to-face interviews with carers aged 25–64 living in 10 selected localities in England, Wales and Scotland.
- 3.8 Key findings included:
- A strong relationship between hours of caring and poverty – those who care for 20 or more hours per week are much more likely to live in workless households than non-carers or those caring for less than 20 hours per week.
 - Some ethnic groups have higher rates of caring than others – Pakistani and Bangladeshi residents of working age were twice as likely to live with someone with a limiting long-term illness as white British residents.
 - A negative impact of caring on younger (aged 16–24) carers' likelihood of continuing in full-time education, and (for carers of working age in the older age groups) a strong negative relationship between caring and full-time employment.

⁵⁴ Yeandle S, et al (2007) Carers, Employment and Services Report Series, London: Carers UK, online version available at: www.carersuk.org/Policyandpractice/Research/CarersEmploymentandServices

- 3.9 The Department of Health has also recently commissioned a review of research on carers from the Social Policy Research Unit (SPRU), University of York, which will provide an overview of the evidence base relating to the outcomes and cost-effectiveness of support. The review will encompass carers of all ages who are supporting adults, including those who are making the transition from children's to adult services, and particular attention will be given to evidence of carers who may fall within other socially excluded sectors of the population. It will map out the extent, range and nature of the identified reviews on support and interventions for carers, summarise the findings and help the Commission and government departments to identify where there may be possible gaps in knowledge and weaknesses in the evidence base. SPRU will present its findings to the next phase of the Commission in 2010.
- 3.10 Independent research commissioned by the Department of Health and published in February 2009 showed individual budgets can greatly improve carers' quality of life when compared with carers of people using conventional services. SPRU and the Personal Social Services Research Unit, University of Kent, undertook the research to determine the impacts on and outcomes for carers.⁵⁵ The Department of Health has commissioned the Social Care Institute for Excellence (SCIE) to tender externally for a piece of work focusing on older people's and mental health users' experience of going through a personal budget process. SCIE will be issuing this tender in September with a view to completing the work by April 2010.
- 3.11 The Department of Health commissioned CIRCLE, the Centre for International Research on Care, Labour and Equalities at the University of Leeds, to carry out research into local authorities' use of the carers grant. The Department recently published CIRCLE's final report and will share it with the next phase of the Commission.
- 3.12 DWP is preparing a literature review on carers' income and employment which it will share with the next phase of the Commission. DWP has also recently published two pieces of research looking at employment-related matters. A short summary paper based on survey data, entitled *Caring and flexible working*,⁵⁶ examined carers' knowledge and use of flexible working options. In addition, *Employment support for carers*⁵⁷ was based on in-depth interviews with carers and explored respondents' needs and experiences of the available support for both finding and remaining in work.
- 3.13 No government research currently exists that reports on carers' income or benefits, and the evidence base on carers who provide substantial care and are eligible to claim Carer's Allowance is limited in detail. To address this, DWP has commissioned a qualitative study to develop a clearer understanding of those eligible for Carer's Allowance and their caring role. Carers will be involved in the research – through carer-led discussion forums and in-depth interviews – which has been commissioned and will be undertaken by CIRCLE. The study will be completed in March 2010.

55 Further details can be obtained at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095420

56 http://research.dwp.gov.uk/asd/asd5/summ2009-2010/summary_caring_and_flexible_working.pdf

57 <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep597.pdf>

- 3.14 A feasibility study, on measuring the eligible population for the Carer's Allowance, has been commissioned and will be undertaken by the Institute of Social and Economic Research at the University of Essex. This is in response to a recommendation by the National Audit Office and a commitment from DWP to the Public Accounts Committee that a study would be undertaken to explore the feasibility of measuring the eligible population for the Carer's Allowance. DWP expects it to be completed in November 2009.
- 3.15 DCSF commissioned the British Market Research Bureau (BMRB) Social Research to conduct a national survey measuring parental satisfaction with services for disabled children.⁵⁸ The main aim of the survey was to generate an overall indicator and set of sub-indicators to measure parental views on the five elements of the Core Offer, as set out in *Aiming high for disabled children*. In 2009/10 and 2010/11, the survey will be conducted in all local areas and the next phase of the Commission will wish to keep in view the results of these surveys, given their relevance to the development of indicators for adult carers.
- 3.16 In addition, the Department of Health has commissioned two surveys to further develop the evidence base, including:
- a survey of a sample of households in England investigating the numbers and situations of carers (DWP has also contributed to the funding of this survey and added a number of questions to the survey to help meet the evidence need on Carer's Allowance recipients); and
 - a carers' experience survey, exploring carers' satisfaction with the health and social care services they have received, to be made available to local authorities who will be invited to participate by distributing it to carers in their areas.
- 3.17 The surveys, however, will only measure the views and experience of adults. **As a next step, the Department of Health should work with DCSF to ensure that relevant future surveys consider the experiences and views of children and young people as both young carers and recipients of care and support services, including the transition to adult services and the impact on the quality of life and opportunities for both the young adult concerned and the family.**

The next phase of the Commission

- 3.18 The next phase of the Commission has the potential to act as an 'observatory' – collecting and disseminating actual and emerging evidence around carers' lives, contributing to the creation of an evidence base and capturing emerging positive practice.
- 3.19 The next phase of the Commission will continue to have an important scrutiny role, collecting evidence from members' own networks as well as analysing evidence provided by government departments and their delivery partners.

⁵⁸ Online version available at: www.dcsf.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=15826&type=5&resultspage=1

The Commission should consider how it can collect evidence about local implementation outside the national performance framework; for example, on how PCTs and local authorities are supporting breaks. The Commission could play a role in capturing information on work-in-progress from carers and other organisations and sharing information about innovative approaches to carer support.

- 3.20 The next phase of the Commission will also wish to scrutinise the impact that the recession has on carers – the majority of carers are female and women are generally more likely to be disadvantaged in a recession.
- 3.21 It would also be helpful for the next phase of the Commission to be able to influence the revision and development of the national performance indicators. The Department of Health is developing the national performance framework for social care, and the specific indicators that act as the building blocks, for the next Spending Review period from April 2011. Considering national indicators relevant to carers is an important part of this project. At present, National Indicator 135 offers limited activity information on the number of carers identified by social services and receiving a service (or 'information and advice'). The extent to which carers are included within other indicators (such as National Indicator 130 on self-directed support) varies, and the overall picture is therefore a very limited one.
- 3.22 The next phase of the Commission will wish to keep in touch with progress on this project and to explore the scope for developing an outcome-focused national indicator to supplement or replace the existing indicator, as well as including carers in other relevant indicators.
- 3.23 The *Manual for Measures of Caring Activities and Outcomes for Children and Young People*,⁵⁹ published by The Princess Royal Trust for Carers in March 2009, will provide researchers and practitioners with accessible instruments for the assessment of caring activities and outcomes in children and young people. The same team is producing a similar tool later this year to identify and measure the outcomes of adult carer support. The Commission will be interested to see early results from both to help inform its view on the development of performance indicators.
- 3.24 The Commission is pleased to note that the World Health Organization (WHO) and the European Commission are co-funding a partnership project to support member states to improve empowerment of people with mental health problems and their carers.
- 3.25 Running from April 2008 until March 2011, the project has four components:⁶⁰
- identification of criteria ('indicators') for user and carer empowerment in mental health;

59 Authors: Joseph, Becker and Becker

60 Further information is available from: david.shiers@nmhdu.org.uk

- identification of good practice in user and carer empowerment;
- support of governments and local actors in creating an environment for user and carer participation; and
- promotion of the mainstreaming of good practice in user and carer empowerment in mental health.

3.26 The Commission welcomes the development of these indicators to help to build a relevant evidence base. The next phase of the Commission will wish to keep in touch with progress in this area.

3.27 The next phase of the Commission will also wish to keep in touch with progress on the evaluation of the 25 Carers Strategy demonstrator sites. It may wish to seek presentations from the national evaluation team on its interim report expected in 2010 and its final report in 2011.

4. The role of the Commission in scrutinising delivery of the Carers Strategy

'The Commission should focus on the vision promised in the national Carers Strategy. It should be a "scrutineer", providing real and positive challenge.'

Imelda Redmond

Chief Executive of Carers UK and member of the first phase of the Standing Commission on Carers

- 4.1 The Commission provides independent expert advice to ministers within the overarching governance arrangements of the Carers Strategy. As well as being a 'critical friend' to government, in the next phase the Commission can be both an ally and a champion in achieving a sustainable transformation of social care and other support for carers. It should have the capacity to scrutinise, identify and work on challenging issues and policy agenda. It should report on key policy issues constructively to ministers, government departments and their delivery partners.
- 4.2 The chair of the Commission attends meetings of the Carers Strategy Inter-Ministerial Group, the Carers Strategy Cross-Government Programme Board and the Transforming Adult Social Care Programme Board, and is also a member of the Secretary of State for Health's Stakeholder Group to support effective liaison.
- 4.3 A key role for the next phase of the Commission will be to assess progress towards fulfilling the strategic vision and the sustainability of new initiatives by developing and maintaining effective working relationships with carers themselves through the development of the Dignity in Care Champions Network, carers' own networks, third sector organisations, professional and regulatory bodies, the NHS, local authorities and government offices for the regions as well as central government departments. The Commission will also wish to engage with user groups and the disability sector to develop a common agenda for carers and those they support.
- 4.4 The next phase of the Commission will also wish to encourage closer links between the implementation plans for the Carers Strategy and other relevant strategies and programmes, including the National Dementia Strategy, *Valuing People Now*, *Aiming high for disabled children*, *Every Disabled Child Matters*, *Building a society for all ages*, *The Right to Control*, the Independent Living Strategy and the End of Life Care Strategy.

Governance arrangements for the delivery of the Carers Strategy

Standing Commission on Carers

Chair: Dame Philippa Russell DBE

Membership: 20 members appointed in individual capacity

Provides independent expert advice to ministers and the Carers Strategy Cross-Government Programme Board on progress in delivering the strategic vision set out in the Carers Strategy and identifying the related opportunities, challenges and practical solutions.



Carers Strategy Inter-Ministerial Group

Chair: Minister for Care Services

Membership: ministers from the government departments that signed the Carers Strategy

Receives advice from the Standing Commission on Carers.

Holds to account government departments – via the Cross-Government Programme Board – for progress on implementing the strategy.



Carers Strategy Cross-Government Programme Board

Chair: Director General of Social Care, Local Government and Care Partnerships Directorate, Department of Health

Membership: officials from government departments that signed the Carers Strategy, plus Chair of the Standing Commission on Carers and representatives from the third sector and other key delivery partners

Receives advice from the Standing Commission on Carers.

Accountable to ministers for delivery of the strategy.

5. Conclusions and recommendations for the next phase of the Commission's work

'All that the Commission has done until now has been entirely right, but now is the time to move to being more proactive. The Commission needs to tread the delicate line of being a "thorn in the flesh" and assisting with the delivery of government policy.'

Baroness Jill Pitkeathley

Vice President of Carers UK, Chair of the Council for Healthcare Regulatory Excellence, Chair of the Third Sector Advisory Body at Cabinet Office and member of the first phase of the Standing Commission on Carers

- 5.1 A year on from the publication of the 10-year strategy, the Commission recognises that a detailed assessment of progress on implementation is not possible. It is, effectively, work-in-progress – but a good start has been made.
- 5.2 The next nine years provide an opportunity to bring about lasting change and it is vital that key initiatives are sustainable beyond the 10-year timeframe. To achieve this objective, it will be important to raise the profile of family carers as equal citizens, committed to caring but needing active support – financial, practical and emotional.
- 5.3 The *Think Family* and personalisation initiatives offer important new opportunities to plan support around families, to encourage innovation and improvement and to monitor progress. They should also facilitate recognition that carers are not a homogenous group. Increasingly diverse communities and a wider geographical dispersion of families mean that 'distant carers' and inter-generational 'sandwich carers' (with multiple caring responsibilities) are becoming more common. The Commission notes that the Government will be publishing a Green Paper on *Families and Relationships* in autumn 2009, which will explore 'the needs of all family members' in the context of changing families and communities. Carers continually emphasise the importance of providing care and support in ways that underpin rather than undermine personal relationships, and the Commission hopes to contribute to the debate.
- 5.4 **In the light of widespread concern about the implications of demographic change (and a recognition that the majority of carers are supporting older people) the Commission should actively consider the range of issues relating to quality of life and care and support for older**

people as identified in the Ageing Strategy *Building a society for all ages* and in the forthcoming Green Paper on *Families and Relationships*. In its discussions, it should also keep in view the role of lifetime carers and ‘sandwich generation’ carers.

- 5.5 Families will often need skilled support in discussing what can be very sensitive and life-changing issues, in part due to the increasing complexity and timeframe of some caring roles due to demographic change and the shift from hospital in-patient care to care and support by the family in the home. Notwithstanding the *Putting People First* focus on rights, choice, independence and control, many people needing care and support will need extra care as their condition progresses. A family caring for someone with dementia may start by coping and then face a crisis as the person’s behaviour deteriorates. One of the challenges for the next phase of the Commission is to acknowledge that ‘needs’ are not static and personalisation *should* enable families and those needing support to constantly re-calibrate the nature and level of support needed.
- 5.6 Carers have repeatedly told the Commission that they wish to be recognised and respected as expert partners in care, to have their contribution valued and to be supported in what is often a very challenging role. Improving carers’ income should be the number one priority: income and employment issues must be addressed to make a real change to carers’ lives. The present economic downturn, coupled with the effects of an ageing population and improved life expectancy for young people living with complex health conditions, means that the importance of investing in carers is greater than ever.
- 5.7 However, difficult financial circumstances can often lead to more innovation. The fact that more people are caring – and caring for longer – is not necessarily a negative development. Indeed, in many ways it is evidence that the UK is not a broken society and that it is capable of building safe, sustainable communities that enable people to care and to value and support their caring roles.
- 5.8 The Commission’s independence and expertise is key to its identity. Indeed its role in pushing forward the agenda could be likened to that of a ‘critical (but constructive) friend’. The next phase of the Commission has an excellent opportunity to ‘horizon-scan’ and watch for emerging trends – advising ministers and the Cross-Government Programme Board on major challenges and how they can be addressed. The Commission should proactively scrutinise as well as provide leadership and quality assurance. It should also gather tangible evidence of progress and advise where progress is proving slower and where remedial action is required.
- 5.9 **On a practical level, the next phase of the Commission should consider forming working groups or arranging thematic meetings to engage with a wide range of key stakeholders in order to consider important issues in depth.** In the shorter term, themes might include personalisation and self-directed support, improving health, employment opportunities, the Green Paper on care and support, the Equality Bill and other cross-government issues. It should also have dialogue and links with stakeholders on the delivery of other relevant strategies, several of which have been highlighted in this report. Others will emerge during the Commission’s next phase.

- 5.10 The Carers Strategy Inter-Ministerial Group agreed in June 2009 that government departments – informed by the work of the Commission – should develop a stronger communications strategy in autumn 2009 about progress on implementation of the Carers Strategy. This will promote more understanding and greater take-up of the support to carers that is already available, as well as greater awareness of the new support coming on-stream. The Commission supports this development.
- 5.11 **Above all, the next phase of the Commission should focus on the vision in the Carers Strategy and use this as its mantra, framework and programme for change, and as its measurement of progress across government and delivery partners in implementing the strategy.**

Summary of the Commission's recommendations

Recommendations to the Government

Department of Health

1. In the next planning round for the NHS Operating Framework (2011/12 onwards), health ministers should consider according support for carers a higher status, building on the higher profile for carers in the 2009/10–2010/11 period.
2. Good information is vital if carers are to make informed choices about the best options for care and support. The issue of information sharing should be explored as part of the work of the national demonstrator sites on better NHS support for carers, and given a priority in the development of *New Horizons*, the new strategy for mental health.
3. Over the next 12 months, the Department of Health should build on the good work of Partners in Policymaking, the Equal Partners project, the National Black Carers and Carers Workers Network and others, and work with the Dignity in Care Champions Network to identify champions to support delivery of the Carers Strategy locally.
4. The Department of Health should support the wide dissemination of the good practice guide on commissioning for both health and social care.
5. The marketing strategy for Carers Direct will have a direct impact on its success and should be supported with sufficient funds. In addition, local and national voluntary organisations should be encouraged to develop a positive partnership with Carers Direct and to signpost carers to the service. Both Caring with Confidence and Carers Direct should seek to create positive partnerships with the third sector and the next phase of the Commission around further development of both programmes in order to address the diversity and complexity of carers' needs (for example, on accessibility for black and minority ethnic communities of carers).
6. The health and wellbeing of carers is vital to their caring roles. The Department of Health should consider prioritising flu vaccinations to carers with significant and complex caring responsibilities, which would help to reduce the risk of them falling ill at times when their care is needed most.

Department of Health and Department for Children, Schools and Families:

7. Links should be made between the pilot workshops for GPs (funded by the Department of Health) to increase awareness of carers' issues and the guidance on young carers being developed for GPs by The Children's Society (funded by DCSF).

8. The Department of Health should work with DCSF to ensure that relevant future surveys consider the experiences and the views of children and young people as both young carers and recipients of care and support services, including the transition to adult services and the impact on the quality of life and opportunities for both the young adult concerned and the family.

Department for Work and Pensions

9. DWP is strongly encouraged to set out its timetable for welfare reform and in particular its plans to review carers' benefits.
10. There should be proactive marketing of the benefits and allowances currently available to carers to reduce the current inequalities in access to financial support. The Carers Direct website and helpline will be useful tools to aid navigation through the benefits system.

Department for Business, Innovation and Skills; Government Equalities Office

11. BIS should reaffirm the undertaking made by the Department for Business, Enterprise and Regulatory Reform to consider extending the right to request flexible working to all carers once the impact of the current extension has been evaluated. The Commission would like to see the Government set out a timetable for this review. A review of the requirement that an employee can only claim for flexible working once they have worked for their employer for 26 weeks would also be welcome.
12. BIS and GEO should continue to target carers and employers to ensure that the awareness-raising campaign on flexible working has maximum impact.
13. During the passage of the Equality Bill, GEO should seek to ensure that the needs of carers are fully acknowledged at every stage and the risk of discrimination and disadvantage because of their caring roles is both recognised and addressed.

Recommendations to the Government's delivery partners

Primary care trusts and local authorities

1. PCTs and local authorities should ensure ongoing support and sustainable funding for local information services through their local strategic partnerships and local area agreements.
2. There should be development of further capacity regarding training courses at a local level so that carers can participate effectively in a wider range of activities including inspection teams, LINKs, local strategic partnerships and the development and review of local area agreements.

3. The National Transition Support team should continue to engage with and exchange good practice in transition to help build capacity and maintain its partnership with regional advisers, DCSF and the Department of Health to improve transition practice. The Commission hopes that PCTs and local authorities can ensure that the benefits of the National Transition Support team's work are sustainable beyond the *Aiming High* lifecycle, in acknowledgement of the challenges facing many carers as well as young disabled people during the transition from children's to adult social care services and support.

Association of Directors of Adult Social Services and Local Government Association

4. ADASS and the LGA should consider how best to ensure that transformation and partnership work are achieving the desired outcomes at local levels and whether there are any associated resource issues.

NHS Care Records Service Programme Board

5. The NHS Care Records Service Programme Board should further explore whether better use could be made of the carers' information held on the record, to improve information sharing about carers' health.

Recommendations to the next phase of the Commission

The Commission was created with the key aim of contributing to the development and delivery of the national Carers Strategy. Our recommendations for the next phase of the Commission reflect its commitment to ensuring that the 10-year strategy achieves its goals by 2018. The main recommendations for the next phase of the Commission are set out below.

1. Following the publication of the Green Paper, *Shaping the Future of Care Together*, the Commission will wish to contribute to the debate from the carers' perspective and within the wider context of the transformation of social care and NHS reforms, to ensure that mechanisms for future funding arrangements fully reflect and respond to the critical role of carers within the health and social care system.
2. The Commission should seek further discussions with DWP on welfare reform and press for a timetable for reform to be established.
3. It is vital that PCTs are encouraged to recognise the importance and value of supporting carers. The Commission should work with both the Department of Health and the NHS to gather evidence of how the new resources in PCT baseline allocations have been spent and on the cost-benefits and improved health outcomes of supporting carers in their caring roles, including the provision of breaks.

4. The Commission should consider holding early discussions with the Department of Health, the LGA and ADASS on the impact of the transformation agenda on the viability of third sector organisations, given the important role they play in developing, designing and delivering innovative services and support for carers at local and national level.
5. The Commission should keep a watching brief on, and contribute to, DCSF's work on improving outcomes for young carers through the development of methods to help to identify and assess young carers at an early stage.
6. In the light of widespread concern about the implications of demographic change (and a recognition that the majority of carers are supporting older people) the Commission should actively consider the range of issues relating to quality of life and care and support for older people as identified in the Ageing Strategy *Building a society for all ages* and in the forthcoming Green Paper on *Families and Relationships*. In its discussions, it should also keep in view the role of lifetime carers and 'sandwich generation' carers.
7. Carers should be fully included within all forthcoming equalities legislation and thereby protected from discrimination. The proposed protection of carers from discrimination in access to goods, services and employment within the forthcoming equalities legislation has been widely welcomed. The Commission should maintain a close watch on the progress of the Equality Bill and contribute to discussions around carers' issues within the emerging equalities agenda.
8. The Commission should scrutinise how the Government includes carers in its consultation on the scope, impact and effectiveness of the NHS Constitution.
9. The Commission should maintain a close watch on the implementation of the Carers Strategy to ensure that carers of both younger and older disabled people receive appropriate information, advice and support around hospital discharge and that community services are age-appropriate and reflect personal preferences and lifestyles.
10. Recognising the importance of co-production, the Commission should develop a range of working groups and thematic meetings in order to bring key stakeholders together to explore key policy issues in depth and inform the Commission's wider work.

The outcomes identified in the Carers Strategy for 2018 are as follows:

- 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.

Appendices

i. Terms of reference, 2007 to 2009

1. To work with ministers to oversee the final stages of the revision of the Prime Minister's Strategy on Carers.
2. To begin a programme of work on the long-term challenges which will impact on carers.
3. To advise ministers on the terms of reference for the second stage of the Standing Commission on Carers.

The terms of reference for the next phase of the Commission's work will be discussed with members and agreed with ministers in autumn 2009.

ii. List of members, December 2007 to June 2009

The following people were, for part or all of the above period, members of the Standing Commission on Carers:

Invited members

Dame Philippa Russell DBE (Chair)

Kauser Ahmed (until August 2008)

Peter Blackman

Don Brereton

Judith Cameron

Baroness Jane Campbell

Professor Barry Carpenter

Professor David Challis

Sheila Dent (until March 2008)

Lynne Elwell

Rosey Foster

Alex Fox

Mark Goldring

Geraldine Green (until November 2008)

John Hannett

Professor Sheila Hollins

Neil Hunt

Paul Jenkins

Anne McDonald

Caroline Marsh (until April 2008)

Dr Helena McKeown

Christine Osborne

Jill Pay

Baroness Jill Pitkeathley

Barbara Pointon

Imelda Redmond

Anne Roberts

Professor Nigel Sparrow

Jo Webber

Dame Jo Williams (until November 2008)

Deputy members

Graeme Betts (deputised for Caroline Marsh)

Jo Bird (deputised for John Hannett)

David Congdon (deputised for Jo Williams)

Mary Garvey (deputised for Neil Hunt)

Lina Patel (deputised for Peter Blackman)

Srabani Sen (deputised for Rosey Foster)

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