House of Commons
Work and Pensions Committee

Valuing and Supporting Carers

Fourth Report of Session 2007–08

Volume I

Report, together with formal minutes

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The Work and Pensions Committee

The Work and Pensions Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department for Work and Pensions and its associated public bodies.

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Philip Dunne MP (Conservative, Ludlow)
Natascha Engel MP (Labour, North East Derbyshire)
Justine Greening MP (Conservative, Putney)
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The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at www.parliament.uk/parliamentary_committees/work_and_pensions_committee.cfm. A list of Reports of the Committee in the present Parliament is at the back of this volume.

Committee staff
The current staff of the Committee are James Rhys (Clerk), Emma Graham (Second Clerk), Amy Sweeney and Hanna Haas (Committee Specialists), Laura Humble (Committee Media Adviser), John-Paul Flaherty (Committee Assistant), Emily Gregory (Committee Secretary) and John Kittle (Senior Office Clerk).

Contacts
All correspondence should be addressed to the Clerk of the Work and Pensions Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 5833; the Committee’s email address is workpencom@parliament.uk
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Summary

Caring matters deeply to families and individuals. Sustaining the ability of carers to provide the care and support they give to others is of critical importance to the Government, care service providers and society in general. All parts of the UK will see further increases in the demand for care because of the increased longevity of the population, and greater survival rates, arising from improvements in healthcare. The unpaid support carers give saves the public purse an estimated £87bn each year.¹

Most informal carers are of working age. Sustaining their ability to remain in work or helping them to return to work after or during a period of caring is essential if the Government is to reach its target of an 80% employment rate. It is also of critical importance to employers who can not afford to lose the skills of valued employees who have to leave work, or reduce working hours, to carry out caring responsibilities.

On 10 June 2008, the Government published its new ten-year vision for carers, Carers at the Heart of 21st Century Families and Communities.² A wide range of commitments were set out, including: the provision of information and advice; breaks provision for carers; improved support from the NHS; and support to help carers better combine work and care. The Government also stated in its Carers Strategy that “Carers will be supported so that they are not forced into financial hardship by their caring role.”³

However, we are disappointed that benefits for carers were not directly addressed in the Carers Strategy and were only identified as a long-term priority from 2011 onwards. We believe that the current system of benefits for carers is outdated and we recommend the introduction of two distinctive ‘tiers’ of support for carers, offering: (i) income replacement support for carers unable to work, or working only part-time; and (ii) compensation for the additional costs of caring for all carers in intensive caring roles.

We have found that the financial pressures on carers arise from the additional costs of caring and from reducing working hours, moving into lower paid work, or giving up paid work. One of the major reasons that carers struggle to remain in work is because of a lack of affordable, reliable and flexible care services. Carers who have had to give up work to care often suffer ‘opportunity penalties’. Through caring and being outside the labour market their vocational skills may become rusty or out of date, and over time they may lose confidence and feel out of touch with the world of work. When caring ends, carers who have spent a long time in demanding caring roles need sensitive, tailored support to re-enter employment, supported by advisers who understand their circumstances and particular needs.

We believe that DWP should support adults who become carers during their working lives to combine work and care and enable those who wish to return to paid work when caring

ends or changes to do so. It must ensure that in caring for family members, young carers are not disadvantaged in accessing opportunities for education, training and employment and it must mitigate the financial strain on those whose pensions have been affected by their caring roles. A ‘joined up’ cross-governmental approach is required to ensure that carers are supported in the wider social care system by adequate arrangements to inform them of their rights and entitlements and of how to access an appropriate range of support and services.
During our visit to Australia, we were shown the following “job advertisement” for the post of “carer” by the Chief Executive of Carers New South Wales. It had been written by a carer. We reproduce this here as an illustration of how some carers see their lives.

Critical role for self starter for hands on role

Experience in first aid, counselling, occupational health and safety, pharmacology, cooking, cleaning, communication skills, stress management and ability to self mediate may be required.

The successful applicant must be able to forgo personal privacy and the choice to do what you want.

You will be required to lose your independent thinking ability and become invisible to the community at large.

The successful applicant must be able to endure the lack of joy, self-love and relationships indefinitely. Must also be able to function alone as friends leave due to your state of depression.

Although entitled to holidays, the successful applicant will not usually be able to have them due to lack of support or financial difficulties.

The successful applicant must be able to function credibly with a smile while dying on the inside from lack of laughter due to losing your mind.

Reassessment qualities are essential while you lose your sense of self, your reasons to get up in the morning, your dress sense, your hair and your sense of humour and identity.

The successful applicant may be required and therefore willing to move home to accommodate the client and be happy developing bad nerves and anxiety 24/7.

The successful applicant may be required to fight every day to remember five things to be grateful for while letting go of everything held dear. Must be able to let go and find comfort in a state of being stunned.

The successful applicant must be able to cope with slowly going insane and back on a continual basis. The successful applicant must learn to live in silence to enjoy this truly challenging lifestyle.

[...]
1 Introduction

The Government’s policy on carers

1. The Carers (Recognition and Services) Act 1995, covering England, Scotland and Wales, defined a “carer” as someone providing “a substantial amount of care on a regular basis”. The Act gave carers the right to request an assessment by their local authority of their own circumstances and needs arising from their care-giving role, but they were not entitled to specific services in their own right. The entitlement depended on the person receiving care having first had an assessment of his or her own needs.

2. In 1999, the Government launched the National Strategy for Carers. The Government’s three strategic elements to help carers carry out their caring responsibilities were: information, support and care for carers. The Strategy stressed that enabling carers to combine paid work and care was a priority for Government. As part of the Strategy, the Government introduced the Carers Special Grant in England to fund new services allowing carers a break from caring. This was the first time that resources were provided specifically for carers’ services. The Scottish Executive and the National Assembly for Wales developed separate National Strategies to help carers in their respective countries.

3. The Carers and Disabled Children Act 2000, which covered England and Wales, strengthened carers’ entitlement to assessment by granting carers for adults and people with parental responsibility for disabled children the right to be assessed irrespective of whether the care recipient was being assessed. Importantly, the Act allowed carers to receive services in their own right. It enabled local authorities to offer carers conventional services or, alternatively, Direct Payments to enable them to buy services they had been assessed as needing.

4. In Scotland, the Community Care and Health (Scotland) Act 2002 recognised unpaid carers as key partners in the provision of care, and entitled them to an assessment in their own right. In addition, the Act placed a duty on local authorities to offer Direct Payments for certain services to all eligible disabled people, including those with mental illness and learning difficulties, and parents of disabled children.

5. The Carers (Equal Opportunities) Act 2004 came into force in April 2005 in England and Wales. The Act was intended to give carers more opportunity to enjoy activities that many people take for granted by requiring assessments to include carers’ wishes in relation to education, training, employment and leisure. Under the Act, councils are obliged to inform carers of their rights to an assessment, and also to promote better joint working with other public bodies (such as education, housing or health bodies) to ensure support for carers is delivered in a coherent manner.

6. In 2007 the Government introduced its ‘New Deal for Carers’ in England and Wales. The package of measures included a revision of the 1999 National Strategy for Carers, the provision of respite care cover in emergencies, the setting up of a national helpline and an

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5 Department of Health, Our Health, Our Care, Our Say: A New Direction for Community Services, 2006.
‘expert carers programme’ (now renamed ‘Caring with Confidence’). In September 2007 the Prime Minister announced a new Standing Commission on Carers. The Commission’s remit includes a key role in the implementation of the Government’s new National Carers Strategy as well as a responsibility to advise the Government on matters it feels are relevant to carers in the longer term.

7. On 10 June 2008, the Government published its new ten-year vision for carers, Carers at the Heart of 21st Century Families and Communities.6 The Strategy is underpinned by £255 million to implement some immediate steps, alongside longer-term plans. A wide range of commitments are set out, including: the provision of information and advice; breaks provision for carers; a review of carers’ benefits; improved support from the NHS; support to help carers better combine work and care. The new Strategy applies in full to England; commitments on income and employment apply UK-wide.

8. Carers, like other groups of employees, can benefit from the 1999 Employment Relations Act which gave all employees the right to (unpaid) time off to deal with family emergencies. This measure allows carers, parents and others with dependants to take a ‘reasonable’ number of days off to deal with the immediate situation and to make any necessary longer term arrangements. The 2002 Employment Act gave employed carers of disabled children under the age of 18 the right to request flexible working arrangements such as changing start and finish times, compressed working hours, part-time working and working from home after six months in post. This right was extended to certain groups of carers for adults under the Work and Families Act 2006.7 All three measures cover England, Scotland and Wales.

9. In terms of UK equality law, carers are not a recognised group protected from discrimination. However, following the Opinion of the Advocate-General in January, the European Court of Justice confirmed on 17 July in the Sharon Coleman case that the UK’s implementation of European disability discrimination protection is inadequate. Since she was not the one suffering from a disability, Ms Coleman, a carer for her disabled son, was unable to claim her employer’s actions were discriminatory under the Disability Discrimination Act 1995 (the DDA). Eversheds Solicitors note that, in respect of other forms of discrimination, it is well established in UK case law that protection extends beyond the characteristics of the individual and includes, for example, discrimination by association.8 Ms Coleman argued that the failure of the DDA to similarly recognise discrimination or harassment of a non-disabled person on the grounds of their association with someone with a disability provides much narrower protection in this area. It also, she contended, did not accord with the much wider wording and interpretation of the European Framework Directive, and, as a result, significant change to the way in which the courts have interpreted the DDA, or change to the wording of the legislation, was required.

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7 A carer was defined by the Department of Trade and Industry as:

“... an employee who is, or expects to be, caring for an adult who is married to, or the partner or civil partner of the employee or is a near relative of the employee (a near relative includes parents, parent-in-law, adult child, siblings, uncles, aunts or grandparents and step-relatives); or falls into neither of those categories, but lives at the same address as the employee”.

8 Eversheds HR e-briefing no 371: The ECJ confirms the Disability Discrimination Act needs to change
Either way, Eversheds believe that the ruling will have a significant impact upon working practices in the UK.9

The inquiry

10. In our call for evidence we stated that we had decided to undertake an inquiry into the effectiveness of the Department for Work and Pensions’ existing approach to carers. In particular:

- Information, advice and guidance. Are carers sufficiently aware of their benefit entitlements and the support available to them? Is the Department providing high quality guidance and advice to carers? How is the Department working across Government to avoid unnecessary bureaucracy for carers when seeking guidance, advice and financial support?

- Income and Carer’s Allowance. What is the impact of caring on carers’ earning potential? Do carers receive sufficient support with additional costs as a result of caring? Are benefits and allowances adequate in minimising the financial impact of caring? Do benefits and allowances impact on barriers and incentives to work or carers’ ability to engage in education and training, and if so how? Do benefits and allowances impact on carers’ pension entitlements, and if so how?

- Employment strategy and training opportunities. Is the Department doing enough to address barriers to employment and training for carers? Is the Department’s welfare reform and employment strategy addressing the needs of carers? How is the Department working collaboratively with employers and other Departments to improve carers’ job retention or return to work? How is the Department working with employers and other Departments to improve support in education, training and skills for carers?

- Equality, recognition and discrimination. Are there barriers to equality for carers? What are the possible implications for equality legislation in the UK following the current EU legal case on disability discrimination by proxy? Does a carers’ profile impact upon their opportunities (e.g. carer of a disabled child, or elderly carer of a partner)?

11. The Committee invited witnesses to submit written evidence by 3 April 2008. Thirty-one memoranda were received from a wide range of individuals and organisations.

12. The Committee took oral evidence from Ms Imelda Redmond, Chief Executive, Carers UK; Ms Amanda Batten, Head of Policy and Parliamentary Affairs, the National Autistic Society; Mr Stephen Burke, Chief Executive, Counsel and Care; Ms Vicky Pearlman, Social Policy Officer (Disability and Older People’s Benefits and the Social Fund), Citizens Advice Bureau; Mr Gary Vaux, Head of Advice (Benefits and Work), Money Advice Unit, Hertfordshire County Council, Joint Representative for ADASS and LGA; Ms Philippa Russell, Chair, Standing Commission on Carers; Ms Sally West, Policy Manager, Income, Consumer and Housing Team, Age Concern; Ms Christina Barnes, Policy Head,

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9 Eversheds HR e-briefing no 371: The ECJ confirms the Disability Discrimination Act needs to change
Economics and Social Inclusion, Equality and Human Rights Commission; Ms Nicola Brewer, Chief Executive, Equality and Human Rights Commission; Ms Ruth George, Political Officer, USDAW; Ms Caroline Waters, Director, People and Policy, BT Group; Mrs Anne McGuire MP, Parliamentary Under Secretary of State (Minister for Disabled People); and Mr Ivan Lewis, MP, Parliamentary Under Secretary of State for Carers.

13. As part of the inquiry, the Committee also undertook a visit to Australia and visited the Carers’ Resource Centre in Harrogate. Reports on each visit are contained in Annex A to this Report. We are extremely grateful to the British High Commission in Canberra for arranging our visit to Australia, and for all the assistance that they provided while we were there. We are also very grateful to Anne Smyth, Director of the Harrogate Carers’ Resource Centre for facilitating our visit, and to all those who took time to meet us.

14. We would also like to thank Sue Yeandle, Professor of Sociology and co-Director of the Centre for International Research on Care Labour and Equalities, University of Leeds, and Dr Hilary Arksey, Senior Research Fellow at the Social Policy Research Unit, University of York, for assisting us as Specialist Advisors during the inquiry. We very much appreciate the contribution they made to our work.

Carers in Britain: who are they?

Carers - definition

15. The 2001 Census defined as carers all those who responded positively to the question: “Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?”. Almost 6 million people in the UK identified themselves in this way and reported their regular weekly hours of caring. Of the carers counted in the UK’s 2001 Census:

- 1,247,291 people provided 50 or more hours of care per week – the value of their contribution has been estimated at £47.02 billion per year;
- 659,069 people provided 20-49 hours of care per week - the total value of their care is estimated at £17.39 billion per year;
- 3,952,572 people provided 1-19 hours care per week - the total value of their care is estimated at £22.59 billion per year.

16. It is nevertheless accepted that many people – including some with intensive caring roles - do not think of themselves as ‘carers’, seeing the caring they provide as simply a normal part of their family and personal relationships or of their roles as neighbours or friends. This is excellent for the strength of family and community roles and relationships

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10 2001 Census Standard Tables, Crown Copyright 2003: ONS, GRO(Scotland) and NISRA.
11 This assumes that each only provides 50 hrs of care p.w., and takes the replacement cost of care as £14.50 per hour (the unit costs figure for one hour of social care support published by the NHS Information Centre (PSS EX1 Return for 2005-2006 Draft 3)).
12 If we assume this group of carers were carrying out, on average, 35 hours of care each week.
13 This assumes that 31% of this group were caring for 15hrs p. w., 31% for 7hrs p. w., and 38% for 2hrs p.w.
but creates some challenges for policy development and implementation, as it can be hard to identify and support those who do not recognise themselves as carers who might be eligible for support. Nevertheless the concept of ‘a carer’ has been vital for policy development in this area, which owes much to an active carers’ movement and to the advocacy of voluntary organisations. Carers often face health, financial and social penalties as a result of the care they give - a situation which the Government’s National Strategies for Carers (in 1999 and 2008) have identified as unacceptable, particularly in view of the vital contribution carers make to society.

**Carers by age**

17. Carers are found amongst men and women of all ages (see Figures 1 and 2), with the peak age for caring among both men and women of 45-69 years. In the 50-59 age group large minorities of people - 17% of all men and 24% of all women - are carers.

18. As shown in Figures 1 and 2, the 2001 Census also identified a small but significant number of young carers, aged under 18. In 2001 over 165,000 young people aged 18 and under in Great Britain were carers. Most of these young carers (80%) were in the 12-18 years age group and most of them (85%) were providing between 1 and 19 hours of care per week. However a minority were caring for many more hours than this each week (over 11,000 caring for 50 or more hours each week), and over 3,000 were young people who were not in good health themselves.

19. It is important to note that caring is often a transitional status, with many people entering and exiting caring roles each year. This means that the total number of people who experience caring during this (and other) stages of their lives is in fact very much larger than the ‘snapshot’ figures recorded in the Census. Carers UK report that 3 out of 5 people will be carers at some point in their lives. Half of these carers will be caring for more than five years. By age 75 years, almost two thirds of women and close to half of men will have provided one or more spells of at least 20 hours of care per week.

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14 Most agencies now discourage the use of the term ‘carer’ to describe paid workers who provide care as part of their professional role. In this report, the term is used exclusively to refer to those who provide unpaid care and support to a relative, partner, friend or neighbour who needs help because of illness, disability or frailty associated with old age.

15 In England, just over 139,000 young carers aged under 18 were identified.

16 *Analysis (2008)* by Dr Lisa Buckner, University of Leeds of 2001 Census Theme Tables on Dependent Children.


20. In their early 60s, women are more likely than men to provide unpaid care; one in five women aged 60-64, and about 1 in 6 men of this age, are carers. In the age groups over age 75, however, men are more likely than women to be carers: there are 179,000 men and 169,000 women providing unpaid care in this age group. After age 70 men are considerably more likely than women to have a caring role. Between ages 75 and 89 years around 10% of men are carers, and even at age 90+ the figure for men is over 6% (Figure 3).

21. Research shows that when men become carers, most often they are caring for a wife or partner, usually someone living in the same household. Women are more likely than men
to be caring for a son or daughter who has a long-term condition or disability (again often living in the same household, quite often as single parents), and they are also more likely than men to care for an elderly parent, frequently taking on substantial caring responsibilities even when they do not share the same household.

22. Many carers live with or near to the person they care for, although some provide caring ‘at a distance’, sometimes travelling long distances at weekends, often to care for an elderly parent, or for someone close to them who lives alone.

Figure 3: Older people who provide unpaid care, by age and sex, UK

Source: Buckner, L. and Yeandle, S. (2005) Older Carers in the UK, data derived from 2001 Census Standard tables, supplied by ONS, GRO Scotland and NISRA. Note: Numbers of carers are shown within the bars.

Carers by employment status

23. In 2001 the Census showed that there were 4.27m carers of working age living in Great Britain (Figure 4). Among those who were men, 66% were in full-time paid work (including 12% who were self-employed), while a further 7% had part-time jobs (Figure 5). Among women who were carers, 32% were in full-time work (including 3% who were self-employed) and another 30% were in part-time employment (Figure 6).

24. In 2001, over a quarter of a million men and over 300,000 women combined their paid jobs with providing 20 or more hours of unpaid care each week. As many as 287,000 people held a paid job alongside an unpaid caring role which occupied an extra 50 or more hours each week. This latter group was fairly equally divided between men (46%) and women (54%). Most men in this group (89%) and almost half of the women (43%) were working full-time hours in their paid job, revealing that (numerically) in 2001 there were in fact more men than women coping with full-time employment at the same time as caring for 50+ hours per week.
### Figure 4: Carers of working age by sex, Great Britain

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<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>number</td>
<td>number</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>All Carers</td>
<td>2,419,957</td>
<td>1,845,754</td>
<td>57</td>
<td>43</td>
<td>100</td>
</tr>
<tr>
<td>Caring 1-19 hrs</td>
<td>1,680,528</td>
<td>1,359,269</td>
<td>55</td>
<td>45</td>
<td>100</td>
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<td>Caring 20-49 hrs</td>
<td>285,523</td>
<td>192,896</td>
<td>60</td>
<td>40</td>
<td>100</td>
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<td>Caring 50+ hrs</td>
<td>453,906</td>
<td>293,589</td>
<td>61</td>
<td>39</td>
<td>100</td>
</tr>
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</table>

Source: 2001 Census Standard Tables,

### Figure 5: Male carers of working age by economic activity status, Great Britain

- Looking after home/family: 5%
- Student: 3%
- Early retired: 6%
- Unemployed: 4%
- Other: 2%

Carers in employment:
- Employee PT: 4%
- Employee FT: 54%
- Self-employed PT: 3%
- Self-employed FT: 12%

### Figure 6: Female carers of working age by economic activity status, Great Britain

- Looking after home/family: 21%
- Student: 3%
- Early retired: 3%
- Unemployed: 3%
- Other: 3%

Carers in employment:
- Employee PT: 27%
- Employee FT: 29%
- Self-employed PT: 3%
- Self-employed FT: 3%
25. It is possible for many people to combine work and care and it is critically important to provide adequate support for those who do so. In a recent study, 40% of over 500 carers who were caring full-time said they would rather be in paid work but needed better support and services to achieve this.\(^\text{19}\) The 2001 Census showed that there were well over half a million carers in this situation (over 260,000 of them providing 50 or more hours of care each week, and about 85% of them women) and it can be assumed that many carers would welcome additional help to re-enter employment, with all the benefits this could bring to their financial and social circumstances.

26. There is a strong relationship between hours of caring per week and length of time caring and poverty, and analysis of the 2001 Census also shows that those who care for 20 or more hours per week are very much more likely to live in workless households than non-carers or those caring for less than 20 hours per week.\(^\text{20}\)

27. In relation to education and training, the 2001 Census shows the 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 (see Annex B in this report). More detailed information about the circumstances of Britain’s working age carers is shown in chapter 5 and in Appendix B to this report.

**Diversity among carers**

28. Some ethnic groups have higher rates of caring than others (see Annex B to this report). This in part reflects the greater demand for care which many people in these groups encounter, with Pakistani and Bangladeshi residents of working age twice as likely to live with someone with a limiting long-term illness (LLTI) as White British residents. Carers in some ethnic minority groups also experience higher rates of poor health themselves.

29. Carers for sick or disabled children are another group particularly in need of support. In England and Wales in 2001, 212,000 households included a child under 16 who had a LLTI and an adult who saw him or herself as a carer. With more than one ‘parent carer’ in some cases, these households contained a total of 305,000 carers, 64% of them women (a quarter of these were lone parents), and 20% were people who themselves had a LLTI. Most (69%) were providing at least 20 hours of unpaid care per week. Parents of sick or disabled children are more likely than other parents to be in poor health and mothers especially are considerably less likely to be in employment than other parents.\(^\text{21}\)
Key public policy issues

30. Sustaining the ability of carers to provide the care and support they give to others is of critical importance for Government, employers and service providers. The unpaid support they give saves the public purse an estimated £87bn each year.22 Caring also matters deeply to families and individuals. We have taken extensive evidence about carers and the care they give, and have been convinced of the importance of finding better ways of supporting carers. For most carers, caring and supporting their loved ones is something they wish to do not in isolation and poverty, risking their own health, but as part of active, socially engaged lives which enable them to continue to earn a living even when caring is required of them.

Demographic change

31. All parts of the UK will see significant increases in the demand for care in the first half of the 21st century. The main causes of this development are the increased longevity of the population, and greater survival rates, arising from improvements in healthcare, among children and younger adults who are sick or disabled (or who suffer injuries or accidents). Old age is associated with increasing health and care needs; dementia cases alone are expected to increase from 0.7 million in 2007 to 1.7 million by 2051.23 The trend towards assisting more sick and disabled people to live or recover at home – which is what most of them wish to do - also significantly increases the demand for care by family members.

32. The need for more people to provide unpaid care - something most people wish to do when someone close to them needs their support – and the fact that many carers suffer disadvantage and feel unsupported in carrying out their caring roles presents a number of challenges. The first is that the changing age structure of the population places dual pressures on the working age population, since the economy and employers need to sustain an adequate labour supply at a time when more people are retiring than are entering the labour force, yet the increased demand for care impacts most on people of working age. This means that growing numbers of people are trying to combine care with paid work. The second challenge is that, unless people can access the support and services they need, caring will cause the early exit of many older workers from the labour force, reducing pension saving and depriving organisations of experienced workers in whom they have made significant human capital investments.

Recognising and responding to carers

33. Many carers do not readily identify themselves as such. It can be hard for carers to secure the support they need if they do not think of themselves as being in a caring role. It is stressful and frustrating for carers coping with demanding and difficult responsibilities, sometimes under considerable emotional strain, if those around them – employers, professionals in the health and social care system, and providers of services (in housing,

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23 Dementia UK: a report into the prevalence and cost of dementia prepared by the Personal Social Services and Research Unit at the London School of Economics and the Institute of Psychiatry at Kings College London for the Alzheimer's Society, 2007.
transport, leisure and education) - do not fully understand the pressures they are under, or offer them appropriate support.

**Diversity of circumstances**

34. Evidence commissioned by Carers UK has highlighted that carers are in a variety of different relationships to those they care for (such as child, partner, parent, sibling, friend) and support people with a range of very different needs (long-term conditions, mental health difficulties, learning difficulties, physical disabilities and impairments, terminal illness, frailty in extreme old age, problems related to alcohol or substance abuse, dementia, serious illness or major operations). Further diversity in carers’ circumstances arises because of the particular needs of carers in some ethnic minority populations, from difference in family circumstances and structures, and because of where carers, and those they care for, live. Particular challenges are faced by those who reside with the person they care for (who may need special support to get a break from their caring role) and those who live some distance from the person they care for (for whom transport costs and time pressures may be especially difficult). In large conurbations, carers face challenges in paying for parking or travelling at busy times; in rural areas, much time and expense may need to be allocated to travelling to hospital and doctor’s appointments, or to day care services. Since services, eligibility criteria and information systems can vary so much from place to place, carers living in a different place from the cared for person can often find it extremely difficult to understand and access available systems of support.

**Tackling the social exclusion carers face**

35. Carers face three main types of penalty as a consequence of the care they give: financial strain; damage to their own health; and social isolation. The financial pressures on carers arise both from the additional costs of caring (discussed in chapter 3 of this report) and from giving up paid work, reducing working hours, or moving into lower paid work. Carers’ health can be affected by the physical demands of their caring role, by lack of rest and sleep, and by mental and emotional stress (sometimes exacerbated by their frustrations in trying to access support). The social isolation some carers experience arises from giving up work, from difficulty in sustaining leisure and other activities if the person cared for cannot be left alone, or if the caring role is particularly exhausting or intense.

**Opportunity penalties: confidence, skills and employment**

36. In addition to health and financial difficulties and social isolation, carers who have had to give up work to care (often reluctantly but feeling they have no choice but to do so) often suffer ‘opportunity penalties’, as through caring and being outside the labour market their vocational skills may become rusty or out of date, and over time they may lose confidence and feel out of touch with the world of work. When caring ends, perhaps when the person cared for dies or enters residential care, carers who have spent a long time in demanding caring roles need sensitive, tailored support to re-enter employment, supported by advisers who understand their circumstances and particular needs.

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37. The two main sources of additional ‘demand’ for caring - the increased longevity of older people and greater survival rates among sick and disabled people - will almost certainly increase the numbers of carers needed in the future. Caring already occupies the time and energy of some 10% of the population, and this will certainly increase in coming decades. Particularly large increases can be expected among people aged 45-69, the very ages at which, both to sustain the pensions system and to maintain the economic efficiency and performance of organisations and businesses, it is Government (and EU) policy, to raise employment rates. It is in this context that we have recognised the crucial importance of achieving the following objectives through a more strategic DWP approach to supporting carers which aims to:

- Support adults who become carers during their working lives to combine work and care;
- Enable those who wish to return to paid work when caring ends or changes to do so;
- Secure adequate financial support for those who provide care when of working age, either by compensating them for the extra costs of caring, or (if they need to give up work to care) through adequate income replacement and pensions protection mechanisms;
- Protect the interests of young carers, ensuring that in caring for family members they are not disadvantaged in accessing opportunities for education, training and employment;
- Provide adequate support for older carers, mitigating the financial strain on those whose pensions have been affected by their caring roles;
- Through a ‘joined up’ cross-governmental approach, ensure that carers are supported in the wider social care system by adequate arrangements to inform them of their rights and entitlements and of how to access an appropriate range of support and services.

**DWP’s approach to carers**

38. Whilst health and social care issues clearly have a huge impact on carers, those related to benefits, employment and equalities are of equal importance. Currently, the strategic lead for carers rests with the Department of Health, and the Parliamentary Under Secretary of State for Care Services, Ivan Lewis MP, was recently given the title Minister for Carers.

39. Ms Redmond of Carers UK pointed out that, “Actually, only a tiny minority of carers go near Social Services. Of the 6 million [carers], last year there were about half a million assessments of carers by Social Services […]. The work we have been doing over recent years is really to […] look at a much more holistic support package which is about employment, equality and about the benefit system working for carers rather than against them.”

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25 Q 2
40. She added that “Carers UK’s evidence over the years has shown that if we do not get all the different parts of society that impact on carers’ lives sorted out in the right way, the negative impact of caring really stacks up and people fall out of work and become ill.”

41. We call on DWP to take a stronger and more proactive lead in Government policy on carers. As well as identifying and implementing specific policies to improve the lives of carers, DWP needs to take specific account of carers in all its work, including its role in reducing child poverty and pensioner poverty, its efforts to see 80% of working age people in employment, and its vision of giving people equality of opportunity.
2 Information, advice and guidance

42. Caring can start suddenly or build up gradually over time. Some people are thrust into a demanding caring role overnight, for example when a family member or partner has an accident or stroke. Others face an increased caring role as an elderly relative starts to require more support or a condition worsens. Regardless of the extent of their caring role, all carers need timely and accurate information, advice and guidance.

43. In its recently published Strategy for Carers, the Government makes the commitment to “Providing every carer with the opportunity to access comprehensive information when they need to. The information will be easily accessible for all groups of carers, and specific to their locality.”

44. The National Autistic Society (NAS) found that 69% of families they surveyed expressed a need for someone to help them find out what services are available to them and over a third stated that they did not understand the benefits system. A survey of members of the Parkinson’s Disease Society found that 77% of carers rated financial advice as ‘important’ or ‘very important’, yet only a fifth (20%) had actually received such advice.

45. The Royal College of Nursing (RCN) stressed that “while information is available if carers choose or are able to look for it, there is a common perception that the support available is inadequate, which results in many carers not even attempting to find out what assistance is out there. When they do, due to complexity of the system, carers can often be very confused regarding what payments they are entitled to.”

46. Research by Carers UK shows that 58% of carers surveyed had missed out on benefits for over 3 years. A similar proportion of carers felt they had missed out on practical support and of those who felt they had missed out, 68% had missed out for over 3 years. Earlier work by Carers UK demonstrated that an estimated £740 million a year in carers’ benefits alone could be going unclaimed every year.

47. The RCN added that not only financial guidance is required; carers also need information on breaks through various respite care schemes, practical support and training to enable them to care safely: “A further problem that arises is that many carers may not realise the scale of the role they have taken on. They are simply carrying out what needs to be done and have just assumed that there is no state help available to them.”

48. Older carers and carers from Black, Asian and Minority Ethnic (BAME) groups are at particular risk of missing out due to a lack of information. The Office of the former Mayor of London stated that: “London has 27% of carers from BAME backgrounds and they have

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28 Ev 157
29 Ev 100
30 Ev 152
31 Ev 139
32 Ev 152
made clear [...] that accessing information and advice are issues for them, due partly but not entirely to language differences and the need for translation and interpretation facilities.\textsuperscript{33}

49. Rethink quotes a 2002 report from the Princess Royal Trust for Carers which found that carers of people with a mental illness were more likely than carers of people with physical disability or the elderly to report that they had not been directed to any source of information or support, and that they had no help or support with caring or advice about benefits and grants.\textsuperscript{34}

50. The Mental Health Foundation and the Foundation for People with Learning Disabilities (MHF and FPLD) stressed that “the speed at which carers of people with mental health problems are identified and provided with support is alarmingly slow.” They report that a project for carers of people with mental health problems in Southwark recently found that it took on average 5 years for these carers to receive the support they needed.\textsuperscript{35}

51. Access to immediate and continuing information, advice and guidance is a major concern for carers, who often go for years without receiving adequate support. We welcome the Government’s commitment to “Providing every carer with the opportunity to access comprehensive information when they need to” and to make this information “easily accessible for all groups of carers, and specific to their locality.” We make a number of recommendations below, suggesting how the Government could address current inadequacies in information provision and help meet this commitment.

**Quality of DWP services**

**Benefit Enquiry Line, leaflets, Directgov**

52. DWP aims to make information for carers available through a combination of leaflets, information sessions, the Benefit Enquiry Line and via the Directgov website. In addition, information about Carer’s Allowance also appears in other relevant DWP leaflets and claim packs. For example, the Department publishes information about Carer’s Allowance in Disability Living Allowance and Attendance Allowance claim packs.\textsuperscript{36}

53. As well as ensuring leaflets are available within Departmental offices or carers’ organisations, the Disability and Carers Service works with organisations to raise awareness and to promote Directgov as a source of information. Directgov provides information about Carer’s Allowance and a link to the E Service which can be used either to claim Carer’s Allowance or to report a change of circumstances. Telephone advice is available either through the Carer’s Allowance Unit or the Benefit Enquiry Line.\textsuperscript{37}

\textsuperscript{33} Ev 91
\textsuperscript{34} Ev 133
\textsuperscript{35} Ev 78
\textsuperscript{36} Ev 104
\textsuperscript{37} Ev 104
54. DWP Disability and Carers Service outreach officers attend events across the country. The DWP Carer’s Allowance Unit officer, for example, attended around 80 events in 2007 giving advice and information on Carer’s Allowance and other benefits to groups of carers. The Department states that staff in both the Pension, Disability and Carers Service and Jobcentre Plus will encourage eligible customers to apply for Carer’s Allowance and carers can access Jobcentre Plus services if they are looking for either employment or training.38

55. However, evidence we received suggests that this information is not reaching enough carers. The Parkinson’s Disease Society (PDS) reports that feedback from recent carers’ focus groups indicates that carers were not receiving information or advice from the Department. Carers find out about Carer’s Allowance from friends, relatives or colleagues rather than the DWP or professionals.39

56. Carerwatch added that the Benefit Enquiry Line is frequently continuously engaged and a source of frustration and delay in claiming the benefits to which they are entitled.40 Carers UK stated that DWP leaflets do not contain all the information carers need, for example on the earnings limit.41 The National Family Care Network pointed out that while some of the Government’s internet-based resources – for example the information on financial support for carers on the Directgov website – are very impressive, many carers are unable to afford computers and Internet access and so are not able to access this form of information.42

57. The Department’s information, advice and guidance services are not reaching significant numbers of carers. We recommend that the Department addresses problems of access to its Benefit Enquiry Line and explores ways to convey the information that carers need in a more accessible way.

**DWP advice staff**

58. Carers UK and the Citizens Advice Bureau (CAB) believed that, in general, knowledge and understanding of carers’ concerns among Jobcentre Plus advisers is low.43 CAB suggested that DWP staff often struggle to correctly identify, and explain clearly, the benefits that individual carers and their families are entitled to. Its evidence showed that carers experience administrative delays and incorrect advice from both the Department for Work and Pensions and other Government departments. Many carers find the experience of claiming the benefits they are entitled to overwhelmingly bureaucratic.44

59. Ms Pearlman of CAB said “It is fair to say that the Carer’s Allowance Unit is generally very helpful, although sometimes there are gaps in their knowledge. But as you spread further through DWP and Jobcentre Plus in particular, then often we see patches where

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38 Ev 104  
39 Ev 100  
40 Ev 127  
41 Ev 139  
42 Ev 116  
43 Ev 71; Ev 139  
44 Ev 72
their knowledge is very poor and people are being very poorly advised.”

Ms West of Age Concern added: “In respect of the Pension Service, we get generally good feedback on the kind of customer service, […] some of the more complicated areas, particularly trying to identify the premiums and the additions, is where there are problems; the staff on the telephone line may not have the training and the knowledge to really be able to help people in a holistic way around the system. They are perhaps good at taking a straightforward pension credit claim but sometimes lacking in the detailed understanding of the other benefits and the interactions.”

60. Carerwatch suggested that carers have reported that Independent Benefit Advice Services (IBAS) and the CAB are more helpful and thorough than Departmental staff in ascertaining whether a claimant is receiving all the financial help to which they are entitled. It stated that IBAS and CAB are also better at taking into consideration the whole financial situation of the carer and the person they care for.

61. The Government stated in its 2008 Carers Strategy: “In recognition of the vital role that third sector organisations play in supporting carers, and the trust they have among carers, we are committing funding over the next three years to build capacity in the sector at both a national and a local level.”

62. The Committee believes that DWP frontline staff should provide a similar service. The Minister for Disabled People, Anne McGuire, said that the Government is committed to “improving the training for our Jobcentre Plus advisers and we are also committed to putting a carer expert into every Jobcentre Plus district in the same way as we have already a childcare expert in every Jobcentre Plus district.”

63. Evidence suggests that Jobcentre Plus personal advisers’ knowledge of carers’ issues in general, and the complexities surrounding benefits for carers and care recipients in particular, is low. We welcome the Government’s commitment to funding for the third sector and training for professionals in local authorities to support carers more effectively. We welcome the Government’s commitments: to training for DWP frontline staff to improve information provision; to advice services for carers; and to placing a carer expert in every Jobcentre Plus district.

Merger of the Pension Service and the Disability and Carers Service

64. In January 2008 the then Secretary of State for Work and Pensions, Rt Hon Peter Hain MP, announced the merger of the Pension Service and the Disability and Carers Service into a single Agency – the Pension, Disability and Carers Service. The new Agency came into existence on 01 April 2008.
65. DWP states that in advance of bringing together the two Agencies, the Disability and Carers Service had already been working closely with the Pension Service to identify ways that services to customers could be improved.\(^{50}\)

66. Carers UK supported the merging of the Carer’s Allowance Unit with the Pensions and Disability services: “This should improve knowledge across the service and make mistakes – particularly overpayments – less likely. A more holistic approach to claims will benefit carers and those they care for.”\(^{51}\)

67. Ms Pearlman of CAB was more cautious: “Although for many people, carers in particular, the merger will be a good thing, we do have some concerns that although 50% of DCS’s customers or clients are the same as the Pension Service, 50% are not, and we are really anxious that disabled people who are of working age with children do not miss out from the merger and that the impetus is retained for them.”\(^{52}\)

68. The merger of the Pension Service and the Disability and Carers Service has the potential to reduce some of the bureaucracy in the system. However, it is still too early to tell what impact it will have and we are particularly cautious about the impact the merger might have on those customers who do not overlap between the two services. We recommend that the Department commission an independent customer survey to assess the potential impact of the merger on carers.

**Appointeeship**

69. Some people with mental illness are not able to manage their own benefit claims. This might be because they do not accept that they have a mental illness, or because they are too ill to organise the claim, or because their life has become chaotic. In these circumstances, a representative can become an ‘appointee’ to manage their claim and receive their money on their behalf.

70. Rethink reported that there is low awareness of appointeeship amongst carers of people with mental illness. Failing to address this problem can lead to the person with mental illness, and the person supporting them, living in poverty. Rethink’s view is that Jobcentre Plus do not adequately promote this option to carers. Rethink states that telephone scripts do not include a prompt to discuss appointeeship with callers.\(^{53}\)

71. There is also a lack of clarity about the application process. Jobcentre Plus literature states that it is necessary for the beneficiary to be interviewed face to face to apply for an appointeeship. However, as Rethink has stressed, in many cases, this is not possible, for the same reasons that they are not claiming the benefit in the first place.\(^{54}\)

72. To raise awareness of the appointeeship scheme, we recommend that automated telephone scripts used by Jobcentre Plus are reviewed and amended to ensure that there

\(^{50}\) Ev 105  
\(^{51}\) Ev 139  
\(^{52}\) Q 78  
\(^{53}\) Ev 136  
\(^{54}\) Ev 136
is a prompt to discuss appointeeship as an option. Jobcentre Plus literature on appointeeship should also be amended to state that, in cases of mental illness, it may be possible to apply for appointeeship without a face to face interview with the beneficiary.

**Working with other agencies**

**Welfare benefits advice and healthcare**

73. Carers UK, Carerwatch and Age Concern all stressed that more needs to be done across all relevant Departments to raise awareness among carers both that they are carers, and that they are entitled to benefits and support. In particular, DWP needs to work better with the Department of Health and others who have regular contact with carers, particularly in the early stages of their caring role. Ms Pearlman of CAB argued that “We often talk about people being hard to reach, particularly in terms of the benefits system, and it is really the wrong way round to look at it because these people are usually seeing GPs, social workers or other professionals, so it is just that the DWP is not able to reach them, not that these people are completely isolated from the system.”

74. A4E’s carers survey also suggests that health and social care professionals - especially Social Workers and GPs - would be the most appropriate source of information regarding access to welfare benefits and other support: “Where diagnosis of an individual suggested that they would be likely to require significant amounts of care, suitable information could be provided to the potential carer at this stage.”

75. The Royal College of Nursing and Rethink supported the suggestion that GPs and nurses maintain a register of carers, so they can be easily identified and offered all possible and appropriate assistance. Carers UK stated that “carers are often shocked that there is no single register of carers where they can inform the authorities that they are a carer and get the information they need.”

76. According to a recent survey by Age Concern, in 2006 there were 889 General Practices with some form of linked welfare benefits advice provision (of which 523 were CAB-linked). This amounted to 10.5% of the 8,433 General Practices in England. In addition to those located in GPs’ practices, the survey found benefit advice services in 74 hospitals, 93 mental health and 27 other health-care settings.

77. The vast majority of benefit advice services were provided through short-term funding. The Citizens Advice Bureau reported a 33% decline in GP-linked services from 2005. The survey by Age Concern suggests that financial pressures on Primary Care Trusts appear to

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55 Ev 139; Ev 110; Ev 127
56 Q 72
57 Ev 94
58 Ev 135; Ev 153
59 Evg 140
be the major reason why such services do not receive ongoing funding after the end of any fixed term funding.\textsuperscript{61}

78. The survey also showed that distribution of services is very variable. For example, Cornwall has no services, but neighbouring Devon has 21 (but none in North Devon). Hampshire has five, five more than neighbouring Surrey. The London Borough of Tower Hamlets has none, while neighbouring Newham with a similar socio-economic profile has 35. The report states that “The huge variability of distribution suggests that there is no over-arching national strategy to develop advice provision in health-care settings and provision is often the result of local initiatives and enthusiasm – something borne out by our interviews and fieldwork.”\textsuperscript{62}

79. In its Carer Strategy the Government announced that: “to encourage partnership working between the health, social care and third sectors, we are making a commitment over the next three years to run pilots looking at ways in which primary care trusts (PCTs) can better support carers. The sites will gather evidence of the benefits to both carers and the NHS of better service provision and interaction for and with carers in hospitals, GP surgeries and other arenas. The pilots will seek to enshrine good practice such as:

- actively involving carers in diagnosis, care and discharge planning;
- providing greater support for carers at GP practices and acute trusts;
- working in partnership with local authorities and the third sector to provide flexible support for carers.”\textsuperscript{63}

80. There is no mention of welfare benefit advice or DWP involvement in the pilots. We believe DWP involvement in the pilots could address the lack of coordination between the benefits system, the health system and local authorities’ Carer’s Assessments. This could have benefits in reducing the bureaucracy that carers face, but also in identifying carers who are entitled to additional support.

81. We believe that health and social care professionals are an appropriate initial source of information regarding access to welfare benefits and other support. We recommend that DWP participates in the planned pilots looking at ways in which Primary Care Trusts can support carers to ascertain how it can work better with healthcare professionals, local authorities and third sector organisations which have regular contact with carers, often in the early stages of their caring role. The Government should develop a national strategy for giving carers advice on benefits in healthcare settings.


“Information prescriptions”

82. The Department of Health White Paper Our health, our care, our say published in January 2006 made a commitment to improving access to appropriate information for people with health or social care needs. It stated “We propose that services give all people with long-term health and social care needs and their carers an ‘information prescription’.”

83. From this year, information prescriptions will be offered to everyone with a long-term condition or social care need, in consultation with a health or social care professional. The Department of Health’s website states that “information prescriptions will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.”

84. The Minister for Carers, Ivan Lewis, said that the concept of information prescriptions is “currently in the context of development of health reform, but [has] the potential to be far more than that, where individuals, as a result of their contact, for example, with their GP, would have information collected in a holistic way, on one piece of paper, which enables information about that person to be transferred from professionals rather than being constantly asked, as people get incredibly frustrated, for the same information from different organisations and different professionals.”

85. Age Concern regarded it as vital that carers are involved, at a local level, in the development of health and social care ‘information prescriptions’, and that these ‘prescriptions’ focus on the needs of carers. Every Disabled Child Matters (EDCM) suggested that electronic prescriptions should enable families to be automatically alerted when key ages or milestones are reached, for example, at age 3 to apply for the high rate DLA mobility component or age 13 to be notified about the ‘transition’ process: “This proposal is virtually cost-free and would have a significant impact on empowering parents to access services and support.”

86. We welcome the introduction of Information Prescriptions for carers. We believe that carers are best placed to contribute to the development of information prescriptions locally. We recommend that information on benefits for carers and the cared for person should be included in information prescriptions.

National telephone helpline

87. There is a particular need for advice and support for carers who are outside the local authority social care system, for example those who are caring for someone who is assessed as not meeting local authority eligibility criteria or those who choose not to be assessed for local authority care because they know they have too much capital to be eligible for local authority funded services. Although some local authorities do refer sick, frail and disabled
people and their carers to further information and support, the quality varies between areas and many carers do not think to approach their local authority in the first place.69

88. This situation will be improved by the National Advice and Information Service which the Department of Health undertook to provide in the Our Health, Our Care, Our Say White Paper in January 2006.70 Mr Burke of Counsel and Care said: “We are disappointed that there have been delays in developing the National Carers Helpline.”71 In its Carers Strategy the Government finally announced the timetable for a single national telephone helpline for carers:

“This will provide, via a website and a single national telephone number, easy access to the comprehensive range of information needed by carers. Carers will be helped by the service directly and through signposting to other services that are more appropriate to meet their needs. We are making available £2.775 million per year to fund the service. […]"

The helpline and website will be in place by spring 2009. The service will work with other similar services to maximise the value of information services for carers.”72

89. However, Ms Redmond of Carers UK noted “that the helpline […] is for England only and, of course, DWP responsibilities are UK-wide. Within the tender it asks the provider to explain how they will turn away calls from Scotland, Wales and Northern Ireland. Really, you need to think very carefully about how you get quality advice to people in Scotland, Wales and Northern Ireland, where the benefit system, employment law, taxation, and pensions are all reserved matters.”73

90. The Minister for Carers, Ivan Lewis stressed that “other than benefits, most of these services are devolved, and therefore it is quite a challenge.” The Minister for Disabled People, Anne McGuire, added that “at DWP we have an interest in ensuring that carers in Scotland, Wales, and England – Northern Ireland have a slightly different system – are given the benefit of full information on their entitlements. But whether or not it will be as cohesive as you might wish it to be, I do not think we are in a position to say that yet.”74

91. We welcome the Government’s planned national helpline and website for carers. This will provide important information for carers in England, including those who are not eligible for local authority support. We recommend that the helpline and website provide up-to-date, accurate, comprehensive information and advice for carers on how to access benefits and other services for carers and the people they care for. We call on the Government to work closely with the devolved administrations in Scotland, Wales and Northern Ireland to ensure that helplines providing equivalent advice are rolled out across the UK.

69 Ev 140
70 Department of Health, Our health, our care, our say, 2006, p178ff.
71 Q 9
73 Q 13
74 Q 158
Carers’ Centres

92. Ms Batten of the National Autistic Society emphasised that “in addition to information and awareness about people’s entitlements, there is a real need for community-based and practical support for families to help them fill out the forms and go through that process.”

93. On our visit to Australia, we were very impressed by the Commonwealth Carelink Centres (CCC). CCCs are information centres for older people, people with disabilities and those who provide care and services. Centres provide free and confidential information on community aged care, disability and other support services available locally, or anywhere within Australia. The network of CCCs has 65 ‘walk-in’ shopfronts throughout Australia. Many are conveniently located near, or within, shopping centres.

94. Each CCC has extensive regional networks and maintains a comprehensive database containing information on community aged care, disability and other support services. Shopfronts are operated by public and voluntary organisations that already provide established services within their region. This regional focus enables each Centre to develop an awareness of the entire range of services available, to establish networks with local providers and ensure information is up to date.

95. There is no national network of Carers’ Centres in the UK. The Princess Royal Trust for Carers (PRTC) is the largest provider of comprehensive carers’ support services in the UK with a network of 133 independently managed Carers’ Centres and interactive websites. The Trust currently provides information, advice and support services to 310,000 carers (some 5% of all carers), including 15,500 young carers (about 11% of all carers aged under 18).

96. The Committee visited the Harrogate Carers’ Resource Centre, a PRTC member. The Carers’ Resource has been an independent charitable company since November 1995. It has 56 paid staff and 54 volunteers, a board of seven trustees, and is in touch with more than 5,000 local carers. The core funding comes from the Primary Care Trusts (PCTs), local authorities and about 25 separate funding streams or contracts. The Carers’ Resource gives tailored support to carers and encourages professionals to be “carer aware”. It provides information, advice and guidance, representation and advocacy - free and in confidence - for all carers. It guides carers to the relevant services which will help them to care, to look after their own health and well-being, to become economically active, or to stop caring (if that is what they feel they must do).

97. The Government’s carers strategy stresses the importance of provision of respite in helping carers return to work. This includes £25 million a year announced as part of the New Deal for Carers for the emergency break provision. Our visits to Harrogate and Australia convinced us of the importance of carers centres in providing information on respite options, including providing information through the internet. We were

75 Q 7
76 See notes of visit in Annex A.
77 See notes of visit in Annex A.
particularly struck by the challenges facing carers in rural areas; carers centres have an important role to play in helping to overcome the isolation and exclusion from information and service provision that can be a particular problem in these areas. Carers centres also provide support for carers in accessing counselling, which can help them to cope with the range of challenges that they face.

98. We were also extremely impressed on our visits to carers centres in Harrogate and Australia by the work that was being done to support young carers. It is particularly important that young carers are provided with this support to ensure that they are informed about the respite options available to them, so that they can participate in the activities that prevent them from becoming isolated, and so that they are supported in continuing their education. Schools have an important role to play in identifying young carers and referring them to carers centres for support.

99. We asked the Minister for Carers, Ivan Lewis, how the Government can address the funding difficulties for Carers’ Centres in the UK and he responded: “The Department of Health has a budget called section 64, which it spends with the voluntary sector, and I am doing a fundamental review of that at the moment. It is about £20 million a year. […] One of the things we have singled out in the strategy is in terms of that review of section 64. We are very seriously considering making projects offering emotional support to carers (that is, Carers’ Centres) as one of the priorities for that grant aid in the future. We have not made a definite decision on it but we are looking at that [at] the moment.”

100. We have been impressed by the Commonwealth Carelink Centres in Australia and examples of independent and third sector Carers’ Centres in the UK. We believe that some Carers’ Centres already offer an effective ‘first stop shop’ for signposting carers to local organisations, services and benefits, and for providing ongoing support as carers’ circumstances change. We welcome the Minister’s review of section 64 funding. We recommend that the Government takes a more strategic approach to Carers’ Centres in the UK with the objective of there being a national network of such Centres, and that it provides adequate core funding to give them financial stability.
3 Carers’ income and benefits

Impact of caring on earnings income

101. Caring has a considerable impact on carers’ income. A Carers UK survey of 3000 carers found that 72% were worse off since becoming a carer. Carers UK stressed that despite improvements in several areas of policy aimed at improving carers’ incomes and helping them to combine caring with paid work, too many carers are struggling financially.80

102. One in five carers gives up work to care and Carers UK research has found that carers had lost out on an average of £11,000 each year as a result of giving up work, reducing their hours or taking a more junior position.81 The National Family Care Network stressed that economic losses are also incurred by carers as a result of the loss of pension contributions during working age and as a result of the cost of living with a disability.82

103. Carers UK believe that an additional factor is carers’ inability to move themselves out of poverty without significant additional support, and therefore the potential for this poverty to be longstanding.83 Ms Pearlman of Citizens Advice Bureau agreed that this is what distinguishes carers from other groups living in poverty: “carers are in a unique position where they find it almost impossible often to earn their way out of debt or other money problems because of their caring responsibilities.”84

104. In its Carers Strategy, the Government highlighted figures which show that while carers are no more likely to be living in poverty than the general population, they do tend to have lower incomes.85 ‘This finding is based on a comparison of carers (of all ages) with ‘non-carers’. However, detailed analysis of the DWP HBAI (Households Below Average Incomes) data on which this is based reveals the importance of age and intensity of caring as contributory factors in poverty amongst carers and highlights the need for more sophisticated analysis.86 Among those aged 25-34, carers (often caring for sick or disabled children) are more likely to be at risk of poverty than non-carers (19% compared with 13% before housing costs; 11% compared with 8% after housing costs). By contrast, among those aged 75 and over, those who provide care are less likely (14% compared with 24%...
before housing costs; 7% compared with 14% after housing costs) to be in poverty than non-carers of the same age (among whom many are sick or disabled themselves). 87

105. Those caring for more than 20 hours per week are more likely to be in poverty than the general population. Those caring for 35-50 hours per week are even more likely, with significant levels also faced by those caring for more than 50 hours who are not receiving Carer’s Allowance. While the evidence in Figure 7 suggests that Carer’s Allowance makes a modest contribution to reducing poverty among carers, further exploration of this data is needed to examine how far the differences shown are related to uneven take-up of this benefit; ineligibility for CA when the cared for person or persons are not recipients of relevant benefits themselves; and issues relating to age, which (as shown above) needs to be carefully taken into account to avoid drawing misleading conclusions from this data. 88

Figure 7: Relative poverty amongst general population and carers

![Relative poverty amongst general population and carers](image)

**Source:** Households Below Average Income series 2004/05

**Note:** relative poverty defined as income less than 60% of median household income

106. Many submissions stressed that no carers should be living in poverty, given that they are fulfilling an important social function and that the value of the care provided has been estimated at £87 billion per annum. 89 Carers UK was critical that the Government says that it values the work that carers do, yet it has not committed itself to a targeted anti-poverty strategy for carers. It suggests that an anti-poverty strategy for carers would help the Government meet its target of eliminating child poverty by 2020. 90

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87 The 2001 Census showed that among those aged 75-84 who were NOT carers, 25% of men and 27% of women were in poor health, and that 55% of men and 60% of women had a limiting long-term illness (Buckner and Yeandle, 2005 *Older Carers in the UK London: Carers UK*). Excluding those with very demanding caring roles, carers in this age group were less likely to be in poor health, and less likely to have a limiting long-term illness than those in the non-carer group.

88 Households Below Average Income series 2004/05 as cited in Ev 143

89 Ev 65; Ev 72; Ev 111; Ev 133; Ev 146; Ev 152 quoting findings from L Buckner and S Yeandle, *Valuing Carers: calculating the value of unpaid care*, Carers UK, 2007.

90 Ev 143
Cost of disability and caring

107. DWP acknowledges that there is not enough research evidence on the extra costs incurred by caring. In particular, the Department suggests, it is not easy to distinguish between the costs of caring and the costs of disability. The Department states that it continues to review available evidence on whether there are separate extra costs for caring, what they are and what their impact is.91

108. Ms Redmond of Carers UK argued that the distinction between the costs of disability and caring “is a bit of an artificial distinction. I understand why it happens, because we have a benefit system that is about individuals, and so you have a disabled person and you have a carer. That is actually not how people live. […] carers will say to us ‘The cost to my family is enormous, the washing bill, the heating on constantly, special food.’ That is the cost of disability. We do not of course say to them ‘I’m afraid that is the cost of disability and therefore we shan’t help you,’ but they do not feel that there is enough recompense for all those additional costs.”92

109. This reflects what most organisations have told us. Examples of additional costs of caring include costs for heating, particularly when caring for a child or elderly person who is at home all day, washing clothes and bed clothes (a particular problem when caring for someone who is incontinent), special food which people with certain conditions need and transport and parking costs (many carers need to run a car, either to transport the person they care for or to travel to them). Many carers also pay for dressings and other medical equipment which is not provided by health services. Families often struggle to get adaptations to their homes and can end up paying for them themselves rather than waiting months for access to the Disabled Facilities Grant.93

110. DWP pointed out that in cases where the care component of Disability Living Allowance is paid, some funds may be used towards the costs incurred by carers.94 However, a Carers UK survey for the Real change not short change report showed 49% of respondents reported that the benefits the family received did not cover all the costs of disability.95

111. We recommended in our report The best start in life?, that Disability Living Allowance be reviewed to ensure it more closely reflects the additional cost of disability.96 DWP stated in its response to our report that the Government acknowledges that studies which have attempted to measure the extra costs associated with disability often conclude that DLA rates should be increased. It added: “However, that ignores the basis on which DLA is
founded; to provide a broad-brush contribution towards the generality of extra costs faced by disabled people.”

112. Ms Batten of the National Autistic Society noted that: “the costs to carers are twofold. There is that impact on income and the impact on spending to meet the additional and long-term costs of caring for someone [with autism]. For carers for people with autism those expenses are so significant because people are not always able to access the service and support they need because of their disability, so the carers make up the shortfall. For example, 60% of adults say they are reliant on their families for financial support and 40% still live at home with their parents.”

113. She added: “Equally, people that live independently or in supported living, about 45% in a recent survey said to us that they rely on their families for most of their support. So not just some but most. That may be financial support, that can be going in and providing help with the washing, help managing bills, social contact, those sort of things, and obviously there is no flexibility in the system to recognize that role.”

114. The National Autistic Society provided us with a case study of the financial burden on the parents of two sons with autism aged 22 and 6 years old, illustrating that the costs of caring for a child do not stop when the child goes into residential care: “We lost all Richard’s allowances when he went into care, which we understand of course, but we still have all the outgoings and more and will do until we die. How will we cope if our younger son needs similar care? How will we be able to support 2 adult children when we are pensioners?”

115. We do not believe that families receive sufficient recognition and compensation for the additional costs of disability. Carers consistently face costs that are not covered by Disability Living Allowance or Attendance Allowance (and in some cases disabled or older people cannot claim DLA or AA). We call on the Department to review the level of DLA to ensure that it provides an appropriate contribution to the extra costs faced by disabled people. We share the belief that the current level of support for carers is too low and call on the Government to commission an independent review of the impact of caring on carers’ incomes and of the long-term costs of caring for an older person or someone with a disability. The additional costs incurred by carers need to be recognised in the Government’s review of benefits for carers.

Carers’ benefits

The history and design of Carer’s Allowance

116. Until April 2003, Carer’s Allowance was known as Invalid Care Allowance (ICA). ICA was introduced in November 1975, following the 1974 White Paper, Social Security

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98 Q 15

99 Q 16

100 Ev 162
Provision for Chronically Sick and Disabled People. It was – and still is – the principal social security benefit for individuals looking after chronically sick, disabled and older people in England, Scotland and Wales. It was intended to be an income replacement benefit, and reflected the fact that it was considered important that those who provided care should have an income of their own rather than be financially dependent on the person being cared for. An important element of the original intention was to protect carers’ pension entitlements, and the new benefit facilitated this protection through National Insurance credits. It was introduced with a range of other new non-contributory benefits, all of which were set at 60 per cent of contributory long-term benefit rates.

When first introduced, ICA was available to men and single women of working age who were no longer 'breadwinners' because they had given up paid employment to care for at least 35 hours per week for a disabled person in receipt of Attendance Allowance (a benefit not payable until the disability had lasted for six months). In addition, eligibility criteria were such that the care recipient had to be a close relative; however in 1981, availability was extended to individuals caring for distant kin and friends. Initially married and cohabiting women, as well as certain categories of unmarried women (not considered breadwinners) were excluded from claiming the benefit, even if they too had quit work to care; however ICA was extended to include married women in 1986.

As noted above, ICA was renamed Carer’s Allowance in 2003. Amendments to Section 70 of the Social Security Contributions and Benefits Act 1992, that came into effect on 28 October 2002, allowed carers aged 65 and over to claim the benefit, and extended entitlement for up to eight weeks following the death of the care recipient. Mr Vaux of the ADASS and LGA said “the original purpose of Carer’s Allowance was as an income replacement benefit, but for a very targeted group of individuals, basically spinster daughters caring for elderly parents […]. It was set at a very low level and has never really been pushed up from that level […]. As the scope of the Allowance has been increased, to include married women initially and then to include people over pensionable age, Carer’s Allowance has become almost a hybrid. On the one hand it is an earnings replacement benefit, on the other it becomes an additional costs compensation, and it fails on both scores because of that.”

The then Department of Social Security commissioned research into the targeting and effectiveness of ICA in the late 1980s. The study identified a number of issues that have also emerged in this inquiry: eligibility criteria were complex; the nature and level of care provided by claimants had adverse implications for their independence, social and employment activities; the majority of carers reported additional expenditure related to disability and caring; a substantial proportion of claimants had been affected by overlapping benefit regulations; very few carers had heard about ICA when they began to

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103 DHSS, Social Security Provision for Chronically Sick and Disabled People, HC 276, 1974, p. 19, para 60.
104 Q 82
provide high levels of care; and take up of the benefit appeared to have been very low prior to 1986 (reflecting the publicity about ICA’s extension to married women). On the basis of the research evidence, the author’s suggestions to improve the effectiveness and targeting of ICA included increasing its value, and permitting higher levels of earnings from part-time work in combination with receipt of ICA – issues that are still current and have been argued for powerfully by contributors to the present inquiry.

**Carer’s Allowance – amount**

120. About 470,000 carers are receiving Carer’s Allowance. To be eligible for Carer’s Allowance, a carer must provide at least 35 hours of (unpaid) care to a person receiving a qualifying disability benefit. The numbers of claimants by age are given in Figure 8 below.

**Figure 8: Carer’s Allowance – cases in payment caseload (thousands): Age of claimant by gender of claimant/ November 2007**

<table>
<thead>
<tr>
<th>Age of Claimant</th>
<th>Total Caseload (Thousands)</th>
<th>Female Caseload (Thousands)</th>
<th>Male Caseload (Thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
<td>1.25</td>
<td>0.77</td>
<td>0.48</td>
</tr>
<tr>
<td>18-24</td>
<td>18.47</td>
<td>12.90</td>
<td>5.58</td>
</tr>
<tr>
<td>25-29</td>
<td>27.21</td>
<td>22.37</td>
<td>4.84</td>
</tr>
<tr>
<td>30-34</td>
<td>42.71</td>
<td>35.93</td>
<td>6.78</td>
</tr>
<tr>
<td>35-39</td>
<td>65.90</td>
<td>54.59</td>
<td>11.31</td>
</tr>
<tr>
<td>40-44</td>
<td>72.53</td>
<td>57.64</td>
<td>14.90</td>
</tr>
<tr>
<td>45-49</td>
<td>65.71</td>
<td>49.67</td>
<td>16.04</td>
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<td>50-54</td>
<td>60.29</td>
<td>43.51</td>
<td>16.78</td>
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<td>55-59</td>
<td>67.24</td>
<td>47.61</td>
<td>19.63</td>
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<tr>
<td>60-64</td>
<td>36.49</td>
<td>14.04</td>
<td>22.45</td>
</tr>
<tr>
<td>65 and over</td>
<td>14.60</td>
<td>11.82</td>
<td>2.78</td>
</tr>
<tr>
<td>Total</td>
<td>472.42</td>
<td>350.83</td>
<td>121.58</td>
</tr>
</tbody>
</table>

Definitions and Conventions: Caseload figures are rounded to the nearest ten; some additional disclosure control has also been applied. Average amounts are shown as pounds per week and rounded to the nearest penny. Total may not sum due to rounding.

Note: Totals show the number of people in receipt of an allowance, and excludes people with entitlement where the payment had been suspended.

**Source: DWP Information Directorate: Work and Pensions Longitudinal Study**

121. Carers UK stated that “carers are insulted by the low level of Carer’s Allowance”. At £50.55 (from 7th April 2008; previously £48.65) it is the lowest of all income replacement benefits. Ms Batten of the National Autistic Society said: “Just to demonstrate how inadequate Carer’s Allowance is, even if you did the minimum caring hours of 35 hours a week, that is equivalent to £1.44 an hour compared to a minimum wage of £5.52, which
really demonstrates how we value that role. So the rate is inadequate, it sends a message to carers about how we value their role.”

122. Most submissions argued that the purpose of Carer’s Allowance is unclear as it does not provide an income sufficient to live on or prevent poverty (the poorest carers have to claim Income Support with a carer premium for an income replacement benefit), but neither is it a benefit paid in recognition of the role of carers or the costs incurred as it is not paid to all who fulfil a caring role (we address eligibility in the following sections).

Ms Redmond of Carers UK said “It is something that is trapped back in the Seventies as if it is a bit of pin money or something, but it is not a proper income replacement benefit. If we are talking about a flat rate income replacement benefit, it has to be of a decent level that replaces income.”

123. The National Family Care Network echoed the argument that the current low level of the Allowance and the limited permitted earnings are both unfair to carers in terms of their day-to-day responsibilities and too low to lift families out of poverty. The Office of the former Mayor of London pointed out that the local authorities in London with the highest proportions of the population providing intensive unpaid care (20 hours or more per week) are Barking and Dagenham, Newham and Tower Hamlets and are also those with the lowest household incomes. He concluded that the level for Carer’s Allowance is set too low to lift families out of poverty.

124. The Government stated in its 2008 Carers Strategy that “Carers will be supported so that they are not forced into financial hardship by their caring role.” However, it makes no short-term commitment to reform benefits for carers. It identified the long term priority (from 2011 onwards) as:

“Reviewing the structure of the benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system.”

125. We believe that Carer’s Allowance is outdated. We welcome the Government’s review of the benefits available to carers and recommend that carers’ benefits should be radically overhauled at the earliest opportunity to recognise the contribution carers make and to be more flexible to reflect carers’ different circumstances. We make a number of recommendations in this report about how the benefits could be reformed.

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107 Q 20
108 Ev 65; Ev 73; Ev 163; Ev 158; Ev 152; Ev 101; Ev 128
109 Q17
110 Ev 117
111 Ev 92
Carer’s Allowance – underlying entitlements

126. Entitlement to Carer’s Allowance is dependent on the person cared for receiving the higher or middle rate of Disability Living Allowance (DLA) or Attendance Allowance (AA). The Citizens Advice Bureau (CAB) reports numerous instances of family finances being thrown into disarray when a DLA award to the person cared for is reduced to the lower rate (from a high or medium award), or withdrawn altogether.\textsuperscript{114}

127. CAB suggested that the current system of medical assessments and decision-making for DLA/AA is not working satisfactorily, either for clients or the DWP: “Many original decisions to refuse or withdraw benefits are incorrect, and the reconsideration process is not working effectively. Too many cases go to appeal and success rates are very high – 57 per cent of DLA decisions that go to appeal are overturned at oral hearings, rising to almost 70 per cent when clients are represented by advisers. People with mental health problems appear to be especially likely to suffer from low quality assessments.”\textsuperscript{115} However, the Minister for Disabled People, Anne McGuire, stressed that “it is probably around about two per cent of our total application load that goes to appeal, so the figures are not quite as horrific.”\textsuperscript{116}

128. The National Autistic Society (NAS) criticised the fact that many carers of people affected by autism will not be entitled to Carer’s Allowance, as the person they care for is not receiving the middle or higher rate care component of DLA. It argued that autism, and in particular Asperger’s syndrome, does not fit easily within the legislative framework for the components of DLA. As a consequence, many people caring for those on the autism spectrum find themselves excluded from Carer’s Allowance because the person they care for is deemed not to have the attention and supervision needs required for the relevant award of DLA - even though caring for children and adults with autism is often extremely demanding and challenging work.\textsuperscript{117}

129. Ms Pearlman of the NAS said “That is often a problem, where individually they do not quite meet the threshold for middle or higher rate care, but collectively the work is clearly more because you are caring for two or more moderately disabled persons.”\textsuperscript{118}

130. In Australia, to be eligible for Carer Payment (the income replacement component of the carer’s benefit) a claimant must be providing care in the home of the person or persons being cared for and also providing one of the following levels of care:

- full-time care to an adult who has a disability or medical condition which is long term and severe and has a minimum level of care needs assessed by the Adult Disability Assessment Tool;

\textsuperscript{114} Ev 75  
\textsuperscript{115} Ev 75  
\textsuperscript{116} Q 171  
\textsuperscript{117} Ev 158  
\textsuperscript{118} Q 91
• care for a person whose care requirements are less severe but who has a dependent child that needs care, so their combined care needs are equivalent to the care needs of a person with a severe disability or medical condition;

• full-time care permanently or for at least six months to a child under 16 with a profound disability;

• full-time care permanently or for an extended period to two or more children under 16 with a disability who, together, need a level of care that is at least equivalent to the level of care needed by a child with a profound disability.

131. These criteria take account of the caring demands on an individual who cares for more than one person, neither of whom would individually meet the threshold of care required for the carer to qualify for a carer benefit.

**Take-up of DLA**

132. The Chair of the Standing Commission on Carers, Philippa Russell, stressed that “It is a very daunting process to apply for the DLA or the Attendance Allowance or indeed to seek a higher level of the DLA […] Perhaps inevitably – perhaps not inevitably – the questions asked in an application form are extremely negative. Therefore, there needs to be proactive encouragement from a relevant professional or, very importantly, from a local voluntary organisation if the family know about it to complete the form for an entitlement and the process towards hopefully having a better life with less financial worry.”

133. Every Disabled Child Matters (EDCM) highlighted problems with take-up of DLA in the context of our inquiry into child poverty and social mobility, *The best start in life?*, as many families with disabled children are not aware they are eligible. We recommended that DWP take steps to improve the take-up of Disability Living Allowance amongst both disabled adults and the parents of disabled children.

134. In response to the report, the Government agreed with us that take-up of DLA is an important issue and reported that it will continue to build on the existing, targeted measures which seek to ensure that as many disabled people as possible receive the support to which they are entitled: “These proactive measures have already resulted in an increase of over 50 per cent in the numbers of people in receipt of DLA in the ten year period ending May 2007.” It added that “Information on benefits is also available from Citizens Advice Bureau and other advice agencies. DWP is also increasingly working with partners such as local authority social services and welfare rights organisations to increase the awareness of benefits.”

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119 Q60


One CA claim to one DLA/AA claim

135. The Association of Directors of Adult Services and the Local Government Association (ADASS and the LGA) call for a review of the rule that links one CA claim to one AA/DLA claim, arguing that there are circumstances where one carer is caring for two or more disabled people but can only receive one CA. Similarly, there are some severely disabled adults and children who require almost constant care and attention and receive it from two or more family members, yet only one person can claim CA for caring for them. The Minister for Disabled People, Anne McGuire, responded by saying “I recognise the criticism, […] but the Carer’s Allowance is legally, technically, and in all senses, an income replacement allowance. Therefore, the basic rules of our social security system […] are that you cannot pay more than one replacement allowance benefit at the [same] time.”

136. The National Autistic Society states that the rule is restrictive and leads to further financial hardship, as autism often affects more than one child within the family. The National Family Care Network claims that it is an anomaly that Carer’s Allowance is only paid on this ‘one per family basis’ when DLA is paid on an individual basis and a family with multiple disabled family members will receive it for each eligible individual. “A growing number of people are now caring for several generations of family members, and the Carer’s Allowance is totally inadequate in these situations.” Mr Vaux, representing the ADASS and LGA, added: “There is a sense that they feel abused by the system, that they are receiving at most £50 a week for caring for more than one disabled person. They do have a sense of unfairness regarding that.”

Qualifying periods

137. Attendance Allowance and the higher two rates of DLA (Care) both have a qualifying period for which care must be required - six months and three months respectively. Until those qualifying periods have elapsed, a carer cannot access Carer’s Allowance, and payment of CA only commences from the start date of the AA or DLA award, at best. This means some carers have had to do 3-6 months ‘unpaid’ caring at the start of their responsibilities, when CA is not payable.

138. Ms West, of Age Concern, said a carer’s “income drops very suddenly without the necessary time to plan and it will be six months before the person, their parent, can get Attendance Allowance, and then that links them into the Carer’s Allowance.” Ms Pearlman, of CAB, added: “For that period, whether it is three months or six months, they are effectively doing their work unrecognised and yet very often at the beginning of that caring relationship, that is where the greatest costs are immediately incurred.” CLIC Sargent, for example, reported that from the diagnosis of their child’s cancer to the first...
payment of benefit, the average family will spend more than £1,500 to provide the care and support that their child requires while undergoing treatment.129

De-linking carers’ and disability benefits: certification scheme for carers

139. ADASS and the LGA suggested there needs to be consideration of whether and how this link between the qualifying benefit and CA can be broken, for example, by verification from a social or health care professional that care is being provided.130 Ms Pearlman of CAB agreed that “we should give serious consideration to how that might work, because the vagaries of the benefits system are such that household income can be thrown into disarray if one part of that jigsaw is removed.”131

140. Mr Vaux, representing ADASS and LGA, pointed out that there is already a precedent for a certification scheme through healthcare professionals: “In the pensions reform that is coming up, the proposal is that the State Pension credit that would be created for carers would be based on an assessment by a healthcare or social work professional and that would be the validation of somebody receiving the credit for their national insurance contribution record. That is already part of the welfare reform package for national insurance contributions and that would seem to provide an alternative method of verification that somebody is a bona fide carer.”132

141. However, the Minister for Disabled People, Anne McGuire, said that she is “not sure what added value we would get with a certification process. I may be wrong in that, but at the moment I cannot see what else it would bring in terms of supporting carers.”133

142. The rule that links one CA claim to one AA/DLA claim provides no recognition for carers who look after more than one disabled person or carers who have to share the caring role for a severely disabled person. This could be reflected in our proposed reform of carers’ benefits which we make later in this chapter.

143. The eligibility rules for Carer’s Allowance also do not take into account those who care for more than one person with a disability, none of whom meets the criteria for CA, but who nevertheless face a very substantial demand for care. We call on the Department to examine the case for extending entitlement to Carer’s Allowance to those who care for more than one person, none of whom qualify them for Carer’s Allowance, but who, nonetheless, face a burden of care equivalent to a carer eligible for Carer’s Allowance.

144. Qualifying periods that apply for AA and DLA are also problematic for some carers. We believe that there is a case for introducing a fast-track procedure for Carer’s Allowance applicants in emergency circumstances, and we call on the Department to look at ways to introduce such a provision.

129 Ev 85
130 Ev 69
131 Q 87
132 Q84
133 Q 172
145. We have received evidence that supports a new accreditation scheme for the purpose of establishing eligibility for benefits for carers. However, because linking carers’ benefits to qualifying benefits for disabled people has the great advantage of simplicity, we are not convinced by the proposals for such a scheme. We recommend that DWP addresses the problems of lack of awareness of disability benefits by investing in a large-scale awareness raising campaign.

Carer’s Allowance – overlapping entitlements

146. The DWP’s view is that Carer’s Allowance is not a ‘carer’s wage’ or a ‘reward for caring’:

“Rather, it is one of a number of income-maintenance benefits, including State Pension, Incapacity Benefit, contribution-based Jobseeker’s Allowance, Widows and Bereavement Benefits and Maternity Allowance, for those unable to fully participate in the labour market. State Pension, for example, replaces income in retirement. Carer’s Allowance replaces income where the carer is retired or has given up the opportunity to engage in full-time work in order to care for a severely disabled person. In both cases the need is the same even though the person qualifies for two different benefits. Hence the overlapping benefit rule operates to prevent both benefits being paid in full at the same time.”

Carer’s Allowance and its overlapping benefits are shown in Annex C of this report.

147. Where a carer claims Carer’s Allowance in addition to one of these ‘overlapping’ benefits, the higher of the two benefits is paid. Effectively, the overlapping benefit is paid in full; if it is payable at a lower rate than Carer’s Allowance, a portion of the Carer’s Allowance is also paid to bring the total benefit payment up to the Carer’s Allowance rate, currently £50.55 p.w.

148. Where someone qualifies for Carer’s Allowance, whether or not an overlapping benefit is paid instead, a Carer Premium (£27.75) is included in the assessment of their income-related benefits, and an additional amount for caring (also £27.75) in the assessment of their Pension Credit.

Impact of overlapping entitlements on Carer’s Allowance

149. There is no age limit for claiming Carer’s Allowance but because it ‘overlaps’ with the State Pension it is not paid to a person who receives £50.55 or more State Pension. The numbers of customers who were awarded CA and were over State Pension age are:

- 2004/05: 71,737
- 2005/06: 67,313
- 2006/07: 66,384
150. Carerwatch and Age Concern, among others, state that carers who have previously been entitled to Carer’s Allowance and find that it is ‘removed’ when they reach State Pension age can experience distress and anger; this can happen after decades of caring for a sick or disabled relative has prevented them from making pension provisions that would ensure that they did not experience an impoverished old age.138 The National Family Care Network stressed that “People are often still providing regular and substantial care well into their 90s and are not able to ‘retire’.”139

151. People may receive additional payments within the income-related benefits system but only if they are entitled to Carer’s Allowance. For many older people this means going through the process of claiming Carer’s Allowance, even though it cannot be paid, in order to then apply for additional support through means-tested benefits. Mr Vaux, representing ADASS and LGA, said: “At the moment it is an illogical system where we are having to put people through a claiming process for a benefit that we know in advance they are going to be refused; I cannot think of any other part of the benefits system where you have to go through a completely pointless exercise to establish the fact that you are not entitled to a benefit but you have underlying entitlement to a benefit.”140 Neil Bateman added “not surprisingly, many carers and their advisers find this concept and the process involved totally perplexing. It is quite Kafkaesque.”141

152. Ms Pearlman of CAB said: “We know that staff in the Carer’s Allowance Unit, like our own organisations, spend an awful lot of time explaining the system to people.” Not only does this complexity have a very significant administrative cost, but also, as Mr Vaux stated: “You also lose people on the journey. […] we have to go back to them, say ‘Oh, you have been turned down? Good, now we can apply for Pension Credit because you get the Carer Premium’ or ‘Have you notified the council tax benefit section?’”142

153. The Minister for Disabled People, Anne McGuire, acknowledged the pattern: “I appreciate that when you say to somebody, ‘You are entitled to something but you’re not going to get it,’ it can cause some confusion. We are working to try to improve that message, particularly working with organisations that have front-facing involvement with individuals.”143

154. Age Concern has made proposals for the systems to be streamlined so that people could claim Pension Credit and Carer’s Allowance through one telephone call; or alternatively they have advocated changes to Pension Credit legislation to enable the carer addition to be paid to people fulfilling certain caring criteria. So far the DWP has not decided to take this forward. Furthermore, the DWP are piloting a scheme whereby the local Pension Service will complete applications for both Pension Credit and Carer’s

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138 Ev 128; Ev 111
139 Ev 116
140 Q 93
141 Ev 163
142 Q 95
143 Q 174
Allowance and provide decisions straightaway.144 Ms West of Age Concern said: “I think that is positive, we hope the pilot works and that it will be extended but we would also like to see all people who really need to claim benefits get that holistic service.”145

**Impact of the Carer’s Allowance on the person being cared for**

155. Another anomaly is that when a carer becomes eligible for Carer’s Allowance, the cared for person loses the Severe Disability Premium from their Pension Guarantee Credit.146 Carerwatch suggests that the removal of the Severe Disability Premium from the means-tested benefits of a cared for person can act as a deterrent to carers claiming Carer’s Allowance.147 It argued that the cared for person is effectively paying the carer via the DWP.

156. However, where the carer qualifies for Carer’s Allowance but it is not paid because of an overlapping benefit (such as State Pension), the person being cared for retains their entitlement to the extra amounts for severe disability. This is the case even if the carer qualifies for the Carer Premium in an income-related benefit, or for the additional amount for caring in Pension Credit.148

157. The overlapping entitlement rules are confusing and over-complicated and DWP therefore ‘loses people along the way’ in the process of claiming carers’ benefits. The system of having to apply for a benefit you know you are not going to get in order to be eligible for a benefit you are not yet claiming is counter-intuitive. The administrative costs to the Department of dealing with almost 64,000 Carer’s Allowance claimants above State Pension age must be substantial. We recommend that the Department urgently streamlines the application process for benefit entitlements for carers of State Pension age. Our recommendations below, on how best to reform Carer’s Allowance in the longer term, aim to address the complexities of overlapping entitlements. We believe that this should be an urgent priority for DWP’s Benefit Simplification Unit and any simplification of benefits for carers should be in line with our recommendations.

**Carer’s Allowance: incentives to work, study and volunteer**

**21 hour study rule**

158. Carer’s Allowance is withdrawn if a carer embarks on an educational course that entails more than 21 hours study per week. This rule has been much criticised by a number of organisations, as it creates a barrier to carers wishing to engage in education and training in order to update their skills with a view to entering or re-entering the labour market. A

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144 Ev 112
145 Q 76
146 Ev 65
147 Ev 128
148 Ev 170
number of submissions called for those on Carer’s Allowance to be exempt from this rule.  

159. Many carers report that their caring responsibilities necessitate training for a new form of employment. However, many vocational and academic courses only attract funding if the participant studies full time and within a particular timescale. This may be impossible for a carer.  

160. At present 16 and 17 year old carers can receive Carer’s Allowance, but only if they are not in education for 21 hours or more a week, forcing them to choose between caring and being educated. Ms Redmond of Carers UK said: “The 21-hours study rule really should go. It does not make any sense at all. Why we should penalise people for studying I have no idea at all.”  

161. Carerwatch added that many financially-assisted educational courses do not have Carer’s Allowance on their list of qualifying benefits for reduced fees, making engaging in education unaffordable. A student in receipt of Income Support, which is paid at a higher rate than Carer’s Allowance, will pay less than someone in receipt of Carer’s Allowance.  

162. The Minister for Disabled People, Anne McGuire, acknowledged that “We need to look at how we dismantle some of the barriers. If we want to encourage people into training and education, to build up skills, to move into the employment market, then we need to look at how some of the elements of our rules perhaps disadvantage people in that respect.”  

163. Carers currently face a stark choice between engaging in education and training without any financial support or living on benefits. Many carers would be able to undertake education or training in addition to providing in excess of 35 hours of care per week. We recommend that the Department evaluates the effect of lifting the 21 hour study rule for carers on Carer’s Allowance to enable carers to engage in education and training as a route into paid employment. We also recommend that the Department evaluates the effect of adding Carer’s Allowance to the list of qualifying benefits for reduced education and training fees.  

**Carer’s Allowance - earnings limit**  

164. Citizens Advice Bureau (CAB), the Office of the former Mayor of London and Carerwatch, amongst others, report that the earnings limit on Carer’s Allowance makes it almost impossible for carers to combine paid work with their caring responsibilities, because the earnings limit is set at too low a level. At present, the earnings limit is £95 a week (2007/08), and the National Minimum Wage (NMW) is set at £5.52 an hour, for

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149 Ev 61; Ev 68; Ev 101; Ev 119  
150 Ev 119 [National Family Care Network], p6, quoting Philippa Russell’s study of the implementation of the Carers (Equal Opportunities) Act 2004 on behalf of the Nuffield Foundation, 2007  
151 Q 20  
152 Ev 129  
153 Q 209  
154 Ev 74; Ev 92; Ev 129
workers aged 22 and over. If a worker earns anything above the earnings limit for CA it is removed in full. This means that a working carer, earning the NMW, can work only 17 hours a week before losing their Carer’s Allowance. For anyone who earns more than the NMW, the number of hours they can work declines dramatically.

165. USDAW argued that “The rule fails to reflect the needs of carers working in our industries, most notably retail, nor does it reflect the needs of employers operating in the fast moving, responsive and high turnover retail industry.” USDAW said that it has the support of a major national retailer in its campaign to change the earnings limit: “They are behind our campaign precisely because they want the working carers they employ to have the flexibility to earn extra money where possible, instead of being stuck in a benefits trap.”

166. Ms George of USDAW stressed that “The Benefits Agency is demanding weekly letters regarding their income if it comes up near the £95 a week limit, as they often do, and that is an extra burden for a personnel manager to have to write letters on people’s behalf to a Benefits Agency. It does trap carers in that either you work and get no recognition or you do very few hours and claim Carer’s Allowance.”

167. ADASS and the LGA suggest that CA should be ‘tapered’ away as income rises, not removed in full. It accepts that this may cause problems in the interplay with other means-tested benefits that the carer may be receiving, such as housing and council tax benefit (and possibly WTC), creating very high marginal ‘tax rates’ of 90 per cent or more. However, it believes that such a measure should be costed, modelled and considered. Ms Redmond of Carers UK agreed: “A taper would be much better so that people have much more flexibility.”

168. Ms Waters of BT added that employees would like to “be able to gradually build up their working hours so that they find that ‘sweet spot’ where they can adequately manage work and it gives gainful employment and a reasonable level of income, and they can manage their caring responsibilities. It is not the case for BT workers generally but for those who are on lower income, the £95 earnings […] cap really does not give carers that choice, and I think that is something that needs to be looked at perhaps in a slightly different perspective on the cliff edge.”

169. The Minister for Disabled People, Anne McGuire, commented however that “It is not just an issue of finance but there are knock-on costs if you increase the earnings’ limit. It is not a no-cost solution, because there are knock-on effects for other parts of the benefits system.”

155 Ev 166
154 Ev 166
157 Q 130
158 Ev 68
159 Q 20
160 Q 130
161 Q 181
170. CAB offered a different solution, suggesting that increasing the earnings limit would help many carers to combine paid work with their caring responsibilities, without undermining their family income.\textsuperscript{162} ADASS and the LGA added that increasing the earnings limit to £150 a week would actually add very little to the social security budget as it would only add a relatively small number of carers to the total number who are claiming CA (those currently earning between £95 and £150 a week). Those who currently limit their hours (and pay) to the present threshold would simply have the capacity to earn more, whilst retaining the same level of CA as at present.\textsuperscript{163} Mr Vaux, representing ADASS and LGA explained:

“\textit{The carers who are working would be able to work longer hours and earn more, it does not actually bring more people into Carer’s Allowance apart from that small group who are currently earning between £95 and £150. If a carer is currently getting £50 a week Carer’s Allowance and earning £94.99, if they can earn £149.99 it does not affect the amount of Carer’s Allowance that is in payment, so there is actually very little additional cost to increasing the earnings disregard apart from that group who are currently in that bracket.”}\textsuperscript{164}

171. We asked the Department for costings and the estimates are as follows:

\textbf{Figure 9: Cost of raising or abolishing the earnings limit}

<table>
<thead>
<tr>
<th></th>
<th>Raise the earnings limit to £150 pw\textsuperscript{165}</th>
<th>Abolishing the earnings limit\textsuperscript{166}</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>£12m</td>
<td>£80m</td>
</tr>
<tr>
<td>Year 2</td>
<td>£24m</td>
<td>£163m</td>
</tr>
<tr>
<td>Year 3</td>
<td>£36m</td>
<td>£248m</td>
</tr>
<tr>
<td>Year 4</td>
<td>£49m</td>
<td>£336m</td>
</tr>
<tr>
<td>Year 5</td>
<td>£62m</td>
<td>£427m</td>
</tr>
</tbody>
</table>

\textit{Source: DWP}

172. Currently the earnings limit also causes other problems, as the earnings limit goes up each year in April, but the NMW is uprated each October. In April, carers whose earnings are just below the limit become eligible for Carer’s Allowance but, when the NMW is uprated in October, they lose their Carer’s Allowance because they are then earning slightly more than the earnings limit.\textsuperscript{167} Ms Pearlman of CAB said “What it means really is that from April to October you can earn slightly more or you can do slightly more hours work, but then the minimum wage goes up and you are back where you started again. It is almost impossible to manage a budget on that sort of insecurity.”\textsuperscript{168}

\textsuperscript{162} Ev 74
\textsuperscript{163} Ev 68
\textsuperscript{164} Q 103
\textsuperscript{165} Ev 171
\textsuperscript{166} Ev 172
\textsuperscript{167} Ev 75
\textsuperscript{168} Q 100
173. DWP said that increases in NMW are implemented in October by the Department for Business, Enterprise and Regulatory Reform: “There are technical reasons for this, notably the time needed to undertake research into wage rates in the various industrial sectors, study the findings and submit the proposed increases in the NMW to the Treasury for approval. This means that October is the earliest practical date for implementation.”

174. Despite recent increases to the earnings limit, its level still represents a major barrier for carers to combine work and care, and/or progress in employment. We recommend that the Department urgently commissions and publishes a thorough analysis of the costs and benefits of increasing the earnings limit and introducing a taper.

175. The different timetable for Carer’s Allowance earnings limit uprating and the uprating of the National Minimum Wage is still a cause of great anxiety for claimants and causes problems for employers. We recommend that the Department finds ways of synchronising the increases in the level of the Carer’s Allowance earnings limit with increases in the National Minimum Wage.

**Carer’s allowance - earnings limit (means-tested benefits)**

176. Neil Bateman points out that while currently people can earn up to £95 per week net when receiving Carer’s Allowance, this earnings figure is effectively over-ridden by the much lower £20 earnings disregard for means-tested benefits if they are in receipt of a means-tested benefit to top up their Carer’s Allowance (as many carers are): “Not surprisingly, claimants also get confused about this.”

177. ADASS and LGA stressed that it is the poorest carers who claim Income Support and other means-tested benefits: “It is therefore ironic that they have the least ability to improve their position by taking paid work.” At present, carers on Income Support lose the benefit at the rate of £1 reduction in benefit for every £1 earned over £20. Mr Vaux said that “a pound for pound reduction above £20 a week is still a major disincentive for carers who are on Income Support – who are often the poorest carers obviously – to retain employment or to move back into employment.”

178. ADASS and LGA argued that there is a strong case for aligning the earnings disregard with that which applies to CA itself: “There also is a precedent for this - the new Employment and Support Allowance will have a common disregard for permitted earnings (currently set at £88.50 a week but rising in October) whether the claimant is getting ESA through their contribution record or a means-test.”

179. Neil Bateman suggested that the different earnings rules are not only a recipe for overpayments because people think the higher Carer’s Allowance limit applies to means tested benefits, but they are also a disincentive for carers who wish to work part-time: “I
believe this raises a wider issue about the way that earnings are treated for social security benefits and that there is an overwhelming case not only to increase the level of earnings disregards in means tested benefits to a realistic level but to have a single earnings rule and amount across the entire social security system. This would be a major simplification measure, reduce the scope for fraud and overpayment and also provide incentives for people to engage in the labour market.174

180. Different earnings rules for carers claiming Carer’s Allowance and means-tested benefits are confusing and increase the risk of overpayments. We believe that there is a case for a complete review of earnings rules across the range of benefits in the social security system to reduce the scope for fraud and overpayment, dramatically simplifying the benefit system and also provide incentives for people to engage in the labour market.

**Barriers to carers’ engagement, volunteering and employment**

181. We understand that, in addition, carers are deterred or prevented from becoming involved in volunteering because:

- The reimbursed costs of a replacement carer are treated partly or wholly as earnings (for Carer’s Allowance 50 per cent of the reimbursement over any disregard, for income support or housing benefit 100 per cent of the reimbursement over any disregard); and

- Travel costs between home and the place of involvement are treated as earnings if reimbursed.175

We have also heard that inconsistent advice from Jobcentre Plus advisers can deter carers from involvement in such activities.

182. The Minister for Disabled People, Anne McGuire, said that “There are certain costs that we take off before we impose an earnings limit. Certainly I am always prepared to look at whether or not we can adjust those costs to meet the needs of carers. This is an opportunity for us to go back and look at the costs that we can deduct before the earnings limit.”176

183. We have been very impressed by the voluntary engagement of carers in carers’ centres and organisations and in developing local carers’ strategies. We believe that it is important for carers to be supported in their voluntary work to help others and to remain in touch with people and organisations outside their caring role. We recommend that DWP take steps to remove obstacles for carers to engage in voluntary work, including ensuring that reimbursed travel costs and the costs of replacement care are not counted as income in calculation of Carer’s Allowance or means-tested benefits.

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174 Ev 164
175 Ev 58
176 Q 183
Passive benefit

184. In contrast to other income-replacement benefits (Jobseeker’s Allowance (JSA), Income Support, and the Employment and Support Allowance (ESA)), Carer’s Allowance is ‘passive’. CA does not provide a package of support to enable people to combine care with employment, and it does not support carers’ engagement with the labour market by encouraging take-up of skills training or employment support. Work-focused interviews are voluntary for those in receipt of CA. As the Government recognised in its Welfare Reform Green Paper, “periods of caring vary significantly, so raising the issue of work-related activity when caring starts may be inappropriate in many circumstances.”

185. Ms Pearlman of CAB said that “Describing Carer’s Allowance as a passive benefit always causes me worry because although you do not have to be looking for work to get Carer’s Allowance you do have to be caring for 35 hours a week or more.” Mr Burke of Counsel and Care argued that the system “at the moment is rather passive, and it needs to become a lot more proactive. There is quite a lot that Jobcentre Plus can do, […] all advisers, for example, being trained and having knowledge about issues that face carers who want to work. We could learn also from the role of the childcare partnership managers in developing perhaps carers partnership managers who understand at a strategic level the Jobcentre Plus area, the issues that carers face, the services that they need, and so on, to be able to return to work.”

186. Ms Redmond of Carers UK stressed that back to work support for carers “needs to be light touch because these are often people under an enormous amount of strain, who will not necessarily trust that the system has their best interests at heart. These people are battling day and night for basic things, like sorting out their incontinence pads, sorting out a day centre a day a week. They battle, battle, battle. So I think any compulsion would actually make it incredibly stressful for people.” Mr Vaux, representing ADASS and LGA, added that if compulsion on carers to seek employment “was done in isolation and if it was done on top of the existing benefits system it would be received very badly by many carers […]. If it was part of a broader reform of Carer’s Allowance and a system of recognition for carers who are working then there may be a place for it, but just sitting it on top of the existing Carer’s Allowance system would send out a very negative message to many carers.”

187. We recognise that although some carers are in receipt of income replacement benefits, they are not ‘unemployed’. We do not believe it would be in the interests of the carer or those they care for, to place the same compulsion on carers to seek employment as those on ESA. We recommend that carers who seek training or employment should be better supported to enter the labour market, but that there should be no conditionality about seeking employment for people with care-giving responsibilities in excess of 35 hours a week.

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177 Department for Work and Pensions, In work, better off: next steps to full employment, Cm 7130, July 2007, p48.
178 Q 107
179 Q 34
180 Q 34
181 Q 108
Replacing Carer’s Allowance

Proposal for a two-tiered benefit

188. Many witnesses have emphasised that Carer’s Allowance, as currently designed, is not fit for purpose, and we are aware that many carers were disappointed that this issue was not directly addressed in the Carers Strategy (2008). We have received evidence about the desirability of introducing two ‘tiers’ of support for carers, offering: (i) income replacement support for carers unable to work, or working only part-time; and (ii) compensation for the additional costs of caring for all carers in intensive caring roles (which would also provide some support in maintaining a ‘life of their own’). Examples include Incapacity Benefit and DLA and State Pension and Attendance Allowance.

189. The Australian Commonwealth Government operates a two-tier system of carer benefits (this is outlined in greater detail in Annex A). Carer Payment is an income-replacement benefit paid to carers, means-tested on all income and assets other than the family home. It is paid at the same rate as other income replacement benefits. The payment “ensures carers have an adequate level of income and maximises the opportunities available to carers to participate in their community”. The maximum single rate is $548.80 per fortnight (approximately £264); the couples rate is a maximum $456.80 per fortnight (approximately £220).

190. The Australian Carer Allowance is an income supplement available to people who provide daily care and attention at home to a person who has a disability or severe medical condition and is meant to cover the additional costs incurred through caring for that individual. Carer Allowance is not taxable or means tested. It is paid at the rate of $100.60 per fortnight (approximately £48). An individual can claim Carer’s Allowance for each person that they care for (but can only receive one Carer Payment). Virtually all recipients of Carer Payment are entitled to Carer Allowance.

191. ADASS and LGA advocated a similar carers benefit scheme that has two distinct elements, which could be claimed jointly or independently of each other but on one form:

- “a basic Carer’s Allowance at around the ESA higher rate figure (the rate paid to those in the support group, who are not expected to be in employment). This is the earnings-replacement element for carers who are unable to work.

- “In addition, there would be a caring costs allowance which recognises the additional costs that carers incur. It also acts as a recognition to all carers that their contribution as carers is valued.”

192. Ms Batten of the National Autistic Society agreed that the income replacement element should be paid at the same rate as the ESA support group, because “the ESA support group are looking at people who are not expected to get back into the labour market in the short term.” Mr Vaux, representing ADASS and LGA, added that the

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182 Ev 70; Ev 83; Ev 146
183 Ev 70
184 Q 17
additional costs element would need to be set, as a minimum, at the level of the existing Carer Premium within means-tested benefits, to act as a recognition that the work of carers is valued and to provide some form of monetary compensation for the additional costs of caring.\(^{185}\)

193. The Minister for Disabled People, Anne McGuire, was cautious about the two-tiered proposal, stressing that “you cannot change Carer’s Allowance overnight. There are so many implications. Once you start to deal with one benefit, the knock-on effect both for individuals and for the benefit system as a whole can be quite profound.”\(^{186}\) She added: “We want to look at how it fits in with other working age benefits, for example. The social care reforms have been led by the Department of Health and there may be implications there depending on what comes out of that consultation.”\(^{187}\) While she was cautious about the two-tiered proposal,\(^{188}\) she emphasised that ‘tinkering’ with the system would not be appropriate:

“We want to get the right support for carers without doing some of the tinkering which will add complexity both to the benefits system and to the life of the individual carer. That is why we want to have time to look at how we do this in the context of some of the other changes that potentially will be coming in our working age benefits system.”\(^{189}\)

194. We asked DWP for an estimate of the cost of raising CA to the same level as Jobseeker’s Allowance (JSA), the level for the Employment and Support Allowance (ESA) (support group) and State Pension level. The Department’s estimates are as follows:

**Figure 10: Cost of raising Carer’s Allowance to the same level as state pension, ESA and JSA**

<table>
<thead>
<tr>
<th>Year</th>
<th>To equal Jobseekers’ Allowance at £60.50 pw(^{190})</th>
<th>To equal state pension at £90.70 pw(^{191})</th>
<th>To equal Employment Support Allowance at £102.10 pw(^{192})</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>£149m</td>
<td>£573m</td>
<td>£730m</td>
</tr>
<tr>
<td>Year 2</td>
<td>£174m</td>
<td>£652m</td>
<td>£830m</td>
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<td>Year 3</td>
<td>£227m</td>
<td>£738m</td>
<td>£935m</td>
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<tr>
<td>Year 4</td>
<td>£240m</td>
<td>£831m</td>
<td>£1050m</td>
</tr>
<tr>
<td>Year 5</td>
<td>£254m</td>
<td>£931m</td>
<td>£1175m</td>
</tr>
</tbody>
</table>

*Source: DWP*

195. The Institute for Public Policy Research (IPPR) suggested that Carer’s Allowance should become part of a single income-replacement benefit, replacing Jobseeker’s

\(^{185}\) Q 83  
\(^{186}\) Q 164  
\(^{187}\) Q 165  
\(^{188}\) Q 166  
\(^{189}\) Q 181  
\(^{190}\) Ev 171  
\(^{191}\) Ev 171  
\(^{192}\) Ev 187
Allowance, Income Support and Employment and Support Allowance as well as CA. This single income-replacement benefit would be available to people out of work for whatever reason. Conditionality would be personalised, based on discussions with a Personal Adviser. Counsel and Care have supported this proposal.

196. IPPR argued that there are two key benefits to this proposal:

“The benefit would be active and personalised. Income-replacement and employment support for carers would be on a par with those for other groups out of paid employment for any other reason. Conditions around work-related activity would be personalised in relation to the intensity of caring; with caring across the life-course clearly a legitimate reason to be out-of-work. Personal advisers would have discretion, in dialogue with the carer, to broker employment and training services for the carer, and carers could top-up their benefit with some level of work.

“Individuals caring would be able to access a simple, single, flat rate benefit, rather than navigate complex eligibility criteria. By not requiring people to self-identify as carers to access support, it would provide support over the spectrum of caring across the life-course and over caring transitions.”

197. While strongly supporting simplification of the benefits system (which many carers currently find hard to understand and difficult to negotiate), we believe carers’ contribution needs to be properly recognised in the benefits system, and reject the suggestion that Carer’s Allowance be replaced by a universal income replacement benefit to which carers would be entitled alongside other (non-carer) claimants.

198. We endorse the commitment in the 2008 Carers Strategy to review carers’ benefits as part of a wider process of welfare reform. We believe that this review should be guided by the principles that carers who are not able to work due to their caring responsibilities should be entitled to an income replacement benefit comparable to other income replacement benefits; and that an additional payment should recognise the additional costs of caring for one or more people.

199. We ask DWP to give urgent and detailed consideration to replacing Carer’s Allowance with a two-tiered benefit for carers, and cost our proposals as soon as possible. They would operate as follows:

Carer Support Allowance, to be paid at the same rate as Jobseekers’ Allowance, with the opportunity to earn a modest amount in a paid job (offering reasonable consistency with CA and in line with the permitted earnings rules). As this will be an income replacement benefit we do not think it should be payable in addition to other income replacement benefits; however we do not believe it is necessary, or desirable, to ‘means-test’ Carer Support Allowance, as carers entitled to receive it will need to be fully occupied by their caring role (for at least 35 hours per week).
Caring Costs Payment, available to all carers in intensive caring roles (35+ hours per week, consistent with existing Carer’s Allowance), but payable also to those over State Pension age, to compensate them for the additional costs of caring, and/or to enable them to buy in some help, goods or services to ease their caring situation. We recommend that CCP should be set at a level commensurate with other parallel payments in the UK social protection system (such as Child Benefit); this would make it likely that CCP could be set somewhere between £25 (£1,300 p.a.) and £50 per week (£2,600 p.a.).

200. The Green Paper, No one written off: reforming welfare to reward responsibility, was published on the day that we agreed our Report. We ask the Department to consider and take into account our report as part of its consultation on the Green Paper.

Concession cards

201. The Government reported that a number of local authorities run schemes that recognise the contribution carers make to society. Some offer discount schemes for transport and leisure facilities for carers, regardless of whether the carer is accompanied by the person they care for; this goes beyond the discounts available to carers when they are accompanying the person they support through schemes such as the disabled person’s railcard and concessionary bus fare schemes. It acknowledged that “these discounts can play a big part in allowing carers to take part in the sort of activities that others take for granted, and can help to address carers’ isolation.”

202. The Princess Royal Trust Salford Carers Centre, for example, is piloting a Carers Leisure Pass, which gives carers unlimited access to council swimming, gym and leisure facilities. Following a carer’s assessment, the assessment worker can request a pass electronically from Salford Leisure. Use of the pass is monitored and if it is not used for a continuous period of two months, the Carers Centre is informed and contacts the carer to check that they are well, or if they are having difficulty using the pass or if they no longer want it. The pass has improved the health of a wide range of carers, including working carers, as it is not limited to off-peak use.

203. In its Carers Strategy the Government stated that “in recognition that much good work is already happening, we will be working with local government to make sure that this good practice is spread more widely.”

204. In Australia, extensive provision is made at State and local authority level to provide concessionary rates for carers. Recipients of Carer Payment are entitled to a pensioner concession card from the Commonwealth Government, which entitles the holder to

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197 The Princess Royal Trust for Carers and Crossroads Caring for Carers, Putting people first, without putting carers second, 2008, p17.

reduced cost medicines. Additional concessions vary depending on the state and local authority but include:

- reductions in property and water rates and utility bills;
- a telephone allowance;
- reduced fares on public transport;
- reductions on motor vehicle registration; and
- free rail journeys within the state each year.

205. We welcome the Government’s commitment to work with local authorities to spread the idea of concession cards for carers more widely. We recommend that the Government follows Australia’s good example and proactively negotiates concession cards for carers for travel, parking, leisure and other activities with local authorities, business and transport operators to help carers cope with the financial burden of caring.

**Impact of caring responsibilities on pensions**

206. The impact of caring on employment and earnings has a knock on effect on the carer’s ability to build up state and private pensions. Many women, carers, disabled people and people with varied work patterns currently qualify for much less than the full basic State Pension because they have incomplete National Insurance records. This contributes to pensioner poverty.\[Ev 199\]

207. Gaps in employment records, decreased earnings due to caring and health problems caused by caring, which then become a barrier to work, all affect carers’ abilities to build up a pension. One in five carers give up work to care, and many more will reduce their hours – with part time working having a long-term impact on earning ability.\[Ev 200\]

208. There is also a gender aspect to pensioner poverty and the provision of care. Women in their 40s are the group identified as least likely to be contributing to a private pension. Caring responsibilities are an additional barrier to pension provision for many women (in addition to forgone earnings for many through childcare).\[Ev 201\]

209. Over 600 women responded to Age Concern’s survey on women and pensions. Around three out of ten said that caring for a disabled or older person had probably or definitely affected (or was affecting) their ability to build up a pension. One respondent stated that "Women are worse off when it comes to pensions. I have to stop work soon as mum is getting old and I have to look after her. I could not start working full time because I had to look after my children."\[Ev 202\]
State Pension

210. Carers under State Pension age who are entitled to Carer’s Allowance are awarded a National Insurance Class 1 credit each week, which protects their entitlement to State Pension. Carers under State Pension age can also accrue entitlement to a State Second Pension if they are entitled to Carer’s Allowance.

211. From 2010, a new carer’s credit will be introduced for people under State Pension age who are caring, for 20 hours or more a week, for one or more severely disabled person(s) receiving qualifying benefit. The new carer’s credit will mean that around 70,000 extra carers a year could be credited into the basic State Pension and around 180,000 people may accrue a State Second Pension.

212. The Government has agreed that the carer’s credit should be based on the carer’s own circumstances, rather than those of the person they care for. Entitlement should not be linked exclusively to disability benefits. A health or social care professional (GP, social worker, health visitor) should be able to certify that someone is a carer for 20 hours a week or more. This would ensure that all carers caring for 20 hours a week or more will benefit.

213. In a House of Commons debate on 18 April 2007 James Purnell, the then Pension Minister said:

“I am pleased to be able to announce that we will explore how health and social care professionals might be involved in certifying that someone is caring for at least 20 hours a week through the review of the 1999 National Carers Strategy, and that we will report back before the end of the year. We are committed to doing that; it is not a question of whether this can be done, but of how.”

214. The Minister for Disabled People, Anne McGuire, added that “We are looking at hopefully laying the regulations on the 20 hours later on this year. […] Our intention is to maximise the coverage in terms of individual carers accumulating the credits for their pension.”

215. We welcome recent reforms to the State Pension which will recognise carers’ contributions to society and begin to ensure that they do not suffer poverty in retirement. We particularly welcome the introduction of a new Carer’s Credit for people caring for 20 hours a week or more for someone who is severely disabled. This will ensure that carers caring for 20 hours or more per week are less likely to experience negative impacts on the value of their State Pension.

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203 These arrangements do not apply to married women who elected to pay reduced rate contributions
204 Ev 106
205 Ev 106
206 Ev 77
208 Q 189
Personal Accounts

216. Age Concern and Carers UK added that carers will still be at a disadvantage in terms of private provision and argued that more needs to be done to ensure that carers have the opportunities to build up additional private pensions. The new system of Personal Accounts is designed to meet the needs of people with interrupted working lives – for example by introducing flexibility so that those who have time out of the labour force can make additional contributions at a later date if they are able to.

217. The Minister for Disabled People, Anne McGuire, acknowledged that “Most carers move in and out of a job at different points in their lives”, but added that “the portability element of Personal Accounts will help that. There are other ways in which people can save for their future retirement but, as I say, we think that Personal Accounts are a significant improvement in the coverage that carers will have in terms of provision for their retirement because of the portability.”

218. Ms West of Age Concern suggested that “there ought to be a possibility of paying a lump sum in. So if you were caring for somebody who perhaps died, you may have a modest inheritance. That might be the time when you think you would like to be putting that additional modest lump sum into a Personal Account, so we have argued for, in addition to the annual limits, the possibility of a lump sum payment to run alongside. I think both the Government and also the Personal Accounts Delivery Authority have had concerns because of the additional costs of complexity.”

219. We recommended in March 2007 in our report on Personal Accounts that “if there is to be a cap it should incorporate a certain amount of flexibility, allowing people to make greater contributions at certain times, either because they have a lump sum to invest or because they want to make up for years when they did not contribute.”

220. In its response to our report the Government acknowledged that “there will be some individuals in the Personal Accounts target market who will take breaks from paid employment to raise families or care for relatives, who might be restrained by a lower limit. Additionally, some individuals may wish to pay one-off lump sum contributions into their pension. We will therefore ask the Personal Accounts Delivery Authority to explore the possibility of an additional lump sum contribution limit, to run alongside the annual limit. This additional limit could operate on a lifetime basis. The Delivery Authority will advise on the operational cost and feasibility of this option, and also on what an appropriate level might be. The Delivery Authority would need to be satisfied that the benefits of this added flexibility were not outweighed by the costs of designing and administering this addition.”

220 Ev 112; Ev 143
219 Q 191
218 Q 120
221. The Committee believes that Personal Accounts will benefit many carers with unstable working patterns and help them to save for retirement. However, we restate our earlier recommendation that the Government examines possibilities for further reform to the system to allow carers to pay in lump sums to save for their pension.
4 Support for caring

222. One of the major reasons that carers struggle to remain in work is because of a lack of affordable, reliable and flexible care services. Ms Redmond of Carers UK emphasised that “The majority of people actually pay for their own social care, purchase it themselves. There is no quality advice and information and guidance to help people pick the right care. The care market is under stimulated. There is not enough quality and quantity out there if you want to purchase it. If we really are going to help people who wish to work return to work, we have to get the care system sorted.”

223. Mr Burke of Counsel and Care added that “Without adequate care and support, many carers simply will not be able to work. They say that time and time again. […] I think we ought to do much more research into the cost of inadequate care and the opportunity costs for carers of inadequate care, and the impact not just on their caring but also what they are not able to do and what they are not able to contribute to the wider society, and the cost to society of that as well as the impact on their own health and well-being.”

224. Ms Waters of BT stressed that “We talk a lot about hard to reach people in this country, but I think we have lots of hard to reach services, and there needs to be a very hard look at that because it is a major barrier to people coming into and staying within the workforce.” She also said that “Anything would help but we need good quality local services, they need to be reliable, they need to reflect 21st century living, and they need to be consistently available.”

Access to information about social care and services for carers

225. Carers have contact with the social care system principally because of the support or services that the person they care for receives. However, eligible carers are also entitled to services in their own right. Evidence from a recent DWP study confirms the difficulties carers can face in obtaining up-to-date information about social services: “Carers claimed that social services did not volunteer information about available services or other entitlements, and that it was up to carers themselves to search this out for themselves. This could be quite daunting for carers who did not know who to ask, or who lacked confidence in dealing with people in positions of authority.”

226. Nearly half (48%) of people responding to a Counsel and Care survey felt that finding out any information about social care services was confusing. Older people found accessing information about social care difficult, with 45% of people aged 65 or over admitting they were unclear about how to inform themselves about where and how to get help. Carers

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214 Q 23
215 Q 24
216 Q 133
217 Q 134
UK argue that there should be more information and support available – and more transparency about what sort of help is available – including for families who are ‘self funders’, i.e. who are not eligible for state-funded care.\textsuperscript{220}

227. The Government’s 2008 Carers Strategy acknowledges that “At present, unfortunately, fragmented information is disseminated by a number of agencies, often leaving the carer wondering where to begin.”\textsuperscript{221} We discussed the Government’s commitment to roll-out a national helpline and website for carers in Chapter 2. The Minister for Carers, Ivan Lewis, added that a “very important element of this Putting People First reform programme is that the universal information advice is for everybody, irrespective of means.”\textsuperscript{222}

228. Quality information and advice is absolutely essential to enable carers to find the right social care support. For the national helpline and website to be successful, it needs to link up with local agencies to ensure carers and those they care for are well informed about local social care services.

\textbf{Access to social care support}

229. The Department of Health introduced a national set of eligibility criteria, known as Fair Access to Care Services (FACS), in 2003. The aim was to try to ensure a more consistent approach to eligibility and fairer access to care services across the country. The criteria are based on service users’ needs and associated risks to independence in order to identify who requires support from adult social care services. In setting local eligibility criteria, councils are required to take account of their resources, local expectations and local costs. There are four eligibility bands: critical, substantial, moderate and low. At present, local councils increasingly provide personal care only to those whose needs are assessed at the ‘substantial’ and ‘critical’ levels of risk, a trend that is expected to continue.\textsuperscript{223}

230. Despite FACS, a report by the Commission for Social Care Inspection (CSCI), \textit{The State of Social Care in England 2006-07}, found little consistency, either within and between councils, as to who was eligible for services. As eligibility thresholds are raised, fewer people receive supported home care. The report found that service users, and their carers, who did not qualify for assistance often struggled and experienced a poor quality of life.\textsuperscript{224} A review of the FACS eligibility is being undertaken by CSCI (Commission for Social Care Inspection), which is expected to report to the Minister for Carers in September 2008.

231. The Minister for Carers, Ivan Lewis said that “we all know the inconsistencies both within local authorities for access to services and between local authorities, which frequently do not make any sense.” He also noted the ‘cliff edge’ of £21,000 of assets for entitlement to services, beyond which individuals receive no help. He added: “Local


\textsuperscript{222} Q 157


authorities will tell you that this is all about resources and I think this is complete nonsense.”

232. Variations between local authorities with regard to carers’ assessments also cause a lot of distress and confusion for families who need to relocate. The Chair of the Standing Commission on Carers, Philippa Russell said “Multiple assessments are draining and expensive on all concerned. […] It is important because very often carers and the people they support do want or need to move and having to start again in trying to identify and realign all your services is enormously complex. We need to find a way of simplifying the system which is equitable and fair to the provider and commissioner as well as to the carer and the person they support.”

233. Ms Russell argued that “a lot more work needs to be done, not on bureaucratic assessment – there is no point investing in assessment to the point that you cannot then deliver and you have no resources, human or financial, left to deliver services – but we need to be more dynamic and creative. Really we are looking at person-centred planning. If we do develop these more proactive models of assessment, we can make a difference. A very important point here is that if you are a self-funder at present – and the majority of older people using social care and other services are self-funders – you are often largely excluded from the assessment system.”

234. It is helpful to have a national framework such as Fair Access to Care Services to set national standards. However, the current system is not achieving the fairness and consistency required. We welcome the review of eligibility criteria and recommend that the Government considers carefully what support it can offer to those who are not eligible for, or who choose to access support without using, social services.

235. We call on the Government to develop a system to enable social care assessments to be ‘carried over’, so that another local authority can make decisions based on (appropriately updated) information previously provided in the social care assessment. This would be less stressful for families, and would also reduce bureaucracy and the waste of resources.

236. Carer assessments have an important role to play in the Government’s strategy for carers as they are designed to assist carers in combining their caring responsibilities with their work, training, education and leisure needs. Practice in the delivery of carer assessments varies widely between local authorities. All carers, including those caring for individuals who do not qualify for local authority social care support, should be able to look to their local authority for support.

Social care funding

237. The Joseph Rowntree Foundation (JRF) reports that there are several areas where evidence on social care funding points to unmet needs. One concerns quality - for example, cost containment has resulted in poorly trained staff, low pay and high turnover. A second
funding shortfall concerns supply - for example, the fall in the number of 'low-level' domiciliary care packages. The third is the affordability of domiciliary packages, with evidence that some people on modest incomes are having in some cases to pay large amounts to get adequate care in their homes.228

238. Currently, most people in England have to pay for home help, including washing, dressing, cleaning and cooking, themselves. At £5.4 billion, privately funded care accounts for 57% of total care expenditure (£14.9 billion), but on current trends this share will grow to 66.5% by 2022; those who need care will be expected to pay more of the cost.229 State support is means-tested, which is especially disliked by older people who have saved hard for their retirement. The JRF argues that current means-testing arrangements effectively impoverish people before they can get state aid.230

239. In the Comprehensive Spending Review in October 2007, the Government committed to reviewing the way that it pays for long-term care and to producing a Green Paper. It said it was committed to a system “that shares the cost between the individual and the state and that provides both universal and progressive elements.”231 This suggests that Government will not abolish the current means-tested regime.

240. The Government’s announcement followed publication in March 2006 of an important report for the King’s Fund by Sir Derek Wanless into the future of social care funding. His report Securing good care for older people called for increases in funding to meet the demand for high quality care in the future. The report found that if the system remains as it is, costs would rise from £10.1bn in 2002 to £24bn by 2026 as a result of demographic change alone, without any improvement to the quality of services.232

241. The Wanless report recommended that the current means-tested funding system should be scrapped and replaced by a ‘partnership model’. Everyone in need would be entitled to an agreed level of free care, after which individuals’ contributions would be matched by the state up to a defined limit. People on low incomes would be eligible for benefits to fund their contributions.233

242. Currently state funding for social care is growing at a much slower rate than the demographic changes require. This means the Government is heading for a funding gap of an estimated £6bn, unless the system is changed. We look forward to the Government’s proposals in the forthcoming Green Paper for funding for a 21st century social care system that is both financially adequate and sustainable.

Provision of social care services

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229 Counsel and Care, A Charter for Change, Reforming care and support for older people, their families and carers, January 2008.
231 HM Treasury, 2007 Pre-Budget Report and Comprehensive Spending Review: Meeting the aspirations of the British people, p100.
232 Derek Wanless, Securing good care for older people, King’s Fund, March 2006.
233 Derek Wanless, Securing good care for older people, King’s Fund, March 2006.
243. The Commission for Social Care Inspection recently published estimates of the numbers of older people with care needs who do not receive services. Even taking into account the support provided by carers they believe there is a shortfall of 1.4 million hours of care to 450,000 people.\(^{234}\) Carers UK research, based on a survey of nearly 2000 carers, showed that about a third of carers in England (35%) and Scotland (30%), and well over a quarter of those in Wales (28%) said that they and the person they were supporting were not using any formal services.\(^{235}\)

244. This finding could not be attributed to very low levels of care need, as the carers questioned typically had 'heavy' caring responsibilities, (59% cared for 50 or more hours per week, and only 19% for less than 20 hours per week). Among those of working age who were caring for 20 or more hours per week, 33% of those caring for two years or longer, and 48% of those caring for less than two years, were not using any formal services. Nor is the finding explained by saying that these carers do not want to use services, since only a minority (20% in England, 12% in Wales, and 17% in Scotland) said they wanted no services. In fact almost two thirds of carers (60% in England, 62% in Wales, and 58% in Scotland) identified at least one service which they were not currently using but would like to have.\(^{236}\)

245. Carers UK research also found that between 40 and 50% of working carers in the study cited indicated that a lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support. The research had found that more than four in ten (42%) of those new to caring said that the person for whom they cared did not want care services.\(^{237}\) This could be for a variety of reasons, for example because the care offered was not perceived as suitable or appropriate. This highlights the need for flexible services tailored to the support that a family requires as a whole, and that are responsive to disabled and older people’s needs.

246. *Putting People First*, published in December 2007, sets out the Government’s new cross-departmental approach to the provision of care services. Services will be more personalised, with greater use of Direct Payments and Individual Budgets. Government announced an extra £520 million of ring-fenced funding to reform social care over the next three years through the introduction of Personal Care budgets.\(^{238}\)

247. Local authorities can offer Direct Payments to people who are eligible for community care services. Direct Payments have the potential to benefit carers by giving them and the people they care for the flexibility to purchase services that are tailored around both their needs rather than having to fit into a ‘one-size-fits-all’ programme of services offered by a local authority.

248. In its Carers Strategy the Government stated: “We recognise, however, that Direct Payments are not the solution for everyone. For that reason, *Putting People First* has


signalled that councils will move in the next three years to a position where everyone in receipt of social care funding will have a transparent, up-front allocation of the funds available for their care and support – a Personal Budget.”

It added that:

“We have also piloted individual budgets in 13 local authorities in 2006/07. Individual budgets bring together a number of income streams from different agencies to see whether providing greater flexibility delivers benefits to the recipients and enables them to look more holistically at their needs and the needs of their carers.

The evaluation of the pilots is due to be published later in 2008 with a specific evaluation being undertaken around individual budgets and carers.”

249. The Minister for Carers, Ivan Lewis said that “too often individuals find organisations functioning in silos, families and households are treated in silos with children’s services, adult services, rather than looking at people in a holistic way. [...] I personally think that personal budgets are arguably one of the most powerful ways to break down those silos, by bringing together different funding streams into one place and giving the people themselves maximum control and power. We now have a reform agenda that is very compelling. [...] carers and people who use services - at the end of three, four years, and hopefully beginning over the next year - will start to see and experience a very different response from the system than they have experienced in recent times.”

I have met very few people in my life who, given a choice, do not want to have maximum control over their own destiny.”

250. We welcome the Government’s move towards the provision of more flexible and responsive social care services through Direct Payments and Personalised Budgets. These new developments have the potential to maximise personal choice and to stimulate the social care market for more personalised, flexible service.

Support for balancing caring and employment

251. Following the Carers (Equal Opportunities) Act 2004 carers now have a right to be informed of their entitlement to a carers’ assessment, which must cover their work, training, education, and leisure needs. However, the extent to which local authorities are addressing and meeting carers’ needs is open to question. For example, CSCI’s report on The State of Social Care in England 2005-06 found that whilst assisting carers to continue or to return to work was regarded as a relatively high priority by councils, only 35 per cent said they were taking proactive steps to support carers in this area. Furthermore, only 4% had linked with employers in their area in their response to the 2004 Act.
252. The National Family Carers Network states that a number of local authorities are reluctant to implement the Carers (Equal Opportunities) Act: "We have examples of family carers who have been refused assistance with care to cover study or employment on the grounds that the local authority in question is only obliged to consider ‘respite’ or social care needs. The DCSF has clarified the position with children’s services, i.e. it has indicated that childcare to cover employment or training is permissible, subject to assessment of need, but there has been no such message with regard to adult services."245

253. The lack of flexible, appropriate, good quality support services is a major barrier to employment, career progression and regular participation in work for many carers. We are concerned about uneven implementation of the Carers (Equal Opportunities) Act 2004.

Employers’ support for caring

254. The Care Vouchers Campaign proposed a system, similar to the existing scheme of employer supported childcare, to provide a means for employers to help employees with care responsibilities to remain in work.246 Counsel and Care suggested that care vouchers would have benefits for carers and those they care for, employers and the wider society and economy, helping carers to stay in work and reducing care-related absences from work.247 Vouchers would be provided to employees either on the basis of salary sacrifice or as an additional payment.

255. Through the proposed scheme, employers would be able to provide a benefit for employees, namely ‘care-vouchers’ that could be used to purchase additional care and support services for the people they care for. These would be exempt from both National Insurance and PAYE (up to a limited proportion of an employee’s salary). At present, employees are able to claim up to £55 per week exempt from PAYE and National Insurance towards the cost of accredited childcare.

256. Research by the London School of Economics, commissioned by the Care Vouchers Campaign, has assessed the economic costs and benefits of the proposal. It predicted that a £37m investment from Government, through tax exemptions, would generate an extra £83m for care services. This would have a significant impact as it could pay for an extra 5.5 million hours of home care.248  

257. Under the care voucher scheme, employees would be able to choose the most appropriate service for them, and the person they supported, from a range of accredited and pre-approved providers. These services could include:

- domiciliary care services such as help with getting up, going to bed, dressing, toileting, personal hygiene, some household tasks, shopping, cooking and supervision of medication.

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245 Ev 118
246 Ev 97
247 Ev 66
• telecare and preventative technologies such as gas detectors, flood detectors, motion sensors and bogus caller alarms.
• residential care, either full time or as a short break.249

258. The Minister for Disabled People, Anne McGuire said she is “not particularly persuaded that they would best meet the needs of carers. For some carers obviously they would be very attractive. I think for other carers there would be a significant benefit to them in managing their care support. Interestingly, I do not think any of the proponents of it yet have costed exactly what it would be. I would suggest that it would be very expensive for the return that carers would get from it.”250 The Minister for Carers, Ivan Lewis added that “my only observation is in a sense if you consider the personal budget model and the potential, there becomes no need for vouchers essentially.”251

259. However, benefits received by employees through this scheme would be used for services that are currently not, or not fully, provided for by the state. Extra funding would be entirely additional to that which is currently funded by the state and would not be a substitute for it. Given the current tightening of criteria for accessing local authority funded social care services, the vast majority of carers provide the only means of support to the older or disabled people they care for, and many would benefit from such an arrangement, as the tax exemption would enable them to pay for more care services than they can currently purchase.

260. The National Family Care Network stressed that many families would prefer to receive Direct Payments of a sufficient level to cover support. However, it argues, Direct Payments are set at local level and there are wide variations in the level awarded. A voucher scheme offers the advantage of agreed national eligibility criteria and the Government can safely assume that the recipient will be repaying all or part of the cost through taxation and/or National insurance.252 Mr Burke of Counsel and Care stressed that “Whatever happens in the Green Paper debate, I am sure that individuals will still be expected to make a contribution towards the cost of the care, and therefore care vouchers will help them to do that in the future.”253

261. Ms Waters of BT stressed that “We know that if we can get money into that area, so if we can prove that there is clear demand and we can organise it sensibly, we can actually stimulate the local market [for care services]. […] One of the most important points about vouchers is it makes access for those people who are not able to get them affordable, and it should stimulate the market because we know that there is not sufficient supply in many cases for carers, particularly where the needs of the person that they are caring for are quite broad, particularly if they are the domiciliary services that just help the carer keep things ticking over and give them peace of mind while they access work.”254

249 Ev 98
250 Q 217
251 Q217
252 Ev 118
253 Q 39
254 Q 135
262. We believe that Care Vouchers may have the potential to leverage significant additional funds into care services and could be a good way of engaging employers’ support for carers. We recommend that the Government undertake a cost benefit analysis of the Care Vouchers Campaign’s proposals at the earliest opportunity. We suggest that DWP should take the lead in piloting such a scheme for its own employees who are carers.

**Family future planning for care**

263. The Australian Commonwealth Government also operates a number of schemes to assist families that wish to make private financial provision for the current or future accommodation and care of a family member with a severe disability. It offers a Family Relationships Services for Carers (FRSC) which provides family counselling and mediation services for families considering arrangements for the current or future care of a family member with severe disability. It has also developed an information package to help people to plan for the future wellbeing of a person who has high support needs. In addition, since September 2006, parents and immediate family members have been able to place up to $500,000 into a Special Disability Trust for the current or future care and accommodation of a person with severe disability, without being affected by means tests and gifting rules.255

264. We were impressed by the measures that the Australian Government has introduced to assist families planning for the future care and accommodation of a family member with a severe disability. We believe that a scheme along the lines of the Australian Special Disability Trust has the potential to help to leverage additional funds into the market for care services. We call on the Department to carry out a cost benefit analysis of the possibility of introducing such a scheme in the UK. The quality of the advice that is provided to families on how to access such a scheme would be crucial to its success.

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255 See visit notes in Annex A
5 Employment and training strategy for carers

Impact of caring on employment of carers

265. DWP acknowledged that carers who care for 20 hours or more per week suffer the greatest disadvantage in terms of employment. These carers have lower rates of employment than the general population, and this employment disadvantage gives rise to income disadvantage. A household where the carer is out of work has a 25% chance of being a low income household, as opposed to only a 7% chance for a household where the carer is in work.256

266. Those caring for 20 hours or more a week who are in employment are also more likely to be in lower paid work than those caring for less than 20 hours and the general population.257 Research commissioned by Carers UK confirmed that carers are often clustered in low skill, low paid jobs and, indeed, that many carers are working below their potential. Almost half of those working part-time said they were only in work of this type because of their caring responsibility.258

267. The IPPR argued that support must be available to those who want to combine work with care.259 A4E stated that it is difficult to quantify what proportion of carers would like to move into paid employment. “Anecdotal evidence from carers suggests that many are entirely unaware of any rights that they have to be supported into paid employment – through mechanisms such as the Carer’s Assessment or employment legislation. Some carers commented that they would like a job, however, many felt that employers were unlikely to offer them the flexible working hours that they would need to accommodate their carer role, or indeed make an initial job offer.”260

268. Carers UK argued that how carers are treated at work has a significant impact on whether they are able to juggle work and care and remain in employment. It reported that only two thirds of working carers (and only about a half of those working in the private sector) said their employer was supportive and ‘carer-friendly’.261

269. Carers UK has estimated that in order to care for the growing older population, the number of carers will need to increase by 3 million by 2037.262 This will have an impact on the labour force. Counsel and Care stressed that for smaller organisations this will be especially important, as they rely on fewer employees and need to manage all of their needs and expectations. It also stressed that access to equal levels of training, flexible working and

256 Ev 105
257 Ev 105
260 Ev 95
promotion prospects will be challenging for employers, and will require government support and funding. The economic case for maintaining carers in the workforce will become stronger as the numbers of carers grows.\textsuperscript{263}

270. We note in chapters 2 and 4 the importance of access to respite care in helping carers to return to or remain in the workforce. In many cases, physical adaptations to the cared for person’s home can make it easier for the carer to return to work or remain in work. The tardiness of many local authorities in responding to needs for adaptations can be a significant obstacle to many carers working.

**Impact of caring on former carers’ employability**

271. Currently there are barriers to carers accessing education and training. Among young adults (aged 16-24) caring reduces the likelihood of being a student and thus of participating in further or higher education, especially for young women. Just 10\% of young women with significant caring responsibilities (more than 50 hours per week) are in education, compared with 26\% of those who are not carers. Amongst those caring 20-49 hours per week the figure is 16\%, showing that there is a considerable impact even at a lower level of caring. Among young men, 17\% of those caring for 50 hours per week are in education, and 21\% of those caring 20-49 hours, compared with 27\% of non-carers.\textsuperscript{264}

272. Ms Waters of BT stressed that “There is a great deal that needs to be done to give young carers better access to education, better access to information about where they get services. The few that we have spoken to as part of our apprenticeship recruitment programme were – I think the only word I would use to describe them is “bewildered”. I think that is a real issue. They certainly had very few aspirations. They definitely need help to get access to training.”\textsuperscript{265} She added that “funding replacement care for people on approved training is an essential part of that journey taking a step back towards the labour market.”\textsuperscript{266}

273. The Minister for Disabled People, Anne McGuire, said “That is why the additional investment for carers that we are putting in through Jobcentre Plus, for replacement care so that an individual can undertake training, is vital for those folk.”\textsuperscript{267} This investment is part of the Government’s commitment in the Carers Strategy, *Carers at the heart of 21st century families and communities*, of “Up to £38 million to enable carers to be better able to combine paid employment with their caring role and re-enter the job market after their caring role has ended through encouraging flexible working opportunities and increased training provision.”\textsuperscript{268}

274. Age Concern suggested that the targets imposed on training providers for retention and achievement can be prejudicial to carers who may have to drop in and out of learning

\textsuperscript{263} Ev 66
\textsuperscript{264} Ev 147
\textsuperscript{265} Q 129
\textsuperscript{266} Q 124
\textsuperscript{267} Q 177
if the person cared for becomes unwell and may act as a disincentive for a provider to actively seek out carer students. Also, because many carers have been out of learning for many years, they often need high levels of support which can be an unwelcome burden on providers. Age Concern argued that more needs to be done to introduce greater flexibility of training courses, including home-based courses, so that they can be fitted around caring responsibilities.269

275. The Office of the former Mayor of London agreed that barriers include a lack of flexibly delivered training options to help carers upskill, flexibility in terms of provision and roll on and off provision during the calendar year and that there is a lack of flexibility in the variety of settings in which training is delivered; his office believed that these barriers are compounded for carers from specific groups, e.g. Black Asian Minority Ethnic carers, disabled carers etc.270 The Carers Strategy pledged to “Ensure that skills training is provided in a flexible manner so it is accessible for carers.”271

276. Ms Redmond of Carers UK pointed out that barriers to training for carers are even more complex: “Because carers are any of us here in this room, there is a whole range of different skills, and a lot of the focus for the Learning and Skills Councils is around quite low basic skills and up to NVQ Level 2. People might well have more than that but they have been out of work for 10 years or eight years.”272

277. Associate Professor Jane Mears of the University of Western Sydney presented her study on relationships between informal care and paid care to us during our visit to Australia. She had examined an organisation providing home care services and discovered that all the women who participated had extensive past experience as informal, unpaid carers for elderly and disabled relatives. Managers at the organisation reported that those who made good care workers tended to be those with experience as informal carers and they stressed the personal qualities of kindness, patience, tolerance and empathy, good communication skills and flexibility as skills that informal carers tended to develop. The conclusion of the study was that informal carers had a vast repertoire of skills, knowledge and experience that was readily transferable to paid care work. This sort of work would be attractive to some informal carers because of the options for part-time and flexible work. Carers returning to work would also feel confident about what they were doing. We note that for some carers and former carers, engaging in formal care work may provide a very effective route back into paid work.

278. There is much evidence that carers are currently disadvantaged in accessing education and training. More needs to be done to introduce greater flexibility of training courses, including home-based courses, which can be fitted around caring responsibilities.

279. We welcome the Government’s commitment to ensure that skills training is provided in a more flexible manner and to provide replacement care for people on

269 Ev 113
270 Ev 92
272 Q 30
approved training courses. We recommend that the Government ensures that this support is available for education and training courses at all levels, as carers have wide-ranging levels of training and re-skilling needs, and provision targeted only at the lowest qualified is often not appropriate for them. We believe there is a case for placing a duty on providers of training and education to ensure that they take all steps to provide for the needs of carers.

The Government’s employment strategy

280. The Government states in In work, better off: next steps to full employment that in order to achieve an 80% employment rate there will need to be a reduction of one million in the number of Incapacity Benefit claimants, 300,000 more lone parents in employment and one million more older people in work.273 Research by Carers UK showed that the number of carers is likely to be significant in all of these groups, either because statistically they fit into that age category, because they have some kind of disability or chronic illness resulting from caring that prevents them from working, or because they are a lone parent caring for a sick or disabled child.274

281. Carers UK said it was “disappointed that […] In work, better off: next steps to full employment mentions carers only relatively briefly, under the general heading of ‘helping parents into work, helping children out of poverty’, whereas they are to be found across a much wider section of the population than this implies.”275 Ms Waters of BT agreed: “We all know the demographics are that we are probably going to need in the next 15 to 20 years another 2 million workers just about at the same time that we are going to need another 3 million unpaid carers. We cannot have those carers being unable to access work, so the Government needs to help, I think, in a number of areas: provision of training, access to some kind of New Deal provision.”276

282. The Office of the former Mayor of London stated that “There has been no equivalent offer of the New Deal for carers despite their needs and it is unclear whether they would be eligible for the new Flexible New Deal. Carers cannot be put in a position of pressure to enter employment without security about the sustainability of the support arrangements for the people they care for.”277 Age Concern suggests that in order for the Flexible New Deal to be effective:

1. “Carers need to be able to access a wide range of jobs suitable to their needs and employers should value the benefits of employing carers over 50;

2. Services need to be provided that focus on overcoming the full range of barriers that older carers face; and

273 Department for Work and Pensions, In work, better off: next steps to full employment, Cm 7130, July 2007.
274 Ev 146
275 Ev 146
276 Q 125
277 Ev 93
3. Personal Advisers need to have the awareness, skills and confidence to provide personalised support suited to the needs of older carers.\textsuperscript{278}

283. DWP acknowledged that evaluation evidence shows that Jobcentre Plus advisers do not always provide effective support for people with caring responsibilities. Evidence from both the evaluation of Jobcentre Plus and Work Focused Interviews for Partners found that, although pockets of good practice do exist, many personal advisers relied on personal experience in dealing with carers, rather than any formal training.\textsuperscript{279}

284. The National Family Care Network stated that “we have examples of family carers who were actively discouraged from considering employment because of their caring responsibilities (but without information on local sources of care or possible financial assistance).”\textsuperscript{280} The National Autistic Society reported a similar experience: “We are aware of anecdotal evidence of parents being requested to attend a mandatory employment interview with Jobcentre Plus, yet once it is realised that they are a carer for a disabled child they are told by staff that there is very little possibility of them being able to find employment because of their caring responsibilities.”\textsuperscript{281}

285. Ms Waters of BT stressed that “carers need more specialist return to work support. That could be provided with Jobcentre Plus and it could be in partnership with some of the third sector organisations, who are trusted by carers and who understand the issues. Jobcentre Plus certainly needs to develop more expertise. It also, I believe, needs somebody in the Jobcentre Plus, at least on a regional level, who has some kind of strategic responsibility for understanding carers’ issues and understanding how they relate to the employment market and trying to make some sense and better engagement with employers to actually shape opportunities for those carers.”\textsuperscript{282}

286. The Minister for Disabled People, Anne McGuire acknowledged that “it is fair criticism that perhaps carers were not seen as a particular priority for Jobcentre Plus. […] We have recognised that gap in our provision. […] Part of it will be about improving the training for our Jobcentre Plus advisers and we are also committed to putting a carer expert into every Jobcentre Plus district in the same way as we have already a childcare expert in every Jobcentre Plus district.”\textsuperscript{283} She added “improving the training for our Jobcentre Plus advisers to allow them to ask those trigger questions which will encourage them to develop an individual package of support for a person who has carer responsibilities in the same way as it is almost taken for granted now that you would do for somebody who has childcare responsibilities.”\textsuperscript{284}

\textsuperscript{278} Ev 113
\textsuperscript{279} Ev 107
\textsuperscript{280} Ev 118
\textsuperscript{281} Ev 156
\textsuperscript{282} Q 127
\textsuperscript{283} Q 202
\textsuperscript{284} Q 205
287. The Government’s Carers Strategy included a commitment to “Improve the support offered to carers by Jobcentre Plus by:

- introducing care partnership managers in every Jobcentre Plus district;
- introducing specialist training for Jobcentre Plus advisers who work with carers;
- ensuring carers have access to appropriate employment programmes;
- the DWP and Jobcentre Plus investigating the feasibility of providing return to work support through third sector organisations.”

288. We have strong evidence that carers feel left out of the Government’s welfare reform agenda. It is also evident that Jobcentre Plus staff have not always provided effective support for people with caring responsibilities. Carers need more specialist return to work support. In order to deliver that, Jobcentre Plus needs better trained staff and specialist return to work programmes. We welcome the Government’s commitment to training for Jobcentre Plus staff and care partnership managers in every JCP district. We also welcome the commitment to investigate the feasibility of providing return to work support through third sector organisations. We recommend that the Government develops and launches pilots for employment support for carers as soon as possible.

**IB/ESA: impact on carers**

289. There are large numbers of carers claiming Incapacity Benefit (around 500,000 altogether). This means that they are not identified and recognised as carers and therefore are not likely to be receiving the support they need in their caring role.

290. We have already discussed the principle of compulsion to seek work on carers claiming Carer’s Allowance in chapter 3 of this report. Carers UK have similar concerns about the introduction of the Employment and Support Allowance (ESA), which will replace IB from October 2008. “We are concerned that carers may be forced to attend interviews and undertake work-related activity which is inappropriate given their caring role.”

291. According to official figures, around 40% of carers on IB care for over 20 hours per week. This means that around 216,000 carers currently provide substantial care and receive Incapacity Benefit. Data from the 2001 Census also reveals that carers are twice as likely to suffer ill-health if they are providing over 50 hours of care per week.

292. The ESA regulations specify that when advisers are creating an action plan for a carer, they must take their caring role into account. The Minister for Disabled People, Anne McGuire, emphasised that “we have embedded it in regulations, that there will be a facility

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286 Ev 142

287 Ev 147

288 Regulation 57
to defer the conditionality on work-focused interviews and carers, [...] and it will be in regulation that Jobcentre Plus advisers will have the facility to recognise at a particular point in an individual's life that their caring responsibilities will make it impossible for them to become involved in work-focused activity in whatever manifestation that needs to be.”

293. However, Carers UK are concerned that because of the limited knowledge and understanding of advisers, disabled carers may be forced or coerced into compulsory activity. Ms Batten of the National Autistic Society agreed that “compulsion is inappropriate if those support services (social care) are not there, and certainly we have anecdotal evidence of parents going into Jobcentre Plus and being just turned away and told there is no point in doing the work-focused interview because they recognise there is little chance they would be able to stay in employment.”

294. One-fifth of Incapacity Benefit claimants are carers. When the rules for the new Employment and Support Allowance come into force, Jobcentre Plus staff need to be fully trained to ask the right questions to ascertain whether a customer is a carer. Many carers will welcome tailored support to return to work. However, any approach needs to be light-touch and personalised. For some carers, their own health and/or heavy caring responsibilities will mean that work is not a possibility.

Flexible working

295. The Work and Families Act 2006 extended the right to request flexible working to employees who care for an adult. This builds on the introduction of the right to request flexible working for parents of children under the age of 6 (or 18 if the child is disabled). The CBI’s 2007 Employment Trends Survey (ETS) shows that following the extension to carers, acceptance rates for requests to work flexibly remain very high – 94% of requests from parents were accepted and 93% of requests from carers were accepted. However, uptake of flexible employment is still limited.

Lack of awareness

296. Ms George of USDAW stressed that “A lot of people do not know about the right. A lot of carers either do not see themselves as carers or they do not know about the right to request and the fact that it refers to them.” Research for the Recognising Fathers project carried out by the Foundation for People with Learning Disabilities found that over 70% of fathers did not know they were entitled to parental leave and over 55% did not know they had the right to request flexible working.
297. The Government’s Carers Strategy promised “an awareness-raising campaign for employers around the right to request flexible working.”\textsuperscript{295} The Minister for Disabled People, Anne McGuire added that “BERR and the Government’s Equality Office have taken that element of criticism on board and are looking at how they mount a significant publicity campaign highlighting the issue of flexible working and details of that roll-out are being finalised. I expect it to move into full play around about the autumn of this year.”\textsuperscript{296}

298. We welcome the extension of the right to request flexible working to include carers. The right to request has been working well so far; most requests have been accepted by employers. However, awareness of the right to request for carers is still low amongst both employees and employers. We welcome the Government’s plans for an awareness raising publicity campaign. We believe this campaign needs to be targeted both at employers, especially SMEs, and employees.

**Fear of rejection**

299. Age Concern stated that few people over 50 are willing to broach the option of flexible working with employers. One study found that only one of a sample of 38 interviewees had negotiated more flexible working patterns with their current employer. Most interviewees said they would not consider approaching their current employer about more flexible working or downshifting in the run up to retirement, although it was something they would like. The most common reason for this was that they did not think their request would be well received.\textsuperscript{297}

300. Ms George of USDAW suggested that employee rights needed strengthening, and noted that “some employment lawyers are touting standard lists of standard reasons which an employer can put in as a refusal for flexible working”.\textsuperscript{298} She argued that the fines that could be levied on employers for unfairly refusing flexible work, at a current maximum of ten weeks at £330 a week, did not provide a significant deterrent. She believed that “The lack of flexible working and the lack of teeth is trapping carers particularly, but also parents as well, on that very lowest level of skill and work.”\textsuperscript{299}

301. Danny Hardy said that “discrimination is rife in employment as carers are seen as ‘unreliable’ and ‘using care as an excuse for time off’. I have shown medical evidence to support my need for flexi time, and encourage carers to do the same. Even then, many employers seem reluctant to allow flexibility for fear of showing ‘favouritism’.”\textsuperscript{300}

302. There is evidence that a fear that a request for flexible working might not ‘go down well’ with the employer deters carers from making requests. We believe that there may be a case for strengthening employee rights in this respect. However, we recommend


\textsuperscript{296} Q 203

\textsuperscript{297} Ev 113 quoting study by McNair. Et al McNair, How different is the older labour market? Attitudes to work and retirement among older people in Britain?. What do Older Workers Want?, Social Policy and Society, 2006.

\textsuperscript{298} Q 141

\textsuperscript{299} Q 141

\textsuperscript{300} Ev 58
that the Government should evaluate first what impact an improved awareness raising campaign would make, before considering further legislative steps.

**Type of flexible working arrangements**

303. Larger companies are more likely to offer employees a range of flexible working arrangements than smaller firms: 88% of organisations with more than 5,000 employees offered at least three flexible working arrangements, compared to 40% of employers with fewer than 50 employees. Smaller firms tend to favour more traditional flexible working arrangements like part-time work (80%) and flexitime (35%). Relatively few smaller employers offered term-time working (5%), compressed hours (10%) and career breaks/sabbaticals (14%) – perhaps because providing cover for absent staff is more difficult in smaller firms. But interestingly, small firms were more likely to accept requests for flexible working – 100% of requests were accepted by the smaller firms (1-49 employees) included in the CBI survey.301

304. The Chief Executive of the Equality and Human Rights Commission (EHRC), Nicola Brewer, stressed that “although there has been a very big increase in the number of part-time jobs, they tend to be in the lower paid and lower status area. That compounds the difficulty of getting back into the labour market. I would say that a focus on widening the approach to what flexible working means today would help carers back into the labour market.”302 Ms Redmond of Carers UK suggested that “we need some targeted advice and guidance to small to medium sized enterprises who instinctively feel that this is a bad thing but instinctively do flexible working.”303

305. Ms Waters of BT stated that “the problem with the medium-sized organisations is that […] they do not know all their employees and they do not have the kind of professional HR function to root out the business case, point out the benefits and help them create a policy that is consistent over a slightly larger number of people.”304 She called for professional help for SMEs to put these policies in place and believed that this support “could be provided through the private sector or it could be provided through, for example, government-based organisations, maybe Business Link. What is the role of the Federation of Small Businesses in this? I think rather than acting at a statutory level and applying something to everybody, when we know that two ends of the market are at least moving in the right direction, we need to get the knowledge to that middle group.”305

306. She noted that Employers for Carers had put together “a self-assessment tool, a very light-touch tool, for businesses so that they could chart where they were on these kinds of issues, and then it presented them with ideas about the next steps that they could take. It gave them role models and case studies to help them understand that. I think there is a key role for that organisation going forward perhaps to work in partnership with Government

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302 Q 128
303 Q 45
304 Q 143
305 Q 151
to reach those other organisations and to push up awareness amongst employees in a responsible way.”

307. The Government made a commitment in its Carers Strategy to “Produce a good practice guide for employers around supporting carers and integrating them into the workforce.”

308. There is a large disparity between flexible working arrangements being offered by large employers and SMEs. Although smaller employers are more likely to agree to requests, the flexible working arrangements offered in these firms are predominately part-time jobs. Government and business need to work together to address the problem that much part-time working is in lower paid, low-skilled jobs, and as such offers limited opportunities for carers unable to work full-time.

309. We welcome the Government’s commitment to produce good practice guides for employers. We recommend that Government, through Business Link, works with employer organisations and federations to spread good practice more widely.

Proposals to extend right to request flexible working

310. Many organisations argued that the right to request flexible working should be extended beyond parents and carers, as it would then be a mainstream option for all. If this is not done then the definition of carers who can request flexible working should be extended to include carers who are neither co-resident nor a close relative of the person receiving care. However, the CBI states that “employers cannot accept further extensions at this stage and it is important that flexible working arrangements are available to those who most need them in the first instance.” Its ETS shows that only half of employers provide the right to request for all their employees.

311. The Chief Executive of the Equality and Human Rights Commission, Nicola Brewer, argued “if you opened it to all, there would be two additional elements in that business case. One is you would get away from the potential […] for resentment from other groups in the workforce who were not currently eligible for it. The second thing, just speaking really practically, as a manager, […] if you have a whole range of people who are looking for different kinds of flexible working, it is, perhaps paradoxically, potentially easier to accommodate.”

312. However, Ms George stressed that USDAW “would like to see how the right to request is working for carers and then for the 4.5 million extra parents who are going to become entitled when the age limit is raised in April next year, just to make sure that it is working well for them before it would be extended across the whole workplace.” She noted
that some workplaces may require staff over extended hours (including 24 hour periods) during the day, but that workers with specific caring needs may find it difficult to work certain shifts (such as evenings) when day care and child care was not available. She wanted to ensure that “the people who absolutely have to be at home to fulfil their caring responsibilities at that time were able to get priority.”

313. The Government has made a commitment in its Carers Strategy to “Review the flexible working definition of a carer.”

314. However, debate is not restricted to the groups of employees who are entitled to a right to request. Currently, the right is only available for those who have worked for their employer for 6 months. Carers UK believe extending the right to ‘day one’ of employment would help carers seeking to return to work. EDCM suggested a right to request at interview stage. EDCM referred to Contact a Family’s 2004 research ‘Flexible Enough?’ that asked 202 respondents whether they had ever not applied for or turned down a job offer because the employer was not able to offer flexible working. 72 (38%) had turned down a job or not applied because there was no flexible working.

315. Ms Waters of BT agreed that “a day one right to request is essential, otherwise you are completing an absolute barrier to work. How can you say to a carer, ‘Yes, we want you to work but you will have to find some way of balancing your caring responsibilities for six months before you can even ask,’ I think there is a danger that we are also asking those potential employees to almost hide something from their employer.” She called for the right to request flexible working to be “a ‘day one right’, where you can build a trusting relationship from day one, you can have the discussion at the interview.”

316. The Chief Executive of the Equality and Human Rights Commission, Nicola Brewer, disagreed: “the argument for the 26 weeks is a period to build up trust. […] I just worry that if you extended the right to request from day one, that might actually disadvantage some carers trying to get back into the workplace. I would like to see how the 2007 extension has worked so far.” She added that “while the right to request is limited to specific groups, that in a sense singles them out […] I think actually you should go much further with the right to request and open it to all employees. Then I would be in the same position [Ms Waters] on day one.”

317. We welcome the Government’s commitment to review the definition of carer for the purpose of the right to request. We have heard differing views on the benefits of extending the right to request flexible working to all workers. We do not, at this stage, call for an extension in the right to request flexible working to all employees, but believe this option should be kept under review.
318. We have also heard differing views on whether the right to request flexible working should be applicable from day one of employment, rather than after 26 weeks, as is the case now. Although we are not yet persuaded of the case for introducing the right from day one, we believe that the current 26-week rule can represent a real barrier for carers and should be reviewed.

**Jobcentre Plus support for flexible working**

319. Ms Waters of BT stressed that “the Jobcentre Plus system […] does not have a way of selecting jobs on whether they are flexible working jobs or not, which obviously makes it really difficult if you have sat down with a carer to identify the kind of roles that they could be matched to.”

320. The Minister for Disabled People, Anne McGuire, stated that “We are looking at how we give carers better access to information and how we also encourage employers to look at whether or not their job vacancies would be amenable to some sort of flexibility in terms of caring responsibilities. Our Jobcentre Plus advisers and those who liaise directly with employers are looking at flagging that up to employers that they might want to look at whether or not the person they are looking for to fill a vacancy could be a carer whose hours might need to be manipulated or adjusted to fit in with their caring responsibilities.” The Government’s Carers Strategy also made a commitment to “improving information about flexible job vacancies in Jobcentre Plus job banks.”

321. We recommended in our report *The best start in life?* that “Jobcentre Plus needs to do more to negotiate flexible working arrangements on behalf of clients who may not have the confidence to do so themselves. Flexible working should play a key role in programmes like the Local Employment Partnerships. DWP should be doing far more than exploring what employers have on offer, they need to be challenging them to offer more.”

322. In its response to the Committee’s report, DWP argued that “Jobcentre Plus is committed to ensuring that those disadvantaged in the labour market have access to as wide a range, type and variety of job as possible. Account Managers negotiate Local Employment Partnership (LEP) agreements with employers and agree the widest possible range of measures to support their recruitment needs, with the aim of ensuring that a broad range of opportunities, including flexible working arrangements, are available to potential recruits. […] At a local level, Jobcentre Plus Labour Market and Recruitment Advisers currently provide employers with advice on the best way to fill their vacancy, which may include asking them to consider if there are any opportunities for flexible working, part-time or job sharing.”

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318 Q 126
319 Q 202
323. As we have recommended in previous reports, Jobcentre Plus needs to be more proactive in negotiating flexible working arrangements on behalf of its clients. We welcome the Government’s commitment to providing information about flexible working in Jobcentre Plus job banks. We also welcome the Minister for Disabled People’s statement that Jobcentre Plus staff will encourage employers to accommodate flexibility in terms of caring responsibilities.

**Jobcentre Plus support for self-employment**

324. Under the New Deal for Self Employment (NDSE), Jobcentre Plus provide support for customers wishing to become self-employed. The provision is targeted at the long-term unemployed and other customers facing disadvantage in the open labour market.

325. The provision is delivered in three stages, the third of which is 'test trading'. The Government changed the rules in April 2006 to ensure that test trading is treated as training which means that IB customers can remain on IB whilst participating in test trading instead of having to leave the benefit and take up a training allowance. This also removed any ambiguity about the earnings and hours limits that might otherwise apply to people on IB.

326. In provider-led Pathways to Work areas, it is open to providers to fund training for self-employment if this is seen as appropriate for the individual concerned.

327. **Self-employment is a potential route for carers into employment who otherwise face barriers to the open labour market. We recommend Jobcentre Plus helps carers to pursue this opportunity.**

**Time off and Statutory Care Pay**

328. Currently, carers have the right to a period of leave to care for a dependent, which can be used in an emergency. There is no limit on this leave but the guidance suggests that one or two days is usually appropriate and that the leave is not intended to actually provide care, but to make alternative arrangements for care. Carers UK believes that in the case of a parent who has just had a stroke, or a child who has had a serious accident, for example, this is not appropriate and that carers should have stronger rights to a period of time off, with a right to return to their job. Ideally, this leave would be paid (by Government reimbursing employers) so that all carers feel able to take it up if they need it.323 Ms Waters of BT argued that “Emergency time off for dependants is not very well understood but offers a good degree of support, certainly to help people in the initial stages.”324 325 Ms Redmond of Carers UK stressed that “The proposal around statutory time off to deal
with care issues is something that we would like to see. It is the whole issue about how, when carers are not in work, they are completely off the radar. We need to keep people in touch with the world of work. It needs to be much more fluid.”

326. CLIC Sargent proposed planned, paid leave for employees through a scheme where days are “matched” by the employee’s annual leave entitlement; paid leave is agreed in advance and lasts for a defined period and it is matched by employees using an equal number of days annual leave to carry out their caring role. It also proposed a Carers’ Career Break Scheme, where an employee would resign from the organisation at the start of an unpaid career break, lasting from three months to two years. Where the career break is for one year or less, the employee’s post is held open. For longer career breaks, the employer commits to keeping the carer employed and should make every effort to find a suitable post at the level held prior to the start of the career break.

327. ADASS and LGA argued that there is a strong case for the introduction of Statutory Carers Pay (SCP), to go alongside Statutory Sick Pay (SSP) and Statutory Maternity Pay (SMP). It recommended a SCP that would be paid, at the rate of SSP and SMP (£117.18 pw from April 2008), for a given number of weeks in any one year. This could be linked to statutory time off for caring. It would enable some carers to provide care at the start of the disabled persons’ illness (before AA/DLA commence) without having to give up their job. It would enable other carers to retain their employment and better combine their caring and employment roles, to the benefit of both.

328. Ms George of USDAW said “we would love to see some paid leave for carers but I do not think it is going to be practical to come from employers. There would have to be at the very least be some sort of matched funding from Government in order to do that.”

329. She added that such a system would need to be more flexible for carers than the existing provisions for parental leave.

330. However, the Minister for Disabled People, Anne McGuire argued that “it would be incredibly expensive and perhaps it would create significant additional burdens for employers. I think actually that I would prefer us to focus on the issues such as flexibility in terms of the job market because, as I say, I think we have indicated in our Strategy that where employers are willing to embrace flexibility for their employees in care positions, there is actually more benefit to both the employer and the employee.”

331. At present, carers in employment are at greater risk of disciplinary procedures because of higher absence levels. We believe that options already available, such as emergency time off, should be better used by employers and employees. To this end, the Government should improve information and advice on emergency time off. We recommend a review of the regulations for emergency time-off to allow employers and employees more flexibility to prevent carers dropping out of employment because of

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326 Q 51
327 Ev B4
328 Ev 70
329 Q 149
330 Q 215
caring responsibilities. We recommend that Government in general and DWP in particular should act as a model employer with regard to its employment of all those with caring responsibilities.

Financial incentives

*Working Tax Credit for carers (at 16 hours)*

335. Working Tax Credit (WTC) contains a number of elements within the calculation that reflect the increased costs and reduced earnings capacity that certain groups of workers have, such as those with child care responsibilities, disability or severe disability. These elements have the effect of increasing the amount of WTC payable and bring some people within the range of WTC who would otherwise miss out. This encourages participation in the labour market.

336. ADASS and LGA pointed out that carers are excluded from this additional support. It accepts that there may be definitional and operational obstacles to this (CA is based on a personal test of income whilst WTC is based on the household) but it believes that households that contain a person in receipt of CA should receive an additional WTC element.\[Ev 69\]

337. WTC allows two groups of people to claim when working 16 hours per week rather than 30 – parents and disabled workers. These rules recognise that these groups are trying to combine work with other responsibilities (children) or that their circumstances are such that they may find it harder to work 30 hours per week or are at a disadvantage in the workplace. Carers are another group who are regularly trying to combine work with other responsibilities and who may find it harder to work 30 hours a week. ADASS and LGA believed that carers should be able to claim WTC if working 16 hours per week, but for this proposal to work, the earnings limit for Carer’s Allowance will need to be significantly increased as discussed above.\[Ev 69\]

338. Carers UK agreed that carers feel it is unfair that lone parents and disabled people can access tax credits at 16 hours, whereas non-disabled people must work for 30 hours. “We believe that introducing a tax credit for carers would provide a significant incentive for carers to work, but would not considerably reduce the amount of care they provide. Most carers wish to continue caring, but feel that their lives could have better balance, which would bring long term benefits to them and their families. Sometimes only a small additional amount of support would be needed for carers to significantly increase the number of hours they work.”\[Ev 146\]

339. *Working Tax Credit (WTC)* allows two groups of people to claim when working 16 hours per week rather than 30 – parents and disabled workers. We agree with the evidence presented to us that carers are a group who try regularly to combine work with other responsibilities and face additional obstacles to work. We recommend that the

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\[Ev 69\]  
\[Ev 69\]  
\[Ev 146\]
Government costs the proposal to grant WTC for carers at 16 hours per week. For this proposal to work, the earnings limit for Carer’s Allowance will need to be significantly increased, as recommended above.

**Working Tax Credit and caring (child care costs)**

340. Help is available through the WTC scheme where a lone parent has childcare costs or where a couple have childcare costs, and both parents are working or one parent is working and the other is incapacitated. ADASS and LGA stated that this misses out a small but significant group of carers who have disabled children. “The need for respite for parents who are caring for disabled children is well-established; however, the cost of that care is not allowable for WTC purposes if one parent is a stay-at-home carer.”

341. In particular, where the parent is caring full-time for a disabled child, childcare provision for other siblings may be essential if there are frequent hospital appointments, medical interventions and so on. After school club provision may be used where the parent at home is unable to collect the children because they cannot get there with the disabled sibling, or if they have to take/collect the disabled child elsewhere. Other parents provide care for an older person; the costs they incur for child care, to enable them to fulfil their caring role, are also not allowable.

342. ADASS proposed that carers should be eligible for the childcare element of WTC where one member of a couple is in full-time remunerative work and the other is entitled to Carer’s Allowance (including claimants with underlying entitlement to Carer’s Allowance).

343. We recommend that the Government costs the proposals for childcare costs for carers to be eligible for the childcare element of WTC where one member of a family is entitled to Carer’s Allowance (including claimants with an underlying entitlement to Carer’s Allowance who are caring for a disabled child).

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334 Ev 68
335 Ev 69
6 Equality, recognition and discrimination

344. The gap in care provision between men and women is closing, but women remain more likely to provide personal and intensive care. Of the 4.3 million working age carers in GB, 1.8 million are men and 2.4 million are women, although women undertake a larger volume of caring than these numbers might suggest: women supply around 70 per cent of caring hours. For women there are associations between types of employment and caregiving. Women working in the public sector are more likely than other full-time workers to be carers, as are women with a history of working in a caring profession.336

345. The proportion of carers providing more intensive levels of care rises sharply from age 65. Furthermore, the number of hours spent providing care rises with age, with a higher percentage of older carers providing more intensive levels of care. Among the oldest carers, around 44,000 people aged 85 and over provide care, with around half of these (51 per cent) caring for 50 or more hours a week. The situation of older carers is compounded by the increased risk of financial hardship, as well as isolation and social exclusion among older people generally.337

Formal recognition of carers

346. A Carers UK survey of 3,000 carers in 2007 showed that better recognition was one of their top concerns. “Despite the fact that they fulfil a vital role in society, providing £87 billion worth of care, many carers feel that [they] have very little reward and are treated as unimportant by some professionals. Even worse, they are often treated as a nuisance by busy professionals.”338

347. A4E also reported from its carer cohort study that the substantial majority of carers questioned felt that their rights and needs as individuals were largely overshadowed by their responsibilities as a carer.339

348. We visited Adelaide, Australia, during the course of the inquiry and examined the effectiveness of the Carers Recognition Act 2005, passed by the South Australian State Parliament.340 The Act provides a statutory basis for the South Australian Carers Charter which sets out seven principles relating to the recognition of the role and rights of carers. These principles are that:

1. Carers have choices within their caring role.
2. Carers’ health and well-being are critical to the community.
3. Carers play a critical role in maintaining the fabric of society.
4. Service providers work in partnership with carers.
5. Carers in Aboriginal and Torres Strait Islander communities need specific consideration.

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336 Ev 108
337 Ev 108
338 Ev 148
339 Ev 94
340 See Annex A for full report on the visit.
6. All children and young people have the right to enjoy life and reach their potential.
7. Resources are available to provide timely, appropriate and adequate assistance to carers.

349. The South Australian Department for Families and Communities notes that the Act is intended to ensure that state government agencies and funded service providers deliver

- a more consistent approach to responding to carers’ needs
- better coordination between service providers
- a strategic, planned approach to funding and resource allocation
- participation by carers at all levels of policy development and services planning
- greater recognition and support for carers by the wider community.\(^\text{341}\)

350. Carers’ organisations and government officials agreed that the Act had been welcomed by carers as recognition of their contribution to society and recognition that they were “partners in care”. It had also had an impact on services as it required Government and non-government agencies to include carers in decision-making and in the development of services affecting carers.

**The role of equality law**

351. DWP stated that a key principle of the DDA is that it provides protection from disability discrimination and harassment for a person who is actually a disabled person. Therefore it does not provide protection from discrimination arising from the victim’s association with a disabled person e.g. an association as a carer or friend. In the Coleman case, the European Court of Justice (ECJ) considered whether the Directive protects only disabled people and, if not, whether it provides protection from direct discrimination and harassment, in employment and occupation, on the basis of an association with a disabled person. The Government’s view is that, when read as a whole, the Directive does not apply to discrimination against a person who is associated with a disabled person (for example a carer).\(^\text{342}\)

352. Now that the ECJ has confirmed that the European Framework Directive does prohibit discrimination by association, the Employment Tribunal dealing with the Coleman case will need to consider whether the wording of the DDA can reasonably be interpreted in that way in order for her claim to proceed. Eversheds Solicitors have suggested that the UK’s age discrimination regulations are similarly limited in their scope of protection against discrimination by association, which means these Regulations may also require amendment.\(^\text{343}\)

353. Eversheds have argued that it is inevitable, in light of the ECJ’s ruling, that further revision of the DDA is needed. A suggestion from the tribunal was that the words "or a person associated with a disabled person" might be added to give proper effect to the European Framework Directive. Many commentators suggested, following the Advocate

\(^{341}\) www.familiesandcommunities.sa.gov.au

\(^{342}\) Ev 108

\(^{343}\) Eversheds HR e-briefing no 371: The ECJ confirms the Disability Discrimination Act needs to change
General’s Opinion in the Coleman case, that the Court’s result could lead to increased requests for flexible working arrangements. There is no doubt that the ruling of the ECJ is significant and will increase the onus on employers to review requests for flexible working very carefully.

354. However, what the case does not support is flexible working on demand. The issue referred to the ECJ was whether the European Framework Directive prevents an employer from treating an employee, such as Ms Coleman, less favourably than other employees who do not have a child with a disability. The principal group to which this ruling applies is therefore likely to be carers of disabled or older people. The Coleman case has not sought to argue that employees such as Ms Coleman should be placed in the same position as those with a disability and for whom employers are obliged to make reasonable adjustments to their working arrangements.344

355. The Chair of the Standing Commission on Carers, Philippa Russell stated that “It seems to me that the Coleman Attridge case illustrates the discrimination and disadvantage that carers can experience.”345 Imelda Redmond of Carers UK added that “changes will need to be made to UK law and Government should take a proactive approach and include all carers, rather than waiting for further cases to be taken through the courts. […] This ruling follows hot on the heels of the Government’s National Strategy for Carers and its proposals for the forthcoming Equality Bill. Neither contained any measures aimed at eliminating discrimination against carers. In the light of today’s judgement we strongly urge the Government to rethink its approach when it publishes its response to the Discrimination Law Review consultation and the Equality Bill.”346

**Single Equality Act**

356. Carers UK, amongst others, believed that carers should be included in the forthcoming Single Equalities Bill. This would extend legal protection to carers against discrimination in the three areas of:

i) employment

ii) provision of goods, facilities and services

iii) the proposed new public sector equality duties (for which Section 75 of the Northern Ireland Act 1998 provides a precedent).347

357. Age Concern agreed that public sector duties have a key role in ensuring that public sector services and workplaces are ‘equality proofed’ and have the potential to deliver benefits for carers. Within the generic public sector equality duty in Northern Ireland (under Section 75 Northern Ireland Act 1998), carers are recognised as a separate equality

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344 Eversheds HR e-briefing no 371: The ECJ confirms the Disability Discrimination Act needs to change

345 Q 67

346 Carers UK press release, Carers to get protection at work following landmark European Court of Justice case

347 Ev 149
category: “Whether a similar duty for carers should be adopted in the rest of the United Kingdom is an issue that should be kept under careful review.”

358. Carers UK believed that serious consideration should be given to all these three areas as:

- “It is only through this combination of measures that the problems of carers’ participation in the workplace, and their general welfare when they need to access benefits and services, can be assured.

- It is only legal protection that would have a really lasting impact in addressing the overall and deep-rooted problems of discrimination and lack of recognition that carers face on a daily basis.

- This approach would provide both the most practical way of tackling discrimination and the most clarity for carers, employers and service providers alike.

- Anti discrimination policy for carers has been tried and tested by the best employers and service providers and should not be a difficult area to address in practice.”

359. The IPPR disagreed and argued that carers are not easily defined or identified as a coherent or static group. It suggested that it is also primarily the relationship to the labour market and gender that drives inequalities affecting carers: “Due to this, it does not make sense to conceive of ‘carers’ in terms of equalities legislation.” However, the IPPR acknowledges that the key groups highlighted by the Equalities Review 2007 as suffering employment penalties in the labour market all provide above average levels of care.

360. On 25 June 2008 the Government published ‘Framework for a Fairer Future,’ which included its proposals to streamline equality legislation with the aim of ending discrimination and closing the gender pay gap. Katherine Wilson, Head of Policy & Public Affairs at Carers UK, said: “We are extremely disappointed that the Government has missed the opportunity to address the discrimination faced by carers, either when struggling to get a job or when trying to access alternative care, medical and support services. We had called on the Government to outlaw discrimination against carers and to include carers in the new duty on public bodies which would mean they have to take action to ‘carer-proof’ their policies.”

348 Ev 149
349 Ev 149
350 Ev 82
Human Rights

361. Carers, like everyone else in the UK, are entitled to rely on the protection of the Human Rights Act 1998 which should ensure that public bodies take account of their human rights when they provide services. However, a report commissioned by Carers UK suggested that there are several articles of the Human Rights Act where carers’ rights may be being violated. These include

- Article 2: a right to life. Carers UK research has uncovered carers who have to delay urgent medical treatment because of inadequate support.
- Article 3: a right to be free from inhuman or degrading treatment. Carers rely heavily on public services for funds, practical support and breaks yet many are pushed to the brink of physical and mental collapse because of the lack of support they receive.
- Article 8: a right to respect for private and family life. Public bodies need to balance and consider the rights of everyone affected by their services, which includes respecting people’s private and family lives. In the area of mental health services, the implications of the Act are potentially particularly significant for the rights of individuals and their carers, e.g. in relation to the procedures under the Mental Health Act 1983 for admission to, treatment in and discharge from hospital.\footnote{Ev 148}

362. Age Concern argued that although the Human Rights Act 1998 (HRA) has been in force for over seven years, carers’ human rights are still breached too frequently and, in practice, they have experienced few benefits from this legislation. Age Concern supported Carers UK’s recommendation that the Government must ensure all public authorities are aware of their responsibilities under the HRA.\footnote{Ev 114}

363. At present, carers are not protected from discrimination in employment, training, goods, facilities, services and public services. We were impressed on our visit to Australia by the requirements placed on public bodies in South Australia to report on how they meet the needs of carers.

364. We believe that the Coleman case will have wide-reaching implications. We hope the Government will respond to these rapidly. It should include carers in the forthcoming Single Equality Act, which would give carers the protection they currently lack in employment, the provision of goods, facilities and services and through public sector equality duties.

365. Placing a duty on public bodies and publicly funded service providers to carer-proof their policies would deliver the benefits to carers that the Carers Recognition Act has done in South Australia. Introducing this duty would ensure improvements in provision of services for carers, in employment, skills, social care and guidance, information and advice, that we have recommended in this report, are delivered.
Conclusions and recommendations

Conclusion

We have recognised the crucial importance of achieving the following objectives through a more strategic DWP approach to supporting carers which aims to:

Support adults who become carers during their working lives to combine work and care;

Enable those who wish to return to paid work when caring ends or changes to do so;

Secure adequate financial support for those who provide care when of working age, either by compensating them for the extra costs of caring, or (if they need to give up work to care) through adequate income replacement and pensions protection mechanisms;

Protect the interests of young carers, ensuring that in caring for family members they are not disadvantaged in accessing opportunities for education, training and employment;

Provide adequate support for older carers, mitigating the financial strain on those whose pensions have been affected by their caring roles;

Through a ‘joined up’ cross-governmental approach, ensure that carers are supported in the wider social care system by adequate arrangements to inform them of their rights and entitlements and of how to access an appropriate range of support and services. (Paragraph 37)

Recommendations

1. We call on DWP to take a stronger and more proactive lead in Government policy on carers. As well as identifying and implementing specific policies to improve the lives of carers, DWP needs to take specific account of carers in all its work, including its role in reducing child poverty and pensioner poverty, its efforts to see 80% of working age people in employment, and its vision of giving people equality of opportunity (Paragraph 41)

2. Access to immediate and continuing information, advice and guidance is a major concern for carers, who often go for years without receiving adequate support. We welcome the Government’s commitment to “Providing every carer with the opportunity to access comprehensive information when they need to” and to make this information “easily accessible for all groups of carers, and specific to their locality.” (Paragraph 51)

3. The Department’s information, advice and guidance services are not reaching significant numbers of carers. We recommend that the Department addresses problems of access to its Benefit Enquiry Line and explores ways to convey the information that carers need in a more accessible way (Paragraph 57)
4. Evidence suggests that Jobcentre Plus personal advisers’ knowledge of carers’ issues in general, and the complexities surrounding benefits for carers and care recipients in particular, is low. We welcome the Government’s commitment to funding for the third sector and training for professionals in local authorities to support carers more effectively. We welcome the Government’s commitments: to training for DWP frontline staff to improve information provision; to advice services for carers; and to placing a carer expert in every Jobcentre Plus district. (Paragraph 63)

5. The merger of the Pension Service and the Disability and Carers Service has the potential to reduce some of the bureaucracy in the system. However, it is still too early to tell what impact it will have and we are particularly cautious about the impact the merger might have on those customers who do not overlap between the two services. We recommend that the Department commission an independent customer survey to assess the potential impact of the merger on carers. (Paragraph 68)

6. To raise awareness of the appointeeship scheme, we recommend that automated telephone scripts used by Jobcentre Plus are reviewed and amended to ensure that there is a prompt to discuss appointeeship as an option. Jobcentre Plus literature on appointeeship should also be amended to state that, in cases of mental illness, it may be possible to apply for appointeeship without a face to face interview with the beneficiary. (Paragraph 72)

7. We believe that health and social care professionals are an appropriate initial source of information regarding access to welfare benefits and other support. We recommend that DWP participates in the planned pilots looking at ways in which Primary Care Trusts can support carers to ascertain how it can work better with healthcare professionals, local authorities and third sector organisations which have regular contact with carers, often in the early stages of their caring role. The Government should develop a national strategy for giving carers advice on benefits in healthcare settings. (Paragraph 81)

8. We welcome the introduction of Information Prescriptions for carers. We believe that carers are best placed to contribute to the development of information prescriptions locally. We recommend that information on benefits for carers and the cared for person should be included in information prescriptions (Paragraph 86)

9. We welcome the Government’s planned national helpline and website for carers. This will provide important information for carers in England, including those who are not eligible for local authority support. We recommend that the helpline and website provide up-to-date, accurate, comprehensive information and advice for carers on how to access benefits and other services for carers and the people they care for. We call on the Government to work closely with the devolved administrations in Scotland, Wales and Northern Ireland to ensure that helplines providing equivalent advice are rolled out across the UK. (Paragraph 91)

10. We have been impressed by the Commonwealth Carelink Centres in Australia and examples of independent and third sector Carers’ Centres in the UK. We believe that some Carers’ Centres already offer an effective ‘first stop shop’ for signposting carers
to local organisations, services and benefits, and for providing ongoing support as
carers’ circumstances change. We welcome the Minister’s review of section 64
funding. We recommend that the Government takes a more strategic approach to
Carers’ Centres in the UK with the objective of there being a national network of
such Centres, and that it provides adequate core funding to give them financial
stability. (Paragraph 100)

11. We do not believe that families receive sufficient recognition and compensation for
the additional costs of disability. Carers consistently face costs that are not covered
by Disability Living Allowance or Attendance Allowance (and in some cases disabled
or older people cannot claim DLA or AA). We call on the Department to review the
level of DLA to ensure that it provides an appropriate contribution to the extra costs
faced by disabled people. We share the belief that the current level of support for
carers is too low and call on the Government to commission an independent review
of the impact of caring on carers’ incomes and of the long-term costs of caring for an
older person or someone with a disability. The additional costs incurred by carers
need to be recognised in the Government’s review of benefits for carers. (Paragraph
115)

12. We believe that Carer’s Allowance is outdated. We welcome the Government’s
review of the benefits available to carers and recommend that carers’ benefits should
be radically overhauled at the earliest opportunity to recognise the contribution
carers make and to be more flexible to reflect carers’ different circumstances.
(Paragraph 125)

13. The rule that links one CA claim to one AA/DLA claim provides no recognition for
carers who look after more than one disabled person or carers who have to share the
caring role for a severely disabled person. This could be reflected in our proposed
reform of carers’ benefits which we make later in this chapter. (Paragraph 142)

14. The eligibility rules for Carer’s Allowance also do not take into account those who
care for more than one person with a disability, none of whom meets the criteria for
CA, but who nevertheless face a very substantial demand for care. We call on the
Department to examine the case for extending entitlement to Carer’s Allowance to
those who care for more than one person, none of whom qualify them for Carer’s
Allowance, but who, nonetheless, face a burden of care equivalent to a carer eligible
for Carer’s Allowance. (Paragraph 143)

15. Qualifying periods that apply for AA and DLA are also problematic for some carers.
We believe that there is a case for introducing a fast-track procedure for Carer’s
Allowance applicants in emergency circumstances, and we call on the Department to
look at ways to introduce such a provision. (Paragraph 144)

16. We have received evidence that support a new accreditation scheme for the purpose
of establishing eligibility for benefits for carers. However, because linking carers’
benefits to qualifying benefits for disabled people has the great advantage of
simplicity, we are not convinced by the proposals for such a scheme. We recommend
that DWP addresses the problems of lack of awareness of disability benefits by
investing in a large-scale awareness raising campaign. (Paragraph 145)
17. The overlapping entitlement rules are confusing and over-complicated and DWP therefore ‘loses people along the way’ in the process of claiming carers’ benefits. The system of having to apply for a benefit you know you are not going to get in order to be eligible for a benefit you are not yet claiming is counter-intuitive. The administrative costs to the Department of dealing with almost 64,000 Carer’s Allowance claimants above State Pension age must be substantial. We recommend that the Department urgently streamlines the application process for benefit entitlements for carers of State Pension age. Our recommendations below, on how best to reform Carer’s Allowance in the longer term, aim to address the complexities of overlapping entitlements. We believe that this should be an urgent priority for DWP’s Benefit Simplification Unit and any simplification of benefits for carers should be in line with our recommendations (Paragraph 157).

18. Carers currently face a stark choice between engaging in education and training without any financial support or living on benefits. Many carers would be able to undertake education or training in addition to providing in excess of 35 hours of care per week. We recommend that the Department evaluates the effect of lifting the 21 hour study rule for carers on Carer’s Allowance to enable carers to engage in education and training as a route into paid employment. We also recommend that the Department evaluates the effect of adding Carer’s Allowance to the list of qualifying benefits for reduced education and training fees (Paragraph 163).

19. Despite recent increases to the earnings limit, its level still represents a major barrier for carers to combine work and care, and/or progress in employment. We recommend that the Department urgently commissions and publishes a thorough analysis of the costs and benefits of increasing the earnings limit and introducing a taper. (Paragraph 174)

20. The different timetable for Carer’s Allowance earnings limit uprating and the uprating of the National Minimum Wage is still a cause of great anxiety for claimants and causes problems for employers. We recommend that the Department finds ways of synchronising the increases in the level of the Carer’s Allowance earnings limit with increases in the National Minimum Wage (Paragraph 175).

21. Different earnings rules for carers claiming Carer’s Allowance and means-tested benefits are confusing and increase the risk of overpayments. We believe that there is a case for a complete review of earnings rules across the range of benefits in the social security system to reduce the scope for fraud and overpayment, dramatically simplifying the benefit system and also provide incentives for people to engage in the labour market. (Paragraph 180)

22. We believe that it is important for carers to be supported in their voluntary work to help others and to remain in touch with people and organisations outside their caring role. We recommend that DWP take steps to remove obstacles for carers to engage in voluntary work, including ensuring that reimbursed travel costs and the costs of replacement care are not counted as income in calculation of Carer’s Allowance or means-tested benefits (Paragraph 183).
23. We recognise that although some carers are in receipt of income replacement benefits, they are not ‘unemployed’. We do not believe it would be in the interests of the carer or those they care for, to place the same compulsion on carers to seek employment as those on ESA. We recommend that carers who seek training or employment should be better supported to enter the labour market, but that there should be no conditionality about seeking employment for people with care-giving responsibilities in excess of 35 hours a week. (Paragraph 187)

24. We endorse the commitment in the 2008 Carers Strategy to review carers’ benefits as part of a wider process of welfare reform. We believe that this review should be guided by the principles that carers who are not able to work due to their caring responsibilities should be entitled to an income replacement benefit comparable to other income replacement benefits; and that an additional payment should recognise the additional costs of caring for one or more people. (Paragraph 198)

25. We ask DWP to give urgent and detailed consideration to replacing Carer’s Allowance with a two-tiered benefit for carers, and cost our proposals as soon as possible. They would operate as follows:

*Carer Support Allowance*, to be paid at the same rate as Jobseekers’ Allowance, with the opportunity to earn a modest amount in a paid job (offering reasonable consistency with CA and in line with the permitted earnings rules). As this will be an income replacement benefit we do not think it should be payable in addition to other income replacement benefits; however we do not believe it is necessary, or desirable, to ‘means-test’ Carer Support Allowance, as carers entitled to receive it will need to be fully occupied by their caring role (for at least 35 hours per week).

*Caring Costs Payment*, available to all carers in intensive caring roles (35+ hours per week, consistent with existing Carer’s Allowance), but payable also to those over State Pension age, to compensate them for the additional costs of caring, and/or to enable them to buy in some help, goods or services to ease their caring situation. We recommend that CCP should be set at a level commensurate with other parallel payments in the UK social protection system (such as Child Benefit); this would make it likely that CCP could be set somewhere between £25 (£1,300 p.a.) and £50 per week (£2,600 p.a.). (Paragraph 199)

26. The Green Paper, No one written off: reforming welfare to reward responsibility, was published on the day that we agreed our Report. We ask the Department to consider and take into account our report as part of its consultation on the Green Paper. (Paragraph 200)

27. We welcome the Government’s commitment to work with local authorities to spread the idea of concession cards for carers more widely. We recommend that the Government follows Australia’s good example and proactively negotiates concession cards for carers for travel, parking, leisure and other activities with local authorities, business and transport operators to help carers cope with the financial burden of caring (Paragraph 205)

28. We welcome recent reforms to the State Pension which will recognise carers’ contributions to society and begin to ensure that they do not suffer poverty in
We particularly welcome the introduction of a new Carer’s Credit for people caring for 20 hours a week or more for someone who is severely disabled. This will ensure that carers caring for 20 hours or more per week are less likely to experience negative impacts on the value of their State Pension. (Paragraph 215)

29. The Committee believes that Personal Accounts will benefit many carers with unstable working patterns and help them to save for retirement. However, we restate our earlier recommendation that the Government examines possibilities for further reform to the system to allow carers to pay in lump sums to save for their pension (Paragraph 221)

30. Quality information and advice is absolutely essential to enable carers to find the right social care support. For the national helpline and website to be successful, it needs to link up with local agencies to ensure carers and those they care for are well informed about local social care services. (Paragraph 228)

31. It is helpful to have a national framework such as Fair Access to Care Services to set national standards. However, the current system is not achieving the fairness and consistency required. We welcome the review of eligibility criteria and recommend that the Government considers carefully what support it can offer to those who are not eligible for, or who choose to access support without using, social services. (Paragraph 234)

32. We call on the Government to develop a system to enable social care assessments to be ‘carried over’, so that another local authority can make decisions based on (appropriately updated) information previously provided in the social care assessment. This would be less stressful for families, and would also reduce bureaucracy and the waste of resources. (Paragraph 235)

33. Carer assessments have an important role to play in the Government’s strategy for carers as they are designed to assist carers in combining their caring responsibilities with their work, training, education and leisure needs. Practice in the delivery of carer assessments varies widely between local authorities. All carers, including those caring for individuals who do not qualify for local authority social care support, should be able to look to their local authority for support (Paragraph 236)

34. Currently state funding for social care is growing at a much slower rate than the demographic changes require. This means the Government is heading for a funding gap of an estimated £6bn, unless the system is changed. We look forward to the Government’s proposals in the forthcoming Green Paper for funding for a 21st century social care system that is both financially adequate and sustainable. (Paragraph 242)

35. We welcome the Government’s move towards the provision of more flexible and responsive social care services through Direct Payments and Personalised Budgets. These new developments have the potential to maximise personal choice and to stimulate the social care market for more personalised, flexible service. (Paragraph 250)
36. The lack of flexible, appropriate, good quality support services is a major barrier to employment, career progression and regular participation in work for many carers. We are concerned about uneven implementation of the Carers (Equal Opportunities) Act 2004. (Paragraph 253)

37. We believe that Care Vouchers may have the potential to leverage significant additional funds into care services and could be a good way of engaging employers’ support for carers. We recommend that the Government undertake a cost benefit analysis of the Care Vouchers Campaign’s proposals at the earliest opportunity. We suggest that DWP should take the lead in piloting such a scheme for its own employees who are carers. (Paragraph 262)

38. We were impressed by the measures that the Australian Government has introduced to assist families planning for the future care and accommodation of a family member with a severe disability. We believe that a scheme along the lines of the Australian Special Disability Trust has the potential to help to leverage additional funds into the market for care services. We call on the Department to carry out a cost benefit analysis of the possibility of introducing such a scheme in the UK. The quality of the advice that is provided to families on how to access such a scheme would be crucial to its success. (Paragraph 264)

39. We note that for some carers and former carers, engaging in formal care work may provide a very effective route back into paid work. (Paragraph 277)

40. There is much evidence that carers are currently disadvantaged in accessing education and training. More needs to be done to introduce greater flexibility of training courses, including home-based courses, which can be fitted around caring responsibilities. (Paragraph 278)

41. We welcome the Government’s commitment to ensure that skills training is provided in a more flexible manner and to provide replacement care for people on approved training courses. We recommend that the Government ensures that this support is available for education and training courses at all levels, as carers have wide-ranging levels of training and re-skilling needs, and provision targeted only at the lowest qualified is often not appropriate for them. We believe there is a case for placing a duty on providers of training and education to ensure that they take all steps to provide for the needs of carers. (Paragraph 279)

42. We have strong evidence that carers feel left out of the Government’s welfare reform agenda. It is also evident that Jobcentre Plus staff have not always provided effective support for people with caring responsibilities. Carers need more specialist return to work support. In order to deliver that, Jobcentre Plus needs better trained staff and specialist return to work programmes. We welcome the Government’s commitment to training for Jobcentre Plus staff and care partnership managers in every JCP district. We also welcome the commitment to investigate the feasibility of providing return to work support through third sector organisations. We recommend that the Government develops and launches pilots for employment support for carers as soon as possible. (Paragraph 288)
43. One-fifth of Incapacity Benefit claimants are carers. When the rules for the new Employment and Support Allowance come into force, Jobcentre Plus staff need to be fully trained to ask the right questions to ascertain whether a customer is a carer. Many carers will welcome tailored support to return to work. However, any approach needs to be light-touch and personalised. For some carers, their own health and/or heavy caring responsibilities will mean that work is not a possibility. (Paragraph 294)

44. We welcome the extension of the right to request flexible working to include carers. The right to request has been working well so far; most requests have been accepted by employers. However, awareness of the right to request for carers is still low amongst both employees and employers. We welcome the Government’s plans for an awareness raising publicity campaign. We believe this campaign needs to be targeted both at employers, especially SMEs, and employees. (Paragraph 298)

45. There is evidence that a fear that a request for flexible working might not ‘go down well’ with the employer deters carers from making requests. We believe that there may be a case for strengthening employee rights in this respect. However, we recommend that the Government should evaluate first what impact an improved awareness raising campaign would make, before considering further legislative steps. (Paragraph 302)

46. There is a large disparity between flexible working arrangements being offered by large employers and SMEs. Although smaller employers are more likely to agree to requests, the flexible working arrangements offered in these firms are predominately part-time jobs. Government and business need to work together to address the problem that much part-time working is in lower paid, low-skilled jobs, and as such offers limited opportunities for carers unable to work full-time. (Paragraph 308)

47. We welcome the Government’s commitment to produce good practice guides for employers. We recommend that Government, through Business Link, works with employer organisations and federations to spread good practice more widely. (Paragraph 309)

48. We welcome the Government’s commitment to review the definition of carer for the purpose of the right to request. We have heard differing views on the benefits of extending the right to request flexible working to all workers. We do not, at this stage, call for an extension in the right to request flexible working to all employees, but believe this option should be kept under review. (Paragraph 317)

49. We have also heard differing views on whether the right to request flexible working should be applicable from day one of employment, rather than after 26 weeks, as is the case now. Although we are not yet persuaded of the case for introducing the right from day one, we believe that the current 26-week rule can represent a real barrier for carers and should be reviewed. (Paragraph 318)

50. As we have recommended in previous reports, Jobcentre Plus needs to be more proactive in negotiating flexible working arrangements on behalf of its clients. We welcome the Government’s commitment to providing information about flexible working in Jobcentre Plus job banks. We also welcome the Minister for Disabled
People’s statement that Jobcentre Plus staff will encourage employers to accommodate flexibility in terms of caring responsibilities. (Paragraph 323)

51. Self-employment is a potential route for carers into employment who otherwise face barriers to the open labour market. We recommend Jobcentre Plus helps carers to pursue this opportunity (Paragraph 327)

52. At present, carers in employment are at greater risk of disciplinary procedures because of higher absence levels. We believe that options already available, such as emergency time off, should be better used by employers and employees. To this end, the Government should improve information and advice on emergency time off. We recommend a review of the regulations for emergency time off to allow employers and employees more flexibility to prevent carers dropping out of employment because of caring responsibilities. We recommend that Government in general and DWP in particular should act as a model employer with regard to its employment of all those with caring responsibilities (Paragraph 334)

53. Working Tax Credit (WTC) allows two groups of people to claim when working 16 hours per week rather than 30 – parents and disabled workers. We agree with the evidence presented to us that carers are a group who try regularly to combine work with other responsibilities and face additional obstacles to work. We recommend that the Government costs the proposal to grant WTC for carers at 16 hours per week. For this proposal to work, the earnings limit for Carer’s Allowance will need to be significantly increased, as recommended above. (Paragraph 339)

54. We recommend that the Government costs the proposals for childcare costs for carers to be eligible for the childcare element of WTC where one member of a family is entitled to Carer’s Allowance (including claimants with an underlying entitlement to Carer’s Allowance who are caring for a disabled child). (Paragraph 343)

55. At present, carers are not protected from discrimination in employment, training, goods, facilities, services and public services. We were impressed on our visit to Australia by the requirements placed on public authorities in South Australia to report on how they meet the needs of carers. (Paragraph 363)

56. We believe that the Coleman case will have wide-reaching implications. We hope the Government will respond to these rapidly. It should include carers in the forthcoming Single Equality Act, which would give carers the protection they currently lack in employment, the provision of goods, facilities and services and through public sector equality duties. (Paragraph 364)

57. Placing a duty on public bodies and publicly funded service providers to carer-proof their policies would deliver the benefits to carers that the Carers Recognition Act has done in South Australia. Introducing this duty would ensure improvements in provision of services for carers, in employment, skills, social care and guidance, information and advice, that we have recommended in this report, are delivered. (Paragraph 365)
Annex A Committee Visit Notes

Note of the Committee visit to Australia

Introduction

The Committee visited Sydney and Adelaide from Monday 12 to Friday 16 May 2008. We are extremely grateful to the following organisations and individuals who spared the time to meet us during our visit:

Sydney: Robyn Oswald and Angela Hope, Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs; Juliet Bourke, Taskforce on Care Costs; Elena Katrakis, Chief Executive Officer, Carers New South Wales; Professor Bettina Cass, Professor Ilan Katz, Professor Deborah Brennan, Dr Trish Hill, and Cathy Thomson, Social Policy Research Centre, University of New South Wales; Associate Professor Jane Mears, Social Policy Research Unit, University of Western Sydney; Sharryn Llewellyn, Manager, South East Sydney Commonwealth Respite and Carelink Centre.

Adelaide: Peter Sparrow, Chief Executive Officer, managers and board members, Carer Support and Respite Centre; UnitingCare Wesley Adelaide; Simon Charlton, Acting Chief Executive Officer, and Board of Directors, Carers South Australia; Sue Vardon, Chief Executive Officer, and David Caudrey, Director, Office of Disability and Client Services; Anne Gale, Director, Office for Carers; Jane Mussared, Executive Manager, and colleagues, Aged Care and Housing Group; David Waterford, Director, Social Inclusion Unit, Department of Premier and Cabinet; Professor Barbara Pocock, Director of the Centre for Work and Life, Hawke Research Institute, University of South Australia; Finola Harrington, Kaylene Brown, Pat Coupland, Sonia Hansen and Yeoun Tat, carers from the Northern Carers Network; Maria Ross and Sharon Hoffman, Northern Carers Network.

We are also extremely grateful to Rt Hon Helen Liddell, British High Commissioner to Australia, and all her team at the High Commission for their support in organising the visit. We are also grateful to the Hon Bob Sneath, President of the South Australia Legislative Council, Hon John Gazzola, Hon Caroline Schaefer and Hon Terry Stephens for welcoming us to the South Australian Parliament during our visit.

Carers are defined by the Australian Bureau of Statistics as those who provide “any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people (aged 60 and over)”. This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance may be for one or more of the following activities: cognition or emotion; communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self care; transport. A
“primary carer” is defined as “a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities”.

In 2003 2.6 million Australians were informal carers including 475,000 people with a primary caring role. 71% of primary carers were women, and 76% of primary carers were of working age.

**Government provision for carers**

**Income support**

The Commonwealth Government is responsible for payment of benefits:

1) **Carer Payment**

Carer Payment is an income-replacement benefit paid to carers, means-tested on all income and assets other than the family home. Carer Payment is subject to income and assets tests and is paid at the same rate as other social security pensions. The payment “ensures carers have an adequate level of income and maximises the opportunities available to carers to participate in their community”. The maximum single rate is $548.80 per fortnight; the couples rate is a maximum $456.80. The maximum rate is payable for those with assets up to $160,000 and tapered down to no entitlement for assets over $800,000. There were 292,000 recipients of carer payment in 2006-07 at a total budget cost of $1.35 billion.

To be eligible for Carer Payment a claimant must be providing care in the home of the person(s) being cared for and also provide one of the following levels of care:

- full-time care to an adult who has a disability or medical condition which is long term and severe and has a minimum level of care needs assessed by the Adult Disability Assessment Tool.
- care for a person whose care requirements are less severe but who has a dependent child that needs care, so their combined care needs are equivalent to the care needs of a person with a severe disability or medical condition.
- full-time care permanently or for at least six months to a child under 16 with a profound disability.
- full-time care permanently or for an extended period to two or more children under 16 with a disability who, together, need a level of care that is at least equivalent to the level of care needed by a child with a profound disability.

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356 FaHCSIA website www.fahcsia.gov.uk

357 Rates for Carer Payment are maintained at 25% of male total average weekly earnings (MTAWE), adjusted twice each year in line with the CPI. If this increase brings the rate to lower than MTAWE, it is adjusted upwards to that benchmark.
A recipient of carer payment can undertake work or study for a maximum of 25 hours per week without losing their entitlement. In addition, recipients of carer payment are passported to entitlement to utilities allowance of $500 a year\textsuperscript{358} and telephone allowance of $132 a year\textsuperscript{359}.

2) Carer Allowance

Carer Allowance is an income supplement available to people who provide daily care and attention at home to a person who has a disability or severe medical condition. Carer Allowance is not taxable or income and assets tested. It is paid at the rate of $100.60 per fortnight. There were 393,000 recipients in 2006-07. An individual can claim carer allowance for each person that they care for (but can only receive one carer payment). Virtually all recipients of carer payment are entitled to carer allowance.

To be eligible for Carer Allowance, a person must be providing care and daily attention to a person with a disability or severe medical condition who is either:

- aged 16 years or over and whose disability or severe medical condition is permanent or for an extended period (as assessed under the Adult Disability Assessment Tool); or
- a dependent child aged under 16 years whose disability appears on a list of disabilities or conditions which result in automatic qualification or who has a substantial functional impairment which has caused the child to function below the standard for his or her age level (as assessed under the Child Disability Assessment Tool).

The person(s) being cared for must be likely to suffer from the disability permanently or for an extended period of at least 12 months (unless their condition is terminal) assessed by a medical practitioner or other approved person as meeting the medical eligibility criteria.

3) Carer Adjustment

Carer adjustment is an ex gratia payment (maximum $10,000) payable in the event of a catastrophic event that leads to substantial care requirements.

4) Carer’s bonus

Carer’s bonus, worth A$600 to carer allowance recipients and A$1000 to carer payment recipients was paid in each of the last four years, contingent on budget surpluses; provision was also made for the bonus in the Federal Budget on 13 May 2008.

\textsuperscript{358} Utilities Allowance was extended to recipients of carer payment in March 2008 and increased from $107.20 a year.

\textsuperscript{359} Telephone allowance was increased in March 2008 from $88 a year.
Concessions

Provision of concessions for those in receipt of benefits is a shared responsibility between Commonwealth and State / Territory Governments. Recipients of carer payment are entitled to a pensioner concession card. The card entitles the holder to reduced cost medicines. Additional concessions vary depending on the state and local authority but include

- reductions in property and water rates and utility bills;
- a telephone allowance;
- reduced fares on public transport;
- reductions on motor vehicle registration; and
- one or more free rail journeys within the state each year.

Recipients of carer allowance (child) are entitled to a health care card which sets a maximum on the amount that the individual has to spend on medicines.

Programmes and services

A range of programmes and services are provided by Commonwealth, State / Territories and local Government and non-government bodies, including:

1) National Respite for Carers Programme (NRCP)

NRCP had a budget of $109 million in 2006-07 providing respite services from state and private sector providers.

2) Respite Support for Carers of Young People with a Severe or Profound Disability

This programme provides immediate and short-term respite, information and other support or assistance to carers of young people with a severe or profound disability aged under 30 and carers who experience significant stress in caring for a person with a disability aged under 65. $30 million has been allocated to this project over four years (from 2007-08).

3) Respite and Information Services for Young Carers

This programme provides respite and information services to support young carers up to 25 years of age in their caring role and provides young carers with up to 5 hours in-home respite per week during the school term to attend education or training and one fortnight of respite each year to undertake activities such as study for exams, training or recreation.

The programme also provides referral and advice services, including counselling, to support young carers in managing their caring role. It is targeted at those who are at risk of leaving education prematurely and not completing secondary or equivalent education
due to the demands of their caring role. The programme has a budget of $26.6 million over four years (from 2004-05).

4) Other respite programmes
$270.3 million over five years has been provided for the Respite for Older Carers of Children with Disability Programme. $190 million over five years has been provided for the Helping Children with Autism package. Additional respite programmes include Veterans’ respite and Mental Health Respite Programme. A FaHCSIA project is currently underway to streamline respite programmes and the many different processes of assessment for eligibility that operate.

5) Home and Community Care (HACC)
HACC had a budget of $1.4 billion in 2006-07. Public, private and voluntary sector providers are used to deliver home modifications; cleaning services; and other external help.

6) Future Planning for Family Members with Severe Disability
This is a package of measures to assist families wishing to make private financial provision for the current or future accommodation and care of an immediate family member with severe disability. The measures include:

- provision for parents and immediate family members to place up to $500,000 into a Special Disability Trust for the current or future care and accommodation of a person with severe disability, without being affected by means tests and gifting rules;
- The Family Relationships Services for Carers (FRSC) provides funding for family counselling and mediation services for families considering current or future care of a family member with severe disability; and
- the development of an information package to help people to plan for the future wellbeing of a person who has high support needs.

7) MyTime Peer Support Groups for Parents of Young Children with Disabilities
This programme provides peer support groups for parents and carers of young children with disabilities or a chronic medical condition. It has established a national network of over 300 MyTime Peer Support Groups, each supported by a facilitator for parents and a play helper for children. The play helper organizes play activities and provides support for the children while parents participate in activities and discussions. The programme receives funding of $9 million over four years (from 2006-07).

Commonwealth Respite and Carelink Centres
Commonwealth Respite and Carelink Centres are funded by the Commonwealth Departments of Health and Ageing and FaHCSIA. They take calls from individuals and
referring agencies; they assess need over the telephone and provide services on a short-term or emergency basis (including emergency respite care). Most of their work comprises provision of advice on community aged care, disability and other support services or brokering of respite services. CRCC is primarily an access point for advice and guidance; they maintain a strong regional focus, ensuring that up-to-date information on the full range of services can be provided.

There are 17 respite centres in New South Wales run by 12 different organisations from the public (including the Department of Health) and voluntary sectors; the national network comprises 65 “walk-in” shop fronts. The private sector is excluded from tendering for this service. Centres broker for services from the for-profit sector.

The successes identified in the Australian system were that

- The CRCCs were well resourced and able to respond quickly to a carer’s call at whatever time of day or night;
- The system was flexible enough to fund very small and specialised groups, for example daycare centres or excursions for particular ethnic groups;
- CRCC was developing the “resilience approach” in carers, helping them to build on their strengths through counselling and networking. Building strong networks and communities of carers reduced the need for emergency respite; and
- The system had been successful in catching carers with very high needs, particularly young carers, providing tutoring assistance and social support.

The Committee visited the Carer Support and Respite Centre (part of the CRCC network) in Adelaide. CS&RC receives funding from FaHCSIA (Commonwealth Government Department), NRCP (Commonwealth) and HACC (State). Local councils also provided funding that was matched by HACC grants. It provides information, respite and carer support in the southern and eastern metropolitan area of Adelaide. CS&RC keeps carers informed about services and provides opportunities for recreation and relaxation. In consultation with carers, the following Carer Support programs have been developed at the centre:

- Volunteers (including Telephone support);
- Information sessions, individual support, support group meetings a newsletter and a resource library;
- Recreational activities and carers days out;
- Specific programmes for male carers, parents, young carers and culturally and linguistically diverse (CALD) carers;

Six out of 10 board members at CS&RC were themselves carers, and saw it as a model of good practice widespread in Australia that carers were involved in decision making at every level. The challenge of translating nationally set guidelines for provision into what carers actually wanted and needed at the local level could not be done without input from carers.
On its visit to Aged Care and Housing Group in Adelaide, the Committee was told of a number of respite options that the Group offered, including cottage accommodation for carers and those they cared for in addition to social groups and networks, including provision for a “Men’s Shed”, which provided a social setting that was particularly appealing to men.

**The challenges facing carers**

Professor Bettina Cass outlined the academic research on carers for the Committee. Most caregivers undertake the equivalent of a part-time job to assist and support a family member or friend. Over a quarter of Australian households caring for an adult or child provide 40 hours or more of care per week, and another quarter work between 20-39 hours. Care involves financial and emotional costs: reduction of labour force participation, reduction of income, emotional and health-related costs. These had life-course impacts on employment and income history, and on retirement incomes.

Dr Trish Hill and Cathy Thomson of the Social Policy Research Centre at the University of NSW presented their findings on the impact of informal care on employment and economic disadvantage. Two-thirds of working age carers were employed compared to three-quarters of working age non-carers. Around 5 percent of employees aged between 45 and 64 and 2.5 percent of employees under 45 years become carers each year.

**Impact of caring on employment: employment status by carer status (HILDA 2001)**

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Individuals who provided informal care were less likely to be employed if they:

- Were caring for more than 5 hours per week;
- Were caring for someone in their own home;
- Had lower levels of education;
- Were from a Culturally and Linguistically Diverse (CALD) background
- Had a disability

Women carers were less likely to be employed if they had young children or a greater number of children. Carers had an increased likelihood of employment if two or more formal services were used by the care recipient and there was some other informal support (a “fallback carer”). Employees who commenced caring were most likely to remain in employment if they had access to flexible workplace arrangements (flexible hours, special leave, home-based work); could work part-time or had a higher level of job security.

A Work South survey of carers in South Australia in 2007 revealed that 91% of carers had looked for work that was more flexible and 94% had looked for work that was closer to home. 76% had considered reducing their work commitments to meet increasing care and support needs.

Professor Cass reported that care-giving is likely to be followed by problems of workforce re-entry when caring responsibilities cease or diminish. The impact of care-giving may involve withdrawal from the labour force or reduction in the hours of paid work, and tends to impact most heavily on women.

Deprivation levels by carer and employment status

[Diagram showing deprivation levels for different types of carers and employment statuses]

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361 SDAC and HILDA
362 (Campbell, and Charlesworth, 2004)
All levels of caring for women and intensive caring for men increased the risk of deprivation.

Carers most at risk of deprivation were:

- Men and women who are younger, not employed, have a disability, or do not own their own home.
- Women without a partner or with young children.

Elena Katrakis, Chief Executive of Carers NSW, told the Committee that caring was one of the leading causes of depression in Australia and carers had the lowest collective wellbeing of any group.\(^{363}\)

- More than 1/3 of carers were found to be severely or extremely severely depressed;
- More than 1/3 of carers were found to be experiencing severe or extreme stress;
- Carers are almost twice as likely to worry whether their income will be sufficient to meet their expenses; and
- Carers are almost twice as likely to experience chronic pain.

By far the most common trigger for carers to seek counselling and assistance from Carers NSW was a negative change in the health of the carer. Carers experienced financial insecurity because of the sacrifices they make to be a carer (including the effect on their superannuation) and the additional expenses that it entails and believed that the level of carer allowance was insufficient; they also faced obstacles to workforce participation and education and training. They expressed anxiety about the future of the person they cared for and themselves. Carers want it to be recognised that caring is a full-time job for many. Carers also feel that the work that they do is undervalued in society.

Simon Charlton of Carers SA noted that many carers operated in an almost constant “pre-depression state of stress” and could be easily pushed into depression by a crisis. Peer support groups and networks had been tremendously valuable; one carer had confided to a Carers SA Board Member that “peer support probably saved my life”. Self-help groups had had to move in due to the inadequacy of support for the families of those in mental health services in particular. Social stigma contributed to the isolation of many carers for people with mental health problems.

There was a consensus amongst carers and those representing them that there is unmet need for respite services. There was a particular shortage of supported accommodation for those aged 16-64.\(^{364}\)

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\(^{363}\) Deakin University/Carers Australia/Australian Unity October 2007

\(^{364}\) The Commonwealth Government announced a package of support for disabled people and their carers on 4 May 2008 which included $100 million in capital funding to build more supported accommodation for people with a disability.
A study by Associate Professor Jane Mears of the University of Western Sydney had concluded that paid work not only provides informal carers with economic security but it has a beneficial emotional and psychological effect. However, many are forced by circumstances to give up work. When they want or need to re-enter the work force when their caring responsibilities change or cease, many are concerned that their skills and qualifications are out of date and they may have lost confidence in their skills. The study found that informal carers had a vast repertoire of skills, knowledge and experience that was readily transferable to paid care work and this could provide a transition back into paid work as it was often available on a part-time or flexible basis.

**The Policy Challenge: carers and workforce participation**

Population projections indicated that there would be an increasing need for informal carers in Australia but that the supply of informal carers would not increase at the same rate. The capacity to provide formal care was a big problem in a country with low unemployment; coverage in remote areas was a particular challenge. Carers SA anticipated a “carer crunch”; the number of informal carers was projected to rise by 57% by 2031, but the number of older people requiring care was expected to rise by 160%.

Professor Bettina Cass, of the Social Policy Research Centre, University of New South Wales, identified three central policy questions that needed to be considered:

- Can all care-giving be located, or re-located within the informal sector (home) supported by cash transfers to carers to compensate them for the indirect and direct costs of caring?
- To what extent can care-giving be commodified to enable carers to maintain or increase their hours of employment (either with increased supply of subsidised formal care or offering support to offset the costs of formal care)?
- How does the approach to care fit with the emphasis on increased labour force participation of adults to the age of 65 in the context of an ageing population?

Professor Cass believed that the Australian research indicates the need for policies which better support and share the costs of care: policies which provide adequate income support; sufficient and reliable respite care; flexible education and training for young carers; flexible employment conditions; and education and training for people returning to the workforce when they no longer have caring responsibilities. Attention also had to be given to the quality, availability and affordability of formal care provision and how most equitably and effectively to make this provision.

David Waterford, Director of the SA Government’s Social Inclusion Unit noted that the benefits payable to a carer were around $200 below the average wage. It was acknowledged that the “carers pension” was not commensurate with the responsibilities and contribution to society of the carer. If the financial disincentive to caring was too great, society would have to pick up the cost of providing more formal social care.
Access Economics had used an opportunity costs model and a replacement of services model to estimate the monetary value of informal care. The opportunity costs model estimated the income foregone by carers who leave employment or reduce the hours of their employment at $4.9 billion. The replacement of services model estimated the cost of replacing informal care with formal care provision at $30.5 billion. These estimates did not place a value on lost leisure time; the costs to health and well-being; and the longer-term costs of difficulties those seeking to return to work experienced after their caring responsibilities end.

**The Taskforce on Care Costs**

The Taskforce on Care Costs was established in November 2003 to examine the financial cost of care and how it affects workforce participation, and to promote reforms on the basis of the principles of (i) financial sustainability; (ii) equity and (iii) choice. The Taskforce was supported by over 45 Australian businesses and non-government stakeholders.

TOCC’s report *The hidden face of care: combining work and caring responsibilities for the aged and people with a disability* highlights the need “to relieve the current work/care tensions experienced by Australians caring for a person who is aged and/or has a disability.” The report continues that “the need for reform will become increasingly acute as the Australian workforce faces the dual pressures of an increasing skill shortage and a decreasing caretaker ratio”.

The report called for a new legislative framework in Australia, citing as a best practice model the UK provisions for employees with caring responsibilities to have a right to request flexible working and the employer’s duty not to unreasonably refuse such requests.

The TOCC had set out to explore the economic case for keeping carers in the workforce through surveys and economic modelling. One in three carers reported that they were likely to leave the workforce due to the cost of care and 44% of carers were working below their skill level to enable them to have the flexibility that they required for their care responsibilities.

TOCC’s surveys had revealed that there was less understanding and acceptance on the part of colleagues and managers of those with caring responsibilities compared with those with child care responsibilities. TOCC was hoping to move the focus that had been successfully directed at childcare on to care for the aged and disabled. It argued that the economic case for supporting carers’ workforce participation was strong (as it reduced welfare payments and helped carers to provide for their own old age). TOCC had concluded that the existing state financial support for care costs was inadequate.

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365 *The Economic Value of Informal Care*, (2005)
Based on its economic modelling and research, TOCC had recommended a 50% Care Costs Reimbursement (CCR) for expenses up to $10,000 pa per household; and multiple delivery mechanisms for the CCR - direct payments to the carer; payments to the care service provider; and via the employer (such as through tax allowances on salary sacrifice, as with care vouchers).

There was also a strong “business case” for ensuring that carers were not marginalised in the workplace, enabling all staff to operate to their full potential. Small businesses, in particular, were often particularly good at providing flexibility for staff with caring responsibilities.

**Current experience of carers in employment**

The Chief Executive and Board Members at CS&RC, Adelaide, believed that employers did not yet see the need to provide support for carers and they were not looking to take on people who were carers. Only if the labour market got tighter would employers see the need for offering greater flexibility. Even local employers who were good employers of older and disabled workers and were supportive of staff who were sick had no understanding of the numbers of carers amongst their workforce and provided limited support to them. A change of culture, going beyond legal entitlement, was needed to support carers in work. Parents required to attend multiple hospital appointments with a disabled child found it very difficult to keep up work.

Simon Charlton of Carers SA agreed that a cultural change to support carers in the workplace and recognise the value of their working contribution was also important, although some employers were becoming more flexible in a bid to retain good employees who were carers. Sharryn Llewellyn from the South East Sydney Commonwealth Respite and Carelink Centre believed that most carers did want to remain in work but employers tended not to be very flexible with repeated problems for carers.

Aged Care and Housing Group in Adelaide highlighted a number of programmes with which they were involved that helped carers to juggle their caring responsibilities with workforce participation.

- The Southern Working Carers programme provided respite for working carers that was “individual, flexible and responsive”. The programme was for carers who were employed, training or looking to return to work/study. It could provide assistance to enable carers to access appointments and other activities.
- Work South was a two year NRCP pilot project in which ACH worked in partnership with CS&RC, Carl Zeiss Vision, Mitsubishi Motors, City of Marion, City of Onkaparinga, and James Brown Memorial Trust. It offered respite to working carers. Employers in the pilots had seen benefits in retention, lowered absenteeism, and flexible work practices (which potentially offered extended hours of office cover or opening).
David Waterford, Director of the SA Government’s Social Inclusion Unit believed that employers in South Australia were increasingly seeing the costs of importing labour rather than maximising the potential of the local work force. Labour demand was projected to exceed supply until at least 2013-14 and the state had an ageing population.

The South Australian model

The Carers Recognition Act 2005 incorporates the South Australian Carers Charter which sets out seven principles relating to the recognition of the role and rights of carers. These principles are that:

1. Carers have choices within their caring role.
2. Carers’ health and well-being are critical to the community.
3. Carers play a critical role in maintaining the fabric of society.
4. Service providers work in partnership with carers.
5. Carers in Aboriginal and Torres Strait Islander communities need specific consideration.
6. All children and young people have the right to enjoy life and reach their potential.
7. Resources are available to provide timely, appropriate and adequate assistance to carers.

The Act formally acknowledged the rights of carers, enshrined the Carers Charter in legislation and required Government and non-government agencies to include carers in decisions that impacted on them and in the development of services affecting them. It aimed to recognise carers as partners in care and provide a mechanism for the involvement of carers in the provision of services and provided for carers to make a complaint about non-compliance with the charter.

The Carers Policy had led to cross-government action and the establishment of a carers reference group (of carers and representatives from service providers and government agencies), a cross government implementation group (of representatives from across government departments), discussion in Cabinet sub-committees and the development of carer impact statements. The obligation on the Government to seek carers’ input in decision-making had led to more consultation of carers and increased opportunities for input.

The South Australian Department for Families and Communities believes that the SA Carers Policy will have an impact on Government, the community, service providers and carers.366

Government: The SA Carers Policy and the Carers Recognition Act aimed to ensure that recognition of carers and their needs was reflected in the delivery and evaluation of

366 www.familiesandcommunities.sa.gov.au
policies, programs and services. All government agencies are required to report annually on how they are achieving the requirements of the Act.

**Community:** An aim of the SA Carers Charter, Policy and the Carers Recognition Act was to improve the recognition of carers, and to reduce the negative impact that caring had on the individual including the sense of isolation from the community.

**Service providers:** Government departments and government-funded agencies are required to show an understanding of the Carers Charter and to adhere to its principles in relevant service provision. Organisations and government-funded agencies must involve carers or their representatives in policy and program development and in strategic or operational planning that might affect them.

**Carers:** The SA Carers Policy, Charter and legislation aim to ensure that carers are recognised as partners in the provision of care and are involved in the assessment, planning and delivery of services that impact on them and their caring role. A Carers Reference Group had been established to advise on the implementation and monitoring of the SA Carers Recognition Act and provide advice to the Government on issues relating to carers. Carers could complain about non-compliance with the SA Carers Recognition legislation, including the Carers Charter, through the Health and Community Services Complaints Commissioner.

Carers SA believed that the legislation had been the “cornerstone” for raising awareness in Government of carers issues and the establishment of the Office for Carers ensured that these concerns remained on the Government’s agenda. Amendment to SA Equal Opportunities Legislation to take account of carers had been advocated by Carers SA who had also pushed for carers to have the right to an assessment of their needs by their local authority (as is the case in the UK).

Officials from the Department of Families and Communities agreed that carers had welcomed the Act as recognition of their role. Every Government Department had had to make adjustments for carers and Departments were now listening to their own employees who were carers and this was making them more flexible in their practices. Some examples of practical effects of the change of culture in Government included:

- a statutory declaration for grandparents to be recognised as legal guardians even without a court order; this made things much simpler for many grandparents who cared for grandchildren; and
- Recognition of and support for young carers in schools had been very mixed; the Act had ensured that this was an area on which schools focussed.

The Office for Carers was responsible for overseeing implementation of the Carers Recognition Act 2005 across Government and developing a reporting framework. Some Government agencies were required to report (including the Departments of Education, Further Education, Health, Transport, Justice and Police), whilst other Departments had
volunteered reports. An accreditor was charged with examining the work of each Department with regard to its support for the disabled and carers. The office was trying to get recipients of state funding to report by getting requirements to report included into service agreements.

The Office for Carers had been established in 2006 and had been welcomed by carers. It was drafting the first strategic plan for carers; there was a need to bring together disparate organisations in Government and the community and be more strategic in the allocation of state and Commonwealth funding.

SA Prime Minister Rudd had committed the Government to increasing funding for respite services and improving planning. The SA Carers Charter stipulated that individuals should have choice in respite care. The extent to which rights under the Charter were enforceable through the courts was, as yet, untested. Some rights could be enforced under equal opportunities and employment legislation.

The Office for Carers had set up a cross-government committee focusing on employment and asking all agencies to do what they could to help carers stay in the workforce. The Police Department operated a “leave bank” – staff donated a day of leave per year that could be accessed by others with caring responsibilities.

The Carers Recognition Act 2005 was broadly drafted and had few teeth, but it had pushed the Government into action and had been hugely symbolic for carers who had driven the process from the start. It had created goodwill and partnership between the Government and carers and had brought different parts of government together to look strategically at the fragmented nature of provision for carers. There was no move yet to tackle rights of carers working in the private sector; the Government had to take the lead. However, many employers valued their older workers and appreciated that measures needed to be taken to help those with caring responsibilities, many of whom would be older, to remain in the workforce.
Note of Committee visit to The Carers’ Resource, Harrogate

5 June 2008

Anne Smyth, Director of Carers’ Resource (CR), welcomed the Committee and introduced the Carers’ Resource Senior Management Team before explaining their service. The Carers’ Resource has been an independent charitable company since November 1995. It has 56 paid staff and 54 volunteers, a board of seven trustees, and is in touch with more than 5,000 local carers. The core funding comes from the Primary Care Trusts (PCTs), local authorities and about 25 separate funding streams or contracts. The Carers’ Resource gives tailored support to carers and encourages professionals to be “carer aware”. It provides information, advice and guidance, representation and advocacy - free and in confidence - for all carers. It guides carers to the relevant services which will help them to care, to look after their own health and well-being, to become economically active, or to stop caring (if that is what they feel they must do).

Helen Brown, Head of Services (Adults, Harrogate), introduced a Carer Support Officer and two Customer Liaison Managers from DWP, Harrogate. CR was often the first contact, and provided a first class service. It was noted that entitlement was often difficult to describe – people do not see themselves as ‘carers’. There was a two-way referral between CR and DWP with CR seen as a ‘friend’ not an organisation. They help carers realise that benefits are not charity, but entitlement. DWP are also able to refer carers to CR for additional services such as sitting. The difficulties in explaining benefits to elderly people were noted.

Carers’ stories

The Committee were divided into groups to hear carers’ experiences:

Tom Levitt, John Penrose and Professor Sue Yeandle met Allyson Campbell – Carer Support Officer. She works at Harrogate District Hospital on the Wensleydale Ward that deals with elderly trauma. The Lottery Fund provides money for her role, and here she can meet patients as they are discharged to discuss their care needs and meet carers.

One major issue was a failure to understand DWP letters. Carer A looked after her husband who had dementia. Since his death she had received a letter that was ambiguous, saying her pension credit was to be £108 or £80. It was hard for CR to understand, so how could the elderly cope? The local Pensions Service said the letter was correct, but the explanation was unclear. She also received letters concerning Carer’s Allowance which were very confusing. It said she was entitled, but would not be receiving anything. Allyson was able to help her, but many people do not have this
support in a time of trauma. Allyson raised problems of overpayment, which are followed by huge repayment demands. How can people be held responsible when the letters are confusing them?

Carer B cared for a friend with a back problem. She had been in hospital for 3 months, and was discharged once her house was adapted. There was no council funding for this, so she had to pay herself. To find out if she could get benefits she rang many people. She eventually got DLA forms, but was considered ineligible. This coincided with a stroke. Carer B was referred to CR to get support as the claim went to tribunal. The doctor at the tribunal was very harsh in questioning. Patients can fill in their forms, but they also rely on their GP to keep up to date and supporting files. As GPs do not visit homes often they do not know the full situation – how could this be overcome? The tribunal awarded her DLA for mobility at the highest level, but not Carer’s Allowance. The Chair suggested if she applied again she would receive it, as her stroke would be taken into account. It was questioned why she had to reapply and noted that there would be no back payment. The complexities of the system were raised, and the need of benefits for independence. Carer B said that as there was no Carer’s Allowance, she wasn’t getting anything – she added she was not caring for the money.

Carer B said her friend had no discharge plan apart from adapting her house and being given a wheelchair. Carer A was introduced to Allyson on the hospital ward. This was one of three Lottery funded posts, and was the only one that was hospital based. CR tried to link staff where cases were going to be found. However, the funding for the post was going to end in November.

Carer C was in her mid-50s, and cared for a sick husband. To care for him she sold her business and applied for benefits. She got the full DLA mobility rate and CA. The forms were misplaced, but the Department said it was not responsible so they wouldn’t backdate payments and she lost out on benefits. There was an appeal, but this was thrown out. John Penrose advised her to write to her MP to take up with the Minister. When asked how this had affected her health, she confessed that she was overwhelmed. The stress she was experiencing was compounded by the frustration of dealing with the bureaucracy. Allyson said it had taken a lot of work – as she has 300 cases to deal with it limited the time she could devote to others.

Before the session finished, Carer A mentioned a carer’s grant she received. A social worker had said she might be eligible. She received a cheque to have a ‘treat’ and was very grateful. Carer B’s experience with a social worker was bad. They had undertaken responsibilities, but had never acted on them.

Terry Rooney, Joan Humble and Harry Cohen met Carer D who cares for both her parents. Her father had a stroke in 1991 and his condition has progressively deteriorated. They also met Carer E who is a carer for her husband who has had a herniated slipped disc for 9 years. Both women only found out about their full benefit entitlements from Carer’s Resource.
In the case of Carer D, her father had a Social Care assessment 17 years ago and was given the lowest level of Attendance Allowance. The family had to fight to be reassessed to gain a higher level. Her mother was told that it was expected that she would give up work to care for her husband. Both women highlighted the particular difficulty of dealing with 2 different agencies (Local Authorities and the Department for Work and Pensions) and the lack of communication between the two.

Carer E highlighted her problems with doctor’s assessments for DLA. The doctor who came to their home was a stranger with a high level of scepticism about her husband’s level of disability and not enough time to carry out a proper assessment.

**Carer Support Officers’ Observations**

The CSOs raised concerns about the system and stressed the difficulties in obtaining the benefits to which carers were entitled and in helping carers back to work.

Sue Clements, Carer Support Officer (Craven), has worked at CR for 18 years. She mentioned that getting DLA and CA was difficult. It could take 4 hours to complete a form. She also noted delays in decision making, which can be up to 1 year if the decision went to a tribunal. It was usually best to apply for DLA and CA at the same time, even though a negative response on CA was likely. The paperwork is very complicated. It would be helped if a statement of reasons for a decision was given. The CA was considered insufficient, especially when compared to the amount that could be gained through employment. There were also issues in how it is assessed. Farmers have a small net income, but find it hard to get CA. This can also be a problem for other self-employed people as they have to show 35 hours caring per week. **Terry Rooney** asked what contact they had with the DLA office at Lawnswood, emphasising their open days on general issues. The CR are in contact with them by phone, but do not meet. They had been invited to a Blackpool conference. Inconsistencies in the application process were discussed. It was thought these could be cured through better training. The CR believed there were inconsistent decisions made contrary to the medical evidence – these are often perceived as a rejection of a person’s disability.

**Realities of combining caring and work: A personal perspective**

The Committee met a carer trustee. After his wife became ill in 1995, he chose to look after his family and work part-time. In this time he tried to balance earning a living with caring for his wife whose condition was deteriorating.

Many carers want to work and also have to find employment when their caring responsibilities end – how do they get back into the labour market? There is a need for reskilling. However, there were problems working with Higher Education providers who wanted to run schemes themselves, and problems of maintaining funding. There was frustration at the inflexibility of public sector organisations failing to communicate
with each other and work constructively together. John Penrose asked if DWP was improving this. There was a degree of improvement, but from a low base. They did not want to enter small contracts, but there was a hope in terms of sub-contracts. Anne Smyth mentioned initial TEC speculative funding which for 7 months paid for 3 streams of work. This funding was difficult to maintain and required flexible working. Since then EU Social funding and LSC grants have been given to CR which required monitoring but this did help CR demonstrate compliance with requirements for future contracts. With their existing contracts the Department asks for performance indicators to be met which can cause difficulties as they change mid-stream. John Penrose asked if there was scope for contracts over a longer period. There had been with the LSC, but the funding was changing.

Carers used the CR as it is independent – an interim step before statutory bodies. Joan Humble asked how things might change with respect to Local Area Agreements. Would this make things easier? Are Local Authorities working across boundaries? Will pooled budgets help? Carers are cross cutting – they are on the hitlist, but not at the top so are often missed. Regarding the LAA system, the 2008 National Carers strategy was seen as positive, but there were concerns about pooled budgets. Joint working was an uphill struggle against vested interests. The principle of LAAs was fine, but in practice it would miss out carers, with young carers at the bottom of the list of priorities. At the moment reskilling was focussed on meeting a Government definition of what was demanded. CR agreed with Joan Humble that DWP support, particularly the 50+ New Deal was appropriate to help reskilling, but that it takes time to regain confidence. Oliver Heald suggested that CR was a good model of support that could be rolled out and funded nationwide. CR said it provided a template for elsewhere, but there were issues regarding management capacity and consistency of core-funding, without which there would be no way to sustain it. There were also 140 similar centres in the UK sharing the same core principles.

Supporting carers in primary care

The Committee met two GPs, Dr Liz Clements and Dr Jacqui Aitken, who talked supportively about CR. It was a great benefit to the GPs to have a linked worker who could have easy face-to-face contact with the patients. Caring was appreciated, but not valued. It drastically changes one’s life situation and finances, and carers have little experience and training to deal with the heavy burdens they have to undertake. GPs have a patient for 10 minutes, when they have to focus on doctoring, not their caring role that can also impact on health. CR was available to refer to, and it was important not to fob someone off with a number, but to refer them to a team member in situ. They mentioned 2 cases: first, a single carer with depression and agoraphobia was referred to the CR. They gained benefits and had their emotional burden relieved. Secondly, an elderly couple had a demanding grown up son. Through CR they found a group with whom they could get help and discuss their problems. This coincided with a drop in their blood pressure.
It was noted that carers have additional health needs and problems caused by the stress and burden of caring. Therefore they require support promptly, both financially and emotionally. Anne Smyth commented that the average GP does not do benefit claims. One Carer Support Officer popped in when required to give face to face contact in the GP’s Practice. In one case they provided a set number of hours, but always on a Tuesday. They were in a position to give feedback to GPs during that time. Anne Smyth said a linked worker was required, who had integrity, confidence and training and was in the practice for over 10 hours per week. In Airedale PCT, CR provided 62 hours with 37 hours more to come. Joan Humble raised the question of GPs’ perception of their role with regards to carers, and what patients expected from them. She also questioned how GPs could liaise better. The GPs felt they needed the resources to deal with carers, or else they would be opening a “Pandora’s box.” Joan Humble asked if a Carer Support Officer could be incorporated into a GP’s team and what impact this would have on GPs work. It was felt that other agencies were avoiding the burden and that GPs were put on a pedestal when they couldn’t know everything. There is a good network of carers centres which needs developing, and they give GPs a confidence boost. Anne Begg noted that other services have been piloted within a GPs team and in general it didn’t work. It was noted that they did not feel part of the team.

Commissioning services for carers

Sue Vasey, Chief Officer, North Yorkshire Learning Consortium, was introduced. Caring and employment required innovative solutions, and to begin with this was helped by local initiative funding. This gave CR the scope to do what was needed, not purely aimed at Government targets. There has since been EU Social Fund money and support from JobCentre Plus and the LSC. Now there was a funding gap which needs to be filled to keep employees in jobs as new funding is secured.

Dave Tinsley, North Yorkshire Partnership Manager, Jobcentre Plus saw the CR as very worthwhile, providing local consultation. Support of carers back to employment was identified as a need.

Martin Wynn, Economic Development Manager, LSC, spoke of their long relationship with CR. In that time they have widened participation, moving people towards employment. It was also noted that CR provided a lot of programmes relative to the funding received which was due to their connections in the community.

Derek Law, Director, Adult and Community Services, North Yorkshire County Council said the County Council was responsible for future funding. There are added difficulties in rural communities such as a lack of local transport and fuel costs.

Oliver Heald asked how elderly carers could be helped with respite. It was felt that this was difficult to do.
It was agreed that personal barriers such as confidence and self-esteem were the biggest issues. Here a little bit of support would help a lot. It was important to put the person at the centre – if they are not ready for work then training could be provided. There is a problem providing client led learning when dealing with million pound schemes so often support workers can be the link to the statutory services.

**Joan Humble** said LAs were having to chase contracts, so how could life be made easier for CR? LAs were looking at carers from different perspectives whilst the CR looked at the person. Dave Tinsley said funding was the issue. Carers have not been a priority group – once their training project ends, that is the end of their support. Interlinked funding streams were required to enable continuity. **Joan Humble** asked how coordination could be achieved. Derek Law said there were good methods for working together at a local level through County strategy groups and locality teams. Martin Wynn thought that they could not cover every need and required flexibility.

**Harry Cohen** felt that with respite there was a lack of supply of what was required. It was felt that a mixture of options was best. A respite bed could be a solution, but some people required a break. Harrogate Nursing Homes were able to offer respite, but people may wish to go elsewhere. Derek Law thought it was best to think of creative solutions near the home.

**Working with parent carers (of children with disabilities) and with young carers to maximise income and opportunities**

Jo Webster was introduced as a Parent Carer Support Worker who had been in post for the past 2½ years. She mostly gave information support and advice on DLA and CA. Benefits was a key issue as they were hard to comprehend, and applications were long and time consuming. In terms of information support, a booklet had been compiled to act as a first port of call, and it was regularly updated.

A Single Parent with three children was introduced. Jo had helped her with wording the DLA forms and getting benefit. She also provided information about CA. Jo mentioned the difficulties in focussing on the negative parts of your child in the applications. **Harry Cohen** asked about respite. She was able to access some shared caring. Jo noted that parents do have to consider the longer term. She told **Terry Rooney** that without CR she would not have applied for benefits, and told **Anne Begg** that she would not buy-in help. As she could only take a job during school hours there were limited options for her to return to work. The Allsorts group that met every Monday provided a point of contact with 25 other families.

The Committee met Helen, a Young people’s mentor. One of her roles was performing 1-to-1 intensive work as someone independent and confidential to talk to. She isn’t just a counsellor, but can provide information and case specific work for events such as anger management and bullying. Some common problems for young carers were
absence, lateness and unpreparedness for school, which often the school wasn’t aware of.

Linda, another mentor, spoke of the courses they provided. They had applied activities at the weekends and school holidays which provided time out, but were also practical or confidence boosting. Some examples were cooking courses; bike maintenance; first aid; music and drama. It was an opportunity to try new things.

The father of Carer F, a young carer aged 18, died 11 years ago. His mother suffers from diabetes and depression, and his brother has learning difficulties. He finds it hard to cope, and suffered from low self confidence until he met the Young carers at school who have provided help. Through them he has been able to go further than he thought he would have, and is glad to have taken part in the scheme. Greg Mulholland asked which of the CR services had helped him most. The ability to talk to someone about problems was important – the simple things. In response to Tom Levitt’s question on contact with other carers, he spoke about a youth club that he attended before he turned 18. He could talk about similar problems and it provided trips away from home. He was still in contact with them and saw them around town. The CR had established with schools the opportunity for carers to call home if they were worried about their parents. Jo said many carers did not want to be seen at school with the carer supporters which required the mentors to be very flexible. Gill Gentle, Head of Services, Children and Families explained the Child Protection, Young Offender and Sexual Health advice and support they provided. They rarely intervene but try to provide stability – it was often hardest to cope with fluctuating circumstances. Around 50% of their work was with drug and alcohol abusers and 50% with families dealing with disabilities, trying to achieve engagement and then working holistically.

**Health matters – issues for primary care**

Dr Peter Brambleby – Public Health Director, NYY PCT – has been in his role for 1 year, and also worked on the DoH budget project. He said that the local NHS looks at providers of services then at small voluntary groups. He thinks they should look in terms of health programmes, not providers. In looking at strategic objectives they should seek to support carers in every programme. Harry Cohen asked if a lack of district nurses was causing problems. Dr Brambleby said more would be beneficial if there was a measurable improvement in health experience – more nurses would give improvements, but it is doubted the benefits would be massive. It was also considered that there would be less money going forward, so it was a case of where the best bang for the buck could be achieved. Oliver Heald commented that family breakdown can be linked to care and asked what the PCT could do to halt this. Not enough was the answer – it required better access to care. Joan Humble noted that GPs were under pressure. Dr Brambleby said there was huge inertia in the system, and a tension that needed resolving. The introduction of world class commissioning could allow a different model to be instilled. This would focus on better life per years rather than adding years to the end of life. Joan Humble
was told that practice care groups could be used to help GPs take on a role for carers. Discussing drugs and alcohol addiction, Anne Begg raised the difficulties of childcare when a parent is trying to come off drugs.

**Employment and training provision**

Nina Derbyshire, Contracting lead, has been part of the Changing Lives team for 5 years. It is a successful model in giving carers opportunities, and raising awareness with employees. Since 2001 it has been funded by the LSC, EU Social Fund and had a contract with JobCentre Plus. It was seeking funding to carry on its good work. In the scheme carers have a menu of activities and courses they can take part in, and CR can identify barriers to help them into work.

Jenny Sengel, Training and Employment Advisor, gave advice and information about carers’ rights in work and how they had been affected by the new flexible working provisions. Previously employers believed that if you were not being paid as a carer you were not a carer. She worked to address carers’ confidence problems and help in CV preparation and job searching.

Dan Marsden, Training and Employment Advisor, explained their training, advice and guidance. They provided a free face to face career advice service which often showed barriers in ICT, Maths and English. As a result they provided courses in these. Skills coaching was given on an ongoing basis to identify and fill any skills gap.

Carer G was introduced. Her husband was severely mentally ill. CR helped her deal with stress; increased her confidence; helped her sit her Level 2 exams which enabled her to start a college course.

Stella, Training and Employment Advisor, spoke about the training. It was holistic and developed around the carers’ needs. 7 IT sessions were provided for 70 carers each week; Maths and English was delivered with Leeds University with whom they have a good working relationship. Most important for carers was a boost in self confidence and self esteem. They are at a crossroads in their life when they try going back to work or take on a course. Non academic courses are also provided such as power tools and car maintenance, plus sewing groups and creative writing. Delivery was only possible through good partnership working, and has allowed Changing Lives to evolve as funding streams means they are able to work with other agencies and with non-carers.

Carer H had cared for his father-in-law for 7 years and didn’t realise that carers had needs. He was introduced to Stella as CR helped him claim CA. As his father-in-law deteriorated his life also got worse. He died a year ago and since his daughter’s second child had died and his son had had a nervous breakdown. At this time he was working on his self esteem at a Brand New You course, and the other participants were supportive. He now does DIY to keep him sane – when he was caring the house fell into disrepair. As he was previously self-employed, getting references was an issue.
Nina summed up saying Changing Lives was a good model with successful funding that hit targets. She noted some carers were well qualified, but a lack of recent work meant they felt like they had never worked, and that in Rural Communities a lack of work also hit hard as there were few socialising activities.
Annex B: Background statistics on carers

Figure 11: People of working age living in a household with no working adult, by amount of care and sex

Source: Yeandle, S. and Buckner, L. (2007) Carers, Employment and Services: time for a new social contract? London: Carers UK; derived from 2001 Census SAM. The 2001 SAM is provided through the Cathie Marsh Centre for Census and Survey Research (University of Manchester), with the support of the ESRC and JISC.

Figure 12: People aged 16-24: economic activity by amount of care provided and sex

Figure 13: People aged 25-44: economic activity by amount of care provided and sex

![Chart showing economic activity by amount of care provided and sex for people aged 25-44.]


Figure 14: People aged 45-64/59: economic activity by amount of care provided and sex

![Chart showing economic activity by amount of care provided and sex for people aged 45-64/59.]

Figure 15: Geographical distribution of carers of working age who are in employment

Source: Yeandle, S. and Buckner, L. (2007) Carers, Employment and Services: time for a new social contract? London: Carers UK; derived from 2001 Census Standard and Commissioned Tables. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC.
### Figure 16: Caring responsibilities and economic activity for men, by age (Eng & Wales)

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<tr>
<th>Economic Activity</th>
<th>16-24</th>
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<th>30-44</th>
<th>45-59</th>
<th>60-64</th>
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Source: 2001 Census SARS, Crown Copyright 2004. This work is based on the SARS provided through the Centre for Census and Survey Research of the University of Manchester with the support of ESRC and JISC.

### Figure 17: Caring responsibilities and economic activity for Women, by age (Eng & Wales)

<table>
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<tr>
<th>Economic Activity</th>
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<td></td>
</tr>
<tr>
<td>Employed: part-time</td>
<td>5</td>
<td>9</td>
<td>13</td>
<td>25</td>
<td>20</td>
<td>16</td>
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<tr>
<td>Employed: full-time</td>
<td>4</td>
<td>5</td>
<td>11</td>
<td>20</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Self-employed: part-time</td>
<td>7</td>
<td>7</td>
<td>13</td>
<td>27</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>Self-employed: full-time</td>
<td>7</td>
<td>7</td>
<td>11</td>
<td>22</td>
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<tr>
<td>Unemployed</td>
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<td><strong>Economically Inactive</strong></td>
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<td>3</td>
<td>17</td>
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<td>6</td>
<td>12</td>
<td>23</td>
<td>12</td>
<td>6</td>
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<tr>
<td>Looking after home or family</td>
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<td>13</td>
<td>18</td>
<td>34</td>
<td>29</td>
<td>22</td>
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<tr>
<td>Permanently sick or disabled</td>
<td>9</td>
<td>10</td>
<td>15</td>
<td>17</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>Other</td>
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<td>7</td>
<td>11</td>
<td>16</td>
<td>14</td>
<td>11</td>
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Figure 18: People aged 60 or over who provide 20 or more hours of unpaid care a week

Source: 2001 Census Standard Tables supplied by ONS, GRO Scotland and NISRA, Crown Copyright 2003. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown.

Note: Map shows the percentage of people aged 60+ who provide 20+ hours of unpaid care per week for each local authority district, with the total number of districts in each category in brackets.
Figure 19: Young Carers in England*: numbers, health and weekly hours of care

<table>
<thead>
<tr>
<th>Age (numbers)</th>
<th>ALL people</th>
<th>Non-carers</th>
<th>1-19 hours</th>
<th>20-49 hours</th>
<th>50+ hours</th>
<th>ALL carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-7</td>
<td>1,837,525</td>
<td>1,832,442</td>
<td>3,872</td>
<td>484</td>
<td>727</td>
<td>5,083</td>
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<tr>
<td>8-9</td>
<td>1,281,474</td>
<td>1,274,170</td>
<td>5,933</td>
<td>566</td>
<td>805</td>
<td>7,304</td>
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<tr>
<td>10-11</td>
<td>1,302,122</td>
<td>1,287,018</td>
<td>12,766</td>
<td>1,098</td>
<td>1,240</td>
<td>15,104</td>
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<td>12-14</td>
<td>1,897,430</td>
<td>1,854,319</td>
<td>37,173</td>
<td>3,178</td>
<td>2,760</td>
<td>43,111</td>
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<td>15</td>
<td>613,049</td>
<td>593,220</td>
<td>16,941</td>
<td>1,700</td>
<td>1,188</td>
<td>19,829</td>
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<tr>
<td>16-17</td>
<td>1,198,947</td>
<td>1,150,179</td>
<td>40,138</td>
<td>5,258</td>
<td>3,372</td>
<td>48,768</td>
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<tr>
<td>ALL</td>
<td>8,130,547</td>
<td>7,991,348</td>
<td>116,823</td>
<td>12,284</td>
<td>10,092</td>
<td>139,199</td>
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<table>
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<th>Age (%)</th>
<th>5-7</th>
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<th>99.7</th>
<th>0.2</th>
<th>0.0</th>
<th>0.0</th>
<th>0.3</th>
</tr>
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<tbody>
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<td>8-9</td>
<td>100.0</td>
<td>99.4</td>
<td>0.5</td>
<td>0.0</td>
<td>0.1</td>
<td>0.6</td>
<td></td>
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<tr>
<td>10-11</td>
<td>100.0</td>
<td>98.8</td>
<td>1.0</td>
<td>0.1</td>
<td>0.1</td>
<td>1.2</td>
<td></td>
</tr>
<tr>
<td>12-14</td>
<td>100.0</td>
<td>97.7</td>
<td>2.0</td>
<td>0.2</td>
<td>0.1</td>
<td>2.3</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>100.0</td>
<td>96.8</td>
<td>2.8</td>
<td>0.3</td>
<td>0.2</td>
<td>3.2</td>
<td></td>
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<tr>
<td>16-17</td>
<td>100.0</td>
<td>95.9</td>
<td>3.3</td>
<td>0.4</td>
<td>0.3</td>
<td>4.1</td>
<td></td>
</tr>
<tr>
<td>ALL</td>
<td>100.0</td>
<td>98.3</td>
<td>1.4</td>
<td>0.2</td>
<td>0.1</td>
<td>1.7</td>
<td></td>
</tr>
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</table>

Source: Analysis (2008) by Dr Lisa Buckner, University of Leeds of 2001 Census Standard, Crown Copyright 2003. All Crown Copyright material is reproduced with the permission of the Controller of HMSO. *Carers aged 5-17 years old are included in this table.

Figure 20: Young Carers by weekly amount of care provided, England %

<table>
<thead>
<tr>
<th>Age group</th>
<th>1-19 hrs</th>
<th>20-49 hrs</th>
<th>50+ hrs</th>
<th>All in age group providing any care</th>
</tr>
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<tbody>
<tr>
<td>5-7 (n=5,083)</td>
<td>76.2</td>
<td>9.5</td>
<td>14.3</td>
<td>100.0</td>
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<tr>
<td>8-9 (n=7,304)</td>
<td>81.2</td>
<td>7.7</td>
<td>11.0</td>
<td>100.0</td>
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<tr>
<td>10-11 (n=15,104)</td>
<td>84.5</td>
<td>7.3</td>
<td>8.2</td>
<td>100.0</td>
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<tr>
<td>12-14 (n=43,111)</td>
<td>86.2</td>
<td>7.4</td>
<td>6.4</td>
<td>100.0</td>
</tr>
<tr>
<td>15 (n=19,829)</td>
<td>85.4</td>
<td>8.6</td>
<td>6.0</td>
<td>100.0</td>
</tr>
<tr>
<td>16-17 (n=48,768)</td>
<td>82.3</td>
<td>10.8</td>
<td>6.9</td>
<td>100.0</td>
</tr>
<tr>
<td>All in these age groups (n=149,199)</td>
<td>83.9</td>
<td>8.8</td>
<td>7.3</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Figure 21: Young people aged 5-17 whose health is ‘not good’, by caring roles: England (numbers)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number in group whose health is ‘not good’</th>
<th>Non-carers whose health is ‘not good’</th>
<th>Caring 1-19 hours with health ‘not good’</th>
<th>Caring 20-49 hours with health ‘not good’</th>
<th>Caring 50+ hours with health ‘not good’</th>
<th>All in caring roles with health ‘not good’</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-7</td>
<td>19,287</td>
<td>19,107</td>
<td>84</td>
<td>23</td>
<td>73</td>
<td>180</td>
</tr>
<tr>
<td>8-9</td>
<td>11,474</td>
<td>11,278</td>
<td>119</td>
<td>18</td>
<td>59</td>
<td>196</td>
</tr>
<tr>
<td>10-11</td>
<td>11,419</td>
<td>11,136</td>
<td>189</td>
<td>30</td>
<td>64</td>
<td>283</td>
</tr>
<tr>
<td>12-14</td>
<td>20,044</td>
<td>19,176</td>
<td>628</td>
<td>102</td>
<td>138</td>
<td>868</td>
</tr>
<tr>
<td>15</td>
<td>7,841</td>
<td>7,397</td>
<td>334</td>
<td>49</td>
<td>61</td>
<td>444</td>
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<tr>
<td>16-17</td>
<td>18,854</td>
<td>17,596</td>
<td>859</td>
<td>185</td>
<td>214</td>
<td>1,258</td>
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<tr>
<td>All</td>
<td>88,919</td>
<td>85,690</td>
<td>2,213</td>
<td>407</td>
<td>609</td>
<td>3,229</td>
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</tbody>
</table>

Figure 22: % of young people in each group whose health is ‘not good’: England

<table>
<thead>
<tr>
<th>Age Group</th>
<th>% in group whose health is ‘not good’</th>
<th>% Non-carers whose health is ‘not good’</th>
<th>% Caring 1-19 hours with health ‘not good’</th>
<th>% Caring 20-49 hours with health ‘not good’</th>
<th>% Caring 50+ hours with health ‘not good’</th>
<th>% All in caring roles with health ‘not good’</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-7</td>
<td>1.0</td>
<td>1.0</td>
<td>2.2</td>
<td>4.8</td>
<td>10.0</td>
<td>3.5</td>
</tr>
<tr>
<td>8-9</td>
<td>0.9</td>
<td>0.9</td>
<td>2.0</td>
<td>3.2</td>
<td>7.3</td>
<td>2.7</td>
</tr>
<tr>
<td>10-11</td>
<td>0.9</td>
<td>0.9</td>
<td>1.5</td>
<td>2.7</td>
<td>5.2</td>
<td>1.9</td>
</tr>
<tr>
<td>12-14</td>
<td>1.1</td>
<td>1.0</td>
<td>1.7</td>
<td>3.2</td>
<td>5.0</td>
<td>2.0</td>
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<tr>
<td>15</td>
<td>1.3</td>
<td>1.2</td>
<td>2.0</td>
<td>2.9</td>
<td>5.1</td>
<td>2.2</td>
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<tr>
<td>16-17</td>
<td>1.6</td>
<td>1.5</td>
<td>2.1</td>
<td>3.5</td>
<td>6.3</td>
<td>2.6</td>
</tr>
<tr>
<td>All</td>
<td>1.1</td>
<td>1.1</td>
<td>1.9</td>
<td>3.3</td>
<td>6.0</td>
<td>2.3</td>
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</table>
Figure 23: Carers by sex and ethnicity (selected groups): England and Wales

<table>
<thead>
<tr>
<th></th>
<th>% of working age MEN who are carers, by age</th>
<th>% of working age WOMEN who are carers, by age</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>16-29</td>
<td>30-64</td>
</tr>
<tr>
<td>All people</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>White British</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>White Irish</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>White other</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Indian</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Pakistani</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Black Carribean</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Black African</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Chinese</td>
<td>4</td>
<td>6</td>
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</tbody>
</table>

Source: Yeandle et al, CES Report 4, London: Carers UK, Using data from the 2001 Census SARs, Crown Copyright 2004. This work is based on the SARs provided through the Centre for Census and Survey Research of the university of Manchester with the support of ESRC and JISC. Note: The 2001 Census used different ethnicity categories in Scotland, so the data here is for England and Wales only.

Figure 24: Poor health among people aged 45 to state pension age by ethnicity and caring situation

Source: Yeandle, S. and Buckner, L. Carers, Employment and Services: time for a new social contract? London: Carers UK; derived from 2001 Census SARs
Figure 25: Male carers of working age in employment by ethnic group, sex and working hours


Figure 26: Female carers of working age in employment by ethnic group, sex and working hours

Figure 27: Carers of disabled children
Formal Minutes

Monday 21 July 2008

Members present:

Mr Terry Rooney, in the Chair

Miss Anne Begg
Mr Harry Cohen
Mr Oliver Heald
Mr John Howell

Mrs Joan Humble
Mr Tom Levitt
Mr Greg Mulholland

Draft Report (Valuing and supporting carers), proposed by the Chairman, brought up and read.

Ordered, That the Chairman’s draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 365 read and agreed to.

Annexes and Summary agreed to.

Resolved, That the Report be the Fourth Report of the Committee to the House.

Ordered, That the Chairman make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Written evidence was ordered to be reported to the House for printing with the Report, together with written evidence reported and ordered to be published on 30 April.

[Adjourned till Wednesday 8 October at 9.15am]
Witnesses

Wednesday 7 May 2008

Ms Imelda Redmond, Chief Executive, Carers UK, Ms Amanda Batten, Head of Policy and Parliamentary Affairs, National Autistic Society, and Mr Stephen Burke, Chief Executive, Counsel and Care

Ms Philippa Russell, Chair, Standing Commission of Carers

Wednesday 21 May 2008

Ms Vicky Pearlman, Social Policy Officer (Disability, Older People’s Benefits and the Social Fund), Citizens Advice, Mr Gary Vaux, Head of Advice (Benefits and Work), Money Advice Unit, Hertfordshire County Council, Joint Representative for ADASS and LGA, and Ms Sally West, Policy Manager, Income, Consumer and Housing Team, Age Concern

Ms Nicola Brewer, Chief Executive, and Ms Christina Barnes, Policy Head, Economics and Social Inclusion, Equality and Human Rights Commission, Ms Ruth George, Political Officer, USDAW and Ms Caroline Waters, Director, People and Policy, BT Group

Wednesday 18 June 2008

Mrs Anne McGuire MP, Parliamentary Under-Secretary of State (Minister for Disabled People), Department for Work and Pensions and Mr Ivan Lewis MP, Parliamentary Under-Secretary of State (Care Services), Department of Health
# List of written evidence

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<tr>
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<tbody>
<tr>
<td>1</td>
<td>Linda Prestano</td>
<td>57</td>
</tr>
<tr>
<td>2</td>
<td>Danny Hardie</td>
<td>58</td>
</tr>
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<td>Judy Scott Consultants</td>
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<td>Princess Royal Trust for Carers</td>
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<td>Counsel and Care</td>
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<td>Association of Directors of Adult Social Services and the Local Government Association</td>
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<td>7</td>
<td>Citizens Advice</td>
<td>71; 168</td>
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<td>Mental Health Foundation and the Foundation for People with Learning Difficulties</td>
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<td>Care Vouchers Campaign</td>
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<td>17</td>
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<td>National Family Care Network</td>
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<td>Every Disabled Child Matters</td>
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