

Memorandum from Carers UK to Work and Pensions Select Committee
Inquiry into Department for Work and Pensions' approach to carers
April 2008

1. Introduction and summary

1.1 Carers UK welcomes the opportunity to submit evidence to the Committee and congratulates the Committee on choosing to carry out this inquiry. Our overall view of the DWP's approach is that it is working to improve its knowledge and understanding of carers' issues but that considerable improvements are needed, both in policy developments and delivery, to end the disadvantage and inequality faced by carers.

1.2 The Government is currently reviewing its National Strategy for Carers and will launch a revised Strategy later in the spring. The DWP has been closely involved in this process, coordinating two taskforces for the review on income and employment. We hope that the Strategy will be ambitious and wide reaching and will tackle the issues that will be facing families over the next decade and beyond.

1.3 Summary of key recommendations:

- Caring should be understood as a normal part of life and something that most of us will experience at some point. Government policy should aim to reduce the impact of caring so that carers are able to combine caring with normal lives (work, leisure, family life) and enjoy good health.
- Demographic change means that caring is one of the key issues facing our society in the 21st century.
- Many carers go for years without identifying themselves and claiming the support they are entitled to. Benefit simplification and stronger duties to provide information to carers are needed.
- Too many carers are living in poverty. A radical new system of financial support is needed which recognises carers' contribution to society, with an explicit target to end poverty among carers.
- In the meantime, Carer's Allowance should be increased and it should be available to all carers. A taper should be introduced on the earnings limit to incentivise carers to work. Tax credits should be extended to carers working 16 hours per week.
- More affordable, flexible and reliable care services are needed to support carers to work and local authorities should have a duty to ensure they are available.
- Carers should have stronger rights to flexible working, and to time off to deal with a crisis.
- We need a new approach to welfare reform which recognises the unique position of carers. At the moment they are ignored, yet many more carers could work if given the right support.

- Carers should be protected from discrimination in employment and in the provision of goods and services. Public bodies should have a duty to promote equality between carers and non-carers.

2. About Carers UK

- 2.1 Carers UK is the leading organisation representing the views and interests of the six million carers in the UK who care for their frail, disabled or ill family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers UK seeks to end this injustice and will continue to campaign until the true value of carers' contribution to society is recognised and carers receive the practical, financial and emotional support they need.
- 2.2 Carers UK is an organisation of carers, for carers, with a reach of around 1,300 organisations (including over 100 branches, run by carers) who are in touch with around 1,000 carers each, making our potential reach around 1,300,000 people. With additional local organisations signing up to Carers Week each year, we are also often in contact with another 2,000 or so organisations which means a potential overall reach to nearly 3.5 million people.
- 2.3 Carers UK run an information and advice service and advise in excess of 18,500 carers and professionals working with carers every year. We also provide training to over 600 professionals each year.
- 2.4 Carers UK has offices in Wales, Scotland and Northern Ireland and we also run a specific project in London. This response reflects the views of the organisation, UK-wide.

3. Action for Carers and Employment, led by Carers UK

- 3.1 From 2001 until 2007, Carers UK was the lead partner in a European Social Fund EQUAL programme, Action for Carers and Employment (ACE National) which worked to support the inclusion of carers in training and work. It was a highly innovative partnership which was successful in putting carers and employment issues on the policy agenda, as well as looking at practical solutions to the barriers facing carers who want to work. Its partners included key public, private and not-for-profit organisations providing information, advice and guidance on accessing training and work, City&Guilds, the UK's leading accrediting body, a leading group of employers, Employers for Carers, chaired by BT, and an innovative partnership consisting of key public, private and not-for-profit social care service providers and key policy stakeholders such as regulatory bodies, including CSCI, and trade unions. All relevant government departments, including the Department of Health, the Department for Work and Pensions and the then Department for Trade and Industry were also partners. The funding stream has now ended, but partners are committed to continuing their working relationship to take the carers and employment agenda forward.

3.2 ACE National's objectives were: to raise awareness in the widest possible forum of the barriers facing carers who want to work; to develop and test the mechanisms that can support carers to return to, or remain in, work; to mainstream support and have the greatest possible impact on local and national policy on carers and work.

3.3 Key achievements, alongside significant lobbying and campaigning activities, include:

- a comprehensive evidence base on the issues facing carers who want to work, and employers and service providers who want to support them (see bibliography in Annex 1)
- the development of *Learning for Living*, a Level 2 pre-vocational return to work e-learning programme for carers
- information and training resources to support implementation of the Carers (Equal Opportunities) Act 2004 and the Work and Families Act 2006
- the establishment of Employers for Carers, an interest group of employers committed to promoting workplace support for carers – this group is currently developing a national membership platform for employers to support the promotion of carers issues and the development and benchmarking of good practice
- the establishment of Eurocarers, a European lobbying and campaigning platform on carers.

4. Comments on DWP's overall approach to carers

4.1 Carers UK has built up a large evidence base on the disadvantages and inequalities faced by carers. Questions on carers were included in the Census for the first time in 2001, providing invaluable evidence on a national and local level, about the numbers of carers and their characteristics. Since then, we have published a considerable number of research reports arising out of the Census data (see Bibliography in Annex 1). All of our comments are based on this evidence and on our regular consultation with carers. In the last year alone, we have held nine events to involve carers in the review of the National Carers Strategy and have involved thousands through surveys and online consultations.

4.2 We believe that caring should be understood as a normal part of life and something that most of us will experience at some point. Carers should not be ghettoised and we must avoid false assumptions about the sort of people who become carers. We know that many MPs have caring responsibilities, or have had in the past, and would urge Committee members to have in mind the sort of support they would expect for themselves or their families, should they find themselves in this situation.

4.3 Government policy should aim to reduce the impact of caring so that people are able to combine normal life (work, leisure, family life) with caring, without damaging their health or future wellbeing. There must also be an essential safety net for those caring very intensively. There are 1.25 million carers who are providing at least 50 hours of care per week. Most of these carers are unable to work (although a surprising number of carers combine this level of caring and paid work) and are at particular risk of ill health and social exclusion.

- 4.4 Whilst health and social care issues clearly have a huge impact on carers, those related to benefits, employment and equalities are of equal importance. The current Parliamentary Under Secretary (Disabled People) does an admirable job in engaging with carers and representing them in the Department, and we feel a change to her formal title would recognise the importance that the Department places on carers.
- 4.5 Carers UK would like to see the Department for Work and Pensions taking a stronger and more proactive lead in driving Government policy on carers, both at Ministerial and Official level. Currently, 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.
- 4.6 Recommendation: The Parliamentary under-Secretary for Disabled People should be also be given the title of Minister for Carers.**
- 4.7 Carers UK also believes that as well as identifying specific policies to improve the lives of carers, DWP should integrate carers better into its other workstreams, for example its role in reducing child poverty, its efforts to see 80% of working age people in employment, and its vision of giving disabled people equality of opportunity.
- 4.8 Policies cannot look at people in isolation but within the context of their families and relationships. Demographic change means that in the future more families will be required to provide care. In his report for the King's Fund¹, Sir Derek Wanless found that during the next 20 years, the number of people aged 85 and over in England is set to increase by two-thirds, compared with a 10 per cent growth in the overall population. His review also found that over the 20 years to 2025, there will be a 44% increase in the number of older people who do not require care, a 53% increase in those who have some needs and a 53% increase in those with a high level of need.

Evidence and recommendations

In the remainder of this memorandum, we will highlight evidence and make recommendations under the four headings that the Committee highlighted in its press notice.

5. Information, guidance and advice.

Questions posed by Committee:

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?

- 5.1 Caring can start suddenly or build up gradually over time. Some people are thrust into a heavy 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 requires more support or a condition worsens. In total 2.2 million people start caring

¹ Securing Good Care for Older People, King's Fund, 2005

and a similar proportion cease caring². One thing that unites all carers, regardless of the extent of their caring role, is the need for timely and accurate information.

5.2 Carers UK research shows that carers do not identify themselves and many go for years without the support they are entitled to. Research in 2006 found that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring. For a third of them (32%) it took over 5 years before they recognised they were a carer³.

5.3 Although 50% of respondents felt that they had not missed out on benefits, many did. Of those who did, 58% had missed out for over 3 years. A similar proportion of carers felt they missed out on practical support. 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 year⁴.

Quality of DWP service

5.4 Staff on Carers UK's advice line Carersline find the Carer's Allowance Unit helpful, responsive and reasonably well-informed. They are also willing to address gaps in their knowledge when they arise. However the fact that there are sometimes gaps is concerning, since this means that carers may have had benefits incorrectly calculated.

5.5 We support 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.

5.6 Our view is that Jobcentre Plus services are variable, but in general knowledge and understanding among advisers is low. There is too much focus on work-focused interviews and not enough on the things that can make a genuine difference to carers, which are often outside the remit of Jobcentre Plus (see Employment section below for more detail on the remit of Jobcentre Plus). Carers find it insulting when they are forced to give up work to care, often as a last resort after struggling, and then get called for a Work Focused Interview with an adviser who shows little understanding of their circumstances. A more sensitive and informed approach is needed.

5.7 In general, DWP leaflets are of good quality and we welcome having the opportunity to comment on these. There is an issue about these leaflets not containing all the information carers need – for example the earnings limit – and DWP should explore ways to convey this information in a more streamlined way.

Bureaucracy

5.8 Like many other benefit claimants, carers face an excessive burden of form filling in order to access their entitlements. A new carer would need to claim DLA/AA for the person they are caring for, Carer's Allowance for themselves and potentially income

² In the Know, Carers UK, 2006

³ In the Know, Carers UK, 2006

⁴ Caring and Pensioner Poverty, Carers UK 2005

support, Council Tax Benefit and Housing Benefit. They will also need to complete forms to get a Community Care Assessment for the person they care for and a Carer's Assessment for themselves, other forms for Disabled Facilities Grant or other forms of local authority support. They may then face forms to request flexible working.

- 5.9 Carers get frustrated that none of the information that they have completed for benefits claims is passed to any other agencies. Although there are data protection issues, reducing the repetition of information would have considerable benefits for carers.

Working with other agencies

- 5.10 We believe that DWP needs to work better with Department of Health and others who have regular contact with carers, often in the early stages of their caring role. For example, a GP will often be the first person who hears about someone's caring role and this is a crucial opportunity to offer first-tier information and advice. Another vehicle is through local voluntary organisations and support services, through employers and through education establishments. 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.

- 5.11 As described above, there is little cross referencing between the benefits system and Carer's Assessments/Community Care Assessments. This could have benefits in terms of reducing the bureaucracy that carers face, but also in identifying carers who are entitled to additional support.

- 5.12 There is a particular need for advice and support for those who are outside the local authority system, for example those who are not assessed as 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 many local authorities do signpost to further information and support, the quality varies locally and many carers do not think to approach their local authority in the first place.

- 5.13 This situation will be improved by the National Advice and Information Service which the Department of Health agreed to provide as part of the Our Health, Our Care, Our Say White Paper in January 2006. Government is currently tendering for this service which should help join up local and national information.

Complexity

- 5.14 The complexity of many of the rules around carers' entitlements make information harder to convey, and harder for carers to understand and act on. Many carers hear about Carer's Allowance and claim it, but do not know about the full range of benefits they may be entitled to, such as means tested benefits.

- 5.15 When they do claim these benefits, the inherent complexity of the rules leaves carers confused. The anti-intuitive process whereby Carer's Allowance is taken into account as income in the calculation of means-tested benefits leaves carers feeling that they are being given money and having it taken away at the same time.

5.16 The process for carers over 60 to apply for the Carer Addition in Pension Credit is another example of a confusing and contradictory process. Under this process, carers must first apply for Carer's Allowance, be turned down but be given underlying entitlement, then apply for Pension Credit, which they may already have been turned down for but may now be entitled to. Messages which are simpler and easier to understand – for example the incorrect assertion that 'people over 60 cannot claim Carer's Allowance – can easily enter into a carer's consciousness and make the provision of correct information much harder.

5.17 Further complexities which are hard to understand include the earnings limit for Carer's Allowance, for which certain deductions can be made, and the interaction between Carer's Allowance and the Severe Disability Premium.

5.18 **Recommendations:**

- **There should be a simplification of carers benefits, with a single pathway for all carers regardless of age and income (see further recommendations on benefits below)**
- **There should be a joint communications strategy for informing carers about their rights to financial support, and to practical support at a local level. The Government has already announced the creation of a national advice and information service⁵. This service should provide a seamless service with national and local level information and signposting.**
- **All opportunities should be taken to provide information to carers – e.g. proactive questioning by advisers on carers' additional information needs regarding benefits, local authority Assessments and services, and support in other areas.**
- **Carers should have greater access to advocacy support, which helps them access the full range of benefits and other entitlements, such as Carer's Assessments.**
- **There should be a duty on the benefits system, local authorities and health bodies to inform carers about their entitlements in their own area and the others.**
- **There should be a particular duty on Primary Care Trusts (Local Health Boards in Wales) to promote and safeguard the health and welfare of carers; set up systems to identify patients who are carers and ensure that carers have the rights kinds of services and advice to help them to care.**

6. Income and Carer's Allowance

Questions posed by Committee:

What is the impact of caring on carers earning potentials? Do carers receive sufficient support with additional costs as a result of caring? Are benefits and allowances

⁵ http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/DH_075480

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, if so how? Do benefits and allowances impact on carers' pension entitlements, if so how?

6.1 We know that caring has a considerable impact on carers' income. In a survey of 3000 carers, 72% said that they were worse off since becoming a carer⁶. 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 and battling to survive.

6.2 The main reason carers' incomes suffer is because of the additional costs of disability, at the same time as a reduction in income due to giving up work.

Cost of caring and disability

6.3 We do not believe that families receive sufficient compensation for the additional costs of disability. In our survey for the *Real change not short change report*, the additional costs of disability were mentioned by 58% of respondents to our survey, with 49% reporting that the benefits the family received did not cover all the costs of disability. Carers consistently say that they face costs which are not covered by Disability Living Allowance or Attendance Allowance.

6.4 Carers often face huge costs for heating, particularly when caring for a child or elderly person who is at home all day. Other costs can be from washing clothes and bed clothes (a particular problem when caring for someone who is incontinent), special food which people on certain conditions need and transport (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.

6.5 In addition, many disabled people cannot claim DLA or AA. The process is complex, bureaucratic and decisions are often incorrectly made. Nearly half of DLA and AA tribunals are successful – the latest figures show that 55% of oral hearing ruled in favour of the claimant and 29% of paper hearings⁷. Those with mental health conditions can find it particularly hard to claim disability benefits because of the fluctuating nature of their condition, as can those with conditions like autism.

6.6 Contact a Family have demonstrated that families with disabled children are considerably more likely to be poor. Contact a Family and the Family Fund surveyed over 1,800 families with disabled children in 2004 about their experiences of debt ('Debt and Disability' Harrison and Woolley 2004). Only 6.0% of families reported that they were 'comfortably off' with, 92.8% reporting some form of financial difficulty. Contact a Family believes that 50% of families with disabled children do not get DLA, meaning that around 100,000 families are missing out on vital extra support to which they should be entitled.

⁶ Real change not short change, Carers UK, 2007

⁷ Quarterly Appeal Tribunal Statistics: March 2006

Problems combining caring with paid work

- 6.7 We know that for many carers it is impossible, or very difficult, to combine caring with paid work. Yet work is crucial both for carers' income and for the social contact it brings. Around 3 million of the 4.5 million working age carer are in paid work, leaving 1.5 million who are relying solely on benefits. (See employment section below for more information about the problems carers have in combining work and care.)
- 6.8 One in five carers gives up work to care⁸ and Carers UK research found that they 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 position⁹.
- 6.9 The earnings limit provides considerable disincentive to work and traps carers in low paid jobs. For those working in professional occupations, this amounts to just a couple of hours work a week.
- 6.10 Carers are also reluctant to take a job because of concern that if it doesn't work out they will have to go through a lengthy process of re-claiming Carer's Allowance, leaving them with no income in the meantime.

Carer's Allowance

- 6.11 Carers are insulted by the low level of Carer's Allowance. At £48.65 (rising to £50.55 from 7th April) it is the lowest of all so-called income replacement benefits. Carers are forced to claim Income Support to survive, which many resent since they know they are contributing positively to society through providing unpaid care.
- 6.12 We believe that Carer's Allowance is not fit for purpose and does not reflect how society and families have changed since it was introduced in the 1970s. The system of financial support for carers should be much more flexible and should provide recognition of the positive contribution carers make, rather than being seen as an 'income-replacement benefit' which is about what they are not doing (i.e. paid work). It should respond to carers' wishes to move in and out of paid work and to fluctuating patterns of caring. It should recognise that some carers face additional costs of caring and challenges, for example through caring for more than one person. A reformed system of financial support would take into account the sacrifices that carers make and would be enabling, rather than restrictive.
- 6.13 The issue of the overlapping benefit rule for those carers claiming a State Pension is a huge issue for carers and one which will feature regularly in MPs mailboxes. Older carers rightly feel that their contribution as a carer is no longer recognised, despite the fact that they are not able to enjoy their retirement as planned. Many are also struggling to survive on a reduced pension because of years of work missed through caring.
- 6.14 In the meantime, there are many changes which should be made to Carer's Allowance to make it fairer, simpler and better able to support carers in the 21st Century. In the recommendations below, we concentrate on measures which we believe could be relatively easily achieved, as a stepping stone to a radical overhaul of carers' benefits.

⁸ Equal Opportunities Commission survey, 2004

⁹ Out of pocket: a survey of carers' lost earnings, Carers UK, 2007

Other benefits

- 6.15 Not all carers are able to claim Carer's Allowance. This is for a number of reasons: they may not be caring for someone who is claiming middle or higher rate DLA or AA (perhaps because the person is regularly in hospital) or they may choose to claim an alternative benefit because it will leave them better off. Around 450,000 carers are receiving Carer's Allowance, with an additional 350,000 who have underlying entitlement but do not receive it. Many of these will be those claiming a State Pension, but there are also a large number of carers claiming Incapacity Benefit.
- 6.16 However, there are also many thousands of carers who are claiming incapacity benefit (around 500,000 altogether, meaning that a majority don't have underlying entitlement to Carer's Allowance) This means that they not identified and recognised as a carer and therefore are not likely to be receiving the support they need in their caring role.
- 6.17 Carers UK believes that discussions around carers' income and benefits must reflect the wide range of benefits that carers are claiming and not focus exclusively on Carer's Allowance.

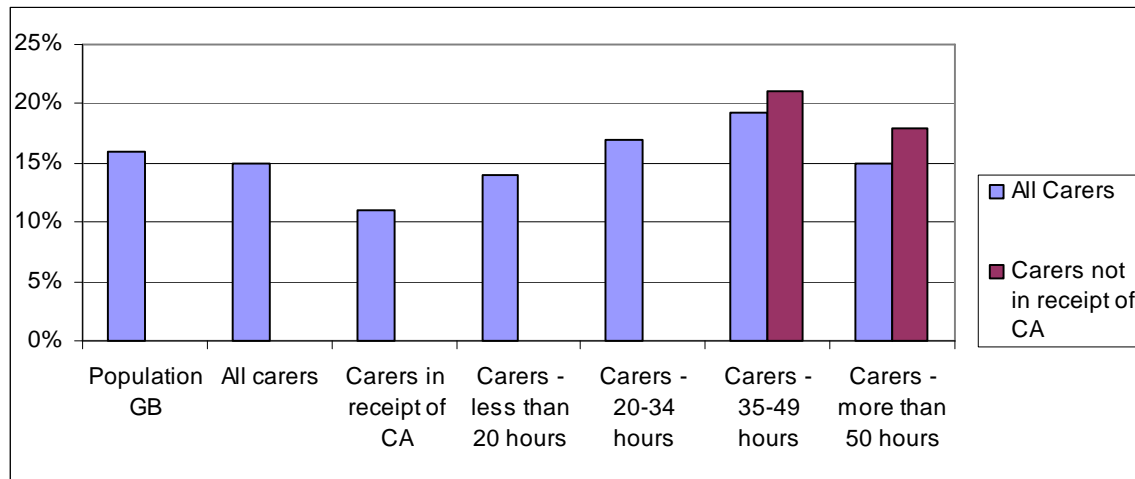
Employment and Support Allowance

- 6.18 We have some general concerns about the introduction of the Employment and Support Allowance (ESA), which will replace Incapacity Benefit from October 2008, in particular that some disabled carers may have to engage in work-related activity which is inappropriate for those with caring responsibilities or else be made worse off.
- 6.19 Our initial reading of the regulations for ESA is that it is clearly expected that disabled carers (i.e. those with underlying entitlement to Carer's Allowance) will engage with the work-focused interview/action plan regime. We are concerned that carers may be forced to attend interviews and undertake work-related activity which is inappropriate given their caring role. In order to gain access to the benefit, disabled carers will have to undertake this process. However, for people with heavy caring responsibilities and no chance of getting back in to work, this will be seen as insulting.
- 6.20 Although they may be able to have their interview deferred (and will be treated as if the plan is being carried out), it is not clear from the regulations that this is the expected path for carers and we will need to ensure that this option is well publicised. Despite this, it is unfair that disabled carers claiming ESA will have to go through this process when those receiving Carer's Allowance do not.
- 6.21 The regulations (regulation 57) specify that when advisers are creating an action plan for a carer, they must take their caring role into account. However, we are concerned because of the limited knowledge and understanding of advisers, disabled carers may be forced or coerced into compulsory activity. The alternative is leaving ESA and receiving Carer's Allowance, which would leave them worse off as they would no longer receive the disability premium.

6.22 We believe that disabled carers should have the option to choose to engage with the new process and undertake work-related activity, but should not be compelled to do so in order to access the higher rates of the benefit.

Poverty amongst carers

6.23 Government evidence¹⁰ on the extent of relative poverty among carers shows that those caring for more than 20 hours per week are more likely to be in poverty than the general population. Those caring 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.



Source: Households Below Average Income series 2004/05

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

6.24 In the past, Government has highlighted figures which show that carers are not considerably more likely to be living poverty than the general population. However we believe that an additional factor that must be considered is carers' inability to move themselves out of poverty without significant additional support, and therefore the potential for this poverty to be longstanding. Living in poverty for many years undoubtedly has an impact on carers' health (and therefore their ability to continue caring) and makes it hard to cope with unforeseen events, such as home repairs. Carers UK believes that this is what distinguishes carers from other groups living in poverty.

6.25 However, we believe that no carers should be living in poverty, given that they are fulfilling an important social function. Government says that it values the work that carers do, yet it has not committed to a targeted anti-poverty strategy for carers. Crucially, an anti-poverty strategy for carers would help Government meet its existing target of eliminating child poverty by 2020 and would have significant social benefits across many families.

Pensions

¹⁰ Households Below Average Income series 2004/05

6.26 The Government has made several improvements to carers' pension entitlements in recent years. The Pensions Act 2007 introduced the Carer's Credit which will provide additional credits to the Basic State Pension and the State Second Pension for those caring for more than 20 hours. This is an important change as it is the first policy which reflects that carers' ability to work is impacted at around 20 hours per week of caring. The reduction in the number of qualifying years for the full state pension to 30 will also benefit many carers.

6.27 It was also groundbreaking in that it now means that someone caring for 30 years receives the same state pension as someone who is in paid work for 30 years. This recognition of the equal status of caring should be replicated elsewhere in Government policy.

6.28 The Pensions Bill currently going through Parliament, and the introduction of a system of Personal Accounts with auto-enrolment and compulsory employer contributions, will also benefit carers since they are more likely to be in low paid, low status jobs which do not have company pension schemes.

6.29 However we do have some continuing concerns about those people who may begin saving in a Personal Account before developing caring responsibilities, which means that their total pot of savings is small and will not take them above the level for Pension Credit. Information and advice for people starting a pension is essential, but caring is often an experience that cannot be predicted. It can start at any point in your life and can have a devastating impact on people's ability to build up pension contributions. We believe that more flexibility should be introduced into Personal Accounts to ensure that even those who only save a small amount reap the benefit of this saving. DWP is currently carrying out a review into these 'pays to save' issues and we hope that this will ultimately lead to further reforms which will benefit carers.

6.30 **Recommendations:**

- **Carers' benefits should be radically overhauled to recognise the contribution carers make and be more flexible to reflect carers' different circumstances.**
- **Government should carry out an extensive review of carers' incomes, identify the specific causes of poverty among carers and commit to a strategy for eliminating it.**
- **In the short term, Carer's Allowance should be changed to a two tier benefit for all carers providing 35 hours care per week, replacing the existing system whereby carers with no other income get Carer's Allowance *and* Income Support.**
- **All carers, irrespective of age and other benefits claimed, should get Carer's Allowance in recognition of the fact they are caring.**
- **Carer's Allowance should remain distinct from other working age benefits. This recognises the unique position of carers in society.**

- The basic level of Carer's Allowance should be raised to the level of the State Pension (£90.70 from April 2008). The second-tier top up for those on a low income (i.e. those who currently get Income Support) should be available in addition to this.
- There should be a trial period when a carer can claim Carer's Allowance and receive earnings over the earnings limit, to encourage them to take a job, safe in the knowledge that if it doesn't work out they will not be worse off.
- Carers should not be penalised for increasing their earnings, leaving them worse off than they were before. There should be a taper on the earnings limit, meaning that carers would no longer lose their entire Carer's Allowance if they earn more than the earnings limit.
- The earnings limit should be increased. Research should be carried out into the numbers of carers earning just more than the earnings limit and struggling to get by, and the numbers earning just within it who are restricting their careers in order to remain there.
- Carers should be able to make more deductions from their earnings when calculating whether their earnings are below the earnings limit. They should be able to deduct 100% of their pension contributions (instead of the current 50%) and all their replacement care costs.
- The rule which prevents carers from studying for more than 21 hours per week whilst claiming Carer's Allowance should be abolished.
- Carers should be able to access tax credits at 16 hours, as disabled people and lone parents can, rather than 30 hours. This would incentivise work and reduce poverty.
- Carers should have access to reduced rates for transport and leisure facilities. Where there are not national schemes, local authorities should introduce discretionary schemes for carers.
- Carers should have access to winter fuel payments and schemes to help pay for other essential utilities, in particular water bills.
- Government should introduce measures to ensure that it always pays to save in to a Personal Account, for example by allowing carers to buy back additional years of contributions to their State Pension at any time. In the long term, Government should consider paying contributions to Personal Account for carers.
- Government should clarify the intended regime for carers claiming Employment and Support Allowance and should exempt disabled carers from compulsory work-focused interviews and work-related activity.

7. Employment strategy and training opportunities.

Questions posed by Committee:

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 together with employers and other Departments to improve support in education, training and skills for carers?

7.1 The 2001 Census showed that there are 4.27 million carers of working age in Great Britain of whom only two thirds are in paid employment. This leaves an estimated 1.5 million carers of working age who are not in employment. Our evidence suggests that carers want to work but are facing significant barriers in being able to do so. Recent research commissioned by Carers UK from the University of Leeds¹¹ found that "significant numbers of carers outside employment want(ed) to work – but were unable to get the support and services they needed to make this possible".

7.2 Despite this desire to work, however, one in five carers gives up work to care, experiencing loss of income, pension and long-term financial security as a result. Such carers are clearly facing serious barriers to combining their caring and employment roles and we believe that any new welfare-to-work strategy needs to give detailed consideration to how to tackle these problems.

7.3 Demographic change and the increased need for care is also coupled with the increased expectation that people will work longer because of later receipt of state pensions and longer life spans. It will be ever more vital, therefore, to ensure that people are better able to balance care and work responsibilities in the future.

The lack of appropriate support services

7.4 One of the major reasons that carers struggle to remain in work is because of a lack of affordable, reliable and flexible care services. Many families receive no social care services because of the difficulty in meeting local authority eligibility criteria and a lack of information and resources to purchase services privately, coupled with an underdeveloped market locally. The Commission for Social Care Inspection recently published estimates of the shortfall of care – i.e. 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 people¹².

7.5 Carers UK research, based on a survey of nearly 2000 carers, showed that most needed at least one type of formal service which they were not currently receiving. Between 40 and 50% of working carers indicated that they felt a lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support¹³.

7.6 Although the Carers (Equal Opportunities) Act 2004 says that a carer's desire to work must be taken into account during their carer's assessment, this is not

¹¹ Managing caring and employment, CES Report Series, Carers UK, October 2007

¹² The state of social care in England 2006-07, CSCI, 2008

¹³ Managing care and employment op cit

happening in most local authorities. According to the CSCI¹⁴, just 27% of councils have identified assisting carers with employment opportunities as a specific theme within their strategic vision for social care delivery for carers. Furthermore, only one in three (35%) were able to cite proactive steps that they are taking to support carers with relation to employment and just 4% had linked with employers in their area in their response to the 2004 Act.

7.7 Recent Carers UK research has highlighted a new dilemma. It showed that more than four in ten (42%) of those new to caring said that the person for whom they cared did not want care services¹⁵. This can 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 which look at the support that a family requires as a whole. After all, if the person being cared for does not want a service and this is causing additional problems for the carer, then the local authority should offer the carer a service directly to support their needs. Equally, providers of care services (in the public and private sectors) need to make their services more responsive to disabled and older people's needs.

Support at work

7.8 How carers are treated at work has a significant impact on whether they feel able to juggle work and care and remain in employment. Yet 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'¹⁶.

7.9 Since April 2007 carers have had the right to request flexible working. This was a significant step and was welcomed by Carers UK, however we believe that more must be done to help carers balance their work and caring responsibilities. Currently, the right is only available for those who have worked for their employer for 6 months. We believe extending the right to day one of employment would help carer seeking to return to work.

7.10 Many carers give up work when they face a crisis – either when caring begins or if there is a deterioration in the condition of the person they care for, or if care arrangements break down. Carers often balance a huge number of responsibilities and if one thing breaks down in can cause a major crisis. In many cases the problem may be quickly resolved and the carer regrets giving up work. At the moment, 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 stresses that the leave is not intended to actually provide care, but to make alternative arrangements. In the case of a parent who has just had a stroke, or a child who has had a serious accident, this is simply not appropriate. Carers UK believes that in situations like these, 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.

¹⁴ The state of social care in England 2005-06, CSCI, 2007

¹⁵ Stages and Transitions in the Experience of Caring, CES Report Series, Carers UK, 2007

¹⁶ Managing caring and employment, CES Report Series, Carers UK, 2007

7.11 The sorts of things that employers can do to help carers balance work and care are allowing (and encouraging) flexible working and allowing paid time off for appointments. They should also have a carers' policy, set up a carers' network in the workplace and provide information to carers about additional support that they may be able to access. We appreciate that many employers find it hard to know how to support carers. Carers UK has developed many resources and provide training and consultancy, but we believe assistance should be available on a much wider scale.

Financial support

7.12 The cost of replacement care, lack of tax incentives, and an inflexible benefits system can mean carers are made worse off by working and are trapped on benefits.

7.13 As described in the income section above, the earnings limit for Carer's Allowance creates a 'cliff-edge' which means that carers are trapped in low paid jobs and cannot increase their hours or take a more senior position without losing their entire Carer's Allowance. Likewise, there is no run-on period so a carer may not want to take the risk of a job which they are unsure about. If a carer is going to enter employment or remain in work they need to know that they are better off in work, and that if the job does not work out they will not end up worse off than before.

7.14 If a financial incentive were introduced for carers to return to or remain in work, three in five working age carers (58%) said this would make them more likely to seek employment¹⁷. A third (34%) said that the extra costs of care would outstrip their earnings, meaning that for these carers it would be uneconomical for them to return to work without support for these costs, perhaps in the form of a tax credit. Carers feel it is unfair that lone parents and disabled people can access tax credits at 16 hours, where as 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.

Current approach to employment support

7.15 Carers UK believes that the existing employment support and welfare to work reforms are failing carers. Whilst conditionality would not be appropriate for carers, they are largely ignored and invisible in the system.

7.16 We are disappointed that Government documents on welfare reform, including *In work, better off: next steps to full employment* mention 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 and, as described above, will become an even more significant group in the future. We therefore think it is crucial to provide a more detailed look at the relevant issues regarding carers, employment and benefits as part of the Department's work on welfare reform. In general, carers are referred to in the context of financial support they need while caring, not in relation to measures that would support them to return to work. We believe there is an inherent tension in

¹⁷ Real change not short change, Carers UK, 2007

Government policy between supporting carers to work and supporting them to provide unpaid care which constitutes a contribution of £87 billion to the social economy¹⁸. We believe policy needs to be clearer in stating that this should not be a conflict and that most carers can be supported to combine work and care, without significantly reducing the overall amount of care available and at considerable benefit to the economy and individual families.

7.17 *In work, better off* states that in order to achieve 80% employment 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. Research by Carers UK shows that the number of carers is likely to be significant in all of these groups, either because statistically they will fit into that age category, they have some kind of disability or chronic illness resulting from caring that prevents them from working, or they are a lone parent caring for a sick or disabled child. In order for the Government to meet these targets, therefore, greater consideration needs to be given to identifying, and addressing the needs of, carers within these groups.

7.18 According to official figures, around one fifth of the 2.7 million Incapacity Benefit claimants are also carers and, of this group, around 40% 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 week¹⁹.

7.19 There should also be awareness of the need for:

- Flexibility in timing of employment support to coincide with times when the carer has alternative care
- Alternative care to be provided in the first place to allow carers to participate
- Access to the right advice about alternative care options
- Attention and sensitivity to the unique challenges that carers face including the complexity of the care packages which they often have to manage as well as the uncertainty and unpredictability of outcomes

Education and training

7.20 There are also 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 for young men, and, especially, for young women. Just 10% of young women with significant caring responsibilities (more than 50 hours per week) are in education, compared to 26% of those who are not carers. Amongst those caring 20-49 per week the figure is 16%, showing that a considerable impact is felt 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-carers²⁰.

7.21 Research commissioned by Carers UK has identified that carers are often clustered in low skill, low paid jobs. This may be because they are forced to access

¹⁸ Valuing carers, Carers UK, 2007

¹⁹ In Poor Health – the impact of caring on health, Carers UK, 2004

²⁰ Time for a new social contract? CES Report Series, Carers UK, 2007

work which can fit around their caring responsibilities and, indeed, there is evidence that many carers are working below their potential. It may also relate to a lack of access to training as a result of caring²¹. Furthermore, in a survey of nearly 2000 carers, almost half of those working part-time said they were only in work of this type because of their caring responsibility²².

7.22 We therefore think it is important that Jobcentre Plus, the Learning and Skills Council and other providers prioritise ways of upskilling and reskilling carers to enable them to reach their potential. This would be of benefit also to their families (and household income), employers and to the economy as a whole.

7.23 In the light of this, we are disappointed with the current rules regarding training for carers and would like to see greater attention given to their distinct needs. For example at present someone studying more than 21 hours cannot receive the main carer's benefit, Carer's Allowance. This is an outdated rule in the age of internet and distance learning and acts as a barrier to many vocational as well as non-vocational courses and should be removed. Other key barriers to carers accessing education and training are the cost of courses and the lack of alternative care services.

7.24 As well as removing the restrictions on students claiming Carer's Allowance, there should be a greater focus in exist lifelong learning policy to ensure that carers' needs are met. For example, some carers will already have Level 2 qualifications (GCSEs or equivalent) or Level 3 qualifications, but require training to refresh or update their skills to facilitate a return to the labour market. Confidence is also a major barrier to carers feeling ready to re-enter work, and carers should be encouraged to use their caring experiences in demonstrating their skills and talents.

7.25 **Recommendations:**

- **A new approach to welfare reform which recognises the unique position of carers and the particular challenges they face in returning to work. Government should fund pilots providing intensive, independent support for carers who need help to return to work, focusing on accessing care services, training and support to access flexible working.**
- **As well as immediately increasing the budget for adult care services and conducting a thorough review of the system of social care (as the Government agreed to do in the Comprehensive Spending Review in October 2007), local authorities should offer more innovative and flexible services. Services like telecare can cost less than conventional services and can increase independence for both the carer and the cared for person.**
- **Government should extend the right to request flexible working to all employees, to make flexibility the norm and reduce stigma around requesting flexible working. The right should also be made a day one right, simplifying the process for carers and employers.**

²¹ Who Cares Wins, A report for Carers UK by the Centre for Social Inclusion, Sheffield Hallam University, 2006

²² Managing caring and employment, CES Report Series, Carers UK, 2007

- **Government should set up a dedicated service to help small employers to provide carers who work in SMEs with guidance and support and help the SME to identify options for flexible working and review their business impact.**
- **Government should fund an awareness campaign about the benefits of flexible working, aimed at both employers and carers.**
- **Carers should have the right to a period of time off to deal with a period of crisis, with a right to return their job. This leave should be paid.**
- **Local authorities should have a duty to ensure that sufficient care services are available for carers who wish to work. There should also be a duty to inform carers about these care services.**
- **Government should introduce a scheme of care vouchers which would help working carers to pay for social care services, thus supporting them to remain in work and stimulating the care market so that appropriate services, designed around the needs of working carers, are more available. Analysis by the London School of Economics shows that a cost of £35 million to Exchequer in lost tax and receipts would generate £87 million in additional spend on services²³.**
- **Government should promote policies which will help employers and communities deal with the impact of demographic change. This should be one of the primary objectives of Regional Development Agencies, who should also have an explicit agenda of stimulating of the care market as part of their regeneration agenda, linking to employment, skills, business and health and well-being strategies.**
- **Carers should be a key element in strategic decisions about local services, for example through Local Area Agreements, Local Strategic Partnerships, Local Employment Partnerships and other mechanisms for achieving social change at a local level.**
- **There should be more support when caring ends, to give people time to adjust, ensure they have somewhere to live (for example, when living in the home of the person who they care for) and the support they need to begin the process of finding work.**

8. Equality, recognition and discrimination

Questions posed by Committee:

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)?

²³ www.carevoucherscampaign.co.uk

8.1 Carers UK believes that carers do not feel recognised for what they do, particularly by professionals and by the systems that are supposed to be there to support them. In our survey of 3,000 carers in 2007, they told us 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 have very little reward and are treated as unimportant by some professionals. Even worse, they are often treated as a nuisance by busy professionals. Yet carers are the people who pick up the pieces when things go wrong.

8.2 Carers feel actively discriminated against in the way that services are provided and in employment. Carers report discrimination and harassment in the workplace, which can cause them to give up work or take a job with less discrimination. The way that services are – or are not – being delivered also discriminates against carers. Poor access to services can have a significant impact on carers' health. People with significant caring responsibilities are twice as likely to be in poor health. If they don't get a break, carers are also twice as likely to suffer from mental health problems.²⁴

8.3 Carers from particular groups do not feel that their needs are recognised and certain groups of carers are vulnerable to social exclusion. For example, carers from BME communities such as Bangladeshi and Pakistani carers, younger carers (i.e. aged 18 to 34), parents of disabled children in relation to their own needs, older carers (aged 75 +), those from different religious groups, gay and lesbian carers, people struggling to combine work and care and carers of people with mental illness.

8.4 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 UK²⁵ suggests 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.

8.5 Public bodies - including local authority services, hospitals and other NHS organisations - must take account of the Act's provisions in carrying out their work. This means that they should demonstrate that they have fully and properly considered a carer's needs before making any decisions about what services they can and can't provide. An assumption that the family will provide care, but without

²⁴ In Poor Health, Carers UK, 2004

²⁵ Whose rights are they anyway? Carers and the Human Rights Act, Carers UK, 2006

necessarily having the knowledge, support or understanding about how to do this (and without providing the family with choice or understanding the impact that it will have on all of their lives) is both directly discriminatory against carers and is also a violation of their human rights.

Implications of Sharon Coleman case

8.6 It is clear that if the European Court of Justice follows the Advocate General's opinion and agrees that the EU Directive on Equal Treatment **was** intended to cover those associated with a disabled person, in addition to the disabled person themselves, the implications of the case could be widespread, particularly since the same legal issue applies to the regulations which prevent discrimination on the grounds of age. This might have implications for any Government policies which specify an age limit and mean that many more policies would need to be objectively justified.

8.7 On an individual level, it would mean that employers have to take steps to ensure that carers are treated equally to employees without caring responsibilities. Whilst this would not mean an automatic right to flexibility, employers would have to look at their practices and ensure that they enabled carers to participate equally in the workplace.

8.8 Carers UK believes that Government should not be seen to be forced into giving carers legislative protection by the ruling in this case, but should decide proactively to extend the Single Equality Act to carers and announce it in the National Strategy for Carers.

8.9 Recommendations:

- **Extending legal protection**
Carers UK believes 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 useful precedent.**

We strongly believe 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.

- It recognises the existence of multiple discrimination which many carers face.
- It recognises the realities of people's lives – by 2034 one in three of us is expected to take up caring responsibilities at some point in our lives. It is at such times of our lives – when we are in most need of accessing flexible employment and services – that the issue of protection against discrimination is at its most relevant.

Better recognition and awareness

- **In tandem with the launch of the National Carers Helpline, the Government should commission a national awareness campaign focussing on the contribution and role of carers. The campaign should aim to reach those who may not immediately identify themselves as carers, eg, parents of disabled children and some BME groups.**
- **There should be a consistent use of language to describe carers: *carers* provide unpaid support to a family member, friend or neighbour. Someone who is paid to provide care to someone is a *careworker*.**
- **There should be a champion for carers in the Cabinet who would take a lead in 'carer-proofing' policies across all Government departments. Similar arrangements should be in place in local authorities (at Councillor and official level) and other public bodies. The champion should be at a senior level.**
- **Carers should be seen as 'partners in care'. The carer will often be the real expert about the person's condition and circumstances and what services will be best. While service providers often think that listening to the carer would be at the expense of the person receiving the care, in our experience that perception is wrong. The carer and the person they care for will usually have exactly the same views and want the same thing from professionals. Listening to the views of the carer should be central to the discussions, rather than them being seen as a secondary concern.**
- **All professionals who have contact with carers, for example those working at Jobcentre Plus, housing offices and other local authority services, should be more aware of the needs of carers. They should have compulsory carer-awareness training which would give them a better understanding of the challenges that carers face and the support they may need to access services. It should also remove misconceptions that they may have about carers, for example that most carers are old (in reality most carers are of working age) or they do not want to undertake paid work.**

9. Other issues

- 9.1 Whilst not raised specifically by the Committee, an analysis of the challenges faced by carers cannot ignore the role of health and social care services. In the context of the work of the DWP, we have already mentioned that health and social care services need to have much greater regard for carers' desire to work, and for them to work more closely with employment services in providing real support for carers wishing to remain in and return to work.

- 9.2 There are other specific reforms which would make a difference to carers and their ability to remain in work and avoid poverty. For example, giving carers more flexibility in making appointments with doctors and other professionals so that they don't have to take too much time off work would benefit both carers and employers.
- 9.3 The Department of Health is currently pushing ahead with a reform agenda in social care which is aimed at personalising services and making them much more responsive to the individual needs of service users and carers. This agenda has huge potential for improving carers' ability to combine work and care and we would urge DWP to ensure that this perspective is heard in cross-Government discussions about the reform of health and social care.
- 9.4 The Department of Health is also undertaking a consultation with the aim of publishing a Green Paper on the future funding of social care. Carers UK is calling for a new settlement for social care which makes it clear what the state will provide and what individuals and families will provide. A clearer, fairer and more generous state system will make it easier for families to provide care, and to combine private funded care with state funded care. This has huge implications for the labour market and for society as a whole.

10. Concluding comments

- 10.1 In this memorandum we have sought to cover a wide range of issues and make recommendations that would make the most difference to carers. There are of course many other problems that carers face and many of the proposals we have made require more detail. We would be happy to provide any additional information the Committee may require.

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Carers UK is registered in England and Wales as a company limited by guarantee number 864097. Registered charity number 246329.

Annex 1. Research bibliography

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 - Report 1: Stages and Transitions in the Experience of Caring
 - Report 2: Managing Caring and Employment
 - Report 3: Diversity in Caring: towards equality for carers
 - Report 4: Carers, Employment and Services in their Local Context
 - Report 5: Action for Carers and Employment
 - Report 6: Carers, Employment and Services: time for a new social contract?
- **Out of Pocket: a survey of carers' lost earnings (2007)**
 - Shows how much working age carers lose out on earnings
- **Real change not short change : time to deliver for carers (2007)**
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- **In the Know (2006)**
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All reports are available for download at www.carersuk.org.