



A New Strategy for Carers: better support for families and carers of older people

Counsel and Care Policy discussion paper 3

October 2007

By Caroline Bernard

A New Strategy for Carers: better support for families and carers of older people

Counsel and Care policy discussion paper 3

Introduction

This is the third in a series of policy papers from Counsel and Care. *A New Strategy for Carers: better support for families and carers of older people* highlights the plight of the families and carers of older people who are often tasked with providing unpaid care. Many of these carers are older, and many of them are female, with existing caring responsibilities for children or grandchildren. As our population ages, there is also a large and growing number of people over 70 providing care to spouses, parents, and older offspring with learning disabilities.

The government announced its Comprehensive Spending Review in October 2007, promising a 'radical rethink' of social care for older people. A green paper on paying for social care is expected next year. And a national carers strategy consultation is underway, which aims to capture the views of carers and those they care for in order to ensure that the new strategy meets the needs of those providing unpaid care in Britain over the next decade and beyond. The new settlement in the Spending Review ought to include provision for better support for carers, through this review of the national carers strategy, in order to ensure that those who provide unpaid care to older people are more recognised and included.

A New Strategy for Carers discusses the problems faced when a sudden crisis occurs, and a new carer has to navigate the system to find the right advice and information, during a time of transition and distress. It will recommend that carers and families be given more time, money and support in their caring role.

Ultimately, this paper calls for carers to be treated as equals in the health and social care partnership agenda.

There is an unpaid army of almost six million carers of adults in the UK today. And of these, one in four people who care for an adult also has dependent children.¹ In order for them to continue in their caring role, they need support, guidance, information and resources. The responsibilities of families are continually increased by the ever-tightening eligibility criteria for social care that mean that many of them have to take on a greater caring role. Far too many carers struggle without claiming the support they are entitled to, often to the detriment of their own health.

The new deal for carers, launched in February 2007, marks a significant development in the improvement of services for the families and carers of older people. The new deal will be delivered by a consultation currently under way, which will inform and extend the 1999 Strategy for Carers, and £25 million of funding will go towards support for carers, including emergency respite support. An Expert Carers Programme will also be set up under the new deal.²

As well as their health, one of the other sacrifices that carers may make is their careers. However, with many carers of older people needing to work, whilst also raising children, it is clear that there is a need to offer flexibility at work. Under the current system, there are major disincentives for carers to choose to work outside the home, as once earnings rise above £95 per week, they are not entitled to receive Carer's Allowance. Whilst this limit increased from £87 from 1 October 2007 as an interim measure, this will still not lift the majority of carers out of poverty.

This paper offers ideas for making life easier for those with caring responsibilities who work, as well as those members of the 'sandwich generation' – middle aged

women with ageing parents and families to support. Many of these women are holding down full-time jobs as well as meeting these caring responsibilities, often not aware that they are entitled to an assessment, and not knowing where to go for advice and information. Carers UK reports that 58% of carers are women, and that 42% are men.³ For carers of any gender, the importance of independent information, advice, and advocacy services are vital in times of crisis. This paper will put forward some of the ways in which positive outcomes, and better holistic support, can be provided for the families and carers of older people, taking a wider approach and providing support at a time of transition.

An additional pressure on older carers is that once they reach pensionable age, pension payments override any Carer's Allowance they may already be receiving. There is a clear case for pensioners to be able to claim Carer's Allowance and the State Retirement Pension, in recognition of the important role of older carers and the savings they make to the health and social care system.

A New Strategy for Carers is made up of three sections. Section One will look at the policy context and the evidence, and will argue that despite the 1999 Strategy for Carers and the Carers Act of 2004, carers are still at a disadvantage, and are not being adequately recognised. The Carers Act aimed to bring about 'a major shift in the way carers are viewed' (Carers Act 2004, in CSCI 2007) but it is clear that attitudes have not changed in the way that the Act envisaged. Clearly, a seismic shift is needed if carers are to be more equally and fairly treated, and better supported and informed in future. The new deal for carers starts this process, but much more needs to be done.

Section Two will offer suggested solutions to improving holistic support for families and carers. These include:

- Independent carers services in every locality providing advice, advocacy,

respite breaks, and support

- A national care advice service: available online and on the telephone
- Making better use of technology to give carers more time for themselves
- Better promotion of flexible working and other employer support for carers who work
- Tax exemptions on care vouchers for carers who work
- Allowing pensioners to claim Carer's Allowance and the State Retirement Pension
- Increasing Carer's Allowance to the same level as the national minimum wage.
- Realising the 'radical rethink' of social care in the forthcoming Green Paper

This section will draw on the experiences of callers to Counsel and Care's advice line, and set out exactly what carers say would help them and the people they care for. Many carers of older people do find it difficult to access reliable information, and there is a real challenge for health and social care professionals to ensure that carers are made aware that they are entitled to a Carer's Assessment, and that the information given does not contravene government policy and guidance.

Section Three sets out some recommendations, reviews the solutions and commitments put forward in the White Paper *Our health, our care, our say*. This section will suggest low cost ways in which these solutions and commitments can be enhanced by existing advice services. It will also suggest that agencies work more closely together in order to ensure that carers services are joined up, responsive, and effective. Like older people, carers do not wish to repeat their story to different agencies - their time is at a premium. Better co-ordination is needed, including joint information sharing systems to enable assessments to be done efficiently.

The Commission for Social Care Inspection *State of Social Care* report makes it clear that the real burden of caring falls upon families and friends of older people, when formal care cannot be accessed. This situation will not change whilst social care services for older and vulnerable people continue to be squeezed by tightening eligibility criteria. Therefore, it will be essential in future that employers, policy makers and other stakeholders work together to ensure that an infrastructure is in place that will ensure flexibility, so that the needs of families and carers are not overlooked as the population continues to age.

Section One: The evidence that families and carers need better support

This section looks in more detail at past and present policy and research. It sets out some of the facts that illustrate that in most cases, it is families who have to take on caring responsibilities for older people, and that there are particular factors which will influence whether a person is likely to become a carer.

Caring About Carers: the missing links

The Carers Strategy of 1999, *Caring About Carers*, recognised the need to address the fact that there were at that time 5.7 million people who were saving the health and social care system more than £50 billion by providing unpaid care to disabled, vulnerable and older people. Today, this figure has grown to £87 billion, as calculated by the University of Leeds for Carers UK.

The 1999 report also states that the average carer is saving the country more than £15,260 per annum.⁴ The terms of reference of the strategy included:

“...to gather examples of best practice in providing help for carers at local level, to assess whether any key needs of carers have been overlooked...”⁵

There was a focus on carers in employment and young carers, with special measures for these two groups. As alluded to in the Introduction, there is a growing number of older carers aged 60 and over caring for the ‘very old’, i.e. those aged 85 and over. In 2001, Help the Aged published a review that suggested that much more could be done to improve the quality of life, and the health of older carers. One of the concerns raised by Help the Aged’s review was that older carers are more likely to experience serious consequences as a result of caring. For example, between 30 and 50 per cent of spouses caring for a person with dementia suffered from depression in the study.⁶ More recently, Carers UK

reports that there are more than 1.5 million people aged 60 and over who provide unpaid care. There are over 8,000 carers who are aged 90 and over, and 4,000 of these people are providing 50 or more hours of care per week.⁷ Compared to people of the same age who do not have caring responsibilities, carers of any age are more likely to be in poor health themselves. And for older carers aged 60 and over who are in paid employment, the health of the carer is more likely to be poor, worsening with the number of hours spent caring per week.⁸

Older carers were mentioned twice in the 1999 strategy, once in the context of defining where the caring role starts and finishes, and again in connection with telephone helplines for specific groups.

Given the number of carers aged from 45-64 (one in five of this group is providing unpaid care), and with a further 13% of the over 65s defining themselves as carers,⁹ this group of older carers is likely to increase as the population ages. It is clear therefore that any new strategy for carers will need to address the needs of older carers as well as their families and friends who support them in their role. Another very important group of older carers are those who look after adult offspring with learning disabilities. Such carers begin their lives as carers with a disabled child, and then go through the inevitable transition where they themselves are becoming older along with their son or daughter. With more learning disabled people living longer, emotional support for parent carers is crucial; they will have fears about their own mortality, and about who will care for their son or daughter after their death.

By the same token, end of life issues for carers need to be more openly discussed. When the caring role comes to an end when the cared for person dies, bereavement counselling and further emotional support have to be in place, particularly when the carer has structured their entire life around the cared-for

person. The new carers strategy will need to be linked with the new End of Life Care Strategy to enable the provision of such support.

The 1999 carers strategy identified what support would help carers:

- Time off from their caring role
- Relief from isolation, help from family and friends
- Reliable and satisfactory services
- Information
- Recognition of their role and contribution.

Eight years on, carers are still waiting for these support elements to be fully delivered. And although services for carers have begun to improve, there is a need to be smarter about the types of support that would actually make a real difference to carers' lives. The impact on carers is well documented: Carers UK has highlighted the damage to financial independence, health risks, social isolation, and the lack of support that carers face.

Research published by Carers UK undertaken by the University of Leeds has produced a series of reports. The first of these reports highlights key issues for 'new' carers. These include:

- A lack of information
- Feeling confused and unsupported
- Problems communicating with health and social care professionals
- Problems combining work and care.¹⁰

An earlier survey by Carers UK found that:

- 72% of carers are worse off as a result of their caring role. This rose to 83% of

carers aged 45-64

- 54% of carers have given up work to care full time
- 49% have to subsidise the costs of caring because of inadequate benefits
- 62% of those surveyed have concerns about their financial circumstances
- And 53% of respondents say that these concerns are affecting their health.¹¹

Clearly, support elements such as those set out in 1999 ought to be enhanced by more practical measures. The new strategy will need to show clear targets and milestones to improve support for carers and families. Counsel and Care's first policy paper in this series, *Fit for the Future*, called for a range of solutions that expand on pledges of the 1999 strategy:

- Tax exemptions on care vouchers for carers who work and care for an adult
- For pensioners to be able to claim Carer's Allowance as well as their state retirement pension, as opposed to having it taken away once they reach pensionable age
- A carers emergency scheme in every local authority
- Better respite provision for carers
- An increase in Carer's Allowance to at least the level of the minimum wage.¹²

This would start the process of providing well-rounded services for carers, that recognise the serious impact of caring on their own lives, and the risks they take on their own financial security in older age as they miss out on pension schemes and other benefits enjoyed by those who work outside the home.

Providing support for families and carers is about more than providing respite, important as this aspect of caring is. One of the things carers said in a Commission for Social Care Inspection (CSCI) survey cited in *The State of Social Care 2005-06*, is that they wanted time to be themselves. Carers do not always define themselves as such, particularly when looking after a close friend, a spouse

or a parent. In these instances, caring is done for love and/or out of a sense of duty. Carers need a life beyond their caring role, and any support given to them needs to take a holistic approach. Local authorities need to be innovative and learn from existing research and best practice. By bringing together their own expertise, that of carers of older people themselves, the experience of third sector providers of carers' services and that of other health and social care professionals, they can support the development of high quality, appropriate and accessible local carers' services. CSCI found that only 20% of councils are taking a strategic approach to meeting carers' needs,¹³ so it is clear that there is need for a rethink. Local authorities need to reprioritise their services to take in this growing group of people.

Ultimately, carers want to be recognised and treated as equal partners with health and social care professionals, and this is where an Expert Carers Programme, as mooted as part of the New Deal for Carers and the health and social care White Paper *Our health, our care, our say*, will make a difference, if it is properly implemented and reaches more hidden carers.

As stated earlier, 24% of adults aged 45-64 are carers. Whilst male carers should not be alienated, there is an unavoidable gender issue that arises when the evidence around the likelihood of caring is examined, primarily because women are traditionally the main caregivers. Carers UK reports that women have a 50/50 chance of having substantial caring responsibilities by the time they are 59. Men can expect to have the same responsibilities at the age of 74. And over a lifetime, 70% of women will be carers.¹⁴ The number of carers is forecast to rise from six million today, to 9.1 million by 2037.¹⁵

In an article marking the launch of *The Business of Care*, a three year project by the think tank Demos, Hannah Green highlights the facts that women, who are clearly the primary caregivers as parents, make up half the workforce, and that

there are more working adults taking care of older relatives as well as children. Given that the number of older people with social care needs is set to increase to 1.2 million over the next 20 years, the potential impact on working age adults who care across the generations needs to be thought through in terms of support and access to information.¹⁶

According to Jane Lewis of the London School of Economics, unpaid work in the home (including caring) is seen to be a part of the private sphere, and is not considered when making policies that encourage more carers to work. Lewis refers to the issue of the demise of the traditional 'male breadwinner model' as being the key piece of evidence of a shift in care models. Historically, the male breadwinner supported women to undertake unpaid care of children in the home, but with more women participating in the labour market, this model has become out of date. Lewis sees the main issues for carers as being (i) time, (ii) money, and (iii) accessible, affordable services.¹⁷ These link well with Counsel and Care's call for more time, money, and support for carers, and, according to Lewis, a wide range of policy solutions will be needed to address these issues.

Balancing work and caring

The second report by Carers UK and the University of Leeds found that many carers in their study would prefer to stay in work, however, more than a third of participants had considered giving up work in order to care. Of those working part-time, almost half reported that they worked part-time due to their caring responsibilities. And most of the carers agreed that caring affected their work.¹⁸ Clearly, then, finding ways of helping carers balance work and caring responsibilities is crucial if these challenges are to be addressed.

Research by the London School of Economics has provided the evidence that tax breaks would help carers balance their roles as employees with their caring role. By using tax exemptions for care vouchers for adults in the same way that is

currently available for childcare, carers could purchase a range of practical support and services - such as additional home care, chiropody, and home repairs - and additional funding would be made available for older and disabled people, thus freeing up more time for carers who need to work. The research finds that by investing just £37 million, government could generate an extra £83 million for care services, and this amount could pay for 5.5 million additional hours of home care.¹⁹

The issue of participation in the labour market is equally as important when assessing one's chances of becoming a carer. Many carers have had to give up full-time work - in 1996 the Caring Costs Alliance found in a survey that half the participants had given up work in order to care, and one-fifth had not been able to start a career due to caring responsibilities.²⁰ If it is taken into account that there is a large caring group aged 45-64, many of these carers who work will be in senior roles and may have to take early retirement when they may have wished to work for longer, thus giving up their careers. Once the caring role has ended, it is difficult for these people to return to the workplace at the same level at which they left, as they may have lost confidence and business acumen. Caring can therefore mean a loss of experience to employers – which is one of the reasons why more support needs to be given to carers who wish to continue working.

The 'costs of caring' are clearly financial, but also emotional – the decision to take early retirement can have a permanent effect on the future of a carer, if they are unable to achieve the same earning power that they had before they gave up work, or reduced their working hours. There are also barriers to receiving benefits that impact on carers' ability and incentive to work. Working Families set this out in their report *Poverty in Work*:

Carers face particular problems in finding work that is worthwhile because of the

interaction of work and benefits. The Carer's Allowance (currently £48.65 per week for the claimant) stops immediately an employee earns more than £95 per week net. This creates a disincentive to work...It also makes it difficult for an employee in receipt of Carer's Allowance to be flexible: working a few hours extra hours when the workload is heavy may actually leave a carer out of pocket..²¹

Campaigners for working carers have shared with Counsel and Care concerns about the government's 'back to work' agenda, which does not take sufficient account of carers' rights. For example, carers are often expected to claim Carer's Allowance as they cease work, whilst at the same time completing forms to join back to work schemes.

Tightening criteria and diversity of the caring role

Further pressures on carers prevail when local authorities only provide care to those with 'substantial' or 'critical' needs. When informal care breaks down, due to the carer's own health failing, or simply because they no longer wish to undertake the care through lack of support, this then leads to emergency intervention when the older person reaches crisis point.²² Obtaining local authority funded care remains a postcode lottery, as budgets are slashed, and the needs of older people and their carers are not matched by local investment. Evidence presented in the Wanless review of social care for older people suggests that the cost of locally provided carers' support such as daycare, respite care, and social worker support/counselling does have substantial benefits.²³

Care Contradictions: higher charges and fewer services, Counsel and Care's 2007 survey of local government criteria, also found that more older people are forced to rely on families and carers for basic care and support.²⁴ *Care Contradictions 2007* recommended a more strategic approach to funding and commissioning of services to address the 'care gap' where the older population is growing but

fewer people are receiving care. It also calls for better funding of preventative services, and for more independent advice and information for older people, their families and carers, to enable them to navigate the social care system. For families and carers, access to advice is crucial, as becoming a carer does not always happen over a long period of time - you can wake up one morning and discover that you have become a carer overnight. And this is where independent advice services are crucial in addressing the care gap.

Therefore, at a local level, carers' needs must be taken more seriously. *The State of Social Care* reports that only 20% of local authorities had a carers' strategy in place.²⁵ This should give cause for concern, given that the 1999 national strategy aimed to ensure that the needs of carers are met at a local level. Clearly, there are pressures and a focus on standards and performance that have perhaps got in the way of progress. The new deal for carers and the updated strategy that follows will have to address the need for investment in sustaining and developing high quality support, tailored to meet the local needs of families and carers as a priority.

Carers are themselves a diverse group, and the caring role itself differs from one carer to another. There are important issues around different cultural groups and traditional caring roles. The third report in the series by the University of Leeds for Carers UK looked at non-white ethnic groups and found that they were more likely to have financial problems.²⁶ Some cultural groups do not have an expectation of support for caring, because they do not see it as separate from their family duties. Any new strategy for carers must address this and suggest ways of reaching hidden carers from different ethnic groups who are less likely to self identify and therefore miss out on benefits and support.

The report also looked at carers in rural and urban areas, and found that carers living in rural areas cited limited choice of services among the challenges they

face, as well as the predictable issues about travelling to and from services. For many rural carers, suitable services are less likely to be available locally.²⁷

Another key group of carers is those who provide care for people with dementia. At a global level, the *Lancet* reports that in 2003, dementia contributed 11.2% of years lived with disability for over 60s, which is more than stroke at 9.5%, musculoskeletal disorders at 8.9%, and cancer at 2.4%.²⁸ Nationally, the Social Care Institute for Excellence (SCIE) estimates that there are around 700,000 people with dementia in the UK today (and this figure is expected to increase to one million), with about one million people who care for them. The vast majority of these carers are family members. SCIE correctly asserts that carers of people with dementia are one of the most vulnerable carer groups, as they care under a great deal of pressure, often experience feelings of guilt, and tend to ignore their own health problems.²⁹

A film shown in August 2007 on ITV1 charted the story of Malcolm Pointon, a person with Alzheimer's who was cared for by his wife Barbara until his death in February 2007. Following the programme, Mrs Pointon published a 'wish list' of things that would, in her view, improve services for people with dementia as well as their families and carers.³⁰ One of the things highlighted was 'stronger carer support – including free regular respite care as of right (not just at times of crisis)'.³¹ The items on Mrs Pointon's list would no doubt benefit all carers, and it is hoped that government will take the comments made into consideration as they develop both a new strategy for carers and the new strategy for dementia announced by the Care Services Minister in August 2007.

A recent report by the National Audit Office (NAO) raised concerns about the low number of carers receiving assessments (only 32%), and those receiving respite care. The NAO set up a web forum for carers of people with dementia, which found that 17% of respondents who had requested respite care were told

that no respite care was available. More worrying is the finding in the NAO survey that 41% of GPs said that there was no carer support group in their locality, with a further 16% stating that they did not know of a carer support group.³²

This brings the discussion back to the overall concern that carers are not being sufficiently recognised for the important role they play. The forthcoming Green Paper on paying for social care promises to examine the balance of responsibility between the individual, the family and the state with regard to care, but there is also a need to reiterate that were it not for the work of unpaid carers, the care system would collapse in Britain today. Carers and families have had to fight to have their needs recognised, and to receive assessments, and entitlements. Many older people who are cared for at home do not receive NHS-funded Continuing Care, and Counsel and Care has had examples of callers who have been told that claiming Carer's Allowance would mean that their relative would have their income reduced. The case studies that follow serve to illustrate these problems in the carer experience.

A more strategic approach needs to be taken towards providing better support to carers and families, and involving carers as key partners in the delivery of health and social care. The next section looks at some solutions and practical measures that could facilitate this.

Case Studies: The challenges faced by carers

For many years, Mrs A was the full-time carer for her husband, who had had a stroke and suffered bleeding on the brain. Unfortunately, Mrs A then suffered a stroke herself. Her daughter, Ms A, contacted Counsel and Care with her concerns about how her parents would manage. She wanted to leave her job and see if she could care for her parents on a full-time basis. She was upset to hear that if she tried to claim Carer's Allowance for looking after them, it would mean her parents' weekly income would be reduced: one of her parents would lose their entitlement to receive Severe Disability Premium. She was also surprised that it was lower than Job Seekers Allowance: £59.15 to £48.65 per week. Ms A felt that she wouldn't be able to leave full time employment and rely on state services.

Mr H is 82 and has repeated falls, following a brain operation. His wife is 79 and is his main carer. She has had repeated problems in obtaining a carer's assessment from her local council to look at how she can be supported to continue with her life outside of her caring role. Mr H was discharged home from a falls clinic without any respite care in place. Mrs H managed to set up two hours sit-in service a week with a local voluntary organisation, but did not hear anything from her local council. Only when her son stepped in and supported her with writing a letter of complaint about the delay and lack of services, did she finally receive an assessment.

Section Two: Improving holistic support for families and carers

This section sets out some possible ways in which better support can be given to families and carers. It takes into account what the family members and carers who contact Counsel and Care’s advice service say they need in order to perform their caring role better.

The Wanless social care review, *Securing Good Care for Older People*, looked at the provision and effectiveness of existing carer support services. Apart from respite care services, there was no one type of service that produced a high level of benefit to carers. Wanless’s analysis is summarised below in Table 1.

Table 1: Carer Support Services: Provision and Effectiveness

Type of service	Current provision	Effectiveness
Respite care and short breaks from caring: day care, at home respite, mixed carer support	<ul style="list-style-type: none"> This service is the most widely used, however only a minority of councils provide good respite support Wide variation in amount, source and type available 	<ul style="list-style-type: none"> Evidence of positive impact on carers’ levels of stress and overall health Psychological comfort which enhances carers’ well being Produces high levels of satisfaction
Carers’ support groups	<ul style="list-style-type: none"> Varied providers and availability 	<ul style="list-style-type: none"> No conclusive evidence
Social work and counselling support	<ul style="list-style-type: none"> Received by a minority of carers 	<ul style="list-style-type: none"> Reduces carer burden Relieves carer stress Can reduce psychological problems in carers
Further formal care services to older people	<ul style="list-style-type: none"> Targeted at older people who live alone rather than those with carers Increasing focus on personal care 	<ul style="list-style-type: none"> Reduces carer stress (less well than above services) Can postpone or reduce rates of institutionalisation amongst recipients of care
Multi-dimensional approaches e.g. community care packages	<ul style="list-style-type: none"> Depends on care managers – most carers in the UK do not have access to care management 	<ul style="list-style-type: none"> Dependent on what services are included Can in some circumstances reduce carer burden and depression Can increase carer stress

Source: Wanless, D (2006) *Securing Good Care for Older People* ³³

What is alarming about the above analysis by Wanless is that it makes it clear that the provision for each type of support service for carers is either patchy, not actually for carers, or is uncertain and dependent on whether there is sufficient access in a particular area. According to this comparison, respite care is the most effective support that carers currently receive, however it is not universally available. The pledge in *Our health, our care, our say* that respite support for carers is to be developed in each council area is welcome, but it does not go far enough, as it will only apply in emergency or crisis situations. Carers need to be able to maintain a social life, take holidays, and do the things they enjoyed prior to becoming a carer. Therefore, respite services need to be available on a regular basis, and not just when the carer has reached breaking point.

Carer's Allowance

The provision of Carer's Allowance can become complicated for both the carer and the cared for person. When a carer is eligible to receive Carer's Allowance, the person they care for loses their severe disability premium from their Pension Guarantee Credit. Policies such as this, together with the overriding of Carers Allowance by State Retirement Pension once the carer reaches 65, suggests that government are 'giving with one hand and taking away with the other'. The aforementioned disincentives to carers who wish to work further bear this out.

Carers' Assessments

The need for carers' assessments, and access to advice and information so that carers are fully aware of their entitlements, are just two of the reasons why it is important that all local authorities are given a duty to develop a carers strategy. Awareness raising in communities about the type of support available to carers locally needs to take place as a matter of course, with councils working alongside voluntary and community groups who, through their networks, can link with carers in the community who may be unaware of their right to an assessment, and who may not necessarily define themselves as carers. Emotional support

such as counselling services and workshops for carers are also important aspects of service provision for carers.

Direct Payments and Individual Budgets

Direct Payments and Individual Budgets (IBs) are another way in which carers can help themselves perform their role. For carers who are becoming frail themselves and have social care needs, the use of a Direct Payment or Individual Budget can make the difference between remaining independent and able to care, if this is the carer's choice.

Mr S, a full time carer to his wife, and increasingly frail himself, uses an IB of less than £35 per week to employ a male personal assistant to take him out for a walk twice a week, give him a bit of male company, and help him with the DIY tasks he can no longer perform.

Source: CSIP (May 2007) Older People's Services and Individual Budgets: Good Practice – Examples and Ideas.³⁴

Counsel and Care's own brief and complete guides to using Direct Payments, *Keeping Control*, advise carers on how they can make use of Direct Payments:

If you live in England and Wales, Direct Payments are also available to carers. Carers can have an assessment of their needs carried out to see if they may be eligible. Direct Payments enable carers to purchase services they are assessed as needing to support them in their caring role and to maintain their own health and wellbeing, such as respite breaks, day care and sit-in services.

If you live in Scotland, while carers can have an assessment of their ability to care and what resources they need to continue in their caring role, they have no entitlement to receive services or Direct Payments in their own right.

Source: Keeping Control: Complete Direct Payment Guide for people over 65.³⁵

Making it easier for carers to care

Counsel and Care made the following recommendations in *Fit for the Future*³⁶ to 'make it easier for carers to care'. These are revisited here with some further options for improving and supporting the role of families and carers.

- Independent care advisers in every locality, providing advocacy and practical support
- A national care advice service: available online and on the telephone
- Making better use of technology to give carers more time for themselves
- Better promotion of flexible working and other employer support for carers who work
- Tax exemptions on care vouchers for carers who work
- Allowing pensioners to claim and receive Carer's Allowance
- Increasing Carer's Allowance to the same level as the minimum wage
- Promoting Direct Payments for carers as well as for the cared for
- Respite care at home, not just within care homes
- Better funding and provision of basic practical support services for carers
- Realising the 'radical rethink' of social care in the forthcoming Green Paper

What families and carers tell us

What families and carers want is to be able to make informed choices about whether and how they take on a caring role, recognition by others of their role, and acknowledgement that it can change over time. Carers also need adequate and appropriate support, including financial support, in order to carry out the role. Ultimately, it is time, money, support and *choice* that carers need in order to carry out their caring role. Below are set out some of the areas that callers to Counsel and Care's advice line say need to be improved for carers and the older people they care for.

Carers need:

- To be included, listened to and kept informed at all times about the assessment and care package of the person being cared for, so that they can manage their time, and make arrangements to be present at assessments.
- To be told of their entitlement to a Carer's Assessment, and to receive the level of day care that the cared for person has been assessed as needing.
- To be given more support in locating and choosing a care home with all information about the need for third party top-ups given at the start of the process. Many carers are given a list of care homes to choose from, and then are told their relative can only go there if the carer pays an additional sum toward the fees. These top-ups can amount to as much as £200 a week.³⁷
- Better access to information about the full range of housing options, eg extra care, sheltered, retirement village, 'staying put' with home adaptations. Housing advice for resident carers living with older relatives who own their home is also needed.
- To have financial disincentives removed so that carers are not penalised for seeking paid work beyond their caring role.
- Better support when the caring role comes to an end.
- To be provided with copies of assessments/care plans without access being denied, allegedly because it is not allowed under the Data Protection Act, despite the fact that they are being asked to provide some of the care that is needed.
- To be given accurate information by health and social care professionals.

Whilst it is understood that the general practitioner's role is purely diagnostic, information from them on where to seek advice on care and support saves members of the public time and money spent searching for reliable information sources. Local authorities need to ensure that their staff do not give information that is in complete contravention of government policy and guidelines.

- Not to fear being seen as 'trouble makers' if they raise concerns or make complaints on behalf of the person they care for.
- Better joint working between health and social care so that the carer is not passed between one and the other.
- Free dental and eye care.
- Better and free respite care.

Moving to a care home: challenges for carers

Many carers are told that their relative must go into a care home because the council has set the care home fee at a rate that is too low. This is often used as a way of limiting the cost of the care package that the person needs in order to return home from hospital. Local authorities are empowered to charge for children's residential care under the Children's Act 1989, but are not obliged to do so. The National Assistance Act of 1948 obliges local authorities to charge for adult residential care. In addition, whilst a parent or carer cannot be charged for residential accommodation if they are in receipt of child tax credit and other benefits, older people on Pension Guarantee Credit must be charged.³⁸

People being cared for need:

- Better practical support services. Many disabled people would like to continue managing their own personal care, but the effort of carrying this out means they have little energy left to undertake household tasks such as making their bed, cleaning, emptying rubbish, gardening, and preparing nourishing meals.
- More funding and access to help with home maintenance is also needed both for carers and those they care for. Government help in this area has continued to diminish, which does not fit with the direction towards more older people living at home with support, for as long as possible.
- A choice of respite care. Much of this is provided in closed local authority care homes, which are still very institutional and basic in their style. The provision of respite care in one's own home is almost non-existent.
- Access to and funding for disability equipment. Counsel and Care receives many requests for charitable funding towards assessed needs such as raiser/recliner chairs or stair lifts. However, the barrier is often a lack of immediate funding.

In general, older people who care and are cared for also need to see better joint working between departments. For example, disability benefit departments ought to work more closely with the Pension Service. If a disabled person is awarded a disability benefit, and has just become entitled to Pension Guarantee Credit, this should be communicated between the departments, but this does not always take place. Callers to Counsel and Care's advice line have reported that they are expected to contact the Pension Service themselves to check their entitlements. As a result, many disabled people lose out on disability, Council

Tax and Housing Benefit.

Better, reliable services for the person being cared for ultimately provide benefits in turn for carers. The more 'joined up' services for carers and cared for become, the closer we can move towards a 'win-win' situation for both carers and those they care for.

Section Three: Recommendations and Conclusions

This final section reviews progress of the commitments made to carers in the health and social care White Paper *Our health, our care, our say*, and makes recommendations to government as to what the new carers strategy should look like.

The proposed New Deal for Carers as set out in *Our health, our care, our say* will consist of:

- **An updated national strategy for carers** which will be cross-government, promoting the well-being of carers, reflecting the development of current carers' rights, direct payments regulations, carers' grants and assessments. A consultation is taking place with stakeholders to develop this.
- **An information service/helpline for carers**, run by a voluntary organisation. This will be awarded on a tendering basis and will offer a wide range of information to families and carers, from advice on benefit entitlements, to straightforward signposting services to support groups.
- In each local authority area, **short term, home based, emergency respite support for carers**.
- Funding for an **Expert Carers Programme** so that carers can have more choice and control over their own health needs and the needs of those they care for.
- **A national framework for NHS-funded continuing care** that will address current anomalies in eligibility criteria and universalise services across the country.

We recommend that government:

- Recognises the diversity of carers. Carers come from a wide range of groups, and there will be inevitable issues that affect their caring role, such as their age, geographical location, culture, gender, sexuality, ethnicity, and physical ability. These need to be taken into account both in the national strategy, and when developing local carers services.
- Make it beneficial for carers who wish to work to do so. The benefits system that penalises carers for choosing to work needs to change to increase the earnings threshold for Carer's Allowance. Employers must also take responsibility to support their employees with adult caring responsibilities. Tax exemptions on care vouchers are one solution to this problem.
- Addresses the serious financial challenges faced by carers. For example, holidays, which people without full time caring responsibilities take for granted, are what most carers value, and need. However, many carers are unable to afford to take breaks away from home. Many applicants for Counsel and Care's Single Needs Grants are seeking funding for a short break which is helpful both to the carer and the person they are caring for.
- As the population ages, we can expect to see an increase in the number of older carers. It will be essential for government to review benefit rules so that carers are able to claim and receive both Carer's Allowance, and the State Retirement Pension.
- Increase the carer's premium for Income Support/Pension Credit, alongside an increase in Carer's Allowance. An increase in this premium is

needed in order to target increased spending on Carer's Allowance at poorer carers.

- Ensure that the information service/helpline for carers is developed to meet the aforementioned diversity of carers. The service must be accessible to people with sensory impairment, learning disabilities, and to people for whom English is not their first language.
- Ensure that the home based, emergency respite support is universally available, so that carers can access respite services whenever they need to, and not just in emergencies.
- Provide funding so that practical support, such as aids and equipment (e.g. hoists and pressure mattresses) are available when carers and those they care for need them, not in a year's time when the next round of funding becomes available.
- Provide the means and support so that carers are able to maintain their own social networks, their independence, and ultimately, their physical and mental health. The more support that is provided for carers and families, the less strain there will be in the long term on emergency respite care.
- Treat carers as equal stakeholders in the health and social care partnership. The development of the Expert Carers Programme is welcome, as it mirrors the existing Expert Patients programme. The training proposed under the Expert Carers Programme must be comprehensive and include areas such as the benefits that can be derived from the use of technology by carers, for example. Whilst support and training are valuable, this needs to be accompanied by 'real money'. £5

million per year will fund the delivery of the programme, but it will not ensure that the carers themselves are not constantly out of pocket, risk falling into deeper debt, and are unable to enjoy a social life.

- Ensure that local authorities and Primary Care Trusts act upon the messages of the new national framework for NHS funded continuing care. Primary Care Trusts and local authorities have a *duty* to ensure that anyone providing 'regular and substantial' care to an individual is offered an assessment. Telecare should also be included as a standard in the Single Assessment Process.
- Ensure that carers are involved and informed throughout the continuing care process, including decisions around eligibility.

Conclusions

The direction of travel by government as it develops a new strategy for carers is the right one, but a 'steer' from carers themselves, those that they care for, and organisations who deal with carers on a day to day basis will clearly be needed. The Care Services Minister has acknowledged the fact that social care is 'one of the great political and public policy challenges facing this country.'³⁹ Having the government acknowledge this is one thing; however, we need to see clearly what action is to be taken by government to deal with this challenge.

Carers are the bedrock of our social care system – six million people from across the age spectrum, often with their own health needs, are supporting vulnerable people, on an unpaid basis, for 24 hours a day, seven days a week. Carers are saving our economy £87 billion per year - were it not for these people, the system would almost certainly collapse.⁴⁰

The number of carers is set to increase, as the population continues to live for longer. The number of older carers is also set to increase. The new strategy for carers must illustrate an understanding of the risks that carers take; that they may eventually need care themselves, and/or be forced to end the caring arrangement if their own physical or mental health begins to suffer. Improving social care services would be the biggest step forward for carers.

Potential carers must also be given the choice of whether they want to care: it is often presumed that a relative will automatically agree to become a carer, with no contingency plans in place should that relative refuse or be unable to do so.

It will be essential that government allows pensioners to claim and receive Carer's Allowance together with the State Retirement Pension. Carers who also need to work must be supported by their employers and by government, so that they can carry out their caring role without fear that they will experience further financial hardship due to loss of benefits.

The 1999 strategy and the Carers Act 2004 raised awareness of the challenges facing carers, but it did not deliver the changes that are needed even more today and in the future. Finally, governments need to be reminded that carers are not a homogenous group: a new strategy needs to set out a sufficiently wide range of choices to make the 'new deal' work in reality, ensuring that it becomes much easier for carers to care.

References:

- ¹ Maher, J, and Green, H (2002) *Carers 2000*. London, Stationery Office.
- ² Department of Health (2006) *Our health, our care, our say*. DH, London
- ³ Carers UK Ten facts about caring.
www.carersuk.org/Newsandcampaigns/Mediacentre/Tenfactsaboutcaring
- ⁴ Yeandle, S, and Buckner, L (2007) *Valuing Carers – calculating the value of unpaid care*. Carers UK, London
- ⁵ Department of Health (1999) *Caring about Carers: A National Strategy for Carers*. DH, London
- ⁶ Milne A, et al (2001) *Caring in Later Life: Reviewing the role of older carers*. Help the Aged, London
- ⁷ Carers UK and Sheffield Hallam University (2005) *Older Carers in the UK*. Carers UK, London
- ⁸ Op cit.
- ⁹ George, M (2001) *It could be you: a report on the chances of becoming a carer*. Carers UK, London
- ¹⁰ Yeandle, S, et al (2007) *Stages and Transitions in the Experience of Caring*. Carers UK, London
- ¹¹ Carers UK 2007 *Real change, not short change: time to deliver for carers*. Carers UK, London
- ¹² Asato, J. (2006) *Fit for the Future: A new vision for older people's care and support*. Counsel and Care, London
- ¹³ Commission for Social Care Inspection (2007) *The State of Social Care 2005-6*. CSCI, London
- ¹⁴ Op cit.
- ¹⁵ ONS, *Carers 2000*
- ¹⁶ Green, H. (March 2007) Long live the kin. *Guardian Unlimited*
<http://money.guardian.co.uk/worklifebalance/story/0,,2039031,00.html>
- ¹⁷ Lewis, J. *Gender, Ageing and the 'New Social Settlement': The Importance of Developing a Holistic Approach to Care Policies*. *Current Sociology*, 2007;55:271-286

-
- ¹⁸ Yeandle et al (2007) *Managing Caring and Employment*. Carers UK, London
- ¹⁹ Snell, T, Fernandez J, and Bennetts R (2007) *Tax exemptions on care vouchers for working carers: an economic analysis: July 2007*. PSSRU, LSE, London
- ²⁰ Caring Costs (1996) *The true costs of caring*. In Carers UK op cit.
- ²¹ Working Families (2006) *Poverty in Work*. Working Families, London
- ²² Local Government Association CSR07 submission factsheet *Vulnerable people wanting to live healthy independent lives*. LGA, London
- ²³ Pickard, L (2004) *The Effectiveness and Cost-Effectiveness of Support and Services to Informal Carers of Older People*. Audit Commission, London
- ²⁴ Counsel and Care July 2007 *Care Contradictions: higher charges and fewer services*. Counsel and Care, London
- ²⁵ Op cit.
- ²⁶ Yeandle et al (2007) *Diversity in Caring: towards equality for carers*. Carers UK, London
- ²⁷ Yeandle et al op cit.
- ²⁸ World Health Organisation (2003) *World Health Report 2003: Shaping the Future*. WHO, Geneva. In www.thelancet.com Vol 366 December 17/24/31, 2005
- ²⁹ Social Care Institute for Excellence, *Support for carers of people with dementia*. From Social Care Online, in Community Care 12 July 2007
- ³⁰ Pointon, B (August 2007) *Malcolm's Legacy*. Accessed at www.bbc.co.uk
- ³¹ Live Care News website
<http://www.livecarenews.com/admin/pdf/Malcolm%20Legacy.pdf>
- ³² National Audit Office (2007) *Improving services and support for people with dementia*. National Audit Office, London
- ³³ Wanless, D. (2006) *Securing Good Care for Older People: taking a long term view*. Kings Fund, London
- ³⁴ Care Services Improvement Partnership (May 2007) *Older People's Services and Individual Budgets: Good Practice – Examples and Ideas*. CSIP, London

³⁵ Counsel and Care (2007) *Keeping Control: Complete Direct Payment Guide for people over 65*. Counsel and Care, London

³⁶ Op Cit.

³⁷ Department of Health LAC(2004)20 Guidance on National Assistance Act 1948 (Choice of Accommodation) Directions 1992, National Assistance (Residential Accommodation) (Additional Payments and Assessment of resources) (Amendment) (England) Regulations 2001

³⁸ Clements, L (2004) *Community Care and the Law* third edition. Legal Action Group Education and Service Trust Ltd

³⁹ *You and Yours*, 7 May 2007, BBC Radio 4

⁴⁰ Yeandle et al op cit.