

## Research and Library Service Briefing Paper

Paper 52/11 4 March 2011 NIAR 162/165-11

#### Research Team

# Carer's Allowance Bill: Supplementary Briefing for the Committee for Social Development<sup>1</sup>

The following information was requested to assist the Committee for Social Development with the Committee Stage of the Carer's Allowance Bill:

- A summary of the key points of the House of Commons Work and Pensions Select Committee report on provisions for carers and the costing for a two-tier Carer's Allowance (pp1-7);
- An overview of the equivalent of Carer's Allowance in the Republic of Ireland (pp7-10);
- The position in respect of benefit tapers associated with caring (pp10-13);
- Overview of the Dilnot Commission the Commission on Funding for Care and Support in England (pp13-14);
- An Overview of the National Care Service (pp14-16);
- The availability of statutory respite care in the UK (pp16-18); and
- The NI Executive's support programme for young carers (p19-20).

<sup>&</sup>lt;sup>1</sup> It is recommended that this paper is read in conjunction with Northern Ireland Assembly Research Paper 31/08 The Carers Allowance Bill (<a href="https://www.niassembly.gov.uk/io/research/2008/3108.pdf">www.niassembly.gov.uk/io/research/2008/3108.pdf</a>).

## 1 House of Commons Work and Pensions Committee Report – 'Valuing and Supporting Carers'

### Background to the report and terms of reference

The House of Commons Work and Pensions Committee report 'Valuing and Supporting Carers' was published in July 2008<sup>2</sup> in response to the then Labour Government's 10 year vision for carers entitled 'Carer's at the Heart of 21<sup>st</sup> Century Families and Communities'. The 10 year vision set out a wide range of commitments for carers including the provision of advice and information; breaks for carers; improved support from the NHS; and support to help carers' better combine work and care. The Government also stated in the vision that carers would "be supported so that they are not forced into financial hardship by their caring role".

The Work and Pensions Committee at that time expressed disappointment that benefits for carers had not been directly addressed in the Carers Strategy. The Committee believed that the current system of benefits for carers was outdated and recommended the introduction of two distinctive 'tiers' of support for carers which offered (i) income-replacement support for carers unable to work, or working only part-time; and (ii) compensation for the additional costs of caring for all carers in intensive caring roles. The Committee reiterated its call for a two tier system in its July 2009 report 'Tackling Pensioner Poverty'<sup>3</sup>.

Included in the Committee's 'Valuing Carers' Inquiry Terms of Reference was a focus on Income and Carer's Allowance:

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

The Committee felt that in general, The Department for Work and Pensions (DWP) should take a more **strategic approach** to supporting carers which aimed to:

- Support adult carers during their working lives to combine work and care;
- Enable those who wish to return to paid work when caring ends or changes to do so;
- Secure adequate financial support for those who provide care support for those who
  provide care when of working age, either by compensating them for the extra cost of

<sup>&</sup>lt;sup>2</sup> House of Commons Work and Pensions Committee (2008). Valuing and Supporting Carers. Fourth Report of Session 2007-08. www.publications.parliament.uk/pa/cm200708/cmselect/cmworpen/485/485i.pdf

<sup>&</sup>lt;sup>3</sup> House of Commons Work and Pensions Committee (2009) Tackling Pensioner Poverty. Fifth Report. www.publications.parliament.uk/pa/cm200809/cmselect/cmworpen/411/41102.htm

caring, or (if they need to give up work to care) through adequate income replacement and pension protection mechanisms;

- Protect the interests of young carers, ensuring that in caring for family members they are not disadvantaged in accessing opportunities for education, training and employment;
- Provide adequate support for older carers, mitigating the financial strain on those whose pensions have been affected by their caring role; and
- Through a joined up cross governmental approach, ensure that carers are supported in the wider social care system by adequate arrangements to inform them of their rights and entitlements and of how to access an appropriate range of support and services.

### Committee Recommendations - Replacing Carer's Allowance with a Two-Tiered Benefit

The Work and Pensions Committee maintained that Carer's Allowance was an outdated benefit and recommended that carer's benefits should be radically overhauled at the earliest opportunity to recognise the contribution carers make and to be more flexible to reflect carer's different circumstances. The Committee maintained that carers who are not able to work due to their caring responsibilities should be entitled to an income replacement benefit comparable to other income replacement benefits and that the additional payment should recognise the additional costs of caring for one or more people.

The Committee recommended that DWP gave "urgent and detailed consideration" to replacing Carer's Allowance with a **two-tiered benefit for carers**. The Committee suggested that this should operate as follows:

- Carer's Support Allowance: to be paid at the same rate as Jobseekers' Allowance, with the opportunity to earn a modest amount in a paid job (offering reasonable consistency with Carer's Allowance and in line with permitted earnings rules). This would be an income replacement benefit which should not be payable in addition to other income replacement benefits. However, the Committee felt that it was not necessary, nor desirable, to 'means test' Carer's Support Allowance, as carers entitled to receive it would need to be fully occupied by their caring role (i.e. for at least 35 hours per week).
- Caring Costs Payment: available to all carers in intensive caring roles (35+ hours per week, consistent with Carer's Allowance) but payable to those over State Pension age, to compensate them for the additional costs of caring, and/or to enable them to buy in some help, goods or services to ease their caring situation. The Committee recommended that CCP should be set at a level commensurate with other parallel payments in the UK social protection system (e.g. Child Benefit) and that this would make it likely that CCP could be set somewhere between £25 (£1,300 p.a.) and £50 per week (£2,600 p.a.).

The Committee noted that the Australian Commonwealth Government operates a twotier system of carer benefits – Carer Payment and Carer Allowance.

### The Australian Two-Tier Carer Benefits System consists of 4:

<u>Carer Payment:</u> an income-replacement benefit paid to carers, it is means tested on income and assets (apart from the family home) and is paid at the same rate as other social security pensions. The maximum single rate in 2010/11 was \$658.40 per fortnight (equivalent to £412.28); the maximum couples rate was \$496.30 per fortnight (equivalent to £310.81)<sup>5</sup>. The maximum rate is payable for those with assets up to \$160,000 and tapered down to no entitlement for assets over \$800,000. A recipient of Carer Payment can undertake work or study for a maximum of 25 hours per week without losing their entitlement. In addition, recipients of Carer Payment are passported to entitlement to utilities allowance of \$500 per year and a telephone allowance of \$132 per year. To be eligible for Carer Payment a claimant must be providing care in the home of the person(s) being cared for and also be providing one of the following levels of care:

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

Carer Payment cannot be received in addition to other income support payments such as 'Age Pension' or 'Parenting Payment'. However, carers of pensionable age may choose to receive either Carer Payment or Age Pension. There are said to be a number of benefits of opting to remain or switch to Carer Payment, e.g. they are paid at the same rate, Carer Payment includes entitlement to bereavement payment (if the person cared for was a non-partner); respite breaks of up to 63 days per calendar year without affecting payment; eligibility for Carer Supplement (see below)<sup>6</sup>.

<u>Carer Allowance</u>: is an income supplement available to people providing daily care and attention at home to a person who has a disability or severe medical condition. Carers Allowance is not taxable or income and assets tested. It is paid at a rate of \$110.00 per fortnight (2010/11 rate – equivalent to £68.88). Virtually all recipients of Carer Payment are entitled to Carer Allowance. To be eligible for Carer Allowance, a person must be providing care and daily attention to a person with a disability or severe medical condition ( or up to two adults under one persons care) who is either:

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

The person being cared for must be likely to suffer from the disability permanently or for an extended period of at least 12 months (unless their condition is terminal). <u>Carer Allowance can be paid in addition to other income support payments such as state pension.</u>

In addition to Carer Allowance, up to \$600 **Carer Supplement** is give to recipients for each person being cared for. Carer Supplement is an annual, non-indexed, tax free, automatic lump sum payment paid every July to assist in meeting the financial challenges of caring.

<sup>&</sup>lt;sup>4</sup> Unless otherwise stated information in this section has been extracted from Australia Government/Centrelink publication. Disability and Carer Payment Rates 1 January to 19 March 2011.

www.centrelink.gov.au/internet/internet.nsf/filestores/co031\_1101/\$file/co031\_1101en.pdf

<sup>&</sup>lt;sup>5</sup> Recent rates extracted from the Australian Government/Centrelink Paper. Disability and Carer Payment Rates 1 January to 19 March 2011.

<sup>&</sup>lt;sup>6</sup> Centrelink. Carer Payment or Age Pension? www.centrelink.gov.au/internet/internet.nst/.../cd002\_0907.rtf

In response to the Committees recommendation for a two-tier payment system for carers, the then Labour Government stated<sup>7</sup>:

"Carer's Allowance provides a degree of replacement for lost or forgone income to those who have given up the opportunity of full-time work. However Carer's Allowance is not a wage for caring, nor is it intended to provide compensation for the extra costs faced by disabled people. There is a range of other benefits to help with these costs, such as Disability Living Allowance.

Disability Living Allowance is intended to provide a broad-brush contribution towards the extra costs faced by disabled people, in addition to the many other sources of financial and practical assistance available. It remains a valuable benefit, being worth up to £5,915 a year, and is increased annually in line with the Retail Prices Index.

Whilst the Government does not accept the general level of support provided to help with caring and the costs of a disability is inadequate, the Government does accept that the support available to carers does not differentiate sufficiently between the different needs and circumstances of carers. Building a system of support that is able to target resources more effectively to those with the greatest need will be one of the main aims as the Department works towards a better system of support for carers."

A number of organisations also recommended to the Committee that the Carer's Allowance should be raised at least to the same rate as Jobseekers' Allowance (JSA), the level of Employment and Support Allowance (ESA) (support group) and State Pension level. DWP provided the Committee with the following estimated costs of raising Carer's Allowance to these levels (please note that these figures were provided in 2008):

Costs of Raising Carer's Allowance to the same level as JSA, State Pension and ESA

	To equal JSA (at £60.50 pw)	To equal State Pension (at £90.70 pw)	To equal ESA (at £102.10 pw)
Year 1	£149m	£573m	£730m
Year 2	£174m	£652m	£830m
Year 3	£227m	£738m	£935m
Year 4	£240m	£831m	£1050m
Year 5	£254m	£931m	£1175m

(Source: DWP)

<sup>&</sup>lt;sup>7</sup> Work and Pensions Committee (2008) First Special Report – Valuing and Supporting Carers. Government's response. www.publications.parliament.uk/pa/cm200809/cmselect/cmworpen/105/10504.htm

### Some other key recommendations from the report

Outlined in this section are some other key recommendations made by the former Work and Pensions Committee. The adoption of the first three recommendations in Northern Ireland may have parity implications. The last three recommendations, however, (i.e. in respect of older people's access to benefit advice and information; carer's centres and concession cards) are more akin to intervention by the devolved administrations and variations on these recommendations could be considered as a means of assisting all carers, including older people who provide care.

### Carer's Allowance and Overlapping Entitlements

The Committee maintained that the overlapping entitlement rules for Carer's Allowance were confusing and over-complicated. It felt that (particularly for older people) the system of having to apply for a benefit that they are not going to get in order (i.e. Carer's Allowance) in order to be eligible for other benefits (i.e. Pension Credit) is counter intuitive. The Committee recommended that DWP streamline the application process for benefit entitlements for carers of State Pension age.

### **Eligibility and Qualifying Criteria**

The Committee made three recommendations relating to Carer's Allowance eligibility and qualifying criteria:

- That the rule that links one Carer's Allowance claim to one Attendance Allowance/DLA claim provides no recognition for carers who look after more than one disabled person.
- That the eligibility rules for Carer's Allowance do not take into account those who care for more than one person with a disability, none of whom meets the criteria for Carer's Allowance, but who nevertheless face a very substantial demand for care. The Committee called on DWP to examine the case for extending entitlement to Carer's Allowance to those who care for more than one person (e.g. to allow carer's to receive the payment if they care for two or more people who taken alone would not usually qualify them for Carer's Allowance but would in combination).
- Qualifying periods that apply for Attendance Allowance and DLA are problematic for some carers. The Committee believed that there was a case for introducing a fast track procedure for applicants in emergency circumstances.

### The Additional Cost of Disability

The Committee believed that carers receive insufficient recognition and compensation for the additional costs of disability and that carers consistently faced costs that are not covered by Disability Living Allowance or Attendance Allowance. It called on the

Government to commission an independent review of the impact of caring on carer's incomes and of the long-term costs of caring for an older people or someone with a disability. The Committee also stressed that the additional costs incurred by carers need to be recognised in any review of benefits for carers.

### Improving older people's access to benefit information and advice

The Committee felt that health and social care professionals, such as GPs and primary care facilities, are an appropriate initial source of information regarding access to welfare benefits and other support. The Committee recommended the Government should develop a national strategy for giving carers advice on benefits in health care settings. The Royal College of Nursing and Rethink (a mental health membership charity) also supported the suggestion that GPs and nurses maintain a register of carers so that they could be easily identified and referred to appropriate assistance with benefits. Improving older people's access benefits and encouraging uptake is a particularly important given the recent report by the Northern Ireland Audit Office which highlighted the significant level of unclaimed Pension Credit and Housing Benefit amongst older people in Northern Ireland<sup>8</sup>.

#### **Carer's Centres**

As part of the inquiry the Committee visited a number Commonwealth Carelink Centres (CCCs) in Australia. CCCs are information centres for older people, people with disabilities and carers. There are 65 CCCs throughout Australia with 'walk in' shop fronts (operated by public and voluntary organisations) and are located within or near shopping centres. The Committee noted that there is no such network of Carer's Centres in the UK and recommended that the Government took a more strategic approach and established a network of such centres in the UK supported by adequate core funding.

### **Concession Cards**

The Committee noted that in Australia, there was extensive provision made at State and local authority level to provide concessionary rates for carers, e.g. reduced costs medicines; reduction in property, water rates and utility bills; telephone allowance; reduced fares on public transport; reductions in motor vehicle registration. The Committee recommended that the Government follows Australia's good example and proactively negotiates concession cards for carers for travel, parking, leisure and other activities. It also recommended that business and transport operators help carers cope with the financial burden of their responsibilities.

It is worth noting that a number of concessions are available to eligible carer's in the Republic of Ireland. A 'Household Benefits Package' is available which includes an Electricity/Gas Allowance; Bottled Gas Refill Allowance; Telephone Allowance; Free

<sup>&</sup>lt;sup>8</sup> Northern Ireland Audit Office (2011) Uptake of Benefits by Pensioners. www.niauditoffice.gov.uk/pubs/onepress.asp?arc=False&id=251&dm=0&dy=0

Television Licence<sup>9</sup>: This package is available to certain groups, e.g. those aged 70 over, those in receipt of Carer's Allowance. However, it is important to note that the package is means-tested.

## 2 An overview of Carer's Benefits in the Republic of Ireland

There are three main benefits available to carers residing in the Republic of Ireland – Carer's Allowance; Carer's Benefit and Respite Care Grant.

## Carer's Allowance<sup>10</sup>

Carer's Allowance is a means-tested benefit payable to those looking after someone who is in need of support due to age, physical or learning disability, and/or mental illness. Carer's Allowance is only payable to those on low incomes who look after those in need of full-time care. In order to be entitled to Carer's Allowance a person must be:

- Aged 18 years and over;
- Living with, or in a position to provide full-time care and attention to a person in need of care who does not normally live in an institution;
- Resident in the State; and
- Must not be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours per week.

The person cared for must be:

- Over the age of 16 and so incapacitated as to require full-time care and attention<sup>11</sup>;
   or
- Aged under 16 and in receipt of a Domiciliary Care Allowance.

Current Rates of Carer's Allowance are as follows:

Carer	Maximum Weekly Rate	
Aged under 66, caring for one person	€204	
Aged under 66, caring for two persons	€306	
Aged 66 or over and caring for one person	€239	
Aged 66 or over and caring for two persons	€358.50	
Increase for qualified child	€29.80 (full-rate) €14.90 (half-rate)	

<sup>&</sup>lt;sup>9</sup> Information extracted from the Department of Social Protection website [access 1 March 2011] <a href="https://www.welfare.ie/EN/Schemes/HouseholdBenefits/Pages/default.aspx">www.welfare.ie/EN/Schemes/HouseholdBenefits/Pages/default.aspx</a>

<sup>&</sup>lt;sup>10</sup> Information extracted from the Department of Social Protection website [accessed 1 March 2011] www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/CarersAllowance/Pages/ca.aspx

<sup>&</sup>lt;sup>11</sup> A person is regarded as requiring full-time care and attention where he or she is so incapacitated as to require continuous supervision in order to avoid danger to themselves or continual supervision and frequent assistance throughout the day in connection with normal bodily functions; or a person is so incapacitated as to be likely to require full-time care and attention for a period of at least 12 months.

The Carer's Allowance scheme provides a degree of flexibility, e.g. two carers who are providing care on a part-time basis in an established pattern can share a single Carer's Allowance. A person who is providing care on a part-time basis to someone who attends a residential institution (e.g. every other week) can also be accommodated by the Carer's Allowance Scheme.

How are means tested with regard to Carer's Allowance?

The means test for Carer's Allowance involves assessing income (excluding the family home). Since April 2008, the amount of weekly income that is not taken into account is €332.50). In the case of the income of a married or co-habiting couple (except for social welfare payments to which special rules apply) the first €665 of combined weekly income is disregarded.

Since September 2007, a person receiving social welfare payments and providing full-time care can keep their main social welfare payment and **receive half-rate Carer's Allowance** in addition to this. If a person is receiving Carer's Allowance and subsequently becomes entitled to another payment, then the person can claim the other payment and get half-rate Carer's Allowance (if the other payment is a qualifying payment).

Carer's Allowance as a passport to other entitlements

Those who qualify for Carer's Allowance also qualify for a range of other entitlements such as **free household benefits** (e.g. free electricity/Natural Gas/Bottled Gas Refill Allowance, Free Television Allowance, Free Telephone Rental Allowance, Free Travel Pass)<sup>12</sup>. The **Respite Care Grant** (see end of this section for further details) is also automatically paid to those in receipt of Carer's Allowance in June of each year.

### Carer's Benefit<sup>13</sup>

Carer's Benefit is a payment made to insured persons in Ireland who leave the workforce to care for a person or persons in need of full-time care. Carer's Benefit is payable for a total period of 104 weeks for each person being cared for which may be claimed as a single continuous period or in any number of separate periods up to a total of 104 weeks. If caring for more than one person, a payment for each care recipient may be available.

To be eligible for Carer's Benefit, a person must:

Be aged over 16 and under 66;

<sup>&</sup>lt;sup>12</sup> For further information on Household Benefits see <a href="www.welfare.ie/EN/Schemes/HouseholdBenefits/Pages/hb.aspx">www.welfare.ie/EN/Schemes/HouseholdBenefits/Pages/hb.aspx</a>

<sup>&</sup>lt;sup>13</sup> Information extracted from the Department of Social Protection website [accessed 1 March 2011] www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/CarersBenefit/Pages/carb.aspx

Been in employment for at least 8 weeks in the previous 26 weeks before becoming a carer and have worked a minimum of 16 hours per week or 32 hours per fortnight.

- Resident in the State:
- Given up work to be a full time carer (i.e. must be living with or in a position to provide full-time care and attention to a person in need of care who is not living in an institution);
- Meet the Pay Related Social Insurance (PRSI) contribution conditions; and
- Must not be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours per week (since April 2008 the maximum amount a person can earn is €322.50.

The current weekly rates of Carer's Benefit are as follows:

Carer Aged Under 66	Maximum weekly rate	
Caring for one person	€205	
Caring for 2 persons	€307.50	
Increase for each qualified child	€29.80 (full rate), €14.90 (half rate)	

If the person cared for dies, Carer's Benefit will continue for six weeks following the death. An addition to Carer's Benefit an annual Respite Care Grant is available.

A carer's right to leave from employment compliments the Carer's Benefit scheme. Carer's leave allows employees to leave their employment temporarily for a period of up to 104 weeks to provide full-time care. The leave period is unpaid but those who avail of carer's leave will have their jobs kept open for them during the duration of the leave period.

## Respite Care Grant<sup>14</sup>

The Respite Care Grant is an annual payment made to carers who may use the grant in whatever way they wish, e.g. for respite care. The grant of €1,700 is usually paid in June each year and is not taxable. The Department for Social Protection pays the grant automatically to carers receiving benefits such as Carer's Allowance and Carer's Benefit. Only one Respite Care Grant can be paid for each person receiving care. To receive Respite Care Grant a carer must be:

- Aged 16 and over;
- Ordinarily resident in the State;
- Caring for the person on a full-time basis and either living with the person being cared for, or be contactable quickly by a direct system of communication (e.g. by telephone or alarm); and
- Caring for the person for at least six months.

<sup>&</sup>lt;sup>14</sup> Information extracted from the Department of Social Protection website [accessed 11 March 2011] www.welfare.ie/EN/Schemes/IllnessDisabilityAndCaring/Carers/RespiteCareGrant/Pages/respite.aspx

### 3 Benefit tapers associated with caring

Tapering is defined at the rate in which benefits are reduced to take account of earnings. Those receiving Carer's Allowance can only earn up to the earnings limit (currently £100 per week), above this limit all of the Carer's Allowance is lost. The Coalition Government is considering whether changes to Carer's Allowance will be necessary to take account of the introduction of Universal Credit. However, the 'Universal Credit' paper did recognise that the current level and tapering associated with Carer's Allowance has been ineffective in both poverty prevention and in meeting the needs of carers:

"For too long the current system of carer benefits has failed to meet the different needs of carers and has trapped some people on benefits....

Carer's Allowance is paid at a lower rate than other income-replacement benefits (currently £53.90). All governments, since 1976, when Invalid Carer's Allowance was introduced have faced the dilemma that increasing the level of benefit is neither affordable nor cost effective. Hence, Carer's Allowance has stayed at this level, playing an ineffective role, neither effective in poverty prevention nor in meeting the wider needs of carers. We can only deliver proper support for carers with the greatest financial burden by addressing the current confusing interactions between Carer's Allowance and other benefits."<sup>15</sup>

## New Deal for Carers – Recommendations of the Income Task Force Report with respect to Tapering

In 2007 the UK Government launched a review of its 1999 Strategy for Carers. The review was led by the Department of Health and four task forces were set up to consider four different elements – health and social care; equalities; employment; and income. Included in the terms of reference for the Income Taskforce review group was the remit to make recommendations for income-related revisions to the National Carers' Strategy.

The Taskforce published its <u>report</u> in July 2008 and made a number of general critical comments in relation to Carer's Allowance. Specifically, the Taskforce maintained that the allowance<sup>16</sup>:

 Did not pay different rates for the type or intensity of care nor for the number of people care for, and therefore, did not work towards alleviating poverty or recognising the different caring roles;

<sup>&</sup>lt;sup>15</sup> Department for Work and Pensions (2010) Universal Credit: welfare that works, p19. <a href="www.dwp.gov.uk/docs/universal-credit-full-document.pdf">www.dwp.gov.uk/docs/universal-credit-full-document.pdf</a>

<sup>&</sup>lt;sup>16</sup> Income Task Force Report (2008) New Deal for Carers – Income Taskforce Report. www.dh.gov.uk/prod\_consum\_dh/groups/dh\_digitalassets/@dh/@en/documents/digitalasset/dh\_086583.pdf

 Has a complicated and confusing process for claiming the carer increase in Pension Credit and other means-tested benefits; making navigation around the system confusing and frustrating;

- Is a non-means tested benefit and so is not focused on minimising financial hardship;
- Is paid at a lower-level than other 'income maintenance' benefits;
- Had a 'cliff edge' earning limit and a full-time education rule which did not support carers staying in work nor gaining qualifications for future employment;
- By being tied to the benefits that the cared for person receives, and by having the 35 hour rule, the allowance failed to reach a significant number of carers; and
- That the overlapping benefit rule can be confusing and can make it appear that there is no recognition of an individual's caring responsibilities, especially older carers in receipt of Pension Credit.

The Taskforce was very critical of the earnings threshold and in particular the impact on lone income earners and work incentives:

"Above £95 per week [the rate in 2008 when the report was compiled] the entire benefit is withdrawn. There is no distinction between whether the carer is the lone income earner in the household or whether they have a partner on a high income. This differs from income-related benefits and tax credits, which consider household rather than individual income as the testing criteria. Thus the situation can arise that an out of work carer (or one with earnings less than the earnings limit) with a high earning partner can receive Carer's Allowance, whereas even a low-income working single carer cannot.

The fact that CA is immediately withdrawn above an income of £95 per week has implications for work incentives."

The Taskforce recommended introducing a tapering effect into the earnings rule to remove the disincentive effects of the 'cliff edge' cut off point in carers earnings at a rate of a £1 reduction in benefit for each £1extra of earnings above the threshold. In terms of impact the Taskforce estimated that [noting that the report was published in 2008].

"Using a £ for £ taper as an illustrative example, an estimated 25,000 carers could gain initially from an earnings taper. Changing the earnings rule is more likely to benefit carers who are able to do more hours of work, or who have higher incomes, and those who are not also receiving Income Support, income-based ESA or Pension Credit. Introducing an earnings taper could promote equality for disabled people by enabling disabled carers to participate more widely in the labour market, and promote equality for women through enabling carers to increase their hours or pay, thus contributing towards reducing the gender pay gap.

When introduced (year zero) the estimated cost of introducing a £ for £ taper, for example, in Carer's Allowance would be £40 million rising to £60 million by year 5. Other tapers with slower reduction rates would be more expensive."

The Taskforce also made a number of other recommendations including raising the level of Carer's Allowance by £10; raising the care premium in income-related benefits; removing the full-time education rule; and introducing an annual grant in addition to the weekly benefit. However, the Taskforce also recognised that these measures would have significant cost implications - £1.4bn in the first year rising to £2.6bn by year 5 (again it should be noted that the report was published in 2008) and that it may not be fiscally possible to introduce them simultaneously.

## 4 The Dilnot Commission – funding for care and support in England

The Commission on Funding of Care and Support (aka the Dilnot Commission) was launched (in July 2010) by the Coalition Government as an independent body to make recommendations as to how to achieve an affordable and sustainable funding system for care and support, for all adults in England, both in the home and other settings. The Commission was tasked with exploring funding in the context of broader support for older people and other users of care services. The Commission was required to report on its findings to Government by the end of July 2011<sup>17</sup>.

Specifically, the Commission was asked to examine and provide deliverable recommendations on:

- How best to meet the costs of care and support as a partnership between individuals and the state;
- How people could choose to protect their assets, especially their homes, against the cost of care;
- How, both now and in the future, public funding for the care and support system can be best used to meet care and support needs; and
- How any option can be delivered, including an indication of the timescale for implementation, and its impact on local government (and the local government finance system), the NHS, and – if appropriate – financial regulation.

In defining its work, it has taken a wide definition of care and support:

"We are looking at all the different ways in which people, of all ages, are supported by the state. This means that we are considering the role played by the adult social care system; the social security system; the National Health Service (NHS); housing support; and public health and prevention

<sup>&</sup>lt;sup>17</sup> For further information on the Dilnot Commission see <a href="www.dilnotcommission.dh.gov.uk">www.dilnotcommission.dh.gov.uk</a>

services. We are not forgetting the valuable contribution made by carers, families, friends and communities.

We are considering the full range of different funding models, including past proposals and new ideas. No options have been ruled out, and we currently have an open mind about the best possible options for reform.

We are examining the different ways care and support can be paid for in the future. This includes looking at ways of encouraging the private market to offer financial products to help people protect their assets; and looking at the different ways in which the state could contribute."

The Commission maintains that there are **two overarching principles** that need to underpin any future system of care and support and that these will be reflected in its recommendations:

- Firstly, the funding system must promote the well-being of individuals and families – enabling people to maintain their dignity, protecting those in the most vulnerable circumstances, and helping everyone to participate in the wider community.
- Secondly, any future system must recognise and value the contributions of everyone involved in care and support, including individuals; carers and families; volunteers and professional carers; private, public and charitable sector organisations; tax-payers and wider society. As outlined in the Terms of Reference, our recommendations will cover all adults in England – working-age and older people.

The Commission will also explore the practical details of any proposal, including issues such as:

- The scope of reform e.g. whether accommodation costs are included within the scheme:
- How any reforms will be delivered e.g. whether any new assessment processes are required;
- How any private products will interact with any state support;
- The impact any suggestions could have on local government and the local government finance system;
- How costs will be managed and controlled within the system;
- Any new regulation that may be required;
- The cost of any new administration; and
- The impact that any suggestions will have on the Devolved Administrations.

The Dilnot Commission launched a <u>call for evidence</u><sup>18</sup> in December 2010, the call for evidence closed at the end of January 2011 and the Commission are reviewing the

<sup>&</sup>lt;sup>18</sup> See www.dilnotcommission.dh.gov.uk/files/2010/12/1.1-Call-for-Evidence-FINAL-pdf.pdf

responses. The Commission is to provide recommendations and advice on how to implement the best option to Government by **July 2011**. There has been some speculation in the media that private insurance schemes could play a part in funding an individual's future care needs particularly for high and middle-income earners<sup>19</sup>.

### 5 An Overview of the National Care Service (NCS)

After releasing their 'Shaping care together'<sup>20</sup> Green Paper on care in England in July 2009, the then Labour Government conducted a consultation exercise known as the 'Big Care Debate' on care and support, with over 68,000 members of the public including individual citizens, carers and representative organisations. This exercise ran until November 2009 and the report that followed highlighted that the main themes people raised during consultation were:

- A need to change things urgently.
- Everyone requires a decent standard of care.
- A body should be created providing this service to everyone in England.
- Uncertainty about how care was going to be provided in the future.
- Disability benefits are important to people.
- Everyone should contribute to a care system that is free when people use it similar to the NHS.

Following on from this the Government issued proposals to establish a new National Care Service which would:

- Be free for anyone over 18 in England.
- Be free for people who need it, at the time when they are using it.
- Work together with other people and organisations.
- Treat everyone who uses it with respect, making sure people have choice and control.

The proposals were set out in a White Paper released by former Health Secretary Andy Burnham on 01 April 2010. This paper acknowledged that such a service could not be established overnight and proposed that it be done in 3 stages:

#### Stage One

Build on the best of the existing system through reforms and deliver the Personal Care at Home Bill

### **Stage Two**

To set in motion the NCS through a National Care Service Bill.

<sup>&</sup>lt;sup>19</sup> The Telegraph. 'Buy private insurance to fund care in old age, Dilnot Commission suggests. 8 November 2010. <a href="https://www.telegraph.co.uk/family/8115919/Buy-private-insurance-to-fund-care-in-old-age-Dilnot-Commission-suggests.html">https://www.telegraph.co.uk/family/8115919/Buy-private-insurance-to-fund-care-in-old-age-Dilnot-Commission-suggests.html</a>
<sup>20</sup> <a href="https://www.official-documents.gov.uk/document/cm76/7673/7673.pdf">www.official-documents.gov.uk/document/cm76/7673/7673.pdf</a>

From 2014 ensure the coverage of free care will be extended so people receive free care if they need to stay in residential care for 2 years or more.

### Stage Three

The introduction of a comprehensive National Care Service funded by contributions and free for all adults in England when they need it.

Once established the six founding principles of the National Care Service would be:

- That the service be universal supporting all adults with care and support needs within a framework of national entitlements.
- Be free at the point of use based on need rather than the ability to pay.
- Work in partnerships with all the different organisations and people who support individuals with care and support needs day-to-day.
- Ensure choice and control putting people in control of their lives.
- Support families, carers and community life.
- Be accessible and easy to understand helping people make the right choice<sup>21</sup>.

Since this paper was released however it appears the creation of this service has stalled. This may be due to a change of government at Westminster this shortly after the White Paper was published. In July 2010 the current Health Secretary Andrew Lansley announced a review into palliative care funding which would report back in 2011 but there is no new information on the NCS<sup>22</sup>.

### 6 The availability of statutory respite care in the UK

Respite is a broad term which allows for much needed breaks for the carer. Research advocates the importance of respite and short care services for carers.<sup>23</sup> This can be for a few hours to a number of weeks. Respite also enables children or adults with disabilities to have a change of scene and a change of carer. As many carers provide high levels of constant and intensive care without payment or holidays, this can place an enormous burden on them and their families. Inadequate respite care can also have a detrimental impact on a carer's physical and mental health.

### Obtaining respite: the assessment

Carers who spend a substantial amount of time caring are legally entitled to an assessment of their needs. In the UK, needs assessments for carers are completed under the following legislation, and this is usually considered with the assessment of needs provision for the person being cared for:

<sup>&</sup>lt;sup>21</sup> The White Paper can be accessed at –

www.dh.gov.uk/prod\_consum\_dh/groups/dh\_digitalassets/documents/digitalasset/dh\_114923.pdf

<sup>22</sup> www.dh.gov.uk/en/MediaCentre/Pressreleases/DH\_117330

<sup>&</sup>lt;sup>23</sup> Social Care Institute for Excellence: Research Briefing Short breaks respite care for children with learning disabilities. Available online at: <a href="https://www.scie.org.uk/publications/briefings/briefing05/index.asp">www.scie.org.uk/publications/briefings/briefing05/index.asp</a>

### England

The Carers (Recognition & Services) Act 1995 and the Carers & Disabled Children Act 2000 provide for an assessment and give authorities *powers* to supply services to carers after their needs are identified.<sup>24</sup>

### Wales

The carer assessment legislation is the Carers and Disabled Children Act 2000, as in England. A new measure has also been introduced that requires the NHS and local authorities to produce a carers' information strategy.

#### Scotland

A carer's assessment is available under the Community Care and Health Act (Scotland) 2002.<sup>25</sup>

### Northern Ireland

The Carers and Direct Payments (Northern Ireland) Act 2002 places a duty to provide an assessment and gives authorities the *power* to offer services to carers to support them. The Act also allows Trusts to make Direct Payments.<sup>26</sup> Child carers under 16 are assessed under the provisions of the Children (NI) Order, 1995.

### What types of respite services are available?

There is a wide variety of respite care services available across the UK which are provided by statutory, private, voluntary organisations and individuals. Respite can be classified as follows:

- Residential respite: this includes residential (nursing care home, hospital or hospice) or holidays.
- Domiciliary care: is provided in the home. Examples include home helps (such as meal preparation or personal care) or "sitting" services which enable carers to have a break. Activities are also offered to the person being cared for, such going to the cinema or shopping. These services can be provided by voluntary organisations, health and social services, and private agencies or individuals.
- Day centres: many social services, health authorities and voluntary organisations run day centres for the care of adults with disabilities throughout the UK. A range of activities, day trips, or training in liaison with colleges can be provided. For children, nurseries, family centres or play schemes are available.

<sup>&</sup>lt;sup>24</sup> Carers UK Available online at: <a href="https://www.carersuk.org/Information/Helpwithcaring/Carersassessmentguide">www.carersuk.org/Information/Helpwithcaring/Carersassessmentguide</a>

<sup>&</sup>lt;sup>25</sup> The Scottish Government: Community Care & Health (Scotland) Act 2002

Available online at www.scotland.gov.uk/Topics/Health/care/17655/guidance-profesionals/9803

<sup>&</sup>lt;sup>26</sup> DHSSPS Carers Assessment and Information guidance <u>www.dhsspsni.gov.uk/ec-carers-assessment-information-guidance.pdf</u> page 12

 Other: There are also a number of independent voluntary/charitable and private organisations that provide specific types of respite care or support to carers.

It is difficult to know the number of organisations, services and beds available for respite care in the UK. This is because the care provided through a statutory assessment care plan, which is funded by Trusts or local authorities, is delivered by a range of agencies or stakeholders. The Belfast Health and Social Care Trust for example, offers services such as short stay residential and day centre care, direct payments and specific services for carers (like complimentary therapies).<sup>27</sup> Direct Payments (as discussed below) are statutory sources of funding which enable carers or those being cared for, to buy specific respite services that have been identified in their care plan.

### **Direct Payments**

Direct Payments are available in Northern Ireland, Scotland, England and Wales. 28,29,30 This is a monetary payment from the Trust that enables services to be arranged by the carer or person being cared for, instead of Trusts directly providing services. Therefore Direct Payments enable more choice and control by allowing individuals to tailor what type of support they need and when. Payments can be used to employ independent individuals to provide assistance, to buy services from agencies, or sometimes to combine statutory services with payments. The recipients might use the money towards driving lessons, a holiday or domestic help, i.e. anything which is an agreed identified need that will help to support them in their caring role. Payments do not affect other types of income-related social security benefits and the recipient may be asked to make a contribution towards the cost of the service or support offered.<sup>31</sup>

### Other respite issues

Often, not enough respite provision is available for all of those who require it, and many carers or people being cared for have to be placed on a waiting list before a respite place or service becomes available. In addition, sometimes the care offered is neither accessible nor appropriate to the individuals' needs.<sup>32</sup> Respite also varies between Trusts, and a lack of funding from social services has been reported.<sup>33</sup>

Providing research and information services to the Northern Ireland Assembly

<sup>&</sup>lt;sup>27</sup> Belfast Health and Social Care Trust: available online at www.belfasttrust.hscni.net/services.htm

<sup>&</sup>lt;sup>28</sup> HSSPS A guide to receiving Direct Payments (2005). Available online at <a href="https://www.cilbelfast.org/guide-to-receiving-">www.cilbelfast.org/guide-to-receiving-</a> <u>DPs.pdf.</u> Website accessed 2.3.2011

29 Carers UK website <a href="www.carersuk.org/Information/Directpayments/Whataredirectpayments">www.carersuk.org/Information/Directpayments/Whataredirectpayments</a> Website accessed

<sup>2.3.2011</sup> 

<sup>&</sup>lt;sup>30</sup> Scottish Executive (2003) A Guide to Receiving Direct Payments in Scotland. Available online at:

www.sehd.scot.nhs.uk/publications/grdps/grdps.pdf Website accessed 2.3.2011

31 NI Direct. Information available online at: <a href="https://www.nidirect.gov.uk/index/information-and-services/caring-for-">www.nidirect.gov.uk/index/information-and-services/caring-for-</a> someone/money-matters/direct-payments-for-carers.htm Website accessed 2.3.2011

Niwa, L. Law Centre NI Respite Care: Facilities for women & young adults found lacking. Available online at: www.lawcentreni.org/publications/frontline-magazine/392.html Website accessed 2.3.2011

Northern Ireland Assembly Debate (3 July 2007) Respite Care. Available online at: www.theyworkforyou.com/ni/?id=2007-07-03.1.22 Website accessed 2.3.2011

## 7 The NI Executive's support programme for young carers

### In general

A strategy for carers, "Caring for Carers" was published in January 2006. The strategy covers a range of issues relevant to the lives and wellbeing of carers including health and personal social services, employment, training, education, information and support services. Section 6 of the Strategy focuses on young carers including identifying and assessing young carers, the provision of information and emotional support for young carers.

The DHSSPSNI also produces guidance for Health and Social Care staff on carers<sup>35</sup> plus an A-Z guide for carers in Northern Ireland<sup>36</sup>.

The *Nidirect guide to government services* provides a page for young carers<sup>37</sup> covering the support that is available, information on assessment and support at school. There are links to other support agencies such as Barnardos, Action for Children and Crossroads Care.

### NI Regional Young Carers Service

In 2007 funding of £0.5m was announced by Health Minister Paul Goggins for the establishment of a regional young carers service for Northern Ireland<sup>38</sup>. In May 2010 the new service was officially launched by Health Minister Michael McGimpsey at Stormont<sup>39</sup>. The Service is funded by the DHSSPSNI and commissioned by the Health and Social Care Board and is jointly delivered by Action for Children NI, in partnership with Newry and Mourne Carers Association and Barnardos NI.

The new service allows young carers access to regional support centres irrespective of Trust boundaries. It aims to improve the lives of young carers in terms of their health, mental and emotional well being, educational attendance and achievement. As well as being a source of better and timelier information, the scheme allows young carers to take part in social and recreational opportunities with young people of their own age and also in organised social and leisure activities. This provides a break from caring and helps make childhood and adolescence a more normal experience. The £0.5m annual funding for the new service comes from the Children and Young People Funding Package, a funding scheme which was first announced in 2006 with the aim of

<sup>&</sup>lt;sup>34</sup> www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

<sup>35</sup> www.dhsspsni.gov.uk/eccu3-2010.pdf

<sup>&</sup>lt;sup>36</sup> www.nidirect.gov.uk/a-z\_guide\_for\_carers-3.pdf

<sup>37</sup> www.nidirect.gov.uk/index/information-and-services/caring-for-someone/caring-and-support-services/young-carers.htm

<sup>38</sup> www.nidirect.gov.uk/index/information-and-services/caring-for-someone/caring-and-support-services/young-carers htm

www.northernireland.gov.uk/news/news-dhssps/news-dhssps-may-2010/news-dhssps-17052010-contribution-of-young.htm

reducing social, health and educational differentials and give children and young people from the most disadvantaged backgrounds the best possible start in life.