



# **Review of the support provision for carers**

**September 2009**

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Advice NI

Age Concern NI

Belfast Carers

British Medical Association NI

Carers NI

Citizens Advice Bureau

Department of Health, Social Services and Public Safety

- Carers' Strategy Implementation Group
- Primary and Community Care Directorate
- Office of Social Services
- Secondary Care Directorate
- Mental Health and Disability Policy Directorate
- Information and Analysis Directorate

Department for Social Development

- Social Welfare Statistics and Consultancy Branch
- Statistics and Research Branch
- Voluntary and Community Unit

Social Security Agency (Department for Social Development)

- Benefit Entitlement Unit
- Disability and Carers Service

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## 1. Executive Summary

- 1.1 In 1999 the then Prime Minister launched the first ever National Carers' Strategy, "Caring about Carers"<sup>1</sup>, which looked at the entire range of support that carers need to help them in their caring role and to ensure they have a life of their own. Information, support and care for carers were identified as the three strategic elements to help carers carry out their caring responsibilities.
- 1.2 In 2007 a review of the 1999 National Carers' Strategy was launched, it was underpinned by a major consultation exercise with carers and four task force teams covering income, employment, social care and equality. In June 2008 "Carers at the heart of 21st century families and communities"<sup>2</sup>, a strategy document building on the progress of the first strategy, was published.
- 1.3 Following the Review of the National Carers' Strategy, Minister Ritchie and Minister McGimpsey agreed that a joint examination of the support available to carers in Northern Ireland should take place.
- 1.4 The terms of reference included reviewing the support available to carers in Northern Ireland in the light of the publication of the National Carers' Strategy in Great Britain.
- 1.5 Extensive research was conducted including a review of all Departmental literature, meetings with Voluntary Support/Advice Organisations with an interest in carers and officials within the Department for Social Development (DSD) and the Department of Health, Social Services and Public Safety (DHSSPS).
- 1.6 During the course of this review it has been evident that there are a large number of carers in Northern Ireland who willingly make an invaluable contribution in caring for family members or friends.

### DSD: Social Security Benefits for Carers

- 1.7 The Social Security Agency administers social security benefits on behalf of DSD. There is a long standing policy of parity in this area between Great Britain and Northern Ireland with the result that people in Northern Ireland have access to the same benefits paid at the same rates and subject to the same rules and conditions as people in Great Britain. Minister Ritchie regularly meets with the Secretary of State and other Ministers in the Department for Work and Pensions in Great Britain in relation to social security matters.
- 1.8 Carer's Allowance is the principal benefit paid to carers who because they provide care for severely disabled persons are unable to work on a full time basis. Carers on low income may also be entitled to income-related benefits, for example, Income Support and qualify for a carer's premium or, if over age 60, receive an additional amount on Pension Credit.
- 1.9 In 2007-2008 almost £87m was paid by way of Carer's Allowance to over 30,000 carers. In addition, 18,000 people received Income Support because they were carers and a further 12,000 carers received an additional amount by way of Pension Credit.

**1.10** DSD also provides funding for voluntary, support and advice organisations which assist carers in their caring role.

## **DSD Recommendations**

**1.11** The review has resulted in the following recommendations:

- the long-standing policy of parity between Great Britain and Northern Ireland in social security should be maintained (**paragraph 6.91**);
- the Minister should continue to liaise with the Secretary of State for Work and Pensions in relation to carers' issues and the Department should work closely with the Department for Work and Pensions on the reform of carers' benefits as part of the process of welfare reform (**paragraph 6.91**);
- the Social Security Agency should include an exercise on Carer's Allowance as part of its Benefit uptake programme (**paragraph 6.63**);
- the Department should work closely with the Department for Work and Pensions and with carers' organisations in examining the future role and scope of carers benefits (**paragraph 6.50**).

## **DHSSPS: Health and Social Care**

**1.12** A key advantage that Northern Ireland has above England in providing support services for carers is its integrated health and social care system which enhances the ability to ensure the essential joined-up planning and provision of services across both the health and social care sectors. The changes brought about by the Review of Public Administration (RPA) – having one Commissioning Board and five Health and Social Care (HSC) Provider Trusts will bring about more efficient, effective and consistent commissioning and service provision arrangements across the whole of Northern Ireland.

**1.13** DHSSPS has provided a strategic direction for the provision of support services for carers through its strategy documents “Valuing Carers” (2002)<sup>3</sup>, and “Caring for Carers” (2006)<sup>4</sup>. DHSSPS has also provided guidance to the health and social care sectors through circulars and guidance, for example, Circular HSS (ECCU) 4/2006<sup>5</sup>, Circular HSS (ECCU) 3/2008<sup>6</sup> and “Carers and Direct Payments Act (Northern Ireland) 2002, Carers' Assessment & Information Guide”<sup>7</sup>.

**1.14** To monitor progress against these strategies and guidance documents and to highlight areas where more work is needed, DHSSPS commissioned the Inspection of Social Care Support Services for Carers of Older People in Northern Ireland<sup>8</sup> and an Audit of Support Services for Carers<sup>9</sup>. More recently DHSSPS has developed a “Trust Self-Audit Tool” which encompasses all the recommendations for action by HSC Trusts which emanated from previous strategies, circulars, guidance and audits. Finally, in order to oversee the implementation of all recommendations, DHSSPS set up the Carers' Strategy Implementation Group (CSIG).

**1.15** In addition to providing this strategic direction and policy guidance, DHSSPS has also provided significant investment to support the implementation of support services for carers.

- 1.16** In 2005/2006, DHSSPS invested an additional £400k of recurrent funding in parallel with the launch of “Caring for Carers” to be used by Health and Social Care Bodies to develop innovative and responsive support services for carers, including flexible respite provision. In response to the need to invest in services for young carers, £0.5 million of recurrent funding was allocated to establish and implement the Regional Young Carers Project. DHSSPS also provides core funding to Carers NI - in 2008/2009 this amounted to £41,115.
- 1.17** DHSSPS already spends some £630m recurrently on services for older people. As part of the Comprehensive Spending Review (CSR), Minister McGimpsey secured additional funding of £60m over a three year period (equivalent to £35m recurrent thereafter) to deal with the demographic increase in the numbers of older people who will require support in the community. This investment will be targeted at a range of flexible and responsive community care services to support at least an additional 1,500 older people in the community by March 2011. Services to be developed will include domiciliary care, day care, respite care, support for carers, intermediate care and the expansion of Direct Payments.
- 1.18** In addition £43m has been committed over a three year period (equivalent to £24m recurrent thereafter) for children and adults with disabilities. A proportion of this money will support an additional 400 respite packages in Northern Ireland and an additional £1.85 million has been allocated to fund an additional 2,000 dementia respite places by 2011, and £2.5 million will be spent on advocacy and support services within the Mental Health Programme of Care, a proportion of which will be available for people with dementia and their carers.
- 1.19** DHSSPS has also allocated an additional £44m over the three year CSR period (£20.5 recurrent thereafter) to take forward new approaches to chronic condition management which will help people to continue to live in their own homes.

## DHSSPS Recommendations

- 1.20** The Review has resulted in the following recommendations:
- membership of the “Carers’ Strategy Implementation Group” (CSIG) should be reviewed to make sure that there is representation at a sufficiently senior level from all Directorates within DHSSPS with responsibility for carers thus ensuring that the voice of carers is heard at Departmental Board level; all Commissioners & HSC Trusts and carers’ representatives also should be represented on this Group. In addition, the ToR for this group should be amended to include a role in monitoring the implementation of the recommendations of this Review (**paragraph 6.104**);
  - the person-centred Carer’s Support and Needs Assessment component of the “Northern Ireland Single Assessment Tool” (NISAT) will be embedded in the process to assess the needs of carers in the Older People’s Programme of Care by June 2010 and in parallel with this process, opportunities for its implementation in all other Programmes of Care should be exploited (**paragraph 6.146**);

- Commissioners and HSC Trusts must use the “Trust Self Audit Tool” developed and issued by DHSSPS to report on and monitor progress towards the implementation of the recommendations of “Caring for Carers” (January 2006), “Promoting Partnerships in Caring” (December 2007), “Audit of Support Services for Carers” (June 2008) and reflected in actions required from Commissioners and HSC Trusts in Departmental Circulars (HSS (ECCU) 4/2006 & 3/2008) and reflected in standards issued by DHSSPS over this period (**paragraph 6.150**);
- DHSSPS should request that the Regulation and Quality Improvement Authority (RQIA) include a thematic inspection of carers’ issues in their work plan for 2011/2012 (**paragraph 6.151**);
- DHSSPS should produce and issue an up-to-date version of the “A-Z for Carers”<sup>10</sup> by December 2009 (**paragraph 6.162**);
- DHSSPS in partnership with Commissioners and HSC Trusts should ensure that there is good quality information collected about carers particularly in relation to carers’ assessments, respite care including unmet need and Direct Payments which can be utilised in planning for future service requirements (**paragraph 6.168**);
- DHSSPS should engage with Commissioners and HSC Trusts to explore the potential for carers to receive better levels of training in the more technical aspects of their caring responsibilities (**paragraph 6.172**);
- DHSSPS should ascertain what provision there is for breaks for carers (including emergency breaks) in Northern Ireland, assessment of level of need and the effectiveness of the models being used both in Northern Ireland and England, with a view to bidding for appropriate resources during the next CSR to allow investment in these important services (**paragraph 6.192**);
- HSC Trusts should have in place procedures to provide emergency respite cover for carers; and carers should be made aware of the Trust’s protocol for when these emergency provisions will be brought into play (**paragraph 6.193**);
- DHSSPS should monitor the progress and outcome of the Department of Health’s evaluation of the demonstrator sites testing: breaks for carers, better National Health Service (NHS) support for carers and health checks for carers (**paragraph 6.194**).

## **DSD/DHSSPS Joint Recommendation**

- 1.21 • DSD and DHSSPS should work more closely in terms of provision of information and signposting for carers (**paragraphs 6.29 and 6.163**).

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## **2. Introduction**

- 2.1** On 9 May 2008, Margaret Ritchie, Minister for Social Development and Michael McGimpsey, Minister of Health, Social Services and Public Safety announced a joint review of the support provisions for carers in Northern Ireland. The purpose of the review was to examine the support for carers in Northern Ireland in a holistic way, following on from the Review of the National Carers' Strategy.
- 2.2** The joint review was carried out by a designated team of DSD and DHSSPS officials.
- 2.3** The following Terms of Reference were agreed:
- To review the support available to carers in Northern Ireland in the light of the publication of the National Carers' Strategy (Carers at the heart of 21st-century families and communities) in Great Britain.
  - The review will be conducted jointly by DSD and DHSSPS and will seek to incorporate the work being undertaken by the Carers' Strategy Implementation Group (DHSSPS) and the Audit of Support Services for Carers.
  - The review will be carried out by Departmental officials and will be independently validated.
  - Time frame – to be completed in early 2009.
- 2.4** The completed report has been independently verified by Professor Judith Hill, CBE.

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### 3. Methodology

3.1 In order to comply with the Terms of Reference (paragraph 2.3) the following actions were taken:

- Extensive literature review including:
  - relevant DHSSPS strategies, policies and guidance;
  - relevant strategies from Great Britain with particular reference to the National Carers' Strategy;
  - relevant documentation about carers issues;
  - other relevant statistical and research reports.
- Meetings with Carers' Representatives and Advice Groups using a semi-structured interview;
- Attendance at Carers' Strategy Implementation Group meeting;
- Observer at Carers' Cross Government Project Board meeting;
- Liaison with officials with an interest in carers' issues in DHSSPS;
- Liaison with officials in DSD.

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## 4. Background

### Carers in Northern Ireland

- 4.1** Our society is becoming more diverse, and the shape and structure of our families more varied. Many people with complex needs, who, in the past may have lived in institutional settings, now choose to remain in their communities, in their own homes, with the help and support of family and friends. Carers enable many thousands of vulnerable people to do this and it is vital that these carers are supported in their caring role so that they continue to care for as long as they wish and it is safe for them to do so.
- 4.2** The 2001 Census<sup>11</sup> defined as carers all those who responded positively to the question “Do you look after or give any help or support to family members, friends or neighbours or others because of long term physical or mental health or disability or problems related to old age?” The question asked the respondent not to count anything they did as part of their paid employment. It also asked the respondent to estimate the time spent caring in a typical week.
- 4.3** In Northern Ireland 184,434 people identified themselves as carers and provided details of their regular weekly hours of caring. Of the carers counted in the census:
- 46,543 people provided 50 or more hours of care per week;
  - 27,933 people provided 20-49 hours of care per week;
  - 109,958 people provided 1-19 hours of care per week.

### Carers by Age

- 4.4** Carers are found amongst men and women of all ages (see Figures 1 and 2) with the peak age for caring in the age bracket of 45-69 years. In the 50-59 age group large minorities of people, 22% of men and 22% of women are carers. In their early 60s, women are more likely than men to provide care: 18% of women aged 60-64, and 14% of men of this age are carers. In the age groups over age 75, however, there is a higher percentage of men providing care nearly 4% men in comparison to just over 2% women (Figure 3).
- 4.5** Research has shown that when men become carers, it is usually for someone living in the same household, most often their wife or partner. Women are more likely than men to be caring for a son or daughter and are more likely than men to care for an elderly parent, frequently taking on substantial caring responsibilities even when they do not share the same household.
- 4.6** As shown in Figures 1 and 2, the 2001 Census also identified a small but significant number of young carers. In 2001, 8,352 children aged 17 or under provided care, of which 974 provided between 20 and 49 hours care per week and 712 provided 50 or more hours care per week.

4.7 Further research using data from the 2007 Young Life and Times Survey<sup>12</sup>, in which 16 year olds participated, showed that approximately 1 in 5 respondents provided some type of care inside and/or outside their own home with significant differences according to gender (22% female; 17% male). Most commonly, caring responsibilities at home related to parents, whilst caring responsibilities outside the home related to grandparents.

Figure 1: Carers (of both sexes) by age Northern Ireland

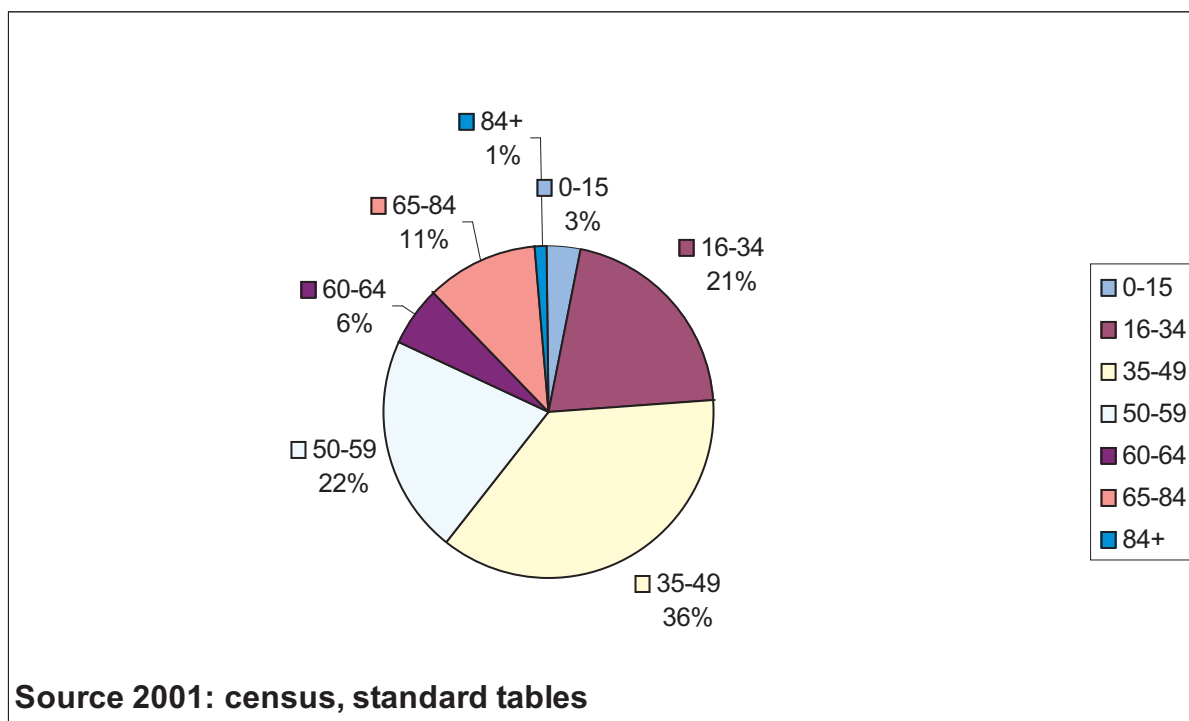
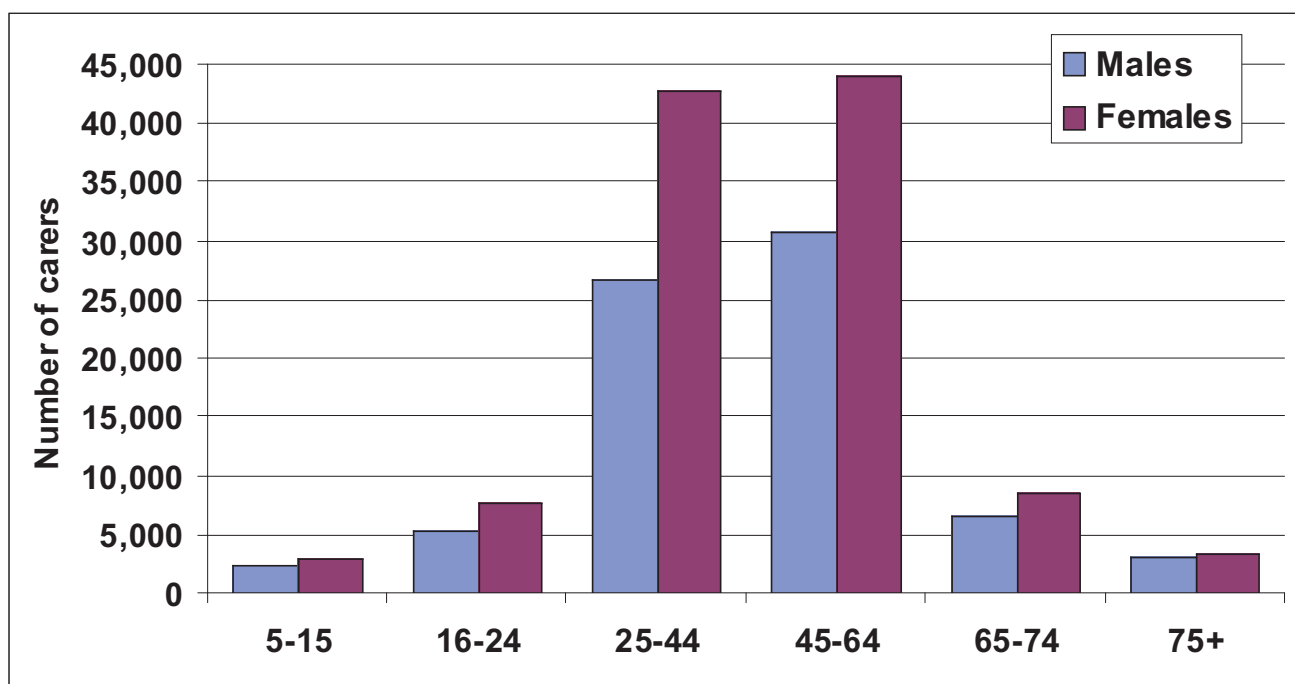
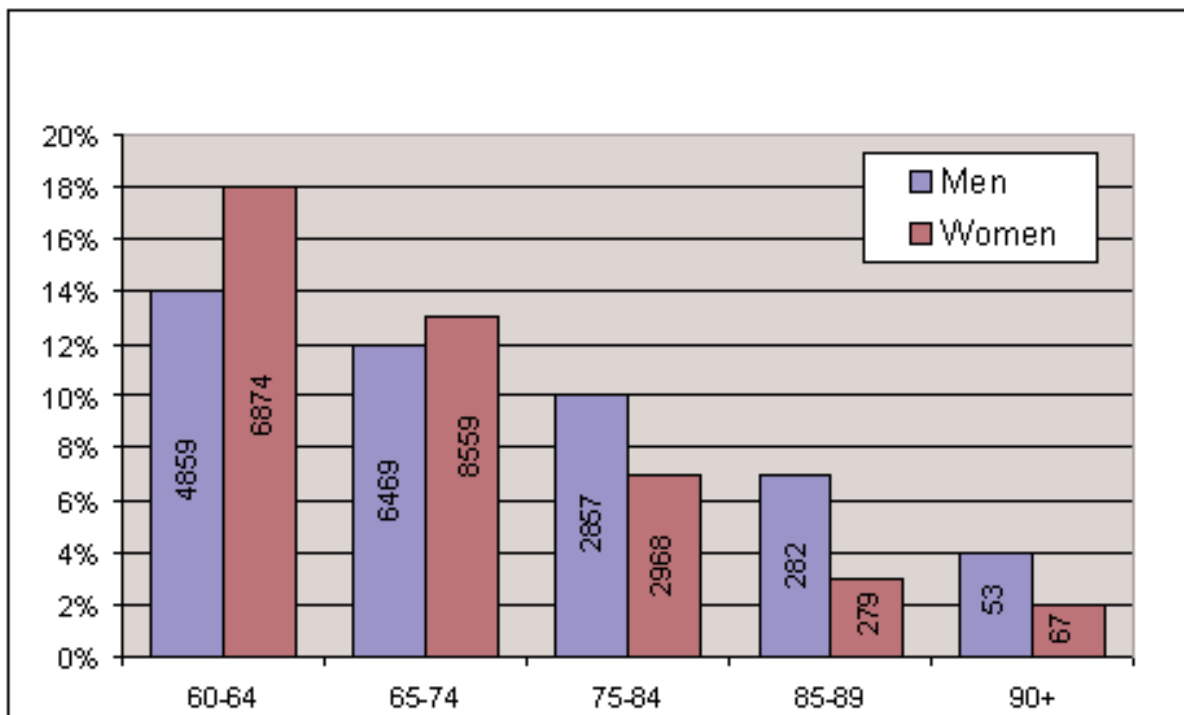


Figure 2: Carers in Northern Ireland, by age and sex



2001 Census Individual Samples of Anonymised Records

**Figure 3: Older people who provide unpaid care by age and sex in Northern Ireland**



2001 Census Individual Samples of Anonymised Records

### Carers by Employment Status

**4.8** The 2001 Census showed that there were 150,663 carers of working age in Northern Ireland (Figure 4); 64% of male carers were in full time paid work while 6% were in part time jobs (Figure 5); 35% of female carers were in full time paid work and a further 25% in part time employment (Figure 6).

**4.9** In 2001, 22,728 men and 34,834 women combined their paid jobs with providing 20 or more hours caring each week. As many as 33,785 people held a paid job alongside 50 or more hours of caring each week.

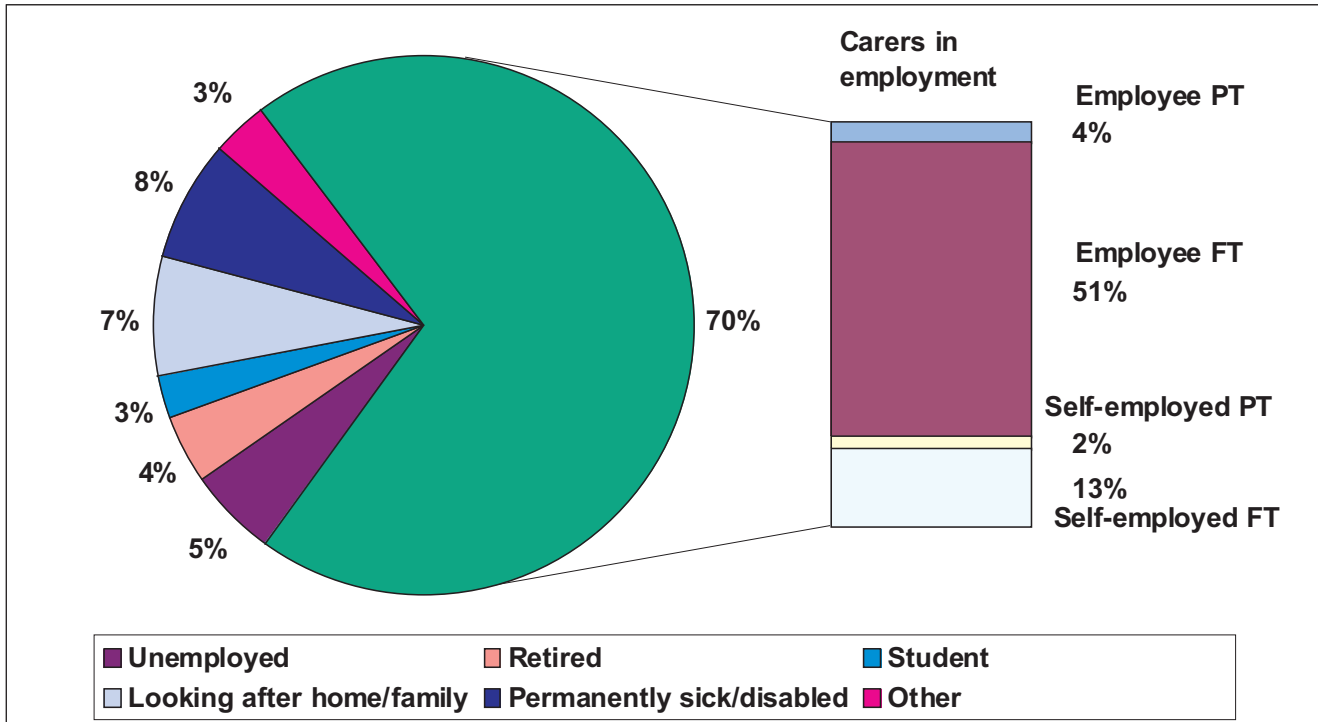
**4.10** There is a strong relationship between the hours of caring per week and the length of time caring and poverty. Analysis of the 2001 Census shows that those who care for 20 hours or more per week are more likely to live in workless households than non carers or those caring for less than 20 hours each week.

**Figure 4: Northern Ireland carers of working age by gender and weekly hours of care**

Weekly hours of care	Women Number	Men Number	Women %	Men %
All who give care	87,669	62,994	58	42
Caring 1-19 hrs	52,835	40,266	57	43
Caring 20-49 hrs	14,195	9,312	60	40
Caring 50+ hrs	20,639	13,416	61	39

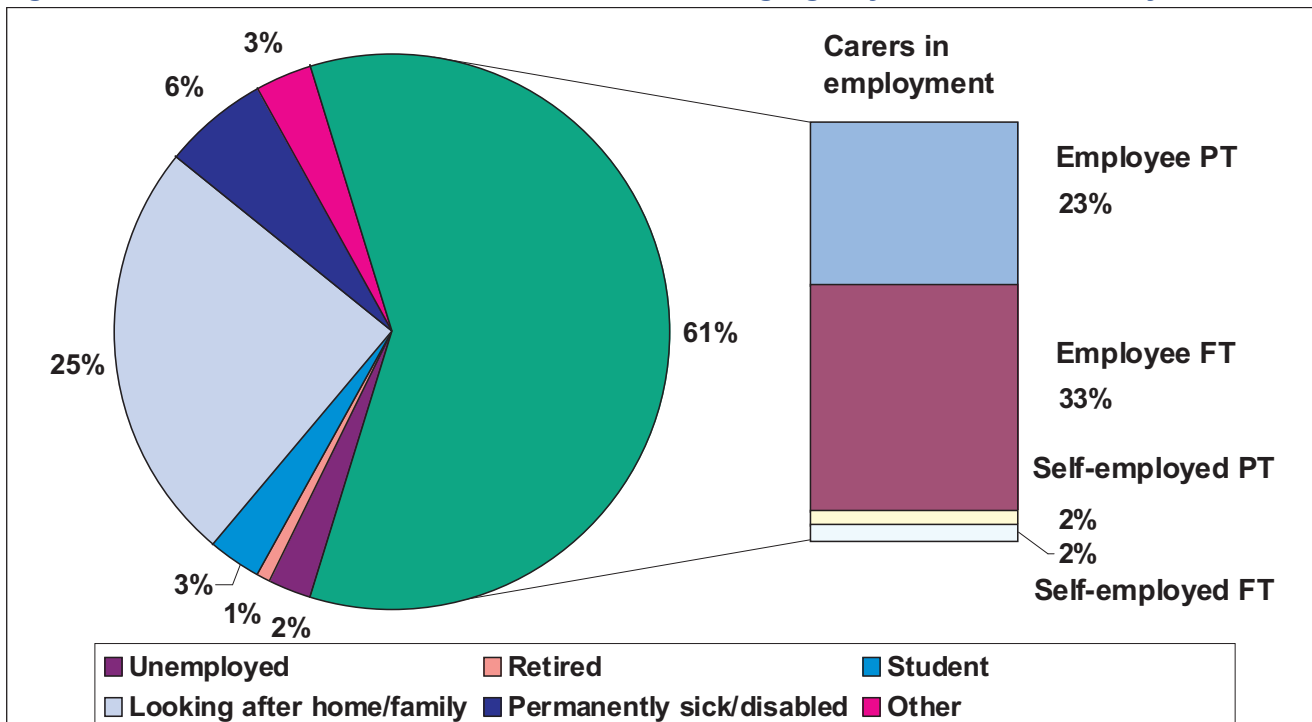
Census 2001 standard tables

**Figure 5: Northern Ireland male carers of working age by economic activity status**



2001 Census Individual Samples of Anonymised Records

**Figure 6: Northern Ireland female carers of working age by economic activity status**



2001 Census Individual Samples of Anonymised Records

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## Carers of Older People

**4.11** A survey of carers of older people was conducted in 2005<sup>13</sup>, to both inform “Promoting Partnerships in Caring”, the overview report of the Inspection of Social Care Support Services for Carers of Older People,” and monitor the implementation of the Carers and Direct Payments Act (Northern Ireland) 2002. The survey was not based on a random sample of carers, and so it cannot be considered to be representative of all carers of older people in Northern Ireland. Nevertheless, it does reflect the experience of a significant number of individuals providing care services to those aged 65 and over.

**4.12** The key results of the survey showed:

- three-quarters of people cared for were aged 75 or over, and almost two thirds were female;
- over four-fifths of the people cared for had physical disabilities, and half had mental health problems;
- about a quarter (26%) said that they never had breaks from caring, and over three-fifths had breaks only occasionally;
- 18% said that they always felt under stress because of caring responsibilities, 21% were under stress very often and 30% were under stress quite often;
- only 43% of respondents knew that they could have a separate assessment of their needs as a carer, and only 39% had been offered such an assessment;
- of those who accepted the offer of an assessment, over half (51%) said that it resulted in more support, almost one-third (32%) said that it did not and 17% did not know whether it resulted in more support or not – almost three-fifths were satisfied with the outcome of the assessment;
- 93% of carers had a single named contact for the organiser of their services, and 87% knew how to contact staff who provided direct care services within working hours, but only 52% knew how to contact staff outside working hours;
- when asked had their Trust or any other organisation asked for their opinion about services for carers in their community or area, 78% of respondents said that they had not been asked;
- whilst almost three-quarters of respondents were satisfied with the amount of services they received (31% ‘very satisfied’ and 42% ‘quite satisfied’), some 14% were dissatisfied;
- almost nine-tenths were satisfied with the quality of services provided (49% ‘very satisfied’ and 39% ‘quite satisfied’). Only 6% were dissatisfied with the quality of services;

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- the service provided which was stated to be most helpful was personal care (mentioned by 20% of respondents), followed by respite care mentioned by 16%).

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## 5. National Carers' Strategy – Overview

- 5.1** In 1999 the then Prime Minister, Tony Blair launched the first ever National Carers' Strategy - "Caring about Carers". The strategy looked at the entire range of support that carers need, both to help them in their caring role and to ensure they have a life of their own. The Strategy identified the three strategic elements to help carers carry out their caring responsibilities as: information, support and care for carers.
- 5.2** In 2007, the Westminster Government commissioned a review of the 1999 National Carers' Strategy. The review was informed by a major consultation exercise with carers, including an online consultation, and a number of associated events.
- 5.3** In June 2008, the Westminster Government published "Carers at the heart of 21st-Century families and communities". This strategy sets out the action that the Government plans to take, working with partners and building on the progress made by the first National Carers' Strategy, "Caring about Carers".
- 5.4** The vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.
- 5.5** In addition:
- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
  - Carers will be able to have a life of their own alongside their caring role;
  - Carers will be supported so that they are not forced into financial hardship by their caring role;
  - Carers will be supported to stay mentally and physically well and treated with dignity;
  - Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods and to achieve against all the "Every Child Matters" outcomes.

## Department for Social Development

**5.6** This section outlines the Westminster Government's view on how to best provide financial assistance to carers by way of social security benefits. DSD work closely with the Department for Work and Pensions in Great Britain in relation to social security provision including in relation to carers' benefits. DSD was represented at cross-Departmental Ministerial meetings in Great Britain throughout the period of the review in relation to the National Carers' Strategy.

*Vision: Carers will be supported so that they are not forced into financial hardship by their caring role.*

### Income Task Force Report

**5.7** An integral part of the National Strategy was the setting-up of four task force teams covering income, employment, social care and equality which were asked to consider problems with the current support for carers and establish objectives for reform. The Income Task Force considered how the National Carers' Strategy could include improvements to carers' incomes in order to enhance the choices available to carers. It recognised that the financial support needs of carers vary hugely and that the current system of social security benefits for carers is not able to adapt to meet these needs. In its report<sup>14</sup>, the Income Task Force acknowledged that because carers are such a disparate group, some objectives and principles will be of greater priority to some carers, while other carers will rank different objectives and principles more highly.

**5.8** In highlighting the need and ambition for further changes, it concluded that in the longer term the current structure of social security benefits for carers should be reviewed within the context of wider welfare reform.

**5.9** The Income Task Force recommended a twofold approach to reforming social security benefits:

- To have more substantial reform that fits with longer-term changes to the social security benefit system;
- To address, in the short term, some of the key problems with the current system. The proposed changes were regarded as "stepping stones" towards the long-term destination; a system of carers' benefits better suited to the needs of carers.

**5.10** The short term changes suggested were:

- Raising the level of Carer's Allowance;
- Raising the carer premium/addition in income-related benefits by a comparative amount;
- Removing the full-time education rule;
- Introducing a taper in the earnings rule;
- Introducing an annual grant (in addition to weekly benefit).

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**5.11** However, the Income Task Force recognised that introducing this package of changes would have significant cost implications and it would not be possible to introduce them simultaneously. Therefore, the changes were viewed as a menu from which it was possible to choose when resources allowed.

### **Westminster Government's Response to the Income Task Force Report**

**5.12** The Westminster Government regarded that the overriding recommendation of the Income Task Force was that benefits for carers should be reformed over the longer term so that they could better meet the needs of carers. It has accepted this recommendation and the following principles suggested by the Income Taskforce to guide longer term reform:

- to recognise the contribution that carers make to society;
- to make it easier for carers to combine caring with work and preparing for work;
- to reflect the diversity of carers' circumstances and caring responsibilities.

**5.13** The Westminster Government is committed to the need to work towards creating a benefit system that not only adapts to the specific needs of carers, but also helps them for their future. Financial support is regarded as only part of the equation and carers need help to combine their caring role with paid employment where possible. Therefore, the challenge is the creation of a flexible benefit system that reflects these principles while ensuring simplicity and alignment in overall welfare reform rather than providing piecemeal changes.

**5.14** The White Paper "Raising expectations and increasing support: reforming welfare for the future"<sup>15</sup> sets out the vision and route map for a welfare state where everyone is given the help they need to get back to work, matched by an expectation that they take up that support.

**5.15** The Westminster Government wishes to explore whether over the longer-term the model of a single income-replacement benefit for people of working age is the right approach. However, it recognises that major changes to the benefits system have to be made in several stages. As an initial step, it intended to abolish Income Support which would lead to a dual-benefits system based around Jobseeker's Allowance and the Employment and Support Allowance. Those who currently claim Income Support and who do not move onto the Employment and Support Allowance would move to Jobseeker's Allowance.

**5.16** However a proposal in the Green Paper "No one written off: reforming welfare to reward responsibility"<sup>16</sup> has been modified to move carers, who are one of the primary groups on Income Support and not currently subject to any work-focused conditionality, to a modified form of Jobseeker's Allowance. Consequently, carers entitled to carers' benefits will not be expected to engage in back to work activity, unless they volunteer to do so and will remain on Income Support until there is a clear and detailed plan setting out how to reform the benefits system over the longer term.

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## **Financial Assistance for Carers – Report of House of Commons Works and Pensions Committee**

**5.17** The House of Commons Work and Pensions Committee, in light of the ongoing review of the National Carers' Strategy, also undertook an inquiry into the effectiveness of the Westminster Government's approach to carers. Its report, "Valuing and Supporting Carers"<sup>17</sup>, published on 29 August 2008, also provides a useful appraisal of the difficulties inherent in the current financial assistance provided to carers. In particular, the Committee expressed disappointment that social security benefits for carers were not directly addressed in the National Carers' Strategy and were only identified as a long-term priority from 2011 onwards. It believed that the current system of benefits for carers is outdated and recommended the introduction of two distinctive 'tiers' of support for carers consisting of:

- a Carer Support Allowance – a non-means tested income replacement benefit; and
- a Caring Costs Payment available to all carers in intensive caring roles to compensate for the additional costs of caring and/or enable them to buy in some help, goods or services to ease their caring situation.

## **Westminster Government's Response to the Report of House of Commons Works and Pensions Committee**

**5.18** The Westminster Government accepts the general principle that a future system of financial support for carers should be able to differentiate between the support that a carer needs because they have no income and the support that a carer needs because of other costs relating to caring responsibilities. However, it considers it would not be right to undertake any review of carers' benefits in isolation as many of the difficulties that carers experience arise from the interactions between different benefits and interactions with different aspects of the wider welfare system.

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## Department of Health, Social Services and Public Safety

### Developments in the Health and Social Care Sector in England

**5.19** This section outlines developments in relation to health and social care support services provided to carers in England.

#### The New Deal for Carers – England

**5.20** In 2006 a White Paper “Our health, our care, our say”<sup>18</sup> announced a New Deal for Carers which was made up of four parts:

1. A national information helpline and website;
2. A training programme for carers called “Caring with Confidence”;
3. £25 million additional funding per year made available to councils in England to provide emergency care cover;
4. A major review of the 1999 National Carers’ Strategy;

of which the review of the 1999 National Carers’ Strategy was the centrepiece.

**5.21** The remit of this joint DSD/DHSSPS Review includes examining the support available to carers in Northern Ireland from a health and social care perspective in the light of the publication of the new National Carers’ Strategy. To this end, the health and social care related elements of the strategy are examined in relation to progress being made in Northern Ireland.

#### National Carers’ Strategy – Carers at the heart of 21st-century families and communities

**5.22** In June 2008, the Westminster Government published “Carers at the heart of 21st-century families and communities”. The Strategy for health and social care services in England sets out the action that the Government plans to take, working with partners and, building on the progress made by the first National Carers’ Strategy “Caring for Carers” which was published in 1999.

**5.23** A Cross-Government Programme Board has been established in England to monitor progress of the implementation of the National Carers’ Strategy. An official from DHSSPS attends meetings of this Board as an observer and reports back on progress to DHSSPS and the Carers Strategy Implementation Group (CSIG) after each meeting.

#### Integrated and Personalised Services

*Vision: Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.*

## Personalisation

- 5.24** The State should help people to get services that are tailored to their individual needs emphasising the individual in making all the relevant decisions. The vision is summed up in “Putting People First”<sup>19</sup> – a formal agreement between central government and local service providers which also sets out the intention to improve information and strengthen advocacy and support services to help people and their carers work with all local services. In the longer term, it is proposed that where appropriate, the offer of a lead professional will be made to help carers access services and to ensure early intervention when circumstances change.

## Personal Budgets

- 5.25** Everyone in social care will in future have a personal budget. This new approach helps to ensure that service users have the flexibility to buy or influence the provision of services to meet their own needs and those of the carer.
- 5.26** Since the “National Carers’ Strategy – Carers at the heart of 21st-century families and communities” was published in 2008, some analysis has been undertaken on the impacts and outcomes for carers in the 13 English Local Authorities that piloted personal budgets<sup>20</sup>. The impacts and outcomes for carers were reported to be varied - practice in terms of assessments and treatment of help given to carers varied according to local practice. Only one pilot site developed separate personal budgets for carers using its Carers’ Grant budget, others continued to offer Carers’ Grant payments to carers alongside personal budgets for service users. Overall compared to conventional social care, personal budgets were associated with statistically significant positive effects on carers’ quality of life and, when other factors were controlled for, on carers’ social care outcomes. However in semi-structured interviews with carers, those caring for older people were more positive than those caring for somebody with a learning disability and carers’ outcomes partly depended on service user outcomes.
- 5.27** The evaluation concluded that further research is needed on the impact of personal budgets on different groups of carers; on carers of different groups of service users; and on attitudes, practices and impacts of including carer payments in users’ personal budgets compared with carer Direct Payments and grants. In the longer term, a priority has been identified to consider extending flexibility of the way personal budgets and Direct Payments can be used.

## Information for Carers

- 5.28** Meeting carers’ information requirements is an important part of ensuring that people can receive personalised services. The New Deal for Carers includes an information service, providing full and easy access to information through a single national telephone number and website. Additional funding is being provided to enhance the information provision for carers focusing on easy to access (ie. translated) and local information.

## Training for Carers

- 5.29** A “Caring with Confidence” training programme to support carers is being established -

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distance learning and face-to-face training is due to be up to full capacity by July 2009. This training programme for carers will build on existing training, empowering and enabling carers to enhance their own wellbeing and that of the people they care for.

## **Relationships with Health and Social Care (HSC) Services**

**5.30** Carers have called for closer working relationships between the National Health Service (NHS), social services and themselves. To encourage this, pilot sites are being established to examine how the NHS can better support carers. This will involve:

- the active involvement of carers in diagnosis, care and discharge planning;
- greater support for carers at General Practitioner (GP) practices and hospitals; and
- closer working with councils and voluntary organisations.

**5.31** In the longer term, a priority has been identified to disseminate models of best practice to Primary Care Trusts in England on how to provide better support for carers.

## **Voluntary Sector Provision**

**5.32** Many carers prefer to deal with voluntary sector organisations than statutory services. Some areas have more developed voluntary sector services than others. Investment is being made to expand the capacity and reach of the voluntary sector.

## **Workforce**

**5.33** The workforce is vital to ensuring that carers and the people they care for get the services and support they need. A training and awareness raising programme is being funded for key professionals in a number of sectors including health.

## **A Life of Their Own- Breaks for Carers**

*Vision: Carers will be able to have a life of their own outside of their caring role.*

**5.34** £370 million has already been committed in England for short breaks for families with disabled children. In addition, a further £150 million will be invested over the next 2 years to fund more planned breaks for carers. This money will be made available from the NHS, and is in addition to the Carers' Grant, which stands at £244 million in 2008/2009, which is provided to councils to support carers. Pilots are also being run to examine cost-effectiveness and flexible provision. Plans are being made to share best practice in supporting carers across Local Authorities. In the longer term consideration will be given to further increases in break provision, taking account of evidence of quality and outcomes.

## **Emergency Respite Care**

**5.35** From 1 October 2007, £25m was made available to Local Authorities in England and is paid in addition to the Carers' Grant. This money has been provided expressly to underpin the development of services to provide emergency cover for unpaid carers

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who, for reasons of an emergency or personal crisis are unable for a short period to continue to provide care. The policy was first signalled “Our Health, Our Care, Our Say” in January 2006 and formally announced as part of the New Deal for Carers on 21st February 2007.

- 5.36** Carers reported that they did not take unnecessary journeys and frequently missed out on attending family events because of the worry of not being able to get home on time, or of being caught up in an accident. They were worried that there would be no one to look after the person they cared for. The policy intention therefore is that short-term, home-based, emergency cover is established in each Council to provide support in crisis or emergency situations. The outcome of the initiative is to provide reassurance and confidence for the carer, that should anything happen to them to prevent them providing care at very short notice, then arrangements have been made such that alternative care can be put in place, wherever possible in the cared for person’s normal home to cover the period or to provide sufficient time to make alternative arrangements.
- 5.37** There is no one preferred model for the provision of this type of service, but guidance has been issued to Local Authorities setting out the principles they would want to take into account in building their emergency cover provisions.

## Technology

- 5.38** Technology can play a major part in giving carers peace of mind and in doing so provide space that they can call their own. One example of new technology that promotes independent living and so reduces the stress placed on carers is Telecare – various sensors placed around the home which trigger alarms at the sign of unusual activity such as leaving the gas on, or leaving the front door open for prolonged periods at night. £80 million has been made available to Local Authorities between 2006 and 2008 through the preventative technology grant to stimulate local investment and the benefits are being disseminated as widely as possible through initiatives such as the whole system demonstrator sites.

## Health and Wellbeing

*Vision: Carers will be supported to stay mentally and physically well and treated with dignity.*

### Annual Health Check for Carers

- 5.39** Annual health checks for carers that will detect emerging health problems from an early stage are being piloted. If successful, these pilots may be extended more widely. In the longer term, consideration will be given to providing replacement care for carers to attend hospital appointments and screenings.

## Emotional Support

- 5.40** Carers are likely to experience high levels of psychological distress, including anxiety, depression and loss of confidence and self esteem than non carers. In addition to psychological therapies being rolled out across the country, consideration is being

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given to prioritising funding to national projects providing emotional support for carers.

- 5.41** In the longer term, it is planned to hold discussions with GPs and other health professionals regarding the measures which can be taken, that will give a sharper focus to the distinct need of carers. It is also planned to establish the legislative and other requirements needed to enable carers to receive appropriate information especially in cases where mental capacity is an issue.

### **General Practitioners (GPs)**

- 5.42** GPs are often the first point of contact with carers and often continue to be the professional with the closest contact with them. The Quality and Outcomes Framework (QOF) provides pay incentives to GPs for delivering certain services. Three QOF points relate to carers on the basis that “The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment”. These QOF points provide an incentive for GPs to provide support for carers in their practices, although more needs to be done to ensure that this is an outcome rather than a process driven measure.

### **Training for General Practitioners**

- 5.43** The Princess Royal Trust for Carers, in partnership with the Royal College of General Practitioners (RCGP), has already published a good practice guide highlighting the needs of carers and carers’ health. The Department of Health (DoH) will work with the RCGP to build on this to develop, pilot and evaluate a training programme for GPs to help them to better understand carers’ needs. The pilots could lead to a national training programme.

### **Younger Carers**

*Vision: Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the “Every Child Matters” outcomes.*

- 5.44** A number of commitments have been made in pursuit of this vision, these include:
- funding to support broader awareness-raising across schools and other children’s settings on caring in families and the issues this raises;
  - tailored training materials to be used with GPs and hospital discharge teams to build awareness and skills in dealing with young carers;
  - programme of work to ensure that the learning we draw from existing young carers projects and other forms of support feeds into, and helps shape, the planning of provision in the future;
  - preventing children from falling into harmful levels of caring: further action to build effective joined-up support around the family and the person cared for and to shift systems of support towards active prevention; and

- an expanded programme of local and regional training on whole-family working for staff in local services.

**5.45** In the longer term a priority has been identified to ensure protections for young carers are fully embedded: further measures are to be considered in the light of research findings over the next two years.

### **Implementation of the National Carers' Strategy**

**5.46** A number of measures to ensure that robust arrangements are in place to help the Government and its delivery partners ensure progress on implementing the Strategy. These new commitments include:

- the establishment of a Standing Commission on Carers to advise on progress in implementing the strategy and a Programme Board to ensure the necessary preparatory work is undertaken to support the delivery of the longer term proposals contained in the Strategy;
- to support this move towards greater measurement of carers' experience of services, work is ongoing with the Information Centre to develop a carer experience survey for Local Authorities to undertake on a voluntary basis in 2009–10;
- additional funding has been secured to ensure that the question on carers is included in recommendations to Parliament for the 2011 Census;
- funding a module on carers in an Omnibus Survey in 2008–09, the module will contain a number of questions about carers and will be tailored around the strategy;
- to in the long term review the National Indicator Set to ensure that carers' experience of services is measured;
- investment of £520m over a three year period through the Social Care Reform grant to support councils to redesign their systems so that they can make the required changes to adult social care to comply with "Putting People First" which is a shared vision and commitment to the transformation of Adult Social Care.

## **Developments in Scotland, Wales and the Republic of Ireland**

### **Care 21: The Future of Unpaid Care in Scotland<sup>21</sup>**

**5.47** The Scottish Executive commissioned the Office of Public Management to undertake a research project and report on the future of unpaid carers in Scotland with the purpose of pulling together thinking on how the situation for unpaid carers can be improved in Scotland, and to make recommendations to the Scottish Executive and other agencies on how this can be achieved. The research was undertaken between October 2004 and August 2005.

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**5.48** The Scottish Executive published its response to the report and accepted most of the recommendations and has made a commitment to a 10 year programme of action to support carers in Scotland. The Executive, Carers Scotland and national carer organisations continue to work together to support developments for the four early priority areas – respite, carers’ health, carer training and young carers.

### **Carers’ Strategy for Wales<sup>22</sup>**

**5.49** The Carers’ Strategy for Wales Action Plan was launched in March 2007 updating the Carers’ Strategy Implementation Plan previously launched in 2000. The need to sustain the 5 main areas for action identified in 2000 – Health and Social Care, Information, Support, Young Carers and Carers & Employment was agreed. The document sets out the Welsh Assembly Government’s strategic direction for carers together with specific action points to help achieve the objectives over the next few years. It is intended that progress on implementing these action points and their impact will be assessed during 2008/2009. The strategic objectives will also be reviewed at this time, in the light of the new National Carers’ Strategy, ensuring that the Carers’ Strategy for Wales remains relevant and responds effectively to change.

### **Republic of Ireland – National Carers’ Strategy**

**5.50** The Government in the Republic of Ireland has stated that it is very conscious of the important role of carers, particularly family carers, and is committed to continuing to support them in their role. A National Carers’ Strategy is being developed by an inter-Departmental working group, chaired by the Department of An Taoiseach with the secretariat provided by the Department of Social and Family Affairs. The Departments of Finance, Enterprise, Trade and Employment, Health and Children, the Health Services Executive (HSE) and the Training and Employment Authority (FÁS) are also represented on the group.

**5.51** The Strategy focuses on all informal and family carers in the community – not just those in receipt of a social welfare payment. Issues faced by people in paid employment, such as care assistants or home helps, are outside the scope of the Strategy.

## 6. Support for Carers in Northern Ireland

### DSD – Social Security System in Northern Ireland

- 6.1** Carer's Allowance is the principal social security benefit paid to carers. Its purpose is to help maintain the income of a carer who has given up the opportunity of being in full-time paid work to provide care for a severely disabled person. In addition carers on low income may be entitled to a Carer's Premium on Income Support or Housing Benefit, or an additional amount of Pension Credit (Pension Credit guarantees a minimum income to persons aged 60 and over).
- 6.2** Significant improvements to Carer's Allowance since the original 1999 National Carers' Strategy include:
- The Carer's Allowance earnings limit has increased from £50 to the current limit of £95.
  - Carers aged 65 and over are able to qualify for Carer's Allowance on the same basis as younger carers.
  - The carer premium in the income-related benefits and the additional amount for carers in Pension Credit was increased by £10 a week over and above the annual increases in line with the rise in prices.
  - An 8-week run-on was introduced to allow Carer's Allowance to continue in payment for up to 8 weeks when caring ceases due to the death of the disabled person.
- 6.3** Carer's Allowance is provided for under section 70 of the Social Security Contributions and Benefits (Northern Ireland) Act 1992<sup>23</sup>. However, since the 1946 National Insurance Acts, arrangements have been made in Great Britain and Northern Ireland to co-ordinate the operation of the two bodies of social security law. This long-standing policy of parity between Great Britain and Northern Ireland has resulted in the legislation in Northern Ireland being closely related to the corresponding Great Britain legislation.
- 6.4** Essentially the principle of parity means that people in Northern Ireland pay the same rate of income tax and National Insurance contributions and, in return, have access to the same range of benefits, contributory, non-contributory and income-related, paid at the same rates, and subject to the same rules and conditions as people in Great Britain.
- 6.5** Section 87 of the Northern Ireland Act 1998<sup>24</sup> gives legislative expression to aspects of parity. This section provides for consultation and co-ordination on social security, child support and pension matters between Northern Ireland and Great Britain, with the intention that single systems should operate across the United Kingdom to the extent that the responsible Ministers agree. Minister Ritchie regularly meets with the Secretary of State and other Ministers in the Department for Work and Pensions in Great Britain and has specifically raised issues in relation to carers.
- 6.6** Crucially, section 87 makes provision for financial adjustments to support the maintenance of these parity arrangements. Social security expenditure is classed as

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part of Annually Managed Expenditure, which is outside the element of the budget that the Department for Social Development has responsibility for managing over the budget period (the managed block), and is not subject to the Barnett formula for adjusting public expenditure. Historically, the amount raised through National Insurance contributions in Northern Ireland is insufficient to meet the costs of contribution-based benefits. The shortfall in the Northern Ireland National Insurance Fund is made up by a transfer from the Great Britain Fund to meet its benefit obligations. To this end, in 2007-2008 the Northern Ireland National Insurance Fund received a transfer of about £452m from the Great Britain Fund.

- 6.7** Non-contributory benefits and income-related benefits are financed from taxation; expenditure is demand led and is outside the Northern Ireland block. Expenditure on non-contributory and income-related benefits is excess of £2.3 billion per year.

### **Carer's Allowance – entitlement conditions**

- 6.8** Carer's Allowance provides an income for a carer who, because of caring commitments, cannot work full time. The current weekly rate is £53.10.

- 6.9** In order to be entitled to Carer's Allowance:

- a carer has to be aged 16 or over;
- not be in full-time education;
- spend at least 35 hours a week caring for a person receiving:
  - Attendance Allowance, or
  - Disability Living Allowance (at the middle or highest rate for personal care), or
  - Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension).
- Carer's Allowance is paid to only one carer looking after the disabled person. A carer caring for more than one disabled person can not add together the hours they spend caring to meet the 35-hour trigger point for entitlement.
- A carer can earn up to £95 a week after certain expenses have been deducted. However, where a carer receives Income Support and/or Housing Benefit, there will be a reduction in those benefits where earnings exceed £20 a week.
- Carer's Allowance counts as income when calculating any amount of income-related benefits payable but the amount of income-related benefit payable is increased by a carer's premium or an additional amount of Pension Credit.
- The weekly rate of Carer's Allowance is reduced or not paid if a carer is also receiving certain other benefits, including State Pension. Where payment cannot be made in these circumstances, "underlying entitlement" may continue. This allows a carer to qualify for the carer's premium in income-related benefits such as Income Support and Housing Benefit and an additional amount of Pension Credit for carers aged 60 or over. The current weekly rate of the carer

premium/additional amount of Pension Credit is £29.50 per week.

- An award of Carer's Allowance could affect the amount of the severe disability premium in an income-related benefit awarded to a person receiving care or the addition for severe disability in their Pension Credit.
- For every week a carer receives Carer's Allowance they automatically get a Class 1 National Insurance credit. This safeguards their future entitlement to State Pension.
- Since April 2002, for each complete tax year a carer is receiving Carer's Allowance, they will automatically build up an additional State Pension payable with the basic State Pension. A carer who has 'underlying entitlement' to Carer's Allowance will also build up an additional State Pension. However, an additional State Pension cannot be paid to women carers who have chosen to pay reduced rate National Insurance contributions.

### **Income-related Benefits and Carer's Premium**

- 6.10** Being a carer for someone who is disabled or elderly is one of the eligibility criteria for entitlement to Income Support. Income Support is an income-related benefit which provides financial help for people who are not required to be available for work and whose income, from all sources, is below a level approved by Parliament. The main components of Income Support are the personal allowances paid according to age and family status and flat rate premiums for groups recognised as having special needs, such as the elderly, disabled and carers.
- 6.11** The amount of Income Support payable varies according to individual circumstances. In addition to personal allowances carers can receive the carer's premium of £29.50.
- 6.12** People entitled to Income Support automatically qualify for Housing Benefit, a tax-free, income-related benefit awarded to people on low income who are responsible for paying rent and/or rates.

### **Carer's Credit – entitlement conditions**

- 6.13** Carer's Credit is a new weekly credit to be introduced from 6 April 2010. It will be available to parents and carers and will mean that thousands more carers will have their National Insurance record protected for any future Bereavement Benefits, basic State Pension and State Second Pension.
- 6.14** The Carer's credit will replace Home Responsibilities Protection which currently protects entitlement to basic State Pension and bereavement benefits for people who do not work or work part-time because of caring responsibilities. There will be two elements, a Class 3 National Insurance contribution credit and an earnings factor credit.
- 6.15** Carers in receipt of Child Benefit or their partners will automatically receive the new credit as will those in receipt of Income Support due to being substantially involved in caring.

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- 6.16** Foster carers will be able to apply to Her Majesty's Revenue and Customs for a credit.
- 6.17** People entitled to Carer's Allowance will automatically be entitled to Carer's Credits – they are already awarded a Class 1 National Insurance credit for the period of the award of Carer's Allowance. The new Carer's Credit will, however, be awarded during breaks in Carer's Allowance entitlement; the earnings factor credit element will contribute to State Second Pension.
- 6.18** Someone who cares for one or more person(s) with disabilities for 20 hours or more a week, but who does not fall within one of the above groups can still apply to the Department for Carer's Credit.
- 6.19** The person(s) they care for must be in receipt of Attendance Allowance at any rate, Constant Attendance Allowance at any rate or Disability Living Allowance at the middle or highest rate of the care component. Even if these qualifying benefits are not in payment, carers will still be able to apply if the person(s) they look after has/have been certified by a health or social care professional as needing at least 20 hours of care per week.

### **Saving Gateway**

- 6.20** The Saving Gateway, to be introduced in 2010, uses contribution matching (a Westminster Government contribution for each pound saved by the individual) to encourage saving by working age people on lower incomes and to promote engagement with mainstream financial services. Carers in receipt of Carer's Allowance will be eligible to open Saving Gateway accounts.

## Administration of Carer's Allowance

**6.21** Carer's Allowance is administered by Disability and Carers Service, Social Security Agency, which is located in Castle Court, Belfast.

**6.22** At March 2009 there were 51,662 carers entitled to Carer's Allowance. Figures from 2005<sup>1</sup> to date indicate a trend of an increasing entitlement to this benefit:

2004/05 – 44,918

2005/06 – 45,826

2006/07 – 46,868

2007/08 – 49,211

2008/09 – 51,662

**6.23** The corresponding amounts of Carer's Allowance paid to carers are:

2004/05 - £84,664,000

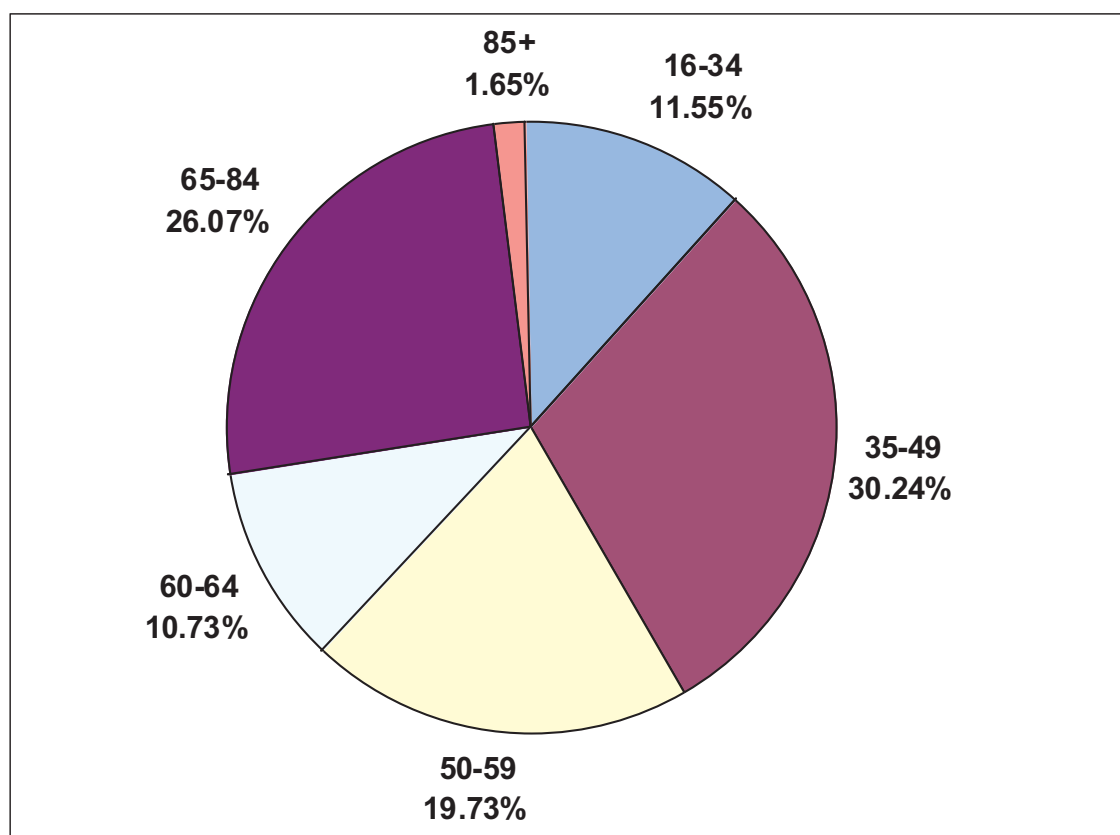
2005/06 - £82,105,000

2006/07 - £84,083,000

2007/08 - £86,976,000

2008/09 - £90,401,000

**Figure 7: Carers entitled to Carer's Allowance by age**



Source: MIDAS Scan October 2008<sup>25</sup>

<sup>1</sup> Social Security Agency Legacy System Printout 2008

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- 6.24** As part of the Social Security Agency modernisation programme, equipment has recently been installed which permits the electronic processing of incoming and outgoing mail. This new technology using on-line document imaging techniques allows instant access to customers' files and associated documentation and greatly assists in dealing with telephone enquiries.
- 6.25** A Benefit Enquiry Line available Monday to Friday, 9.00am to 5.00pm, provides telephone assistance in the completion of claim forms for Carer's Allowance.
- 6.26** During the year April 2008 to March 2009, Disability and Carers Service received 11,296 new claims for Carer's Allowance. The target date for deciding a new claim is 30 days; during 2008-2009 the average clearance time was 22.6 days and a 98.86% accuracy rate was achieved.

### **Publicising Carer's Allowance**

- 6.27** The Social Security Agency pages of the Department for Social Development website and specific Carer's Allowance leaflets provide information on entitlement and details how to claim this benefit. From 30 March 2009, Carer's Allowance also has a number of dedicated pages on NI Direct which provide a single point of contact to interact with public services across central Government through a single number and a single website.
- 6.28** Disability Living Allowance and Attendance Allowance leaflets contain advice notes signposting Carer's Allowance. In addition, a number of Income Support/Jobseeker's Allowance forms signpost Carer's Allowance.

### **Joint DSD/DHSSPS Recommendation**

- 6.29** DSD and DHSSPS should work more closely in terms of provision of information and signposting for carers.

### **Liaising with independent advice sector organisations**

- 6.30** A forum consisting of Disability and Carers Service, Advice NI, Disability Action, Citizens Advice Bureau and Law Centre NI meet on a quarterly basis.
- 6.31** The overall aims of this forum are twofold:
- To enable Disability and Carers Service to seek the views of intermediary organisations who represent a broad spectrum of claimants on operational delivery and proposed change initiatives, and
  - To enable intermediaries to tell of their concerns and also what they think is going well in terms of service delivery.
- 6.32** The Social Security Agency is happy to advise individual groups and organisations on benefit entitlement etc. For example, during 2007-2008 Disability and Carers Service sent a representative to the Huntington's Disease Carers Conference to give a presentation on benefit entitlement in relation to Disability Living Allowance and Carer's Allowance.

## Funding independent advice sector organisations

- 6.33** Through the Community Support Programme, which is delivered by local councils, DSD in 2008/09 has allocated £5.15 million of funding of which £1.9 million has been targeted specifically for providing frontline voluntary advice services. DSD funding via the Community Support Programme sits alongside contributions of £1.9 million from councils' rateable income. The combined Department and council allocation to the Community Support Programme in 2008/09 to voluntary advice is in the region of £3.8m. Local Citizen's Advice Bureau and other local voluntary advice providers can apply to councils for financial support.
- 6.34** In addition through the Regional Infrastructure Programme the Department provides £1.6m per annum to support the core costs of three regional bodies, Citizens Advice, Advice NI and the Law Centre which provide voluntary advice services.
- 6.35** All of these services are directly or indirectly available to carers in Northern Ireland who may wish to avail of independent advice. DSD will continue to promote a strong, vibrant and sustainable voluntary and community sector to enable better delivery of services.

## Views of Voluntary Support/Advice Organisations in Northern Ireland with an interest in Carers

- 6.36** The Review Team met with the following support/advice sector organisations with an interest in carers:
- Advice NI
  - Age Concern
  - Belfast Carers
  - Carers NI
  - Citizens Advice Bureau.
- 6.37** The organisations were generally appreciative of the improvements made to Carer's Allowance since its inception as Invalid Care Allowance. In particular, "underlying entitlement", although a complex concept, was viewed as a necessary method of ensuring carers on low income receive additional financial assistance by way of the carers premium on Income Support, Housing Benefit or the additional amount of Pension Credit. This process requires a claim for a benefit (Carer's Allowance) which the carer knows they may not receive because they are receiving another income maintenance benefit, in order to be eligible for the carer's premium or the additional amount in Pension Credit.
- 6.38** They also recognised the difficulty of designing a benefit to cater for the diversity of circumstances that carers face but stressed the importance of recognising the role of carers and providing them with appropriate financial assistance.
- 6.39** In particular, the organisations acknowledged the reality that Northern Ireland is not self sufficient in relation to social security and there was consensus regarding the importance of maintaining parity with Great Britain. Therefore, they accepted that there is little or no scope to make unilateral changes in Northern Ireland to benefits assisting carers.

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**6.40** The organisations raised the following concerns in relation to benefits available to carers. However, they acknowledged that, as none of these concerns were specific to Northern Ireland, social security legislation would continue to be closely tied to the corresponding Great Britain legislation.

#### **No immediate increases in rates of carers' benefits**

**6.41** The organisations highlighted the value of the contribution provided by carers in caring for disabled persons. They believed that the current level of financial support for carers is too low and indicated they would support proposals for improvements in the rates of benefit.

**6.42** Carers NI had real hopes that the National Strategy would deliver some immediate improvements and was very disappointed that there are no immediate changes to carers' benefits. Therefore, it endorses the recommendations of Carers UK for an urgent review and overhaul of Carer's Allowance and other benefits for carers and that the Government publish a plan and timetable ensuring that its 2018 vision that no carer falls into financial hardship because of their caring role becomes a reality. Advice NI expressed the view that consideration should be given to equalising Carer's Allowance and the carer's premium at the Carer's Allowance rate; which would serve to target need and in particular benefit those carers on means tested benefits which were the lowest income levels.

**6.43** All Carers Organisations considered that a two-tier benefit, as recommended in the House of Commons Work and Pensions Committee report "Valuing and Supporting Carers", merits further consideration.

#### **DSD Response**

**6.44** The Department recognises the tremendous personal commitment of carers who are prepared to give their time so freely to their caring role. However, Carer's Allowance is not intended as a payment for caring, rather, it provides a degree of replacement for lost or foregone income to carers who have given up the opportunity of full time work. Carers who need additional help can access income-related benefits including Pension Credit. Where carers are entitled to Carer's Allowance any income-related benefit they receive will be automatically increased, leaving them up to £29.50 per week better off.

**6.45** The Department notes that the Westminster Government accepts that benefits available to carers do not differentiate sufficiently between their different needs. The Department also notes the Government view that targeting resources more effectively to those carers with the greatest need should be a foremost aim of a better system of support for carers.

**6.46** The Department also notes that the Westminster Government accepts the general principle that a future system of support for carers should be able to differentiate between the support that a carer needs because they have no income and the support that a carer needs because of other costs relating to caring responsibilities. The Department also notes that the Westminster Government considers it would not be right to undertake any review of carers' benefits in isolation as many of the difficulties that carers experience arise from the interactions between different benefits and interactions with different aspects of the wider welfare system.

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## **Welfare Reform**

- 6.47** The White Paper on Welfare Reform sets out how the Westminster Government seeks to improve the social security benefit system where more support is matched by higher expectations for all.
- 6.48** Carers NI and Citizens Advice Bureau do not believe that carers can be properly supported in a single benefit for all working age people. They argue for a separate stream of benefit which applies to all carers and can take into account their different circumstances and needs allowing them to opt into employment support if they wish.

## **DSD Response**

- 6.49** The Department notes that the Westminster Government remains attracted to the idea of a single working age benefit and that it will continue to explore whether, over the longer term, this is the right approach. The Westminster Government believes this approach will provide an appropriate opportunity to examine the role and scope of carers' benefits and remains committed to working closely with carers' organisations. In the short term carers will continue to be entitled to Income Support until there is a clear and detailed plan setting out how the benefits system will be reformed over the longer term.

## **Recommendation**

- 6.50** The Department should work closely with the Department for Work and Pensions and with carers' organisations in examining the future role and scope of carers' benefits.

## **Complexity of Carer's Allowance**

- 6.51** The organisations expressed concerns about the complexity of Carer's Allowance, in particular, how the overlapping benefits rules and underlying entitlement rules are confusing and overly complicated and act as barriers to claiming. Age Concern has drawn up a flow chart to explain to carers of pension age the application process in establishing underlying entitlement. This process requires a claim for a benefit (Carer's Allowance) which the carer knows they may not be paid (because they are receiving State Pension) in order to be eligible for the "additional amount" in Pension Credit. Belfast Carers considered that the administrative process often intimidates carers and there are often misconceptions about entitlement rules and the impact entitlement to Carer's Allowance has on other benefits.
- 6.52** Belfast Carers also mentioned previous leaflet and publicity drives undertaken in conjunction with the Social Security Agency. Advice NI mentioned its involvement in a benefit uptake exercise sponsored by the Social Security Agency. Both groups emphasised the importance of localised targeting, Advice NI suggesting the possibility of sharing databases, and sustained follow-up action.

## **DSD Response**

- 6.53** The Department agrees that simplicity and ease of application should be one of the guiding principles in the design of any changes to the benefit system.

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- 6.54** A shortened claim pack has been developed (11 pages instead of 27 pages) to cater for carers over pension age who know they do not satisfy conditions for payment of Carer's Allowance but because they have underlying entitlement may qualify for pension credit. This has been in use since December 2006.
- 6.55** Furthermore, in February 2007, an additional question was introduced in the Pension Credit application process to identify relevant caring responsibilities in order to invite carers, where appropriate, to claim Carer's Allowance using the new shortened claim pack.

### **Uptake of Carer's Allowance**

- 6.56** Underclaiming of carer benefits is a major concern for the organisations with a widespread belief that there are a significant number of carers entitled to but not receiving these benefits. Age Concern, Belfast Carers and Advice NI identified a lack of knowledge about entitlement, and the stigma attached to claiming for caring for a loved one or neighbour, particularly in the 60+ age group, as prime reasons for the lack of uptake.
- 6.57** Although some severely disabled people will have a social worker not everyone does and social workers may or may not signpost for benefits. Age Concern pointed out that for many people their first contact with the benefit system arises when they become a carer and they do not know what questions they need to ask. In their experience people contact Advice NI or Citizens Advice Bureau to ask a question about benefit when they know what question to ask. Age Concern sees itself as having a role in giving knowledge and advice to carers who may not know what it is they need to ask.
- 6.58** Both Age Concern and Belfast Carers also expressed concern that there are a substantial number of hidden carers who remain outside the reach of the network of Advice/ Carer organisations and Social Services.

### **DSD response**

- 6.59** Benefit uptake is a key priority for the Social Security Agency. Since 2005, a targeted approach has been adopted to increasing benefit uptake which involves working under contract with the independent advice sector to offer clients a comprehensive benefit assessment. As part of the 2006/2007 Benefit Uptake Programme an exercise was developed to target carers who may not be receiving their full benefit entitlement or even be aware of their entitlement to benefit. The organisations highlighted the vulnerability of older carers who are no longer able to remain in employment, and the importance of full benefit checks to address the need of these carers.
- 6.60** An exercise was developed offering 1,500 people who potentially have caring responsibilities a full benefit assessment. As a result of this exercise over £5.3k was paid out in additional weekly benefit and almost £30k in arrears (this included a range of benefits other than Carer's Allowance).
- 6.61** A follow-up exercise in 2007/2008 contacted a further 2600 potential carers resulting in almost £11.7k generated in additional weekly benefit and almost £41k in arrears (also including benefits other than Carer's Allowance). In addition in 2007/2008 a mailshot

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highlighting the criteria for Carer's Allowance was issued to 66,136 older people in receipt of Attendance Allowance/Disability Living Allowance.

- 6.62** The Social Security Agency is committed to promoting benefit uptake across several client groupings including carers to ensure that clients receive the financial assistance and services to which they are entitled. Another exercise focusing on over 3000 carers is planned as part of the 2009/2010 Benefit Uptake Programme.

### **Recommendation**

- 6.63** The Social Security Agency should include an exercise on Carer's Allowance as part of its Benefit uptake programme.

### **Carer's Allowance Bill**

- 6.64** The organisations were asked for their views on the Carer's Allowance Bill<sup>26</sup>. This Bill, which David McNarry MLA has presented in the Assembly, makes provision to remove the overlapping benefit rules in relation to Retirement Pension and Carer's Allowance.

### **Background – Social Security System**

- 6.65** The social security system is an integrated system of interlocking benefits which can be divided into 3 broad strands:
- national insurance benefits (with entitlement dependent on paid or credited national insurance contributions), for example, basic State Pension, Incapacity Benefit, contribution-based Jobseeker's Allowance and contributory Employment and Support Allowance;
  - income-related benefits (based on financial need), for example, Income Support and Housing Benefit, and
  - non-contributory benefits (not dependent on financial need or national insurance contributions), for example, Disability Living Allowance and Carer's Allowance.
- 6.66** Many clients can satisfy the eligibility criteria for several benefits at the same time. However, since 1948 one of the fundamental tenets of the social security system has been that there should not be double provision for the same contingency. This principle of adjusting one benefit against another where a certain contingency is addressed by more than one benefit ("the overlapping benefits rule") enables finite resources to be focused most effectively on the people who face the greatest financial pressure. In relation to income-related benefits, the same practical result is achieved by taking the amount of other benefits into account when calculating the client's income.

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## Overlap between State Pension and Carer's Allowance

- 6.67** State Pension is designed to provide an income in retirement. Carer's Allowance is designed to provide a measure of income replacement for those who are unable to work full-time because of caring responsibilities. Therefore, a person not working for two reasons – because of caring commitments and because they have reached state pension age does not receive double provision from the social security system for income maintenance.
- 6.68** Where State Pension is in payment, Carer's Allowance will not usually be payable. However, where someone would receive less from State Pension than from Carer's Allowance, an amount of Carer's Allowance can be paid to make up the difference. In addition, where Carer's Allowance cannot be paid, the person will keep underlying entitlement to the benefit. This gives access to the carer premium in the income-related benefits such as Housing Benefit or the equivalent additional amount in Pension Credit.
- 6.69** The existing enabling power – section 71 of the Social Security Administration (Northern Ireland) Act 1992<sup>27</sup> which the Carer's Allowance Bill proposes to amend - makes general provision for overlapping benefits. The Overlapping Benefits Regulations<sup>28</sup> then set out the various relationships between different benefits where entitlement to both benefits leads to the payment of one of those benefits being adjusted to prevent both being paid in full.

## Views of the Voluntary Support/Advice Organisations on the Carer's Allowance Bill

- 6.70** Carers NI, Belfast Carers, Advice NI and Age Concern welcome the Bill for raising the issue of benefit provision for carers who reach pension age and the opportunity it provides for highlighting the impact of the “overlapping benefits” rule. The above groups highlighted the concerns expressed by carers of pensionable age when learning that Carer's Allowance is no longer payable although they are continuing to provide care into their retirement. For carers in that situation it can appear simply that once they reach retirement age recognition for their caring role is lost.
- 6.71** Citizens Advice Bureau acknowledge the Bill would assist carers over pension age who have savings or an additional work pension but were concerned that carers on low incomes will gain no financial assistance and may indeed lose their passport to additional help from income-related benefits such as Pension Credit and Housing Benefit.

## DSD Response

- 6.72** The Department acknowledges the very important role played by carers who have the responsibility of caring for severely disabled persons and, therefore, understands the sentiments behind the Carer's Allowance Bill.
- 6.73** However, the Bill poses very real problems. The Department is not convinced that it would target resources most effectively to those carers with the greatest need which should be a foremost aim of a better system of support for carers.
- 6.74** Furthermore, the Department considers that the Bill does not take cognisance of the

complexity of the structure of the social security benefit system and the logical cohesion to the “overlapping benefit” rules. More fundamentally the Department is concerned that the Bill would incur very significant cost implications and would have ramifications for the wider policy of parity in social security throughout the United Kingdom.

### **Effect on carers under pension age**

- 6.75** The Carer’s Allowance Bill concentrates on one relationship that of Carer’s Allowance and State Pension. However, a number of other income-maintenance benefits are affected by these rules, for example, Incapacity Benefit, contributory Employment and Support Allowance, Maternity Allowance and Bereavement Allowance, none of which can be paid in full at the same time as Carer’s Allowance. Therefore, isolating one relationship for removal from the overlapping benefits rules will lead to provision of different levels of financial assistance for carers on benefits other than State Pension. For example, if the Bill were enacted a female carer aged 59 on Incapacity Benefit (£67.75 short-term lower rate: £80.15 short-term higher rate) could not receive Carer’s Allowance, however, a female carer aged 60 could receive £95.25 State Pension and £53.10 Carer’s Allowance.
- 6.76** Therefore, it would be difficult to justify preferential treatment for carers over pension age and if the Bill were to progress the Department would anticipate calls to extend the exemption to Carer’s Allowance and all other overlapping benefits.
- 6.77** Furthermore, over 61% of carers entitled to Carer’s Allowance are under pension age and would not be assisted by the Bill.

### **Effect on carers over pension age**

- 6.78** Carers over pensionable age on low income can receive additional help from income-related benefits such as Pension Credit and Housing Benefit, which are paid at higher rates for carers. Where carers are entitled to Carer’s Allowance - even if Carer’s Allowance is not payable because of the overlapping benefits rule - any income-related benefit they receive will be automatically increased, leaving them £29.50 per week better off. The Carer’s Allowance Bill would do nothing to help poorer carers who have reached pension age. This is because any increase in income would be fully taken into account for income-related benefits and consequently receiving Carer’s Allowance in addition to State Pension would reduce or extinguish any Pension Credit and/or Housing Benefit payable.
- 6.79** Approximately 11,000 carers over pension age are in receipt of Pension Credit; of these, 8,300 would see a reduction in the amount paid and be financially no better off; 2,700 would no longer be entitled to Pension Credit and therefore not be passported to full housing benefit entitlement. They would also not automatically get help with the cost of dental treatment and dentures, help with the cost of glasses, help with fares to hospital, help with court fees.
- 6.80** The Bill therefore has the potential to adversely affect a number of poorer pensioners.

## **Cost implications** (based on October 2008 figures)

- 6.81** Almost 15,500 Carer's Allowance claimants over pension age are not currently receiving a payment of Carer's Allowance due to the overlapping benefits rule and a further 800 receive a reduced amount. It is estimated that the proposed Bill would therefore generate additional gross expenditure of up to £42.6 million per annum to these claimants (Source: MIDAS Scan October 2008 – additional gross expenditure calculated on the basis that the number of claimants entitled to State Pension and Carer's Allowance at October 2008 would remain constant throughout the financial year and are based on 2008 benefit rates).
- 6.82** This cost does not take account of the potential increase in claims by those who currently do not claim Carer's Allowance because of the overlapping benefits rule. It is estimated that around 6,000\* informal carers over pension age, caring for a sick, disabled or elderly person for over 35 hours, are not claiming Carer's Allowance. This would generate additional gross expenditure of £15.7m per annum. (\*Source: Family Resources Survey<sup>29</sup> – due to small sample sizes, several years of the Family Resources Survey data have been put together. Since the estimates are based on survey data, there is a certain degree of uncertainty surrounding any results).
- 6.83** A further factor to be taken into account is the projected increase in caring which is the inevitable consequence of an ageing population. The Northern Ireland Statistics and Research Agency estimate that the number of people over current pensionable age will increase by 39% between 2006 and 2021. The number of people aged 65 and over will continue to rise after 2021, and there are projected to be twice as many people aged 65 and over in 2041 as there are today. Therefore there is the potential for the costs to rise very substantially in the coming years.
- 6.84** If the Assembly were to pass the Bill, the Department would not be able to find the potential £58.3m (£42.6m for existing claimants and £15.7m for further potential claimants) additional gross costs from its budget.
- 6.85** Furthermore, extending an exemption to Carer's Allowance and overlapping benefits other than State Pension is likely to attract additional gross expenditure in the region of £9m (Source: MIDAS Scan October 2008 – additional gross expenditure calculated on the basis that number of claimants entitled to State Pension and Carer's Allowance at October 2008 would remain constant throughout the financial year and are based on 2008 benefit rates).

## **Parity**

- 6.86** If enacted, the Bill would break the long-standing policy of parity with Great Britain and in effect no longer maintain a single system of social security across the United Kingdom. Under the policy of parity, Northern Ireland benefit costs are funded in line with the actual entitlement of claimants.
- 6.87** This results in an annual subvention from the Great Britain National Insurance Fund to meet its contributory benefit obligations, In 2007-2008 Northern Ireland National Insurance Fund received a transfer of £452m from the Great Britain Fund and in excess of £2.3 billion from general taxation to fund non-contributory benefits (including Carer's Allowance) and income-related benefits.

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- 6.88** The proposals in the Bill clearly breach parity in social security with Great Britain. Therefore, the Northern Ireland block would be liable for the gross costs of removing overlapping benefits rule for carers over pension age. Based on 2008 benefit rates and actual claimant numbers the additional gross expenditure would be £42.6m per annum.
- 6.89** It is also important to note the Statement of Funding Policy for Devolved Administrations provides for a review of the funding arrangements if Northern Ireland social security policy is changed to differ from the rest of the UK. In addition to Northern Ireland having to find the additional benefit costs, it could be argued that if £42.6m can be found to pay enhanced benefits, Northern Ireland does not need the current level of subsidy to maintain parity with the rest of the United Kingdom.
- 6.90** Therefore the Department would oppose the progression of the Carer's Allowance Bill.

### **Recommendations**

- 6.91** The long-standing policy of parity between Great Britain and Northern Ireland in social security should be maintained.

The Minister should continue to liaise with the Secretary of State for Work and Pensions in relation to carers' issues and the Department should work closely with the Department for Work and Pensions on the reform of carers' benefits as part of the process of welfare reform.

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## DHSSPS – Developments in the Health and Social Care Sector in Northern Ireland

### Valuing Carers Review (2002)

- 6.92** In October 2000, the then Minister for Health, Social Services and Public Safety, Bairbre de Brun, commissioned a report aimed at developing a Strategy for carers in Northern Ireland. The aim was to identify the needs of carers; to identify any unmet need; to gather information about policies, practices and services that affect carers and to prepare the way for an integrated strategy for future action. The reference point for this work was the “Caring About Carers”, national strategy launched in February 1999 by the Department of Health (DoH) in England.
- 6.93** In drawing up recommendations for a Carers’ Strategy in Northern Ireland, DHSSPS consulted a reference group of carers and organisations representing carers to find out what they saw as solutions to the difficulties they face in carrying out their caring role. Carers identified five principles as the key requirement of any strategy development:
1. Carers are real and equal partners in the provision of care;
  2. Carers need flexible and responsive support;
  3. Carers have a right to a life outside caring;
  4. Caring should be freely chosen;
  5. Government should invest in carers.
- 6.94** The outcome of this consultation was reported in “Valuing Carers” which was published in April 2002. The report contained 19 recommendations all of which were accepted. The report’s most fundamental conclusion was that carers should be recognised as key partners in the provision of care. Additionally, carers were identified as a priority group under the then Executive’s Promoting Social Inclusion (PSI) programme and an inter-departmental Carers Working Group was established and tasked with developing a strategy to improve the practical support given to carers.
- 6.95** Four priority areas were identified for action:
1. Information and training;
  2. Support Services;
  3. Employment;
  4. Help for young carers.

### Caring for Carers Strategy (2006)

- 6.96** In direct response to the recommendations contained in “Valuing Carers”, a Strategy - “Caring for Carers, Recognising, Valuing and Supporting the Caring Role” was published by DHSSPS in January 2006. It addressed in a practical way the support that carers want, and need, to allow them to continue caring, and to give them as much access as possible to the same opportunities that others enjoy. It set out what had been done, and a vision of what needed to be done in the future to give carers the quality of life that they deserve.
- 6.97** The PSI Carers’ Working Group decided to use the 19 recommendations contained in “Valuing Carers” as a starting point for developing “Caring for Carers”. To ensure that all of the recommendations were properly examined and addressed, the recommendations were allocated to sub-groups, with leaders from the main working

group and appropriate representation from carers and their representative organisations.

- 6.98** The Strategy was developed around six key themes:
1. Identification of and interface with carers;
  2. Information for carers;
  3. Training;
  4. Employment;
  5. Support Services; and
  6. Young Carers.
- 6.99** The Strategy was inter-departmental and inter-agency, dealing with health and personal social services, employment, training, education, information and support services.
- 6.100** A significant amount of progress was found to have already been made in implementing various aspects of the proposed Strategy, however further work was identified as being required to fully implement these proposals. “Caring for Carers” documented 15 further key actions that needed to be undertaken to ensure full implementation of the recommendations set out in “Valuing Carers” (see Appendix 2).
- 6.101** “Caring for Carers” also included a framework for support services to carers both individually and collectively. It provided guidance on the ways in which such support can be delivered and suggested further research into models that ensure carers experience a responsive service designed to meet individual needs (see Appendix 3).
- 6.102** In 2005/2006, in parallel with the launch of “Caring for Carers”, DHSSPS allocated an additional £400k of recurrent investment to be used by Health and Social Care (HSC) Bodies to develop innovative and responsive support services for carers, including flexible respite provision.

### **Carers’ Strategy Implementation Group**

- 6.103** A Carers’ Strategy Implementation Group (CSIG), which includes DHSSPS officials, representatives from HSC organisations and carers’ representatives, has been established to ensure that the health and social care aspects of “Caring for Carers” are fully implemented. This group has also been tasked to take forward the recommendations from “Promoting Partnerships in Caring”, the overview report from the Inspection of Social Care Support Services for Carers of Older People, published by DHSSPS in 2007.

### **Recommendation**

- 6.104** Membership of the Carers’ Strategy Implementation Group (CSIG) should be reviewed to make sure that there is representation at a sufficiently senior level from all Directorates within DHSSPS with responsibility for carers thus ensuring that the voice of carers is heard at Departmental Board level; all Commissioners, HSC Trusts and carers’ representatives also should be represented on this Group. In addition, the ToR for this group should be amended to include a role in monitoring the implementation of the recommendations of this Review.

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## Implementation of Caring for Carers Strategy (2006)

- 6.105** DHSSPS has to date issued two circulars providing practical advice and direction on implementing key aspects of the Caring for Carers Strategy.
- 6.106** Circular HSS (ECCU) 4/2006 was issued to Chief Executives of Health and Social Services (HSS) Boards and HSC Trusts, Chief Officers of HSS Councils and all General Practitioners in November 2006. The key actions required are summarised below:
- the presence of a carer should be recorded on all relevant patient/client and carer records;
  - HSC professionals should be particularly proactive in identifying the presence of older or younger carers;
  - HSC professionals should ensure they are fully aware of guidance relating to seeking consent to share information;
  - HSC Trusts should have a formally identified Carers' Co-ordinator;
  - HSC Trusts should support the establishment of a carers' reference group within their areas;
  - HSS Commissioners, HSC Trusts and HSS Councils should identify a board member with overall responsibility of carers' issues across their organisations;
  - HSC Trusts should co-operate fully in the development of the necessary information systems; and
  - HSC Trusts must engage directly with the voluntary and community sector about the development and delivery of sustainable carer support initiatives.
- 6.107** Circular HSS (ECCU) 3/2008 was issued to Chief Executives of HSS Boards and HSC Trusts in November 2008. The circular provided information on HSS and HSC personnel with lead responsibilities for carers' issues across their organisations together with guidance on the role of these officers. HSC Trusts were tasked with developing a protocol, drawing on existing policy and good practice in the Trust, which would clarify how the "carer training" process would be managed. DHSSPS undertook to develop good practice guidance, in relation to training for carers, which would allow Trusts to develop this protocol. "Good Practice Guidance – Training for Carers" was attached to this circular.
- 6.108** DHSSPS in partnership with CSIG, is currently developing a guide for carers informing them about the process of discharging a patient from hospital and intermediate care, the decisions that may have to be made and what they can expect to happen during the discharge process. A guide is also being developed for managers and policy makers to help HSC Trusts develop policy and practice in identifying and involving carers in planning for a patient's discharge from hospital and intermediate care. This and any further guidance will be issued to commissioners and HSC Trusts as required.

## **“Promoting Partnerships in Caring” – the Overview Report of the Inspection of Social Care Support Services for Carers of Older People**

- 6.109** The need for an inspection of social care support services for carers of older people in Northern Ireland was identified during the consultation of the former Social Service Inspectorate’s inspection programme for 2002 – 2005. The overview report presents the main findings of an inspection of social care support services for carers of older people in Northern Ireland. The inspection was undertaken by the Social Services Inspectorate (SSI) of DHSSPS in 4 HSC Legacy Trusts and their commissioning HSS Boards. The report, its recommendations and the associated draft standards provide a framework for the future provision of flexible, high quality social care services for carers of older people.
- 6.110** The reports arising from this inspection identified many areas of good practice and good quality work undertaken by highly motivated staff. The reports sought to identify both what was working well and where improvements were still needed.
- 6.111** The reports, with their recommendations to HSS Boards and HSC Trusts and their partner agencies, together with draft standards and other initiatives from DHSSPS, provided a clear and coherent framework for the future provision of robust, high quality support for carers.
- 6.112** The overview report “Promoting Partnerships in Caring” was issued in December 2007. The report highlighted the need for HSS Boards and HSC Trusts to clearly differentiate between services designed to support the caring role and those which meet the needs of the cared for person. It indicated that it must not be assumed that services provided for the cared for person, albeit, in many cases, shaped by the carer, also meet the needs of the carer. It concluded that more work was needed in promoting Carers’ Assessment and the use of Direct Payments.
- 6.113** The inspection found that the need to build on and to create new partnerships with the voluntary and community sectors was a central part of promoting, developing and maintaining support services which listen to the voice of carers and reflect their needs.
- 6.114** The report made 23 key recommendations to HSS Boards and HSC Trusts under the following 6 headings:
1. Planning, Commissioning, Delivery and Review of Social Care Services (3 recommendations);
  2. Assessment, Care Planning and Review (8 recommendations);
  3. Support Service (7 recommendations);
  4. Information for Service Users (2 recommendations);
  5. Workforce Planning, Workforce Management, Training, Supervision and Support (2 recommendations);
  6. Human Rights and Equality (1 recommendation).
- 6.115** The Carers’ Strategy Implementation Group (CSIG) was tasked with taking forward these recommendations in parallel with the work already being undertaken in implementing the recommendations in “Caring for Carers”.

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**6.116** As part of the preparation for the inspection, standards were developed to test their applicability to support services to carers in all Adult Programmes of Care and were found to be fully applicable with only minor modification. The final “Standards for Adult Social Care Support Services for Carers”<sup>30</sup> were issued in July 2008 and complemented other published standards with regard to practice and social care provision. The standards were designed to be of use to Commissioners and Providers of social care support services for carers; social care workers; regulatory and training providers and most importantly to carers and their representative groups to inform them what they can and should reasonably expect from social care support services and from the organisations and practitioners commissioning and providing them.

**6.117** The standards were developed through a reference group comprising individuals and representatives from a wide range of agencies from across Northern Ireland, including carers’ organisations and carers; HSS Boards and HSC Trusts; voluntary and community organisations (including service providers); and academic and policy interests. The standards were also influenced by:

- A review of existing standards;
- A review of a wide body of literature and research on carers’ support;
- An analysis of carers’ experience of services;
- Meetings with representatives of the Indian and Chinese communities in Northern Ireland;
- A formal widespread consultation process with all HSS Boards, local health and social care groups, HSC Trusts, HSS Councils, Trauma Advisory Panels, Universities and Colleges and over 80 groups and independent sector providers reflecting Section 75 of the Northern Ireland Act 1998.

**6.118** The standards were reviewed in collaboration with the Reference Group to reflect the learning derived from the inspection and further feedback received from the HSS Boards and HSC Trusts inspected.

**6.119** The standards are applicable to all HSC organisations, regulated services and practitioners, who commission, plan or provide services to carers in all Adult Programmes of Care. Such services include:

- Information, advice and counselling;
- Domiciliary care, including help with personal care and domestic tasks;
- Respite/breaks in the home or in appropriate residential settings;
- Help with disablement and home adaptations;
- Meals;
- Laundry;

- Day care;
- Help with transport;
- Carer support groups and emotional support;
- Rehabilitation;
- Out-of-hours social work service response;
- Help lines; and
- Residential care.

**6.120** The implementation of the standards will provide a foundation for informing best practice and assist with the planning, delivery, audit, review and inspection of social care support services for carers across the region.

**6.121** Under each of 6 headings there is a standard statement which explains the level of performance to be achieved, this is supported by criteria which provide further detail of the areas to be considered in the application of the standard to practice, service provision, governance and workforce issues.

### **Audit of Support Services for Carers**

**6.122** DHSSPS's "Value for Money Strategy" is designed to ensure that the full benefits of an appropriately structured programme are realised across the HSC sector. This is achieved by selecting and prioritising topics for examination based on DHSSPS corporate objectives, focusing on the audit of services at the regional level and by ensuring that DHSSPS drives the process. One of the topics approved by the HSSPS Departmental Board for the 2007/08 audit programme was "Support Services for Carers".

**6.123** It was within this context that DHSSPS commissioned Pricewaterhouse Coopers LLP (PwC) to examine provision of support services for carers by HSC Trusts in Northern Ireland. The Terms of Reference (TOR) for the audit covered four broad themes:

- Types of services;
- Support for Government policy;
- Engagement with carers; and
- Resources and monitoring.

**6.124** The audit commenced in August 2007, shortly after the merging of HSC Trusts as part of the Review of Public Administration. As a consequence the report acknowledged that some of the information provided by HSC Trusts as part of the audit was likely to

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change/have changed as new management arrangements and working practices were embedded within the new structures. Also during this time there has been an impact on HSS Boards with movement of staff to varying degrees and changes to the planned timescale and configuration of commissioning mechanisms.

- 6.125** The audit report examined the provision of support services for carers by HSC Trusts in Northern Ireland and identified 26 recommendations for action. These were grouped under three headings and are summarised below:

### **Types of Services (11 recommendations)**

- 6.126** A carer's assessment must be offered to identified carers and there should be a consistent regional assessment format. In cases where assessments are declined these cases should be monitored and reviewed. There is a need for effective commissioning with demonstrated outcomes (this includes the commissioning of a range of respite services reflecting the needs of both carer and cared for person), there should be greater use of Direct Payments, increased availability of interventions such as befriending and assistance for carers to plan and access support arrangements. It was recommended that an oversight group for young carer issues was established. Carer support was identified as a trans-Departmental issue and it was recommended that DHSSPS bring the strongly held views of carers represented in the report to the attention of the other relevant Government Departments. A range of up-to-date accessible information guides should be made available to carers.

### **Support for Government Policy and Engagement with Carers (9 recommendations)**

- 6.127** HSC Commissioners and providers must fully engage with carers in their assessments of unmet need and they should actively engage with carers to ensure that the actual carer experience is taken into account in planning, review and delivery processes. They should also increase the level of engagement they have with front line practitioners and review the information gathered from GPs as part of the Quality Outcome Framework (QOF) process. Carers should be provided with contact details of their local Carers' Co-ordinator and other key staff within HSC Trusts and/or independent sector organisations from whom they can seek advice or assistance in a crisis situation. Relevant training should be provided to carers and DHSSPS should ensure that staff training providers and associated regulatory bodies reflect the need to recognise, value and support the caring role and routinely involve carers and their actual experiences. DHSSPS should inform relevant Government Departments of the need to provide teachers with training on the challenges facing young carers. DHSSPS, Commissioners and HSC Trusts should continue to implement and support the ethos of the Partners for Change Strategy for the support of the voluntary and community sectors.

### **Resources and Monitoring (6 recommendations)**

- 6.128** Every HSC organisation should have a designated Board member who is accountable for the delivery of support services for carers and each HSC Trust should have a carers' advocate or equivalent. Commissioners and providers should ensure that access criteria are appropriately and consistently applied and any issues in respect of statutory returns for carers' assessments and Direct Payments should be resolved

quickly to allow good quality data collection to commence. Standards for the inspection of social care should be finalised and made the basis for carer standards across all adult Programmes of Care. Budgetary processes and accountability mechanisms at Commissioner and provider level should be put in place to allow resources allocated to support services for carers to be reported on.

- 6.129** Whilst a number of the recommendations will require concerted action, many of them have subsequently been implemented or partially implemented. Many of the recommendations echo messages identified in “Caring for Carers” (published January 2006) and in “Promoting Partnerships in Caring” (published December 2007) and are reflected in actions required from HSS Boards and HSC Trusts in Departmental Circulars (in particular HSS (ECCU) 4/2006 and HSS (ECCU) 3/2008) and reflected in Standards issued by DHSSPS over the period.
- 6.130** To ensure that all recommendations are fully implemented a “Departmental Action Plan” has been produced and progress against it will be monitored on a regular basis. A “Trust Self-Audit Tool” which has been developed by DHSSPS will assist HSC Trusts in satisfying themselves that all the recommendations in relation to engagement with carers are either being met or are being significantly progressed. DHSSPS will be examining the results of the audits to establish a baseline from which future progress can be measured.

### **Carers’ Assessments and Direct Payments**

- 6.131** In 2003, the Northern Ireland Assembly brought into force the “Carers and Direct Payments Act (Northern Ireland) 2002”, which imposes a legal requirement upon the Health and Personal Social Services (HPSS) to advise carers of their statutory right to an assessment. In response to assessment, HSC bodies are empowered, within local priorities and available resources, to provide a range of services directly to carers to help them in their caring role. The legislation also brought carers within the scope of Direct Payments, which can be made in lieu of service provision to meet an assessed care need.
- 6.132** The “Carers and Direct Payments Act (Northern Ireland) 2002, Carers’ Assessment & Information Guide” was issued by DHSSPS in April 2005. The guidance was prepared to assist HSS Boards and HSC Trusts in understanding the Act and the policy behind it and replaced original guidance issued in March 2003.
- 6.133** DHSSPS continues to advocate increased use of Direct Payments for carers and has circulated guidance in the form of “Carers and Direct Payments Act (Northern Ireland) 2002, Carers’ Assessment & Information Guidance” (2005) and Circular HSS (ECCU) 1/2007: “Direct Payments - Training of Personal Assistants” (2007)<sup>31</sup> to assist the HSC in promoting their use. The Department currently has a Priorities for Action Target for Direct Payments which is that “by March 2010, the number of Direct Payment cases should increase to 1,250 (rising to 1,500 by March 2011)” - at 31st December 2008, 1,134 clients were receiving Direct Payments. At this point the target is generic in nature, with no specific targets set by Programmes of Care or for carers.
- 6.134** DHSSPS contributes to the Regional Direct Payments Group (RDPG) which is

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charged with promoting Direct Payments and bringing forward solutions to overcome barriers to uptake. In addition, DHSSPS continues to monitor developments in relation to personal budgets for carers in England.

**6.135** DHSSPS Community Information Branch is currently working with policy colleagues and the RDPG to resolve a number of issues identified in the monitoring of Direct Payments for carers – in particular issues relating to one-off payments. It is anticipated that these issues will be resolved and that accurate and consistent information relating to Direct Payments for carers will be available late in 2009. The availability of this information will facilitate the development of more focused target setting.

### **Voluntary Sector Funding**

**6.136** DHSSPS provides core funding to Carers NI, which in 2008/2009 this amounted to £41,115. This funding is to enable Carers NI to deliver on the following objectives:

- increase awareness about carers amongst politicians, health and community care practitioners, planners and the public;
- support and enable carers to contribute to the planning, development and delivery of services;
- promote the development of policies that will alleviate and prevent the negative impact of caring;
- provide high quality information to carers so they can make positive choices;
- conduct awareness raising and outreach campaigns to promote uptake of benefits and services;
- promote and monitor the implementation of “Caring for Carers”;
- enable an increased understanding of human rights and equality issues amongst carers and professionals;
- develop a strategy to identify and support hard to reach or hidden carers;
- encourage carers, carers groups and branches to identify both specific and shared needs;
- work co-operatively with and through all networks and organisations that support carers; and
- participate in appropriate inter-sectoral working groups.

**6.137** DHSSPS will shortly begin a review of its funding arrangements to the voluntary and community sector in light of the new HSC structures. Pending the findings of that review, the Department will not be entering into any new core funding arrangements.

**6.138** Commissioners and providers also provide funding on a local level to promote carers’ issues and support to carers, for example, through provision of access to premises and transport.

## Northern Ireland Single Assessment Tool

**6.139** On 11th February 2009, Michael McGimpsey, Minister of Health, Social Services and Public Safety launched the Northern Ireland Single Assessment Tool (NISAT). This is an assessment tool for assessing the health and social care needs of older people in Northern Ireland. DHSSPS commissioned the development of NISAT from the University of Ulster with Professor Brendan McCormack and Dr Brian Taylor as the project leads. NISAT is currently being rolled out in the older people's Programme of Care across all HSC Trusts and will be completed by June 2010.

**6.140** NISAT will standardise and streamline assessment and care planning processes and ensure a consistent approach to assessment across Northern Ireland. There are three primary components of the Tool: contact screening, core assessment and complex assessment. There are also four additional components which are to be used in conjunction with the primary components, one of which is a Carer's Support and Needs Assessment which facilitates an independent assessment of the carer in his or her own right.

**6.141** Among other matters, the Carer's Support and Needs Assessment component of the Northern Ireland Single Assessment Tool (NISAT) prompts exploration of:

- the impact of the caring role on the carer;
- social security benefits received and the need for information about benefits or financial planning;
- the use of Direct Payments as a vehicle for personalised service delivery;
- contingency planning;
- issues for the future;
- unmet need; and
- consent to information sharing and any restrictions to this.

**6.142** The NISAT, as well as facilitating a person-centred assessment of the service user's needs, also addresses:

- the impact of a breakdown in carer support arrangements;
- the capacity of the carer to continue caring;
- risk to the carer;
- unmet need;
- consent to information sharing and any restrictions to this; and
- prompts consideration of the need for a carer's assessment.

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- 6.143** The views of carers and significant others inform the assessment of need and help shape the subsequent action and care plans in relation to the cared for person.
- 6.144** The NISAT is a multi-disciplinary tool, designed to capture holistic information on an older person's health and social care needs, from non-complex to complex (care management). Initially the NISAT will be completed with older people, but will extend to all adult Programmes of Care. At each level of assessment within the NISAT, the Carer's Assessment can be triggered. Practitioners are prompted to inform the carer of their right to an individual carer's assessment, offer this assessment and record where an offer has been accepted or declined.
- 6.145** In order to facilitate Carer's Assessment a standardised "Carer's Support and Needs Assessment" form was developed. This will be used in conjunction with the NISAT, but is also a "stand-alone" form that is appropriate for use in all Programmes of Care. The Northern Health and Social Care Trust is currently carrying out a Carer's Assessment Study to be completed mid 2009. Objectives of the study include increasing the number of carer's assessments completed within all Programmes of Care and to inform recommendations for the regional implementation of the NISAT Carer's Support Needs Assessment. The results of this study will be logged and discussed by the NISAT Implementation Project Board.

### **Recommendation**

- 6.146** The person-centred Carer's Support and Needs Assessment component of the "Northern Ireland Single Assessment Tool" (NISAT) will be embedded in the process to assess the needs of carers in the Older People's Programme of Care by June 2010 and in parallel with this process, opportunities for its implementation in all other Programmes of Care should be exploited.

### **Trust Self-Audit Tool**

- 6.147** A key message from carers' representatives was that although DHSSPS has published strategies and issued policy & guidance to the HSC, there are still issues to be addressed in relation to the extent to which implementation has proceeded and the consistency of implementation across all geographical areas and Programmes of Care. DHSSPS recognised that a system is needed to ensure that all policies relating to carers have been fully implemented in a consistent manner across Northern Ireland and in all Programmes of Care.
- 6.148** To that end, to monitor progress towards implementation in full of the recommendations identified in "Caring for Carers", "Promoting Partnerships in Care", "Audit of Support Services for Carers" and reflected in the actions required in Departmental Circulars HSS (ECCU) 4/2006 and HSS (ECCU) 3/2008 and reflected in standards issued by the DHSSPS during this period, a "Trust Self-Audit Tool" has recently been developed by DHSSPS. During the development process DHSSPS consulted with HSS Boards and HSC Trusts. This tool was distributed to Chief Executives of HSC Trusts in April 2009 and they have been asked to use it to satisfy themselves that all the recommendations are either being met, or are being significantly progressed. Chief Executives have been asked to complete the self-audit and return it to DHSSPS so that an assurance can be provided to the Minister that carers are being put at the forefront of HSC Trusts' agendas.

**6.149** The “Trust Self-Audit Tool” will establish a baseline position for HSC Trusts against which future progress can be measured. DHSSPS officials will review the material submitted along with supporting evidence in consultation with CSIG and provide feedback on the analysis to HSC Trusts. The information provided by HSC Trusts through the self-audit and any subsequent analysis undertaken by DHSSPS, will also be shared with the Regulation and Quality Improvement Authority (RQIA). The results of the self-audit will inform RQIA in its ongoing role in assuring the quality of services by HSC Trusts to ensure that every aspect of care reaches the standards laid down by DHSSPS and expected by the public. To allow time for full implementation and to ensure that these standards are being achieved in a consistent manner across Northern Ireland, a thematic inspection on carers’ issues should be undertaken in 2011/2012.

## **Recommendations**

**6.150** Commissioners and HSC Trusts must use the “Trust Self-Audit Tool” developed and issued by DHSSPS to report on and monitor progress towards the implementation of the recommendations of “Caring for Carers” (January 2006), “Promoting Partnerships in Caring” (December 2007), “Audit of Support Services for Carers” (June 2008) and reflected in actions required from Commissioners and HSC Trusts in Departmental Circulars (HSS (ECCU) 4/2006 & 3/2008) and reflected in standards issued by DHSSPS over this period.

**6.151** DHSSPS should request that the Regulation and Quality Improvement Authority (RQIA) include a thematic inspection of carers’ issues in their work plan for 2011/2012.

## **Engagement with Carers and Their Representatives**

**6.152** In September 2007, DHSSPS issued circular HSC (SQSD) 29/07 – “Guidance on Strengthening Personal and Public Involvement in Health and Social Care”<sup>32</sup>. The guidance was to assist HSC organisations improve the quality and effectiveness of user and public involvement as an integral part of good governance arrangements and to support the development of a more patient and user-centred HSC. It was developed in collaboration with service users, carers, local communities and service providers.

**6.153** The purpose of the circular was to:

- strengthen personal and public involvement (PPI) in every HSC organisation;
- promote greater uniformity and consistency in PPI activity across HSC organisations;
- improve the quality of the individual’s experience of HSC services by involving people in plans and decisions about their own care or treatment and learning from their experiences to improve service delivery;
- ensure HSC organisations take the public’s views into account in the planning, commissioning, delivery and evaluation of services; and

- support the integration of PPI into individual and organisational clinical and social care governance arrangements within HSC organisations.

- 6.154** The need to actively engage with carers and carers' representatives to ensure that their experiences are used to inform the planning, delivery and evaluation of services for carers has consistently been recognised as crucial in improving the delivery of services to carers. Recommendations on carer engagement and provision of relevant, up-to-date information for carers have featured in strategies, inspections and audits, from "Valuing Carers" to the recent "Audit of Support Services for Carers". Whilst it is clear that much is still to be done, there has been progress in this area, for example, all HSC Trusts have formally identified one or more local Carers' Co-ordinators, a major part of their role is to support Carers' Reference Groups, facilitate links between carers, carers' organisations and the HSC Trust, and promote awareness of carers issues within HSC Trusts.
- 6.155** The "Trust Self-Audit Tool" which has been developed by DHSSPS will assist HSC Trusts in satisfying themselves that all the recommendations in relation to engagement with carers are either being met or are being significantly progressed. DHSSPS will be examining the results of the audits to establish a baseline from which future progress can be measured.

### Information for Carers

- 6.156** The need for up-to-date, relevant information which is easily accessible to be available to carers has been highlighted by carers' representatives as being vital. Feedback was generally positive in terms of the quality of information available, but it did vary according to geographical location. The need to signpost services provided by the Health Sector, DSD (in respect of information about benefits) and, the voluntary & community sector about services available to carers was highlighted as important. The "A-Z for Carers" issued by DHSSPS in 2006, was found to be particularly helpful and a revised and updated version of the document would be welcomed.
- 6.157** The importance of information for carers has been a theme in recommendations found in "Caring for Carers", "Promoting Partnerships in Caring" and the "Audit of Support Services for Carers". The "Trust Self-Audit Tool" which was issued to HSC Trusts in April 2009 will monitor compliance with the recommendations set out in all of these reports.
- 6.158** Key recommendations include that HSC Trusts and partner Agencies should have a range of information guides for carers in place and these should be:
- comprehensive, up-to-date, accessible and actively promoted to carers;
  - available in a variety of formats (e.g. hard copies and electronically);
  - reviewed on a regular basis (every six months) in light of changes to services and/or staff; and
  - distributed in accessible areas for carers e.g. GP surgeries, pharmacies, libraries and other public places, in order that 'hidden' carers may have access to this information.

- 6.159** HSC Trusts will also be expected to provide a dedicated page for carers on their websites to provide information about services to carers, contact details for Carers' Co-ordinators and links to other relevant websites.
- 6.160** The involvement of carers and their representative groups in the production and review of information guides is also important so that their needs are truly reflected in the end product. In addition, HSC Trusts are expected to engage with front line practitioners such as GPs, community nurses, social workers and Allied Health Professionals (AHPs) in raising awareness about carers and carers' issues.
- 6.161** A key step forward in Government providing a one-stop-shop for information for carers is the NI Direct website which was launched on 31st March 2009. The website is part of the Northern Ireland Civil Service Reform Programme and a key target in the Programme for Government. The aim for NI Direct is that it will carry a range of information in an easily-read and understood style and that the information on it will be accurate, comprehensive and relevant to the citizen. There is a link specifically entitled 'Caring for someone' and it takes the individual into a page where they can access information about Caring and support services, Money matters, Caring for a child with disabilities, Health and taking a break, Carers and employment and Carers' rights. This information will be updated regularly by the relevant Government Departments.

### **Recommendation**

- 6.162** DHSSPS should produce and issue an up-to-date version of the "A-Z for Carers" by December 2009.

### **DSD/DHSSPS Joint Recommendation**

- 6.163** DSD and DHSSPS should work more closely in terms of provision of information and signposting for carers.

### **Information about Carers**

- 6.164** The need to have up-to-date and accurate information about carers in Northern Ireland has been recognised as vital to inform health and social care commissioners, providers and policy makers about the current needs of carers and to assist in planning for future service developments. The collection of accurate data about carers and the services they avail of has posed a number of challenges, for example, it has been vital to develop clear definitions of services of which carers are the direct beneficiaries and those services which have the cared for person as the primary focus, but which carers undoubtedly also benefit from.
- 6.165** Progress is being made on several fronts:
- a question about caring will feature in the 2011 census;
  - DHSSPS will fund questions on carers in an Omnibus Survey in September 2009;

- statisticians in DHSSPS are currently piloting data returns relating to carers assessments and respite care and are currently working with policy colleagues and the Regional Direct Payment Group to resolve a number of issues identified in the monitoring of Direct Payments for carers;
- as part of the Quality and Outcomes Framework (QOF), GP practices are monitored on having a protocol to identify carers and a mechanism for referral for social services assessment;
- in December 2008, Minister McGimpsey launched a new survey to seek patients' views of GP services. The survey will measure the quality of services that patients receive and provide greater accountability to delivering services that better meet the needs of local patients. One of the questions asks about caring responsibilities and this survey will provide the opportunity to ask more focussed questions about services provided to carers in the future;
- HSC Trusts are expected to undertake surveys of carer satisfaction with services to carers, involving carers in the process of design and consultation – progress made by HSC Trusts in this area will be measured by the “Trust Self-Audit Tool”.

**6.166** In addition HSC Trusts are expected to:

- collect, collate and act upon appropriately, information about unmet need across all Programmes of Care;
- fully co-operate in the development of information systems in relation to carer's assessments and identification of unmet need;
- ensure that there is consistent interpretation and application of guidance in relation to statutory returns for carer's assessments and Direct Payments across all Programmes of Care.

**6.167** The “Trust Self-Audit Tool” which has been developed by DHSSPS will assist HSC Trusts in satisfying themselves that all the recommendations in relation to information about carers are either being met or are being significantly progressed. DHSSPS will be examining the results of the audits to establish a baseline from which future progress can be measured.

## **Recommendation**

**6.168** DHSSPS in partnership with Commissioners and HSC Trusts should ensure that there is good quality information collected about carers particularly in relation to carers' assessments, respite care including unmet need and Direct Payments which can be utilised in planning for future service requirements.

## **Training for Carers**

**6.169** The importance of appropriate and timely training for carers has been a theme in recommendations found in “Caring for Carers”, “Promoting Partnerships in Caring”, circular HSS (ECCU) 3/2008 Implementation of the Carers' Strategy and the “Audit of

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Support Services for Carers”. The “Trust Self-Audit Tool” which was issued to HSC Trusts in April 2009 will ensure that recommendations relating to training for carers set out in these reports are either being met or are being significantly progressed.

**6.170** Recommendations for action by HSC Trusts are summarised below:

- training for carers must be accessible and relevant to the needs of carers, and include :
  - training on the use of aids and equipment;
  - training on lifting and bathing;
  - training on giving medicine and first aid and on dealing with, for example, catheters, PEG tubes and colostomies;
  - training on behavioural management; and
  - specialist training such as sign language, as appropriate;
- carers’ training needs must be assessed and relevant training and support provided, for example, to undertake practical aspects of caring (e.g. back care), and also in relation to condition-specific (e.g. Alzheimer’s) and service-specific topics, as appropriate;
- support must be provided for the training and development of carers’ advocates;
- carers must be involved in the design, planning and delivery of training for carers;
- the development of a carer training protocol must be taken forward as a priority.

**6.171** Carers’ representatives indicated that most HSS Boards and HSC Trusts have involved them in staff training, for example, one HSC Trust has produced DVDs using words that carers have provided in respect of carers’ assessments. However they highlighted a general need to improve awareness across health and social care professionals of the training needs of carers, particularly in the areas of manual handling, stress management and dealing with challenging behaviour.

### **Recommendation**

**6.172** DHSSPS should engage with Commissioners and HSC Trusts to explore the potential for carers to receive better levels of training in the more technical aspects of their caring responsibilities.

### **Training for HSC Staff Providing Services to Carers**

**6.173** DHSSPS recognises the importance of having well informed and appropriately trained staff to ensure that the best possible service is provided to carers.

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**6.174** The importance has been highlighted in “Caring for Carers”, “Promoting Partnerships in Caring” and the “Audit of Support Services for Carers”. The “Trust Self-Audit Tool” which was issued to HSC Trusts in April 2009 will ensure that recommendations relating to training for staff set out in these reports are either being met or are being significantly progressed.

**6.175** Recommendations for action by HSC Trusts are summarised below:

- HSC Trusts value care workers and this is reflected in the support and development opportunities available to them;
- HSC Trusts ensure the appropriate use of staff skills and resources;
- HSC Trusts provide ongoing appropriate training for Trust and independent sector staff, consistent with their roles;
- HSC Trusts ensure staff training promotes:
  - respect for, and partnership working with, carers;
  - the uptake of carers’ assessments and Direct Payments; and
  - recognition of the carer’s role;
- HSC Trusts involve carers in in-service training for staff and use the DVD “Children First - Carers Second” as a training aid for staff who look after young carers;
- HSC Trusts ensure that staff are aware of the range of support services for carers in their area and actively encourage carers to avail of this support;
- HSC Trusts ensure consistency with regard to the appropriate vetting of staff and assurances over the level of training and skills possessed by them.

**6.176** In situations where carers feel that things could have been done better it is important that the HSC learns from comments and complaints and;

- creates an environment where learning from comments and complaints can take place;
- has mechanisms in place to monitor, resolve and learn from comments and complaints;
- provides training to front line staff to ensure that they respond openly and positively to comments and complaints;
- disseminates learning from comments and complaints; and
- can identify what has changed as a consequence.

**6.177** To what degree HSC Trusts are meeting the recommendations relating to comments and complaints will be assessed by the “Trust Self-Audit Tool”.

### **Younger Carers**

**6.178** Young carers generally care for members of their immediate family whether a parent with a physical illness, disability, mental health problem or alcohol or drug dependency; a grandparent who is frail, ill or disabled or a brother or sister who is ill or disabled. It remains DHSSPS policy that a sufficient level of service should be provided to the ill or disabled person so as to prevent young people from having to take on inappropriate levels of responsibility for providing care. The wishes of the young person must be respected when considering the planning and delivery of services, so as to afford him or her, the opportunity to contribute, where appropriate, to the caring role in a way that does not compromise his or her own developmental needs.

**6.179** HSC Trusts must ensure that where younger carers are identified, appropriate referral to, or consultation with, the relevant child care team takes place to prevent these young people from having to take on inappropriate levels of responsibility for providing care.

**6.180** The ‘Understanding the Needs of Children in Northern Ireland’ (UNOCINI)<sup>33</sup> is a framework to support professionals in assessment and planning to better meet the needs of children and their family’s. The framework offers a logical process within which children and their family’s circumstances can be considered, analysed and understood in order to develop robust plans that lead to action with the aim of improving outcomes for the child. The UNOCINI assessment framework has been developed by Health and Personal Social Services in conjunction with colleagues from other public agencies such as education and the police. It is hoped that the UNOCINI assessment framework will be used by all professionals working with children as a tool to help them identify the needs of children at an early stage.

**6.181** Carers’ representatives tell us that there is a continuing need to identify young carers and provide them with the support that they need. This involves building co-operative working relationships at local level between the statutory and voluntary sectors both in the sphere of health and social care, and education. These needs have been reflected in the recommendations emanating from “Caring for Carers” and the “Audit of Support Services for Carers”. The “Trust Self-Audit Tool” which was issued to HSC Trusts in April 2009 will ensure that recommendations relating to younger carers set out in these reports are either being met or are being significantly progressed.

**6.182** Recommendations for action by HSC Trusts are summarised below:

- HSC Trusts operate on the general principle that a sufficient level of service is provided to the ill or disabled person to prevent young people from having to take on inappropriate levels of responsibility for providing care;
- Each HSC Trust has an oversight group to ensure identification of a minimum specification for the type and standard of services to be made available to younger carers;

- HSC Trusts pay particular attention to the needs of younger carers to ensure that they do not assume inappropriate caring responsibilities which may compromise their educational or development needs; HSC Trusts actively engage with schools and the further and higher education sectors, as appropriate, to examine and remind them of their role in supporting young carers and how they can work with health and social care to support younger carers. Carers' Co-ordinators in each Trust have specific responsibility to establish and maintain links with schools to advise and assist them in supporting young carers;
- HSC Trusts make the information needs of younger carers a specific consideration when looking at ways of improving the information about services to carers available, for example, on website links to other relevant websites, e.g. Barnardo's Young Carers, Action for Children etc.

**6.183** Progress is already being made by four Area Children and Young People's Committees (ACYPC) in Northern Ireland. These Area Committees bring together senior representatives from statutory, voluntary and community organisations, with the aim of planning services for vulnerable children and young people. The legacy Health and Social Services Boards were each required to establish an Area Committee and to ensure Children's Services Plans were produced and implemented. The four Committees were charged with improving the health and well-being of vulnerable children and have long recognised that services for vulnerable children are more effective when they are planned alongside services for all children. All committees agreed that a Northern Ireland Children's Services Plan 2008-2011<sup>34</sup> should be produced on a regional basis. This plan was issued in November 2008 and it will be monitored through an Annual Review process. "Young Carers" has been identified as a priority theme in the Children's Services Plan and it has highlighted Identification of Young Carers, Information to Young Carers, Assessing the Needs of Young Carers and Provision of Service as key priorities.

**6.184** One of the areas currently being implemented and monitored is the Regional Young Carers Project which DHSSPS has awarded £0.5 million recurrently to establish and implement. The proposal for the service was developed by the four HSS Boards and recommended a regional approach to ensure the standardisation and uniformity of service delivery across Northern Ireland. The aims of the service include improved outcomes for young carers in respect of health, mental and emotional wellbeing, availing of social and recreational opportunities, awareness raising, one-to-one support, respite and assistance with transport.

**6.185** To ensure that issues affecting carers are reflected at the highest level within HSC Trusts, each HSC Trust has a designated board member with responsibility for carers' issues across their organisation. This Board member has an agreed remit for reviewing, monitoring and reporting to the HSC Trust Board on a separate adult and young carer basis.

### **Breaks for Carers**

**6.186** DHSSPS already spends some £630m recurrently on services for older people. Additional funding of £60m over a three year period (equivalent to £35m recurrent thereafter) was secured as part of the CSR to deal with the demographic increase in

the numbers of older people who will require support in the community. This investment will be targeted at a range of flexible and responsive community care services to support at least an additional 1,500 older people in the community by March 2011. Services to be developed will include domiciliary care, day care, respite care, support for carers, intermediate care and the expansion of Direct Payments.

- 6.187** The total budget secured under the CSR for children and adults with disabilities in Northern Ireland is £43m over a three year period (equivalent to £24m recurrent thereafter). Of this, £10m over a three year period (£7m recurrent thereafter), has been made available for the physical and sensory disability Programme of Care and £33m over a three year period (£17m recurrent thereafter), has been made available for the learning disability Programme of Care. Targets have been set under Priorities for Action which will provide a range of services, benefitting both children and adults with disabilities, including the provision of an additional 200 new or enhanced learning disability respite packages by 2011, providing 800 people with respite care and a further 200 new or enhanced physical and sensory disability respite packages by 2011. Disabled children and people with learning and physical disabilities, and their families and carers, will benefit from improved respite services. The expansion within respite services will include flexible short term respite provision; day activities; residential respite care, and domiciliary support.
- 6.188** An additional £1.85 million has been allocated to fund an additional 2,000 dementia respite places by 2011, and £2.5 million will be spent on advocacy and support services within the Mental Health Programme of Care, a proportion of which will be available for people with dementia and their carers.
- 6.189** Breaks from caring have been identified by carers' representatives as especially important in supporting carers in their caring role. This view has been corroborated in recommendations in "Caring for Carers", Circular HSS (ECCU) 3/2006: Care Assessment and Placement Guide - July 2006<sup>35</sup>, Older People and Domiciliary Care, NIAO - October 2007<sup>36</sup>, Older People and Domiciliary Care, DFP Memorandum on the Tenth Report from the Public Accounts Committee Session 2007-2008 - June 2008<sup>37</sup> and Standards for Adult Social Care Support Services for Carers, June 2008.
- 6.190** The "Trust Self-Audit Tool" which was issued to HSC Trusts in April 2009 will ensure that recommendations relating to breaks for carers set out in these reports are either being met or are being significantly progressed. Key recommendations include that HSC Trusts must provide/procure a range of respite services that:
- properly reflect the needs of modern living for both the carer and the cared for person;
  - ensure, wherever possible, that respite in an institutional setting is only offered where it is the preferred option of all parties;
  - are flexible; and
  - offer choice.

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**6.191** The services must be:

- a mix of traditional and more innovative models which aim to combine stimulating activities, safe placements, well-trained staff and age appropriate settings;
- available both in and out-of-hours and at weekends; and
- provide back up in an emergency or at times of crisis.

## **Recommendations**

**6.192** DHSSPS should ascertain what provision there is for breaks for carers (including emergency breaks) in Northern Ireland, assessment of level of need and the effectiveness of the models being used both in Northern Ireland and England, with a view to bidding for appropriate resources during the next CSR to allow investment in these important services.

**6.193** HSC Trusts should have in place procedures to provide emergency respite cover for carers; and carers should be made aware of the Trust's protocol for when these emergency provisions will be brought into play.

**6.194** DHSSPS should monitor the progress and outcome of the Department of Health's evaluation of the demonstrator sites testing: breaks for carers, better NHS Support for Carers and health checks for carers.

## **Chronic Condition Management & Health Care Technology**

**6.195** DHSSPS has allocated an additional £44m over the three year CSR period (£20.5 recurrent thereafter) to take forward new approaches to chronic condition management which will help people to continue to live in their own homes. This funding will be used to develop proactive case management arrangements and provide more specialist nursing and treatment services to ensure that people are not admitted to hospital unnecessarily. More community-based specialist palliative care services will also be developed to allow more patients to be cared for and die in their place of choice in the community.

**6.196** The additional resources will also provide for the introduction of more patient education programmes and a "remote vital signs monitoring service" for 5,000 patients with chronic conditions. The service will help patients to manage their own condition more effectively. It will also alert HSC professionals to sudden deterioration in a patient's condition and enable them to react quickly and ensure that prompt and effective services are delivered to support the patient.

**6.197** The DHSSPS Primary and Community Care Infrastructure Programme is designed to put in place a care infrastructure that is fit-for-purpose and facilitates effective alternatives to hospital care. A number of new Health and Care Centres will provide a greater range of diagnostic and other services which will cut down unnecessary hospital referrals. The Centres will also provide for the co-location of community-based multi-disciplinary teams which will facilitate the development of a more

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integrated approach to the delivery of services by teams of HSC professionals to support and maintain people in their own homes.

**6.198** DHSSPS recognises the need to help individuals and their carers to sustain their ability to live independently in their own homes. The application of technology to support independent living offers additional choice in service provision and can be used to help reduce risks in the home environment.

**6.199** Minister McGimpsey has indicated that a priority for the DHSSPS is to develop a five to seven year strategy for the development of connected health. This will include the consideration of the benefits of Telecare which is the term given to the provision of remote care to, for example, older and vulnerable people, or people at risk of falling or who have significant physical disability - providing the care and reassurance needed to allow them to remain living in their own homes. The use of sensors may be part of a package which can provide support for people with illnesses such as dementia, for example, to alert a carer that the front door has been opened, or people at risk of falling, for example, to alert a carer that the cared for person has got out of bed. Telecare refers to the idea of enabling people to remain independent in their own homes by providing person-centred reactive technologies to support the individual or their carers.

### **Emotional Support for Carers**

**6.200** DHSSPS has asked HSC Trusts to ensure that they are working towards increased availability of interventions such as emotional support through befriending and carer support groups. It is expected that carers should have access to emotional support especially during times of transition and after the caring role has ended in order to help them adjust to the changes which they may experience during this period. This support should be co-ordinated by HSC Trusts but should, in the main, be provided primarily through sustainable engagement with the independent/voluntary and community sector.

**6.201** The importance of appropriate provision of emotional support has been highlighted in “Caring for Carers”, “Promoting Partnerships in Caring” and the “Audit of Support Services for Carers”. The “Trust Self-Audit Tool” which was issued to HSC Trusts in April 2009 will ensure that recommendations relating to provision of emotional support set out in these reports are either being met or are being significantly progressed. Key recommendations for HSC Trusts include:

- HSC Trusts engaging directly with the voluntary and community sector about the establishment, development and delivery of sustainable carer support initiatives, including carer support groups and carer support networks;
- HSC Trusts exploring the development of more localised support services for carers which offer a wider range of high quality services within their own localities; and
- considering ways in which it can better proactively support individual carers. In particular, attention should be paid to carers who may not wish to join groups or who are unable to do so because of their geographic location or personal circumstances; and

- providing opportunities for “peer mentoring”.

**6.202** All organisations (whether statutory or voluntary) in each HSC Trust which have contact with carers:

- are encouraged to see their role as part of a wider network of support for carers; and
- are able to refer carers to services which can help them.

**6.203** Following a number of recommendations made by the Bamford Review of Mental Health and Learning Disability, a draft Strategy for the Development of Psychological Therapy Services was issued for consultation<sup>38</sup>. The consultation period closed at the end of March 2009. The strategy proposes a framework for the development of psychological therapy services with the aim of improving access to these services coupled with promoting early intervention, self help and support in the community. It acknowledges that carers need psychological support, to maintain and improve their mental health and to assist them to look after their loved ones with long-term physical, mental health and learning disabilities.

**6.204** The Psychological Therapy Services Strategy proposes that:

- service users and carers should be involved at all levels of service development, planning and implementation of psychological therapy services.
- a Regional Psychotherapies Group should be established as a matter of urgency to oversee implementation of this strategy and to advise the Department on the future development of child and adolescent and adult psychological therapy services. It should be representative of commissioners, service providers, carers and users.
- psychological therapy services should be subject to service, therapeutic and economic evaluation which takes account of the views of service users and carers.

**6.205** An additional £7 million will be invested recurrently from 2010/2011, for implementation of this strategy. Improving access to psychological therapies has huge potential to improve outcomes for individuals, families and carers and for the wider community.

### **Working with Doctors**

**6.206** DHSSPS recognises the important work that doctors can do in helping carers and the Review Team has liaised with the British Medical Association in Northern Ireland (BMA (NI)) during the course of this Review.

**6.207** They told us that the BMA’s Committee on Community Care produced guidance in November 2007 “Working with carers: guidelines for good practice”<sup>39</sup> to assist doctors in all settings in their work with carers, this was a UK wide document and it outlines:

- who carers are;

- the legislation and government guidance which relates to services for carers;
- what carers need;
- how doctors can help and support carers;
- the special needs of young carers;
- dealing with issues of confidentiality;
- other support available to carers;
- other sources of information on caring issues for doctors and carers.

**6.208** On a regional level, the BMA (NI) patient liaison group ran a Carers and Young Carers Workshop in November 2008 to develop its policy on carers and young carers. As a result of the workshop, a Briefing Note for BMA members in NI is being developed and this will highlight what doctors can do to help carers.

### **General Practitioners (GPs)**

**6.209** GPs are often the first point of contact with carers and often continue to be the professional with the closest contact with them. As is the case elsewhere in the United Kingdom, the Quality and Outcomes Framework (QOF) is a system to remunerate general practices for providing good quality care to their patients, and to help fund work to further improve the quality of health care delivered. It is a fundamental part of the General Medical Services (GMS) Contract, introduced on 1 April 2004.

**6.210** Three QOF points relate to carers, the indicator is "The Practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment". During 2007/08 in the 361 participating practices, 98.6% of the points available were achieved. Commissioners require practices to provide evidence to support achievement of this indicator.

**6.211** Although this indicator is useful in raising GPs' awareness of carers and ensuring that there is a mechanism for referral for social services assessment, it is deficient in terms of providing evidence of the outcomes achieved for carers as a result of this identification and where appropriate referrals have been made.

**6.212** A recently announced development may potentially provide a vehicle by which this situation may be remedied. The National Institute for Health and Clinical Excellence (NICE) is to oversee an independent, transparent and objective process for prioritising, developing and reviewing Quality and Outcomes Framework (QOF) indicators for GPs from 1 April 2009. A key part of the new NICE process for QOF is the creation of an independent Primary Care Quality and Outcomes Framework Indicator Advisory Committee that will review existing indicators and recommend new ones. NICE will also ensure that all stakeholders have a clear opportunity to contribute to the development of indicators at every stage of the process. This will include enabling interested parties to submit ideas for priority topics via the NICE website, as well as submitting comments on proposed indicators during the consultation phase. NICE will

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make recommendations on QOF indicators, but the decision on which ones are and aren't included in the framework will continue to be a matter for consultation between NHS Employers, on behalf of the Department of Health and the devolved administrations, and the General Practitioners Committee (GPC) of the BMA.

## **Palliative and End of Life Care and Bereavement**

- 6.213** Carers' representatives told us that when the person cared for dies, carers often feel isolated and alone. They indicated that carers often need more support before, at the time of and after death.
- 6.214** On 29th May 2009, Minister McGimpsey announced the development of a Strategy for Palliative and End of Life Care which will be published by the end of March 2010. The aim of the strategy will be to improve the quality of care for adult patients with advanced progressive illness in Northern Ireland. The Strategy will help ensure that palliative and end of life care services, wherever possible, will be provided in a way that meets the particular needs and wishes of patients, their carers and families. During the development of the strategy the views of a wide range of stakeholders will be sought, particularly the views of patients and carers.
- 6.215** On 22 June 2009, DHSSPS published a "Strategy for Health and Social Care Bereavement Services in Northern Ireland"<sup>40</sup>.
- 6.216** The aim of the NI Health and Social Care Strategy for Bereavement Care is to promote an integrated, consistent approach to all aspects of care across the public Health and Social Care services in supporting individuals and families who have been bereaved and those that support them, appropriate to their individual needs and preferences. Many individuals in the Health and Social Care services come into contact with those who are dying and those affected by bereavement. The aim of the Strategy is to build the capacity of all those who have such contact to respond in the most appropriate way according to their respective roles and the needs and preferences of those affected.
- 6.217** A number of standards have been developed around key themes to assist Health and Social Care services in the delivery of services to people who are dying and their families, friends and carers and for those services coming into contact with them at other times. This has been done with the users as well as the providers of Health and Social Care services and those with a specialist interest. It is intended that these standards will inform regional guidelines and local policies and procedures where appropriate. Six principal standards were identified:
- 1. Raising awareness:** That Health and Social Care staff will be suitably trained to have an awareness and understanding of death, dying and bereavement. Staff should also acknowledge the fact that grief is a normal process following loss, and that needs vary according to an individual's background, community, beliefs, and abilities.
  - 2. Promoting safe and effective care:** That all Health and Social Care staff who have contact with people who are dying and/or with those affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death according to individuals' backgrounds,

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communities, beliefs and abilities.

3. **Communication, information and resources:** That people who are dying and those who are affected by bereavement will have access to up-to-date, timely, accurate and consistent information in a format and language which is appropriate and will be helpful to their particular circumstances consistent with their needs, abilities and preferences. Staff will remember that the availability of written or other information does not negate their personal support role.
4. **Creating a supportive experience:** That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs, abilities and preferences.
5. **Knowledge and skills:** That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development; and by having systems in place to support them.
6. **Working together:** That good communication and co-ordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

**6.218** It is hoped that this Strategy will ensure that carers receive the support they need, whether it be before, at the time of or after death.

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## 7. Conclusions and Recommendations

- 7.1 Minister Ritchie and Minister McGimpsey agreed that, following on from the Review of the Carers Strategy, that an examination of the support available to carers in Northern Ireland should take place.

### Department for Social Development

- 7.2 The Department recognises that an enormous amount of work is done by those who have the responsibility of caring for others and acknowledges the importance of benefits in providing financial support for carers. Although Carer's Allowance is the primary benefit designed to support carers, a number of other benefits are also available in particular, Income Support, Housing Benefit and Pension Credit.
- 7.3 Following the review of the National Carers' Strategy the Westminster Government has acknowledged the need for benefits for carers to be reformed. However, it considers it would not be right to undertake a review of carers' benefits in isolation as many of the difficulties that carers experience arise from the interactions between different benefits and interactions with different aspects of the wider welfare system. Consequently reforms to benefits for carers will take place as part of ongoing welfare reform.
- 7.4 There is a long-standing policy of parity between Great Britain and Northern Ireland which has resulted in the legislation in Northern Ireland being closely related to the corresponding Great Britain legislation.
- 7.5 The Voluntary Support/Advice Organisations who met the Review Team welcomed the improvements in Carer's Allowance and other benefits for carers and acknowledged the reality that Northern Ireland is not self sufficient in relation to social security. There also was consensus regarding the importance of maintaining parity with Great Britain. Therefore, they accepted that there is little or no scope for the Department for Social Development to make unilateral changes to benefits assisting carers.
- 7.6 The Department, however, is, fully committed to working closely with the Department for Work and Pensions in Great Britain to ensure the vision in the National Carers' Strategy, that carers are supported so they are not forced in to financial hardship by their caring role, is realised.
- 7.7 The Department also noted the concerns of the Carer/Advice organisations, regarding information about and the uptake of Carer's Allowance, the complexity of the overlapping benefits rules and underlying entitlement rules. It acknowledges that there is scope for tackling some of these concerns within the Northern Ireland context.

### Recommendations

- 7.8 The review resulted in the following recommendations:
- The long-standing policy of parity between Great Britain and Northern Ireland in social security should be maintained.
  - The Minister should continue to liaise with the Secretary of State for Work and Pensions in relation to carers' issues and the Department should work closely

with the Department for Work and Pensions on the reform of carers' benefits as part of the process of welfare reform.

- The Social Security Agency should include an exercise on Carer's Allowance as part of its benefit uptake programme.
- The Department should work closely with the Department for Work and Pensions and with carers' organisations in examining the future role and scope of carers' benefits.

## **Department of Health, Social Services and Public Safety**

**7.9** During the course of this review it has been evident that there are a large number of carers in Northern Ireland who willingly make an invaluable contribution in caring for family members or friends.

**7.10** Through "Valuing Carers", "Caring for Carers", "Promoting Partnerships in Caring", "Audit of Support Services for Carers" and Departmental guidance and standards, DHSSPS in partnership with commissioners, providers, independent/voluntary sector organisations, carers and their representatives has put in place a framework of policy, guidance and standards which is designed to support carers in their caring role. When examined against the work being taken forward in England as part of the National Strategy developments being made in Northern Ireland have shown to compare very favourably.

**7.11** A key advantage that Northern Ireland has above England in providing support services for carers is the integrated health and social care system which enhances the ability to ensure the essential joined-up planning and provision of services across both the health and social care sectors. The changes brought about by the Review of Public Administration (RPA) - having one Commissioning Board and five HSC Provider Trusts - will bring about more efficient, effective and consistent commissioning and service provision arrangements across the whole of Northern Ireland.

**7.12** There is evidence of a committed and caring workforce, and many examples of good practice have emerged – however as the Audit of Support Services for Carers evidenced, there is still progress to be made. One of the key findings has been that although there is a comprehensive framework of policy, guidance and standards in place, more work needs to be done to ensure that these are implemented effectively and on a consistent basis - both geographically and across all Programmes of Care.

**7.13** DHSSPS has recognised the need for effective implementation of policies, guidance and standards, and has issued the "Trust Self-Audit Tool". Chief Executives of HSC Trusts and have been asked to use this tool to satisfy themselves that all policies, guidance and standards relating to support services for carers, are either being met, or are being significantly progressed and that appropriate governance structures are in place to deliver better outcomes for carers. The launch of the Northern Ireland Single Assessment Tool with its Carer's Support and Needs Assessment is another major step forward in ensuring a consistent approach to carers' assessment across Northern Ireland, initially in the Older People's Programme of Care but this also opens up

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opportunities in all other Programmes of Care.

- 7.14** Some important work is being set up at pilot sites in England testing breaks for carers, support services and health checks. The results of these pilots will provide interesting learning for Northern Ireland and the opportunity to seek out innovative, efficient and effective models which could be considered for implementation in the future.
- 7.15** There continues to be significant investment in respite care across Northern Ireland as a result of funding secured as part of the CSR. Emergency breaks for carers has been identified as a particular area for funding in England, this provision is undoubtedly important to carers and merits investigation as to possible future bidding for funding in Northern Ireland.
- 7.16** The Carers' Strategy Implementation Group (CSIG) has proved to be a very effective collaboration of DHSSPS, commissioner, provider and carers' representatives. However, to ensure that it has the required membership which would support the Group's effort to fully implement recommendations from the Carer's Strategy and Promoting Partnerships in Caring, there would be merit in reviewing the membership of this group to ensure that all relevant Directorates in DHSSPS are represented and that Commissioners, HSC Trusts and carers' representatives are also appropriately represented.
- 7.17** Information about carers is essential to inform health service commissioners, providers and policy makers about the current needs of carers and to assist in planning for future service developments. It is therefore essential that DHSSPS, Commissioners and HSC Trusts work together to develop accurate, timely and relevant information systems.
- 7.18** The availability and accessibility of information for carers is also an important issue which needs to be addressed. There is a need to make it as easy as possible for carers to access information particularly when they most need it. The "A-Z for Carers" has been identified as a useful regional resource for carers - this should be updated and reissued. DHSSPS and DSD need to work together to ensure that the information they provide to carers is accurate and up-to-date and that they signpost carers to relevant information, for example, information about health and social care issues should sign post carers to information about social security benefits.

## **Recommendations**

- 7.19** The review resulted in the following recommendations:
- membership of the "Carers' Strategy Implementation Group" (CSIG) should be reviewed to make sure that there is representation at a sufficiently senior level from all Directorates within DHSSPS with responsibility for carers thus ensuring that the voice of carers is heard at Departmental Board level; all Commissioners & HSC Trusts and carers' representatives also should be represented on this Group. In addition, the ToR for this group should be amended to include a role in monitoring the implementation of the recommendations of this Review;
  - the person-centred Carer's Support and Needs Assessment component of the

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“Northern Ireland Single Assessment Tool” (NISAT) will be embedded in the process to assess the needs of carers in the Older People’s Programme of Care by June 2010 and in parallel with this process, opportunities for its implementation in all other Programmes of Care should be exploited;

- Commissioners and HSC Trusts must use the “Trust Self-Audit Tool” developed and issued by DHSSPS to report on and monitor progress towards the implementation of the recommendations of “Caring for Carers” (January 2006), “Promoting Partnerships in Caring” (December 2007), “Audit of Support Services for Carers” (June 2008) and reflected in actions required from Commissioners and HSC Trusts in Departmental Circulars (HSS (ECCU) 4/2006 & 3/2008) and reflected in standards issued by DHSSPS over this period;
- DHSSPS should request that the Regulation and Quality Improvement Authority (RQIA) include a thematic inspection of carers’ issues in their work plan for 2011/2012;
- DHSSPS should produce and issue an up-to-date version of the “A-Z for Carers” by December 2009;
- DHSSPS in partnership with Commissioners and HSC Trusts should ensure that there is good quality information collected about carers particularly in relation to carers’ assessments, respite care including unmet need and Direct Payments which can be utilised in planning for future service requirements;
- DHSSPS should engage with Commissioners and HSC Trusts to explore the potential for carers to receive better levels of training in the more technical aspects of their caring responsibilities;
- DHSSPS should ascertain what provision there is for breaks for carers (including emergency breaks) in Northern Ireland, assessment of level of need and the effectiveness of the models being used both in Northern Ireland and England, with a view to bidding for appropriate resources during the next CSR to allow investment in these important services;
- HSC Trusts should have in place procedures to provide emergency respite cover for carers; and carers should be made aware of the Trust’s protocol for when these emergency provisions will be brought into play;
- DHSSPS should monitor the progress and outcome of the Department of Health’s evaluation of the demonstrator sites testing: breaks for carers, better NHS Support for Carers and health checks for carers.

### **DSD/DHSSPS Joint Recommendation**

- 7.20** DSD and DHSSPS should work more closely in terms of provision of information and signposting for carers.

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## 8. References

- 1 Caring about Carers: A national strategy for carers; HM Government 1999
- 2 Carers at the heart of 21st -century families and communities; HM Government, June 2008
- 3 Valuing Carers – A Strategy for Carers in Northern Ireland; Department of Health, Social Services and Public Safety, 2002
- 4 Caring for Carers – Recognising, Valuing and Supporting the Caring Role; Department of Health, Social Services and Public Safety, 2006
- 5 Circular HSS (ECCU) 4/2006 – Implementation of the Carers’ Strategy; Department of Health, Social Services and Public Safety, 2006
- 6 Circular HSS (ECCU) 3/2008 – Implementation of the Carers’ Strategy; Department of Health, Social Services and Public Safety, 2008
- 7 Carers and Direct Payments Act (Northern Ireland) 2002, Carers’ Assessment & Information Guidance; Department of Health, Social Services and Public Safety, 2005
- 8 Overview Report, Promoting Partnerships in Caring – Inspection of Social Care Support Services for Carers of Older People; Department of Health, Social Services and Public Safety, 2007
- 9 Audit of Support Services for Carers; Department of Health, Social Services and Public Safety, 2009
- 10 A-Z for Carers; Department of Health, Social Services and Public Safety, 2006
- 11 Northern Ireland Census of Population 2001, Northern Ireland Statistics and Research Agency
- 12 Young Carers, ARK Research Update Number 56; Paula Devine and Katrina Lloyd, 2008
- 13 Survey of Carers of Older People in Northern Ireland, DHSSPS, 2006
- 14 New Deal for Carers: Income Task Force Report, July 2008
- 15 Raising expectations and increasing support: reforming welfare for the future; Department for Work and Pensions, December 2008
- 16 No one written off: reforming welfare to reward responsibility; Department for Work and Pensions, July 2008
- 17 Valuing and Supporting Carers; House of Commons Work and Pensions Committee Fourth Report of Session 2007-08, August 2008

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- 18 "Our Health, Our Care, Our Say" White Paper, DoH, 2006
  - 19 Putting People First, HM Government, 2007
  - 20 Individual Budgets: Impacts and Outcomes for Carers; ibsen, 2009
  - 21 Care 21: The Future of Unpaid Care in Scotland; Scottish Executive, 2006
  - 22 Carers' Strategy for Wales, Action Plan 2007; Welsh Assembly Government, 2007
  - 23 Social Security Contributions and Benefits (Northern Ireland) Act 1992 (c. 7)
  - 24 Northern Ireland Act 1998 (c. 47)
  - 25 Matching Intelligence and Data Analysis Services October 2008
  - 26 Carer's Allowance Bill; NIA Bill 13/07 Session 2007-2008
  - 27 Social Security Administration (Northern Ireland) Act 1992 (c. 8)
  - 28 The Social Security (Overlapping Benefits) Regulations (Northern Ireland) 1997 (S.R. 1997 No. 242)
  - 29 Family Resources Survey
  - 30 Standards for Adult Social Care Support Services for Carers; Department of Health, Social Services and Public Safety, 2008
  - 31 Circular HSS (ECCU) 1/2007: Direct Payments – Training of Personal Assistants; Department of Health, Social Services and Public Safety, 2007
  - 32 Circular HSC (SQSD) 29/07 – Guidance on Strengthening Personal and Public Involvement in Health and Social Care; Department of Health, Social Services and Public Safety, 2007
  - 33 UNOCINI Guidance, Understanding the Needs of Children in Northern Ireland, DHSSPS, 2008
  - 34 Northern Ireland Children's Services Plan 2008-2011, 2008
  - 35 Circular HSS (ECCU) 3/2006: Care Assessment and Placement Guide, DHSSPS, 2006
  - 36 Older People and Domiciliary Care, NIAO, 2007
  - 37 DFP Memorandum on the Tenth Report from the Public Accounts Committee Session 2007-2008, 2008
  - 38 Draft Strategy for the Development of Psychological Therapy Services;

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Department of Health, Social Services and Public Safety, 2008

- 39 Working with carers: guidelines for good practice; British Medical Association, 2007
- 40 Draft Strategy for Health and Social Care Bereavement Services in Northern Ireland; Department of Health, Social Services and Public Safety, 2008

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## 9. Glossary of Health and Social Care Terms

Assessment	process whereby the needs of an individual and their impact on daily living and quality of life are evaluated.
Carers' Co-ordinator	an individual appointed to raise awareness about issues, establish and support carers' networks and facilitate links between carers, carer organisations and HSC Trusts.
Carers	people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people under 18 who care for another family member. It excludes paid care workers and volunteers from voluntary organisations.
Direct Payments	money paid by HSC Trusts that allows individuals to arrange for themselves the social care services required to meet their assessed needs.
Hospital Discharge	the process of leaving hospital after admission as an inpatient.
Respite Care	any activity or service of limited duration designed to provide a break for a dependent person and their carer/family from the usual routine. The activity or service can be provided on a planned or emergency basis to meet the needs of either the dependent person or the carer and to sustain the carer in their caring role. The distinctive feature of respite care is that it should be a positive experience for both parties in order to enhance the quality of their lives and to support their relationship. It offers carers valuable and necessary independent time and clients the opportunity to experience a change of environment and stimulus. However, although the dependent person benefits from the experience, it is primarily the carer who will benefit.

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## 10. Glossary of Abbreviated References

ACYPC	Area Children and Young People's Committees
AHP	Allied Health Professional
BMA	British Medical Association
CSIG	Carers' Strategy Implementation Group
CSR	Comprehensive Spending Review
DHSSPS	Department of Health, Social Services and Public Safety
DoH	Department of Health (England)
DSD	Department for Social Development
ECCU	Elderly and Community Care Unit
GP	General Practitioner
GPC	General Practitioners Committee
FÁS	Foras Áiseanna Saothair (Training & Employment Authority)
HPSS	Health and Personal Social Services
HSC	Health and Social Care
HSE	Health Services Executive
HSS	Health and Social Services
NHS	National Health Service
NIAO	Northern Ireland Audit Office
NICE	National Institute for Health and Clinical Excellence
NISAT	Northern Ireland Single Assessment Tool
PEG	Percutaneous endoscopic gastrostomy
POC	Programme of Care
PPI	Personal and Public Involvement
PSI	Promoting Social Inclusion
PWC	Pricewaterhouse Coopers LLP
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RDPG	Regional Direct Payments Group
RPA	Review of Public Administration
RQIA	Regulation and Quality Improvement Authority
SQSD	Safety, Quality and Standards Directorate
SSI	Social Services Inspectorate
UNOCINI	Understanding the Needs of Children in Northern Ireland

## CONTRIBUTORS TO THE REVIEW REPORT

### Advice NI

Advice NI is a membership organisation whose mission is to develop an independent advice sector that provides the best possible advice to those who need it most. Advice NI exists to provide its members with the capacity and tools to ensure effective advice services delivery. This includes advice and information management systems, funding and planning, quality assurance support, NVQs in advice and guidance, money advice training, social policy co-ordination and ICT development.

Membership of Advice NI is normally for organisations that provide significant advice and information services to the public. Advice NI is normally for organisations operating throughout Northern Ireland, annually providing information and advocacy services to over 100,000 people. Over 200,000 enquiries are dealt with each year on an extensive range of matters including social security, housing debt, consumer and employment issues.

### Age Concern NI

Age Concern NI is the only regional age organisation governed by Northern Ireland Trustees who seek to represent the interests of older people.

For over 30 years it has been providing essential support services to older people including day and domiciliary care, advice and information services, community development and health promotion programmes and the provision of an effective lobbying voice on behalf of older people.

Age Concern NI is committed to reducing poverty and fighting disadvantage, defeating ageism and recognising diversity, addressing social exclusion and promoting more effective and responsive public services for older people. In 2009, Age Concern NI and Help the Aged in Northern Ireland joined together to form the single charity legally known as AgeNI, dedicated to improving the lives of older people.

### Belfast Carers

Belfast Carers is part of The Princess Royal Trust for Carers, a national network of over 120 independently managed Carers' Centres across the UK, dedicated to supporting carers of all ages, from all walks of life. Since 1997 it has provided a range of services to carers across Belfast and the Greater Belfast Area. Belfast Carers takes pride in being a Centre where carers, former carers and those who work with carers can access practical help and assistance in an environment that is supportive and designed to respond to carers' concerns.

### British Medical Association (NI)

The British Medical Association is the doctors' professional organisation established to look after the professional and personal needs of its members and it represents doctors in all branches of medicine. The organisation is committed to keeping members in touch with the profession's collective views and policies and to being at the forefront of healthcare development.

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## **Carers Northern Ireland**

Carers NI is a membership organisation run by carers, for carers across the whole of Northern Ireland and is part of Carers UK. It is actively involved in policy development work and campaigns for the changes that make a real difference for carers.

It operates an information service for carers and professionals, dealing with a range of issues such as carers' benefits, community care and services for carers. It also provides a wide range of leaflets and booklets and a regular newsletter for carers, members and professionals.

Carers NI also offers carers the chance to meet with other carers, share experiences and reduce the feeling of isolation that carers often feel.

## **Citizens Advice**

Citizens Advice is the largest advice charity in Northern Ireland, working against poverty and meeting the information and advice needs of some 250,000 people each year across a wide range of advice categories. Advice is available to all communities from 30 main offices across Northern Ireland and from over 120 other outlets. They also represent the public at approx 1,800 social security appeal tribunals a year.

**“CARING FOR CARERS” – SUMMARY OF FURTHER KEY ACTIONS**

1. The Department will issue guidance to all health and social care professionals, including GPs, stating that they must identify the presence of a carer, and the level of care being provided, and record it in a readily accessible way on all patient/client and carer records, paper and electronic. Where a carer is identified, health and social care professionals must offer a carer’s assessment in order to take a holistic view of the health and wellbeing and associated needs of the carer.
2. The Department will issue guidance to all HPSS bodies, advising them that it is essential they collate the information gathered on carers and their needs, and take it into account fully in reaching their commissioning and service delivery decisions.
3. The Department will advise all HPSS professionals that they should actively encourage patients to consent to the sharing of information about their illness or disability, medication and symptoms with their carers. The care management process will include a specific requirement to seek such consent.
4. The Department has commissioned the development of a single comprehensive assessment tool for use with older people. It is anticipated that the completed tool will be ready for implementation throughout Northern Ireland in 2007. Any such assessment for community care services will include a prompt for the offer and completion of a carer’s assessment and seek permission for the sharing of relevant information.
5. HSS Trusts will be advised that they must have a clear policy for discharge. Guidance for Service Managers, Practitioners and Carers on Discharge Planning to support this, is being developed and will be issued by the Department.
6. Trusts will be advised that they should pay particular attention to the needs of older people who are themselves providing substantial care to others.
7. On completion of an inspection of social care support services for carers of older people, the Department will publish standards for such services. The standards will identify what carers can reasonably expect from such services and will provide the basis for self-audit by organisations commissioning and/or providing such services.
8. HSS Trusts will be advised that they should provide information packs for carers setting out details of information services specific to the local Trust area.
9. An index of services, A-Z for Carers, will be developed, setting out the range of statutory and voluntary organisations that provide advice and information for carers on a regional basis.
10. Trusts will be encouraged to work closely with the voluntary sector to support the establishment of carer support groups.

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11. A Framework for Support Services to Carers will be issued to HSS Trusts. The framework will help Trusts to examine the ways in which support to carers can be best provided and will help them to develop new and more flexible services in consultation with carers and their representative organisations.
  12. A DVD/video on young carers will be produced for distribution as a training aide among staff within the Health and Social Services and the Education sectors.
  13. Good Practice Guidance for Trusts, taking into account the recommendations contained in Training for Carers in Northern Ireland – Issues and Opportunities, will be developed and issued by the Department.
  14. A pilot “carer peer mentoring scheme” is being researched and designed, and will be tested in the Northern Board area as part of a joint carers initiative between Carers Northern Ireland and the Northern Board. These carer advocates will be able to guide and support carers through the complaints process. A report will be published with findings and recommendations. The Department will then consider how this can best be implemented across Northern Ireland.
  15. In terms of younger carers engaged in further education studies, pastoral guidelines issued by the Department of Education to schools, which gives advice to teachers on supporting students with caring responsibilities, are being reviewed and updated. When this process is complete, the Department for Employment and Learning will examine the guidelines and assess the potential for read across to the Further Education sector.

## “CARING FOR CARERS” – FRAMEWORK FOR SUPPORT SERVICES TO CARERS

1. This section identifies the key issues in relation to support services for carers both individually and collectively. It provides guidance on the ways in which such support can be delivered and suggests further research into models that ensure that carers experience a responsive service designed to meet their individual needs.

### Partners in Care

2. Partnerships with carers should be achieved at both an individual and strategic level. That is, carers should be involved not only in decisions about their own situation, but also where services are being designed to support carers. Carers should be involved where Boards and Trusts (and other agencies) are planning new services; reviewing existing services and undertaking evaluations of the services they provide. These organisations should actively involve people who are directly caring as well as representatives of carers groups.
3. Of fundamental importance is the relationship between carers and those professionals and staff who provide services both to them and to the person for whom they are caring. In most situations the carer or family is the authority on the person needing care and support. Yet carers often feel that their knowledge of the person and experience of caring is neither recognised nor valued. Creating partnerships that recognise the expertise of carers, ensuring that they are meaningfully involved in processes for planning and delivering services to the individual, is the building block for effective support.
4. To achieve genuine partnership the following principles should be incorporated into every planning process where there is a carer involved:
  - identification of the carer with the main service user should be undertaken at the beginning of the process;
  - identify the individuals who will provide services;
  - the expertise of the carer should be recognised and respected;
  - the expertise of the professional should be acknowledged and accepted;
  - the legal/medical framework within which professionals have to operate should be recognised;
  - information which is pertinent to the caring role should be shared;
  - there should be consultation and negotiation about the type of support the carer feels they need and how this will be provided; and
  - the carer’s situation should be reviewed periodically and changes to the level and type of support negotiated.

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5. Practical measures should be in place to identify carers, including a protocol for identifying the main carer. This is an important issue particularly for primary care. Many carers would not identify with the term 'carer', therefore its use must be carefully considered. Staff should have training to ensure that carers are visible to them and heard by them.
  6. Health and care systems frequently focus on individuals without considering their place within families and communities, yet families usually take primary responsibility for the care of those within them. All organisations involved in the delivery of services must see the individual within this wider environment of family, neighbourhood and community.
  7. Assessments can be seen as a means of supporting the family and of considering both their strengths and the areas in which they need support. Care planning for the service user should be explicit about all who contribute to care and the nature of their contribution. Those who are affected should be offered support in order to avoid adverse consequences to their own health and well-being. It is in the interests of all concerned that social support networks be maintained.

### **Reviewing services for carers**

8. Carer involvement when it works well can offer a service that is truly based on people's needs, enhancing choice for individuals and creating an environment in which carers, those being cared for, and workers, are treated with equal respect and consideration. Involving carers in reviewing the services they receive is a fundamental component of improving those services.
9. People who actually experience services are in the best position to point out which areas work well and which could be improved. A range of methods for involvement can be used but the key components for meaningful involvement should be present, including:

**Access** - extending from physical access to the design of structures and arrangements, including locations and times of meetings, that enable and encourage people's involvement to meaningful participation in planning and review processes.

**Support** - for personal development to increase confidence, and support to develop skills allowing people to participate fully and effectively.

**Practical help** – including accessible information, advocacy, payment and expenses, and alternative support arrangements for the person being cared for. Recognition also needs to be given to the time required to come to meetings prepared.

**Working together** – opportunities for carers to come together and work in groups with equal access regardless of age, race, gender or disability.

**Feedback** – be honest and be clear that change takes time but give some indication of the timeframe being envisaged. Keep carers informed of progress, or of reasons why progress has not, or cannot, be made.

10. Boards and Trusts should review services with carers on a systematic basis to ensure they are providing services sensitive to need. Ideally each programme of care should have a carer forum that would work with service providers to plan, manage and review services on an ongoing basis. As already highlighted, carers should be supported and trained to ensure meaningful participation but it is equally important that organisations develop inclusive carer friendly systems and support staff to involve carers. Boards and Trusts should develop policies to provide practical, including financial support, to carers, to participate in planning and reviewing services.

### **Support services**

11. Maintaining good health and well-being is very important for carers, however very often carers neglect their own needs because they become pre-occupied with providing care.
12. They may be too busy or are unable to make alternative care arrangements to facilitate necessary medical appointments for check-up, screening or investigation. They may not recognise early symptoms which suggest the need for a medical appointment, or perceive the need as non-urgent in the scheme of things given their day-to-day priorities.
13. Evidence suggests that carers are more likely to suffer from a great deal of stress than non-carers, with significant implications for health and well-being.
14. Awareness is the first stage in managing stress. Carers and professionals should understand that good health and well-being is often within their own hands and within their own control. It does not however happen without effort, and this may be considerable given the demands and pressures of being a carer.
15. Health promotion activities are carried out within all Trust areas, however professionals must be mindful of the range of difficulties which impact on carers and a more proactive approach adopted to support and enable them to participate in planned health events and healthy lifestyle activities. In recognition of this, from 2005/06, the Department has made carers a priority group for receiving the influenza vaccine, and as such, they will be targeted in the winter advertising campaign.
16. Recognising carers as carers is critical to achieving good health and well-being. Missed medical appointments should be followed up, possibly through a standard letter from the GP, with an offer of contact with a professional to discuss any difficulties. A further example of such support is the GP outreach service provided by Belfast Carers Centre. Regular check-ups and screenings when arranged should be facilitated with appropriate support services. Timely and appropriate support is essential to the continued well-being of the individual who as a carer may be under pressure, worried or experiencing personal health difficulties. These might be readily alleviated or resolved by prompt referral to the appropriate service and follow up support offered and provided where necessary.
17. A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks will help carers to continue to provide support to the person being cared for. Services that carers value

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include short term breaks, day activity and support in the home, particularly in an emergency or at times of crisis. Carers need these services to be accessible, consistent, reliable and safe. Also valued are opportunities for access to education, leisure and activities that promote health and well-being, such as alternative therapies.

- 18.** Carers have consistently advised that the key to effective support is that the service they receive is flexible, meaning that the service should as far as possible fit with their individual needs and requirements. Arrangements for carers' breaks are often criticised because they are experienced as rigid and predetermined with limited choice. Likewise, domiciliary care services are sometimes viewed as limited in their ability to respond to individual need and changing circumstances as they adopt a standardised approach.
- 19.** In addition, carers need to know how to access services in times of change and particularly crisis. As a minimum, all providers should work with families to draw up contingency plans for such events and these should be integrated within the care plan. In the longer term, Trusts need to increase their capacity to provide services at short notice and there is a need to determine which services should be available on a 24hr basis, seven days a week and how these could be provided.
- 20.** There is clearly a need to re-shape statutory services to achieve flexibility. It is also clear that care workers need to be valued and reflected in the support and development available to them. Wholesale change, however, is difficult to achieve where there are concerns about the management of such services and the cost of changing service models.
- 21.** There is value in 'testing' such models to demonstrate the impact on carers and the real cost and effectiveness of providing services in a more flexible way. The Department of Health, Social Services and Public Safety is examining how to commission such a project that would be steered by a coalition of families and carers and professional staff, where the family and carer membership is at least 50%.
- 22.** Direct Payments provide an opportunity for carers to take more control over the decisions that affect their lives. The Carers and Direct Payments Act (NI) 2002 gives HSS Trusts the power to make Direct Payments:

  - to carers (including 16 and 17 year old carers) for the services that meet their own assessed needs;
  - to people with parental responsibility for disabled children;
  - to disabled people with parental responsibility for a child; and
  - to 16 and 17 year old disabled children for services that meet their own assessed needs.
- 23.** However, there is a danger that Direct Payments are used only to purchase existing services. Families and carers need help to think creatively about what best suits their individual and collective needs. They need to be given the authority to design their own support package that is responsive, flexible and individualised. Trusts need to

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respond by accepting that often such support will not reflect a use of traditional services but that the support chosen is a legitimate use of resources.

24. Consumer/family governed initiatives in other countries have demonstrated how these ideals can be achieved by developing projects in which ordinary people maintain a fair degree of personal influence. In these, the emphasis is on participation, dialogue, negotiation informality and relationships. The Department is examining how to support further developments in community support services to enable people to live independently in their own homes. As the concept is to develop projects from the carer's perspective, they will require time and financial investment but would serve to demonstrate the capacity for developing flexible support solutions.

### **Specific carer focused services**

#### **Carer Co-ordinators**

25. There are currently nine carer liaison or co-ordinator posts established within Trusts. In addition, there are 13 carer support posts that are either programme or location specific. The majority of acute Trusts, however, consider support for carers as a matter primarily for community Trusts. Two models and two key components have emerged from the development of these posts. The key components involve 'championing' the cause of carers within the Trust and raising awareness about carer issues (the Trust component), and developing the carer support infrastructure (the community component).
26. Of the two models, the first entails the carer co-ordinator being employed directly by the Trust, while the second model sees the function being contracted out to a carers association or carers organisation. Both models have merit and in general terms co-ordinators employed by Trusts have had the most impact on systems within the Trust, whereas those within carer organisations have put greater emphasis on developing and supporting the carer support infrastructure.
27. However, the potential for change is maximised where the carer co-ordinator is employed by the Trust.
28. All Trusts with experience of a carer co-ordinator report the benefits of the post and remaining Trusts, including acute Trusts, should appoint a carer co-ordinator with an appropriate level of support and access to resources. The primary functions should be:
- proactively raising awareness of carers issues within the Trust;
  - establishing and supporting a Carers Forum in each Trust area which will promote and cultivate carers' networks across all programmes of care; and
  - facilitating links between carers, carer organisations and the Trust.
29. Trusts should consider how best to involve carers in the appointment of the carer co-ordinator.

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30. In addition, Trusts should identify two directors to champion the rights of carers at a strategic level within the Trust and identify a senior officer in each programme of care to represent the interests of carers within the programme.
  31. In this way, the Trust component of the role will be managed effectively and the expected outcomes from this approach are greater carer involvement, promotion of carers assessments, innovative use of Direct Payments and greater availability of carer driven services and information.

### **Carers' Groups**

32. Carers' Groups can play a vital role for many carers. They can be condition specific groups meeting in a local area and nurtured by larger professional organisations, or they can be the myriad smaller carer support groups who function independently of the input of such big organisations. Although many are small in size and may be limited in the scope of their interest, they can occupy a vital position in the lives of carers. For many, they can be the only local and immediate form of external support, a place where carers can receive help from others who know exactly what it is to be a carer. Carers welcome the opportunity to come together.
33. The challenge with groups like this is to ensure that the common themes and the enthusiasm that first brought them together can be maintained as time moves on. There are also practical issues to consider such as transport and accessibility issues and support to attend. A formal link between carers and the statutory provider enables carers to be real and equal partners in the provision of care. This can be provided by the carer co-ordinator for each Trust or by another organisation, be it Carers NI, or by the proposed Carer Centres.

### **Carers' Centres**

34. The feedback from carers indicates strong support for a carers resource centre in each Trust area, in that it would provide a focal point for support to individuals and groups. The centre would facilitate the following outcomes:
  - proactive engagement with carers and carers groups;
  - the provision of a vital source of information, emotional support and advocacy;
  - the identification of sources of help for carers and support carer related volunteering;
  - communication with carers not in contact with services;
  - co-ordination and support of the network of carer support workers in the area; and
  - the identification of gaps in carer support and the stimulation of growth to meet identified need.

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35. The resource centre would provide accessible premises for groups to meet and potentially arrange for carer-determined services to be available on site. These might include I.T. training, aromatherapy, and 'outreach' services to promote the community development aspects of carers support.
  36. The centre would also support and promote the development of Carers Forums at each level. These forums could nominate individuals to a Regional Carers Forum under the auspices of the Department to inform future policy and strategy development.
  37. DHSSPS is examining the ways in which local support services for carers can be improved including carers' forums and carers' centres. The Department believes that this can be best achieved by building upon the role of the Trust carer co-ordinator as the focal point for support to individuals and groups. The carer co-ordinator would be in a position to establish links with existing carers groups, identify their needs, make facilities available to them as necessary and offer advice and practical support.

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**Independent Verification**  
**DHSSPS/DSD Joint Review of Support Provisions for Carers**  
**Prof Judith E Hill CBE, Chief Executive, Northern Ireland Hospice**

## **Methodology**

### **Terms of Reference for review**

The aim of the review was to examine the support for carers in Northern Ireland in a holistic way. The definition of “support” is implied rather than expressed, drawing on the National Carers Strategy in Great Britain, i.e. information, support and care for carers in the following areas – of income, employment, social care and equity.

Whilst the review focuses on the role of DSD and DHSSPS by officials from these departments, I think reference could be made to links with other relevant departments e.g. Department for Employment and Learning and Department of Education within the terms of reference.

## **Literature Review**

This is limited in scope being essentially a policy trawl with some statistical analysis. Documents from England, Wales, Scotland and Northern Ireland are included and information about young carers. However, there is very little non-statutory/independent research or literature offering a commentary on the policy documents and carers’ own views are not clearly demonstrated in the literature review.

It may be felt that this aspect would be covered by meetings and interviews with carer representative organisations.

## **Meetings**

The Review Team attended appropriate meetings locally and nationally to gain perspective on progress on carers’ issues.

The meeting with carers’ advocacy/service groups seemed representative. The direct engagement with carers might have been demonstrated by an open café style event to check out the importance of the themes and recommendations from the local policy documents, and to assess their impact.

## **Accuracy of Information**

I have only sampled some of the documents, but I believe the presentation of facts and figures is accurate and reflects the current priorities and policies.

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## Recommendations

There are 15 recommendations:

4 for DSD  
10 for DHSSPS  
1 jointly for DSD/DHSSPS

### **DSD Recommendations**

The DSD recommendations seem consistent with its role in working to maintain parity for benefits, working with Westminster colleagues and working with DHSSPS to improve communication and information and signposting for carers. There is no recommendation about continuing to support the voluntary sector role in support and advocacy for carers, nor is there any recommendation to work with Department for Employment and Learning to support employment opportunities for carers in line with the aims of the National Carers Strategy.

### **DHSSPS Recommendations**

I recognise that a considerable amount of work has been done by DHSSPS in developing a strategy for carers and carrying out an inspection, and audit each building a raft of recommendations to be addressed.

I find these recommendations therefore consistent with the findings of the review.

**Recommendation 1** could be strengthened to include in the Terms of Reference of the Carers Strategy Implementation Group a role in monitoring the implementation of the DHSSPS recommendations from this review.

**Recommendation 5** in relation to the update of A-Z for Carers could be strengthened by including a timeline for completion.

A further recommendation in relation to carers for people receiving palliative care and bereaved carers could be included indicating DHSSPS will monitor and report on progress to achieve the outcomes of the relevant strategies under development.

## General Comments

The review is concise yet clearly presents the key issues.

Carers' issues are being addressed in a comprehensive way by DSD/DHSSPS. Links with other relevant departments e.g. Department for Employment and Learning and Department of Education, could be more explicit with clear actions.

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## **Departments' responses to independent verification**

The Department for Social Development and the Department of Health, Social Services and Public Safety would like to thank Professor Hill for using her time and expertise to independently verify the report.

### **Methodology**

#### **Terms of Reference for Review**

The Terms of Reference for this Review included only support provisions for carers in Northern Ireland for which DSD and DHSSPS have direct responsibility. DSD and DHSSPS acknowledge the important role that other Government Departments have to play in providing support provisions for carers and will continue to liaise with these Departments to ensure that carers' issues are addressed.

### **Literature Review**

The DSD and DHSSPS Review Team met with a range of carer representative organisations in order to obtain current and relevant views about the strategies policies and guidance currently in place to provide support provisions for carers in Northern Ireland. All DHSSPS strategies, policies and guidance have evolved through in depth discussion with carers and their representative organisations.

### **Meetings**

DSD and DHSSPS are satisfied that carers' views were represented through the meetings and interviews held with carer representative organisations.

### **DSD Recommendations**

DSD will continue to promote a strong, vibrant and sustainable voluntary and community sector to enable better delivery of services. This is now reflected in the report at paragraph 6.35. DHSSPS also supports the voluntary sector role in support and advocacy of carers which is covered in the report at paragraphs 6.136 to 6.138.

The joint DHSSPS/DSD review examined the support available to carers in the light of the publication of the review of National Carers' Strategy in Great Britain. Whilst the review of the National Carers' Strategy covered income, employment, social care and equality issues, the terms of reference and methodology of this review were limited to an examination of the immediate areas of responsibility of the respective Departments. Therefore a recommendation to work with the Department for Employment and Learning to support employment opportunities for carers is outside the scope of the review. However the Department for Employment and Learning has initiatives which support employment opportunities for individuals, including carers, such as Steps to Work, which offers a flexible menu of work-related activities that can be tailored to suit employment needs, and the right of carers to request flexible working hours.

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## **DHSSPS Recommendations**

Recommendation 1 – has been strengthened to include in the Terms of Reference of the Carers' Strategy Implementation Group a role in monitoring the DHSSPS recommendations of this Review.

Recommendation 5 – the A-Z for Carers will be published by December 2009.

Whilst no specific recommendation is being included in this Review, DHSSPS will continue to have a role, in conjunction with the Health and Social Care Board, to monitor and evaluate all Departmental Strategies including the Bereavement and the Palliative & End of Life Care Strategies.

## **General Comments**

The Terms of Reference for this Review included only support provisions for carers in Northern Ireland for which DSD and DHSSPS have direct responsibility. DSD and DHSSPS acknowledge the important role that other Government Departments have to play in providing support provisions for carers and will continue to liaise with these Departments to ensure that carers' issues are addressed.