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Carers: Legislation, Policy and Practice

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This paper looks at the provisions for supporting carers in law and policy across the UK; key issues for carers, with additional reference to wider EU work in this regard; and some particular examples of good practice in selected EU countries. It may be read in conjunction with RaISe briefing paper NIAR 44-17 (March 2017, Dr Raymond Russell).

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Key Points

Across the European Union, 80% of all care is given by informal and family carers and an overwhelming majority are women. Without the work of these carers the formal care systems across the EU and the UK would be unsustainable.

Around 218,000 people in Northern Ireland (NI) currently have a caring role. There are 72,630 Carer's Allowance claimants and 46,090 recipients in NI (November 2016) and almost 50% of claimants have been caring for 35+ hours for over 5 years.

NI is lagging behind the other jurisdictions of the UK in terms of both a strategy for carers and recent law development. *Caring for Carers (2006)* is the most recent NI strategy, whereas strategies have been published in Scotland in 2010, in Wales in 2013, and in England in 2014.

The most recent legislation in NI was the *Carers and Direct Payments Act (NI) 2002*, whereas legislation has recently been updated across the UK - *The Care Act 2014* and *Children and Families Act 2014* in England; the *Social Services & Well-being (Wales) Act 2014*; and the *Carers (Scotland) Act 2016*.

A key benefit of the *Care Act 2014* is that it places a *duty* on local authorities to *provide* the services required, provided the carer meets the national eligibility criteria. In NI the HSC Trusts retain discretion to decide whether or not to provide a service to meet a need identified in a carer's assessment.

The Carers (Scotland) Act 2016 will commence on 1st April 2018. It introduced a stronger focus on young carers than is apparent in current NI law and policy. *The Scotland Act 2016* provided for the devolution of Carer's Allowance to Scotland.

The Social Services & Well-being (Wales) Act 2014 provides a wide-ranging single Act bringing together the duties and functions of local authorities with the aim of improving the 'well-being' of all people who need care and support, and carers who need support.

The NI Department of Health is currently taking forward a three stage *Reform of Adult Care and Support*. The project is currently at stage two with the Department working to develop proposals for change to adult care and support for consultation in April 2017.

Issues facing carers are the impact on their own health; detriment to their own life outside of their caring role; difficulties in balancing caring with paid work often leading to financial difficulties or outright poverty; for young carers, the impact on development of social skills, family relationships, and education/career prospects.

Key concerns for carers are being addressed in policy and legislation in a range of countries, including the UK and Republic of Ireland. Examples are provided in the paper for a selection of OECD countries under three main categories - helping carers combine care responsibilities with paid work; improving carers' physical and mental wellbeing; and compensating and recognising carers.

Executive Summary

Carers are persons who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework.

Informal and family care is often an ignored sector of the economy, yet 80% of all care across the EU is given by family carers and an overwhelming majority are women.

Across the UK there are around 7 million informal or family carers and the number is rising - 42% are men and 58% women. The economic contribution they make is estimated at over £130bn per year.

Around 218,000 people in Northern Ireland (NI) currently have some form of caring role. Department for Communities data shows there were 72,630 Carer's Allowance claimants in NI and 46,090 recipients in November 2016, and that 48% of claimants have been caring for 35+ hours for over 5 years.

Without the work of these informal carers the formal care systems across the UK would be unsustainable. This 'resource' is, however, under pressure due to various demographic and socio-economic developments.

Although caring can be a source of personal satisfaction for carers, if they are not adequately supported there are substantial health and financial challenges facing them.

NI appears to be lagging behind the rest of the UK in addressing carers' issues in terms of both lack of a current strategy and recent law development. *Caring for Carers (2006)* is the most recent NI strategy, whereas strategies have been published in Scotland in 2010, in Wales in 2013, and in England in 2014.

Similarly, the most recent legislation in NI was the *Carers and Direct Payments Act (Northern Ireland) 2002*, whereas in the rest of the UK legislation for carers has recently been updated with new laws passed in all three jurisdictions. The *Care Act 2014* and *Children and Families Act 2014* in England (April 2015); the *Social Services & Well-being (Wales) Act 2014* (April 2016); and the *Carers (Scotland) Act 2016* (will be commenced 1st April 2018).

The ***Carers and Direct Payments Act (Northern Ireland) 2002*** places a duty on HSC Trusts to inform carers of their legal right to a care assessment, gives carers the right to an assessment of their own and to be considered for services to meet their own need and gives HSC Trusts the right to provide personal social services to support carers directly.

One of the key benefits of the ***Care Act 2014***, compared to NI law, is that it places a *duty* on local authorities to *provide* the services required, provided the carer meets the national eligibility criteria. In NI the HSC Trusts retain discretion to decide whether or not to provide a service to meet a need identified in a carer's assessment.

With regard to respite care, in the *Carers and Disabled Children Act 2000* England had already introduced the power for local authorities to offer carers short respite breaks via local authorities providing vouchers for temporary care provided by community care services. The *Care Act 2014* now broadens the eligibility criteria for respite care breaks, for example, to allow carers to engage in work, training, education or volunteering or engage in recreational activities.

In NI, when a carer's assessment is carried out, a Trust must consider whether or not it should provide services to the carer to meet any needs identified - including a need for respite. Again a Trust has discretion to decide whether or not to provide this service to meet the carer's identified need.

The Carers (Scotland) Act 2016 passed on 4 February 2016 and will be commenced on 1st April 2018. It introduced a stronger focus on young carers than is apparent in current NI law, with the intention that young carers in Scotland should be able to have a childhood that is similar to their peers who do not have a caring role.

An important progression potentially compared to NI law is that it replaces the carer's assessment with a new adult carer support plan (ACSP) and provides a young carer statement (YCS) for all young carers.

It also introduces a *duty* to support carers whose needs cannot be met by general services in the community (carers' needs must meet local eligibility criteria in order for the duty to apply). It also *requires* local authorities to prepare local carer strategies for their area and to involve carers in carer services for carers and cared-for persons.

The Social Services & Well-being (Wales) Act 2014 (in force since April 2016) provides a wide-ranging single Act bringing together the duties and functions of local authorities with the aim of improving the well-being of people who need care and support, and **carers** who need support. It is thought that this will create a quite distinct social care legal jurisdiction in Wales.

A key principle is to support people who have care and support needs to achieve well-being, and places a *general duty* on local authorities to promote the *well-being* of people 'in need' and their carers. Assessments of carers of any age must include:

- Whether the carer is willing and able to provide care;
- Outcomes the carer wants in their day to day life; and
- Whether the carer works, or wishes to work (and/or) to participate in education, training or recreation.

A national eligibility framework will determine at what level individuals and *carers* have an *enforceable right* to support from the local authority. It will also define the point where a local authority has a *legal duty* to provide, or arrange the provision of care and/or support.

The Act also places a *duty* on local authorities to promote the development of social enterprises/co-ops/third sector organisations to provide care and support and

preventative services, which involve users in their design and operation. This is seen in contrast to the Care Act in England, where it is likely there will be a significant increase in privatisation of social care provision, particularly in relation to carrying out assessments.

Although progress has been made with legislation in England, in July 2016 the Westminster Government announced its decision to delay the implementation of Phase 2 of the *Care Act 2014* to April 2020, thus delaying the introduction of a cap on the costs of care that an individual is liable to pay, and a change that was to have made capital limits on the means test more generous.

Problems remain with the implementation of the *Care Act 2014*. One-year post-introduction, the Carers Trust found that 69% of carers who responded to their survey had noticed no difference, with too many carers still unaware of their rights; 65% had not received assessments, and 34% who had been assessed did not find the assessment helpful.

With the *Carers (Scotland) Act* not yet commenced and it being early days for the implementation of the *Social Services & Well-being (Wales) Act 2014*, evaluation on the ground for carers from those jurisdictions is likely to be some years away.

Carers in NI are concerned their issues are not being addressed. Key issues facing carers are the impact on their own physical and mental health; detriment to their own life outside of their caring role; difficulties in balancing caring with paid work often leading to financial difficulties compounded by cutbacks in social provision and increases in direct costs, in severe cases leading to outright poverty; for young carers, the impact on development of social skills, family relationships, and education/career prospects.

The NI Department of Health is currently taking forward a three stage *Reform of Adult Care and Support*. The first stage was a six-month consultation and report published in 2013. The project is currently at stage two with the Department working to develop proposals for change to adult care and support for consultation in April 2017. Priority areas have been identified, including how to recognise and support carers in their caring role.

Key concerns for carers are being addressed to various extents in policy and legislation in a range of countries, including the UK and generally fall into three main categories.

1. Helping carers combine care responsibilities with paid work

The law for requesting flexible working hours and practices has improved in the UK, potentially helping carers to remain in the labour force, although in practice tends to be used for care of children rather than the elderly as carers are concerned it will impact on their career prospects.

Options for official paid ‘care leave’ are available in a number of countries, including Belgium and in Scandinavian countries. In the UK, carers often use annual leave or sick leave to fulfil their caring responsibilities. Carers UK have called for a statutory entitlement to ‘care leave’ in the UK.

2. Improving carers’ physical and mental wellbeing

The provision of well-planned and flexible respite care is known to be key to improving carers’ physical and mental wellbeing. A range of different services is thought to be most appropriate including day-care services, in home respite and institutional respite.

In NI access to respite care is based on a community care assessment of needs by the HSC Trust and people being cared for *may* be eligible for care at a day centre, or 24-hour care in an institution for a number of days or weeks.

Policies across OECD countries generally include respite care, but legal entitlement varies and is not always clear. In the Republic of Ireland, an annual grant for respite care can be used throughout the year.

3. Compensating and recognising carers

Financially compensating carers is an important way to recognise their contribution, but the benefit to those in receipt of care can only be maximized in the context of a proper care plan which includes training for carers, flexible working arrangements and adequate respite care.

Many OECD countries provide financial support to carers through a ‘carer allowance’ and/or direct payments to those in need of care, part of which they can use to compensate family members. Both types of payments are available in some countries, including the UK.

In Nordic European countries the ‘carers allowance’ is considered as remuneration and Municipalities employ family caregivers directly with varying salaries but are not obliged by law to provide them. Such ‘care wages’ aim to keep the care recipient at home instead of moving to an institution.

Care ‘wages’ may seem a promising avenue but they remain a relatively costly option and there is a legitimate question as to whether or not more qualified or experienced formal carers should be used instead.

1 Introduction – key issues and potential guiding principles

There are estimated to be around 7 million informal or family carers in the UK and the number is rising. Three in five people will be carers at some point in their lives. Of the UK's carers, 42% are men and 58% women. The economic contribution they make by providing this care is estimated at over £130bn per year.¹

Across the EU as a whole, approximately 80% of care is provided by families and friends. Even in countries with well-developed formal care systems, such as in the UK, the number of informal carers is estimated to be twice as large as the formal care workforce.²

There is no official definition of a 'carer'. A range of definitions include:

*Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage 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 who care for another family member.*³

*Carers are persons who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework.*⁴

Census 2011 notes that:

*a person is a provider of unpaid care if they give any help or support to family members, friends, neighbours or others because of long-term physical or mental health or disability, or problems related to old age.*⁵

The Carers Trust⁶:

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

According to RalSe paper NIAR 44-17⁷ around 218,000 people in Northern Ireland (NI) currently have some form of caring role with the majority in the 35 – 64 age band. However, over 6,000 young people (aged 0-17) provide between 1 and 19 hours of

¹ Carers Trust <https://carers.org/about-caring>

² Enabling carers to care, Eurocarers, 2014, Introduction, www.eurocarers.org/ENABLING-CARERS-TO-CARE

³ Caring for Carers, Department of Health, Social Services and Public Safety, (2006), <https://www.health-ni.gov.uk/publications/caring-carers>

⁴ Definition of a Carer, Eurocarers, <http://www.eurocarers.org/>

⁵ NISRA (2015) 2011 Census Definitions and Output Classifications, updated April 2015. Available at: http://www.nisra.gov.uk/Census/pop_def_2011.pdf

⁶ Carer's Trust, <https://carers.org/what-carer>

⁷ Dr R. Russell, (March 2017) *Background Information and Statistics on Carers in Northern Ireland*, NI Assembly Research and Information Services

unpaid care per week, over 900 provide 20 – 49 hours, and over 800 provide 50 hours or more ⁸.

Without the work of these informal carers the formal care systems across the UK would be unsustainable due to an ageing society and the increasing prevalence of people living with chronic diseases and multi-morbidities. Although policies, and in some cases laws, to support carers have been or are under development in many countries across the world, it is generally thought that they are not adequate.⁹

The ‘resource’ of informal carers is under pressure due to various demographic and socio-economic developments – such as lower birth rates, a trend toward smaller families, increasing mobility (leading to greater physical distance between relatives), a rising number of women in the labour market and generally longer working lives for men and women.¹⁰

Although caring can be a source of personal satisfaction for carers, if they are not adequately supported there can be substantial challenges facing carers including¹¹:

- Impact on their own physical and mental health;
- Detriment to their own social integration and inclusion, especially if care is provided round the clock;
- Financial difficulties due to cutbacks in social provision and increases in direct costs – heating, special diet, medical devices, home adaptations etc.;
- Difficulties in balancing caring with paid work – direct loss of income and further financial impact;
- For young carers – impact on development of normal social skills, family relationships, and education/career prospects.

Although it is clear that informal carers provide a substantial economic saving and ‘prop up’ the formal care system in most countries, there is a knock-on consequence for the labour market and economy. Providing informal care can cause lower productivity from those carers who combine care with paid work in an unsupportive workplace, often leading to time off for their own health problems.¹²

The Confederation of Family Organisations in the EU have highlighted key issues for carers common across the EU¹³:

- The gender distribution of care is unequal with women representing the majority of carers, with great impact on their paid employment. Often care duties force women to work part-time, leave work early in their careers or take up low paid employment;

⁸ NISRA (2013) Table DC3304NI, Census 2011

⁹ Eurocarers, About us, Eurocarers guiding Principles, http://www.eurocarers.org/about_principles

¹⁰ Enabling carers to care, Eurocarers, 2014, Introduction, www.eurocarers.org/ENABLING-CARERS-TO-CARE

¹¹ As above

¹² As above

¹³ Carers, Confederation of Family Organisations in the European Union (coface), <http://www.coface-eu.org/en/>

- Labour market policies and business practices often do not reflect the needs of an ageing and inclusive society with workers forced out of work due to the difficulty of reconciling work and caring responsibilities; and
- Recognition of informal care work should mean recognition of skills and possibility of training for future employment. Those who are out of employment for long periods and can only enter paid work again in later years find it difficult to get quality employment due to long absence from the labour market.

The European Association Working for Carers - *Eurocarers*, has adopted ten principles to strengthen the position of carers and aims for the implementation of these principles as a guide in all policy areas relevant to carers across the EU¹⁴:

1. Principle 1: Recognition

Carers should be recognised for the central role they play in community care, and this recognition should be reflected in all policies having effect on carers.

2. Principle 2: Social Inclusion

Carers have a right to a social life.

3. Principle 3: Equality of opportunity

Carers should have equal opportunities in all spheres of life.

4. Principle 4: Choice

People should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers.

5. Principle 5: Information

Carers should have easy access to the information, guidance, advocacy, advice and training they desire - fitting to the stage of their carer's career.

6. Principle 6: Support

Carers need financial, practical and emotional support in their role as carers as well as access to needed formal care that is available and affordable.

7. Principle 7: Time off

Carers should have the opportunity of taking time off. Therefore, adequate relief i.e. respite care arrangements, acceptable both to the carer and the cared for person, must be readily available and tailored to carers' needs.

¹⁴ Eurocarers, About us, Eurocarers guiding Principles, http://www.eurocarers.org/about_principles

8. Principle 8: Compatibility of care and employment

Carers should have the possibility to combine caring with paid employment. This presupposes labour market policies that allow for caring activities as well as formal care available during working hours.

9. Principle 9: Health promotion and protection

Carers' own health care needs should be recognised.

10. Principle 10: Financial security

Carers should be covered by social security schemes such as income replacement benefits, accident insurance and pensions, in order to avoid impoverishment as a consequence of caring.

The ten principles listed above deal directly with tackling the range of challenges identified for and by carers. It would seem prudent to give consideration to allowing any new policy direction or law development in relation to carers to be led and guided by them to provide optimum support for informal carers in all the key areas identified.

2. Northern Ireland Law, Strategy and Policy

2.1 Relevant NI Legislation and Benefits

2.1.1 Carers and Direct Payments Act (Northern Ireland) 2002

The Carers and Direct Payments Act (Northern Ireland) 2002 is the most recent legislation and was implemented in two stages. The first stage which came into force in March 2003 made three main provisions¹⁵:

- The Act allowed the HSS (now HSC) Trusts to provide personal social services to support carers directly;
- It gave carers the right to an assessment of their own needs; and
- Placed a duty on Trusts to inform people of their legal right to a care assessment and to be considered for services to meet their own needs.

The Act provides a legal definition and recognition of carers, and places duties on public authorities. It also recognises children adversely affected by caring responsibilities as children in need under the *Children (Northern Ireland) Order 1995*. In particular, it provides a right for carers to request an assessment of their ability to

¹⁵ Carers and Direct Payments Act (NI) 2002, Centre for Independent Living NI, Legislation and guidance, <http://www.cilbelfast.org/content/legislation-and-guidance>

provide and to continue to provide care for the person cared for, and this can be offered independently of whether the person they care for is having an assessment. The legislation directs the relevant authority to consider whether the carer has needs in relation to the care they provide; if so, whether those needs could be met by the provision of services by the authority and if they could, whether or not to provide such services. The relevant authorities are obligated to promote the availability of the carer's assessment.¹⁶

The second stage of the Act, implemented in April 2004, widened the availability of Direct Payments. Originally, Direct Payments were available to disabled people over the age of 18 who were eligible for Social Services and deemed by the Trust as being willing and able to manage them, with assistance as necessary. The new legislation allowed HSC Trusts to make Direct Payments to:

- Disabled people (including 16-17 year olds) for services to meet their own assessed needs;
- Older people who get services from the Trust;
- Disabled people with parental responsibility for a child;
- People with parental responsibility for disabled children; and
- Carers (including 16/17 year olds) for services to meet their own assessed needs.

Trusts have a duty to make a Direct Payment, where someone who has been assessed as needing services requests a Direct Payment and meets the conditions.

The Carer's Assessment looks at each carer as an individual with their own personal circumstances, and will identify any particular needs they may have as a result and risks to the carer's own health and wellbeing. Service providers in NI should be responding with flexibility, offering carers real choice as to how their needs will be met. Before the assessment, carers are advised to make a list or keep a diary of everything they do when looking after the person they care for, including¹⁷:

- Does the carer get enough sleep?
- Is their health affected by caring?
- Can they leave the person they are looking after?
- Are they worried about having to give up work, study or other commitments?
- Do they get any time to themselves?

Services that may be offered to help the carer and the person they care for include:

- A break from caring;
- Help with housework;
- Changes to equipment or adaptations to the home; and

¹⁶ The Human Rights of Carers in Northern Ireland, NI Human Rights Commission, November 2014, page 24, www.nihrc.org/uploads/publications/The_Human_Rights_of_Carers.pdf

¹⁷ Assessments for Carers, NI Direct Government Services, <https://www.nidirect.gov.uk/articles/assessments-carers>

- Emotional support.

Staff across the HSC are required to identify carers, and receive training coordinated by the HSC Trusts' Carer Coordinators. GP surgeries are expected to have a protocol for identifying carers and referring them to HSC services.

Recent statistics from the Department for Health show that for quarter ending 31 December 2016¹⁸:

- A carer's assessment was offered to 3,504 carers in NI;
 - 52% (1,829) were accepted / completed and
 - 48% (1,675) were declined.
- Of the 559 carers' re-assessments offered;
 - 71% (396) were accepted / completed and
 - 29% (163) were declined.

From the quarterly statistics June 2011 to September 2016 more people had declined carer's assessments than accepted them – with the exception of just one quarter. The highest proportion of carers who decline a carer's assessment state that they do not feel that they require any additional support.

2.1.2 Employment Act (2002)

The Employment Act 2002 gave working parents (therefore carers) of children with disabilities (under 18) the right to request flexible working arrangements.¹⁹ Since then there have been a number of further legislative changes with regard to flexible working that impact positively on carers.

From April 2007, the *Work and Families Act 2006* (for NI - *The Work and Families (NI) Order 2006*) gave specified carers, as well as parents, the right to request flexible working. The *Work and Families Act (NI) 2015* changed the situation further^{20, 21}:

- All employees with 26 weeks' service can request flexible working with the requirement to be a parent or carer removed;
- The statutory procedure for considering requests has been replaced by a duty on employers to deal with requests in a reasonable manner, considering whether the request can be accommodated on business grounds.

A flexible working pattern could mean the difference between a carer continuing to work or having to resign.

¹⁸ Publication of Quarterly Carers' Statistics for NI (October – December 2016), Department of Health (8 March 2017),

¹⁹ Employment Act 2002, <http://www.legislation.gov.uk/ukpga/2002/22/introduction?view=extent>

²⁰ Supporting Working Carers, a guide to requesting flexible working, Carers UK, <https://www.carersuk.org/for-professionals/policy/policy.../supporting-working-carers>;

²¹ Carson McDowell, Welcome the *Work and Families Act (NI) 2015*, <https://www.carson-mcdowell.com/news-and-events/insights/welcome-the-work-and-families-act-northern-ireland-2015>

2.1.3 Carer's Allowance

Carer's Allowance is the main benefit for carers in NI and across the UK. Not every carer can get Carer's Allowance, but may be eligible if they meet all the following conditions²²:

- Look after someone who gets a qualifying disability benefit;
- Look after that person for at least 35 hours a week;
- Are aged 16 or over;
- Are not in full-time education;
- Earn £110 a week (after deductions) or less (this earnings limit will be increased to £116 a week from 1st April 2017²³); and
- Satisfy UK presence and residence conditions.

Carer's Allowance is currently £62.10 per week and is increasing to £62.70 on 1st April 2017.²⁴

If a carer meets the above conditions but already receives certain benefits (including a State Retirement Pension), then the amount of Carer's Allowance they may be entitled to could be affected. A carer cannot usually be paid Carer's Allowance if they receive one or more of the following benefits:

- State Retirement Pension;
- Contributory Employment and Support Allowance;
- Incapacity Benefit;
- Maternity Allowance;
- Bereavement or widow's benefits;
- Severe Disablement Allowance; and
- Contribution-based Jobseeker's Allowance.

This is because of the 'overlapping benefits' rules (*Social Security (Overlapping Benefits) Regulations (Northern Ireland) 1979*) – meaning that if a carer is getting more than the amount of Carer's Allowance from one of the above benefits, they cannot be paid Carer's Allowance, however they can still claim an 'underlying entitlement' to Carer's Allowance. To do this the carer must meet all of the conditions for Carer's Allowance and must still make a claim for Carer's Allowance.

Having an 'underlying entitlement' to Carer's Allowance can increase any means-tested benefits they are already getting or might mean becoming entitled to means-tested

²² Carer's Allowance Fact Sheet, Carers UK, <https://www.carersuk.org/help-and-advice/financial-support/help-with-benefits/carers-allowance>

²³ Carer's Allowance, Contact a Family, for families with disabled children, <http://www.cafamily.org.uk/advice-and-support/money-benefits-work-and-childcare/benefits-and-tax-credits/carers-allowance/>

²⁴ Carer's Allowance, Disability Rights UK, <https://www.disabilityrightsuk.org/benefit-rates-april-2017-2018>

benefits for the first time, because the carer premium, carer addition or carer element can be included in the calculation for means-tested benefits. If any of the benefits listed above are paid at less than the amount of Carer's Allowance, the carer could be paid a small amount of Carer's Allowance on top of the other benefits.

While there is no upper age limit for claiming Carer's Allowance, payment usually stops at retirement age because the State Retirement Pension will be paid instead.

In 2008, David McNarry, MLA introduced a Private Member's Bill, the *Carer's Allowance Bill*, proposing to amend the Social Security Administration (NI) Act 1992 to exclude the state retirement pension from consideration in the assessment of carer's allowance.²⁵ The Bill passed first stage in 2008 but then stalled when the then Departments of Health, Social Services and Public Safety (DHSSPS) and Social Development (DSD) initiated a joint internal review of provision for carers.²⁶ Highlighting inaction on the issue, David McNarry brought his Bill back to the Assembly where it passed second stage on 8th February 2011.²⁷ The Committee stage completed in March 2011 but was not moved further due to dissolution of the NI Assembly on 24th March 2011 (end of the mandate). The following conclusions were published by the then Social Development Committee²⁸:

40. The Committee concluded that as the Bill was not subject to consultation prior to introduction and owing to the restricted timescales, it would be impossible to undertake a satisfactory review of the clauses of the Bill.

41. The Committee also concluded that although it supported the principle of improving help for carers, the Bill as drafted would not be an appropriate means to achieve this. Members were particularly concerned with respect to suggestions that the implementation of the Bill as drafted could lead to some groups of pensioner carers being financially worse off.

42. The Committee recommended that a wider study is needed of the best way to help carers in Northern Ireland who are experiencing financial hardship or have limited respite, employment, educational or other opportunities.

²⁵ Carer's Allowance Bill, http://archive.niassembly.gov.uk/legislation/primary/2007/nia13_07.htm

²⁶ NI Assembly, Official Report (Hansard), Tuesday 8 February 2011, Volume 61, No 2, http://archive.niassembly.gov.uk/record/hansard_session2010.htm

²⁷ Carer's Allowance Bill, NI Assembly, Second Stage, Official Report (Hansard), Tuesday 8 February 2011, Volume 61, No 2, http://archive.niassembly.gov.uk/record/hansard_session2010.htm

²⁸ Social Development Committee, Report on the Carer's Allowance Bill (NIA 13/07), Together with the Minutes of Proceedings of the Committee Relating to the Report and the Minutes of Evidence, Ordered by The Social Development Committee to be printed 21 March 2011, Report: NIA 47/10/11R Social Development Committee, http://archive.niassembly.gov.uk/social/2007mandate/reports/2010/report_47_10_11r.htm#4

43. The Committee noted the experiences of other jurisdictions where the contribution of carers is recognised in different ways. The Committee also noted the ongoing review of social care in England and therefore recommended that a further study of support and recognition for carers in Northern Ireland should be informed by the findings of this review.

The Department for Communities (DfC) data for end November 2016 shows that at that time there were²⁹:

- 72,630 total Carer's Allowance claimants, a rise of 2,460 in the past year (46,380 females, 26,240 males and in total 22,390 aged 65 and over):
 - 46,090 were in receipt of a payment (30,940 females, 15,150 males and in total 650 aged 65 and over);
 - the remaining 26,540 were on credits only (22,600 of them are pensioners); and
- 48.44% of all claimants have been caring (35+ hours) for more than five years.

The DfC recently highlighted the following actions it has taken in regard to Carer's Allowance³⁰:

- The proactive targeting of carers with potential entitlement to Carer's Allowance, including indirect targeting, such as the 'Make the Call' advertising campaign; direct targeting, with customers pre-selected for a benefit entitlement check; and partnership working with groups, organisations and statutory bodies who work with carers;
- From Autumn 2016, a new campaign (*Supporting People – Maximising Income through the Uptake of Benefits (2016 – 19)*) will also include a focus on carers and specifically those customers who have a potential entitlement to Carers Allowance and / or Carers Credit; and
- The Welfare Reform Mitigations Working Group Report³¹ contains proposals to ensure that a person, who is no longer entitled to Carer's Allowance or Carer's Premium and if the person in receipt of Disability Living Allowance, who they currently provide care for, doesn't qualify for Personal Independence Payment after their assessment, receives a supplementary payment for one year.

²⁹ Department for Communities, Carer's allowance November 2016, <https://www.communities-ni.gov.uk/publications/benefits-statistics-summary-publication-national-statistics-november-2016>

³⁰ Personal Communication with Carer's NI (March 2017), DfC information provided to 'Carers NI'.

³¹ Welfare Reform Mitigations Working Group Report, The Executive Office (January 2016), <https://www.executiveoffice-ni.gov.uk/publications/welfare-reform-mitigations-working-group-report>

Research has shown that carers are failing to apply for benefits for their caring role. In November 2013 Carers UK calculated that 35% of carers in the UK were not claiming the benefits to which they were entitled.³²

Changes to disability benefits have the potential to further impact numbers claiming Carer's Allowance. The changes include certain rates of Disability Living Allowance (DLA) being replaced by Personal Independence Payment (PIP). The Government has estimated that around 600,000 fewer people who would formerly have met the criteria for DLA will be eligible for PIP. This will mean that those caring for people who fail to qualify for PIP will in turn be unable to apply for Carer's Allowance.

PIP was introduced in NI from 20 June 2016. All new claimants aged 16-64, and existing claimants whose benefit ends, or whose circumstances change, will be assessed for PIP. However, those aged under 16, whether existing or new claimants, and existing claimants aged 65 or over will continue to receive DLA rather than PIP.

2.2 Carers' Strategy NI (2006)

Caring for Carers was published in 2006 by the then DHSSPS.³³ In terms of an up to date carers' strategy, NI is certainly lagging behind the rest of the UK - *the Carers Strategy: Second National Action Plan 2014 – 2016* for England was published in 2014; *Caring Together: The Carers Strategy for Scotland 2010 – 2015* was published in 2010; and the *Carers Strategy for Wales* was published in 2013.

In 2006 the NI strategy did recognise the importance of carers and that thousands of people in NI are able to retain their independence because of the informal care provided. During the development of the strategy, carers in NI identified five key principles of importance to them:

- Caring should be freely chosen and carers should be allowed to decide what level of caring support, if any, they can offer at any particular time;
- Carers are real and equal partners in the provision of care and must be recognised as such at every level of public sector planning and service delivery;
- All carers are individuals with their own needs and need real choices based on relevant, timely and accessible information;
- Carers have a right to a life outside caring - if they wish to work outside the home, they should have the opportunity; and

³² Carers UK, *Estimates on the number of carers missing out on Carers Allowance*, 28 November 2013, <https://www.carersuk.org/for-professionals/policy/policy-library/carers-allowance-takeup>

³³ *Caring for Carers*, Department of Health, Social Services and Public Safety, (2006), <https://www.health-ni.gov.uk/publications/caring-carers>

- Government should invest in supporting carers - most of the resources which carers devote to caring are their own – time, energy and emotional commitment, but in order to carry on caring, carers need support.

The key recommendations in the 2006 strategy were based on responses to an earlier consultation *Valuing Carers (2002)*³⁴ and although the strategy is a decade old, it gives a good indication of the direction of travel of departmental policy and support for carers over the past ten years. The recommendations in the 2006 Strategy covered a broad range of areas including³⁵:

- Overall, carers should be viewed by clinical staff as partners in care;
- The importance of HSC Trusts, staff and all organisations who have contact with carers using all opportunities to identifying carers, to reach out to support carers, particularly older carers, and provide them with information about local services;
- HSC Trusts should be informing carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded. There should be a carer liaison or co-ordinator post in each Trust;
- General practitioners and other clinicians should seek their patient's consent to sharing information with the carer about the patient's illness/disability, medication and symptoms;
- Regarding discharge from hospital - carers should be fully involved in the timing of discharge from hospital and be given all the information that they require about the future care of the patient; and
- HSC Trusts should review (in conjunction with carers and those being cared for) the provision currently being made for carers' breaks and the information on which they base their funding decisions.

2.3 Review of the Support Provision for Carers (2009)

In 2009, the then DHSSPS and DSD conducted a joint review of the support provision for carers in NI, in the light of the publication of the 10-year, cross-departmental *National Carers' Strategy (Carers at the heart of 21st-century families and communities)* in England. The review resulted in a number of recommendations at that time, including³⁶:

- Review membership of the "Carers' Strategy Implementation Group" to ensure representation at a sufficiently senior level;

³⁴ Valuing Carers, Department of Health, Social Services and Public Safety, (2002), <https://www.health-ni.gov.uk/publications/carers-guidance>

³⁵ Caring for Carers, Department of Health, Social Services and Public Safety, (2006), <https://www.health-ni.gov.uk/publications/caring-carers>

³⁶ Review of the Support Provision for Carers, September 2009, DSD and DHSSPS, <https://www.health-ni.gov.uk/publications/carers-guidance>

- Commissioners and HSC Trusts to use the “Trust Self Audit Tool” developed by DHSSPS to report on and monitor progress towards the implementation of “Caring for Carers” (January 2006), relevant follow-up documents and circulars;
- Good quality information to be collected about carers in relation to carers’ assessments, respite care and Direct Payments;
- DHSSPS should explore the potential for carers to receive better levels of training in the more technical aspects of their caring responsibilities; and
- DHSSPS should ascertain what provision there is for breaks for carers (including emergency breaks), assessment of need and the effectiveness of the models being used in NI.

2.4 The Human Rights of Carers in Northern Ireland

In 2014, The NI Human Rights Commission (NIHRC) published its report into the Human Rights of Carers in NI. The NIHRC collated the human rights standards relevant to the identified needs of carers and made a series of recommendations directed towards an increased level of compliance. The report was particularly concerned with the rights of child carers. Some of the key recommendations included:

- The (then) DHSSPS should give specific consideration to the concerns and needs of older carers;
- The (then) DHSSPS and the Office of the First Minister and deputy First Minister should assess the level of support currently given to families where a child is involved in a caring role;
- NI Executive programmes aimed at alleviating poverty, including fuel poverty, must take full account of the challenges faced by carers;
- The (then) Department of Social Development should evaluate whether the Carer’s Allowance adequately compensates carers for the cost of caring in all circumstances.
- The NI Executive, and the (then) Department for Employment and Learning, should consider taking steps to enhance legal protections for carers seeking to exercise the right to work;
- Noting the reality that child carers encounter difficulties in obtaining qualifications and employability skills, the NIHRC recommends the prioritisation of support for child and young carers in relevant educational initiatives and the Department of Education should create a statutory duty on educational bodies to support young and student carers;
- The (then) DHSSPS should assess how effectively HSC Trusts are meeting their duty to ensure all carers are made fully aware of their right to seek a carer’s assessment; that human rights considerations be fully integrated within the process for determining what supports are to be provided to carers by HSC Trusts; and

specific consideration should be given to the rights of children aged 16 or 17 who undergo a carer's assessment; and

- Considering the impact which caring responsibilities will have on a child, specific provision is required to ensure that the NI Executive is fulfilling its human rights obligation towards child carers. The NIHRC recommends that the (then) DHSSPS introduce a child carer assessment similar to that operating in England and Wales.

2.5 Future Direction for Provision of Support to Carers in Northern Ireland

The Department of Health in NI is currently taking forward the three stage **Reform of Adult Care and Support** project which aims to establish the future strategic direction and funding of adult care and support. The first stage of the reform process was a six-month consultation on the discussion document "Who Cares? The Future of Adult Care and Support in Northern Ireland". This consultation process concluded in March 2013, and a report was published in August 2013.³⁷

The project is currently at stage two, which involves the development of proposals for change. A number of priority areas have been identified, including how best to recognise the contribution of carers and support them in their caring role. The Department is currently working to develop proposals for change to adult care and support for consultation in April 2017, in accordance with the commitment made in the Minister's ten year vision *Health and Wellbeing 2026: Delivering Together*. The aim is to publish a final strategic document at stage three setting out the planned direction of care and support services in NI and the Department notes that legislation may be required.³⁸

The consultation in 2013 sought views on two areas: a vision for a future system of care and support and the balance of responsibility for care and support between government, people who use services, communities and carers.³⁹ From the consultation, the Department noted that the majority of people in NI are unhappy with the current balance of responsibility. Identifying a fairer balance will be a key objective.

A number of key points in relation to carers were raised during the consultation process of 2013 and are very similar to the issues raised in advance of the 2006 NI carers' strategy, including⁴⁰:

³⁷ Reform of Adult Care and Support, Department of Health, <https://www.health-ni.gov.uk/articles/reform-adult-care-and-support>

³⁸ Reform of Adult Care and Support, Department of Health, <https://www.health-ni.gov.uk/articles/reform-adult-care-and-support>

³⁹ Who Cares? The Future of Adult Care and Support in NI, Consultation Analysis Report, DHSSPS, August 2013, page 14, <https://www.health-ni.gov.uk/publications/who-cares-consultation-analysis-report>

⁴⁰ Who Cares? The Future of Adult Care and Support in NI, Consultation Analysis Report, DHSSPS, August 2013, page , <https://www.health-ni.gov.uk/publications/who-cares-consultation-analysis-report>

- Carers save government significant sums of money by providing care that government would otherwise have to provide and pay for;
- Support for carers to continue in their caring role was the issue raised most consistently - carers should be seen as an equal and valued 'fourth sector' partner working alongside the statutory, private and voluntary sectors. Others made the case that carers should have a legal right to support as was the intention in England at that time (this has now happened in the *Care Act 2014*);
- Reform will have the biggest impact on older women, who live longer than men and who are also more likely to be carers;
- There should be an explicit right to a life outside caring with carers able to lead the same life as non-carers;
- The HSC should not assume that family members are willing and able to take on caring responsibilities, and that the impact of changing family dynamics needed to be recognised;
- The rules around Carer's Allowance should be re-examined so that people over 65 remained eligible, that more than one person could claim Carer's Allowance (where more than one carer was needed), and that the level of Carer's Allowance should reflect lost income if a carer had given up employment;
- Concerns remain with carer's assessments, mainly that such assessments were just a paper exercise with no outcome;
- Respite care remains a key issue with considerable anxiety about current levels and without guarantees of support, some carers would be unable to continue caring; and
- The impact of caring on mental health, and the need for education and training as carers take on more complex tasks were highlighted.

Aside from the provisions of the *Carers and Direct Payments Act (NI) 2002*, NI is currently the only part of the UK where the protection of carers is not more fully enshrined in law. A group of parents, aged 60 and over, who are caring for their disabled children (now adults) have called on the Assembly to change that situation. The charity Positive Futures has been assisting many such families to put together a proposal for a Carer's Charter.⁴¹

3. England – Law and Policy for Carers

3.1 Legislation in England

Since 2000, a number of pieces of legislation have demonstrated a recognition of the needs of carers. Three *Private Members' Bills* became Acts including the *Carers*

⁴¹ Carer's Charter: Parents call for Stormont Law Change, <http://www.bbc.co.uk/news/uk-northern-ireland-37488804>

(*Recognition and Services*) Act 1995, the *Carers and Disabled Children Act 2000*, and the *Carers (Equal Opportunities) Act 2004*. Recent legislation has further strengthened the rights and entitlements of carers, most recently the **Care Act 2014** and **Children and Families Act 2014**.⁴²

3.1.1 Changes under the Care Act 2014

The *Care Act 2014* came into force in England from 1 April 2015. Historically, The *Carers (Recognition and Services) Act 1995* introduced the entitlement for carers to be assessed by their local authority to identify services required to assist them to continue caring. However, the onus was placed on carers to request the assessment, and it was restricted to carers who provided a “substantial amount of care on a regular basis”.⁴³

Now, the *Care Act 2014* gives any carer the right to an assessment of their needs for current or future support, whether or not this is considered to be a “substantial amount of care on a regular basis”. Additionally, the Act:

- Places a duty on local authorities to identify carers in their area in need of an assessment and to carry it out, although the carer can refuse;
- Places a duty on local authorities to provide the services required, provided the carer meets the national eligibility criteria. Previously local authorities were only required to ‘take into consideration’ the carer’s assessed needs, with no requirement to meet those needs;
- The carer is also entitled to request a direct payment to allow them to control how services are provided.

3.1.2 Respite for carers

The *Carers and Disabled Children Act 2000* introduced the power for local authorities to offer carers short respite breaks in accordance with their assessment via local authorities providing vouchers for temporary care provided by community care services. The *Care Act 2014* broadens the eligibility criteria for respite care breaks to allow carers to develop and maintain family and personal relationships; engage in work, training, education or volunteering; make use of necessary facilities or services in the local community, including recreational facilities or services; or engage in recreational activities.⁴⁴

⁴² House of Commons Library briefing Paper Number 7219, 5 June 2015 “Carers’ rights and benefits (England) available: <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7219> (accessed 9.9.2016)

⁴³ *Carers (Recognition and Services) Act 1995* as amended, <http://www.legislation.gov.uk/ukpga/1995/12/contents>

⁴⁴ Care and Support (Eligibility Criteria) Regulations 2015, SI 313/2015, para 3(2)(b)(v-vii), www.legislation.gov.uk/uksi/2015/313/pdfs/uksi_20150313_en.pdf

Additional funds for carer breaks were made available in 2015-16 through a joint fund from NHS England and local authorities - the Better Care Fund. However, concerns have been raised that the funding has not been ring-fenced.⁴⁵

3.1.3 Young carers

Prior to the *Children and Families Act 2014* there were no legal provisions specific to young carers under 16 years of age.⁴⁶ Section 96, amended the *Children Act 1989* giving young carers the same right to an assessment as adult carers, to include the appropriateness of the child providing care in respect to their own needs. However, there is no national eligibility criteria in England for the provision of services for young carers and local authorities only have to 'consider' the assessment when deciding whether to provide support for young carers.

3.1.4. Parents of disabled children

Parent carers of disabled children are now entitled to an assessment under section 97 of the *Children and Families Act 2014*. However, local authorities need only 'consider' whether to provide services identified in the needs assessments. The 2011 regulations⁴⁷ state that a local authority, as far as is practicable, should provide a range of services to assist parent carers to provide care and is also required to produce a "short breaks services statement" that sets out these services and the eligibility criteria for accessing them.

3.1.5 Employment and discrimination rights

The right for those caring for adults to request flexible working was extended to cover all employees by the *Children and Families Act 2014*. Employers may only refuse such requests on limited grounds covered by statute. Employees also have a right to a reasonable amount of time off if a dependant is ill, or if care arrangements have been disrupted. Local authority assessments of carers' needs must consider a carer's intention to work as part of their needs.⁴⁸

Carers of disabled and elderly people are also protected from discrimination at work by the *Equality Act 2010* that provides protection from "discrimination by association" related to age or disability. The purpose is to prevent carers being treated less favourably in the workplace, or not being offered a job on the basis of their caring responsibilities, while also protecting carers from harassment.

⁴⁵ Carers UK, *Carers UK responds to the publication of Guidance on Care Funding*, 20 December 2013,

<https://www.carersuk.org/news-and-campaigns/news/carers-uk-responds-to-the-publication-of-guidance-on-care-funding>

⁴⁶ As defined in *Carers and Disabled Children Act 2000*, <http://www.legislation.gov.uk/ukpga/2000/16/contents>

⁴⁷ *Breaks for Carers of Disabled Children Regulations*, SI 2011/707, <http://www.legislation.gov.uk/uksi/2011/707/made>

⁴⁸ *Children and Families Act 2014*, <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

3.1.6 Welfare benefits for carers

Welfare benefits are not a devolved matter and apply across the UK. Details on Carer's Allowance have already been covered in the NI section of this briefing (see 2.3.4).

Since 1 April 2013 working age social housing tenants receiving **Housing Benefit in England, Scotland and Wales** have had a reduction to their benefit if they live in a house that is deemed too large for their needs (the so-called 'bedroom tax'). However, those receiving care are entitled to have an extra bedroom in social housing without incurring a reduction in Housing Benefit provided they meet the 'overnight care condition'. A renter satisfies the overnight care condition if -

- (a) they are in receipt of –
 - (i) the care component of disability living allowance at the middle or highest rate;
 - (ii) attendance allowance; or
 - (iii) the daily living component of personal independence payment;
- (b) one or more persons who do not live in the renter's accommodation are engaged to provide overnight care for the renter and to stay overnight in the accommodation on a regular basis; and
- (c) overnight care is provided under arrangements entered into for that purpose.⁴⁹

If the conditions are met the renter is entitled to one additional bedroom when their Housing Benefit is calculated. However, the overnight care condition does not apply to all carers. In November 2013 it was estimated that around 60,000 households affected by the spare room subsidy policy were in receipt of Carer's Allowance, or had an underlying entitlement to Carer's Allowance.

NB: The "bedroom tax" now also applies to housing benefit law in NI from 20th February 2017. However, for the next few years, the money will be replaced from a separate fund. The NI Assembly established a fund to offset these cuts to Housing Benefit, meaning that most people in NI will not actually lose out financially (due to getting a supplementary payment) because of the changes. This fund will be available until March 2020.⁵⁰

3.1.7 Outcomes for carers in England

While progress has been made in relation to legislation in England, in July 2016 the Westminster Government announced its decision to delay the implementation of phase

⁴⁹ *The Housing Benefit and Universal credit (Size Criteria) (Miscellaneous Amendments) Regulations 2013, SI 2013/2828*, <https://www.gov.uk/government/publications/the-housing-benefit-and-universal-credit-size-criteria-miscellaneous-amendments-regulations-2013>

⁵⁰ Housing Rights (NI), Bedroom Tax, <http://www.housingadviceni.org/housing-benefit/bedroom-tax>

2 of the *Care Act 2014* (England only) from April 2016 to April 2020. This delays the introduction of a cap on the costs of care that an individual is liable to pay, and a change that was to have made capital limits on the means test more generous. The main reasons given for the delay were the cost of the policy, concerns of local government, and a lack of insurance products available in the private insurance market.⁵¹

One year after the implementation of the Care Act, the Carers Trust found that 69% of carers who responded to their survey had noticed no difference since the Care Act was introduced. Too many carers were still unaware of their rights; 65% had not received assessments, and 34% of those who had been assessed did not find the assessment helpful.⁵² The Carers Trust recommended⁵³ that Government, local authorities, and the NHS urgently invest in the legal rights for carers provided in the legislation to ensure carers receive assessments, support, and care breaks. Systems for monitoring progress in implementing the Care Act should also be reviewed to capture all assessment and support activity for carers, including prevention.

3.2 Carers Strategy (2008): Second National Action Plan 2014-2016

The Carers Strategy: Second National Action Plan 2014-2016⁵⁴ ('Action Plan 2014-2016') was published prior to the implementation of the Carers Act 2014 and the Children and Families Act 2014. It builds on the Government's strategic vision for carers first published in 2008 - *Carers at the heart of 21st century families and communities*⁵⁵, which was updated in 2010.⁵⁶

The Action Plan 2014-2016 takes an overview of achievements since 2010, aimed at addressing issues for carers identified since the 2008 strategy. Issues and concerns were identified through third sector research, and government and carer organisation surveys. The vision remains that:

⁵¹ Carers UK policy Briefing August 2015 *Delayed Implementation of Care Act phase two: Implications for carers, their families and the wider care system*, available: <http://www.carersuk.org/search/delayed-implementation-of-care-act-phase-two-implications-for-carers-their-families-and-the-wider-care-system>

⁵² *Care Act for carers one year on: Lessons Learned, Next Steps* Carers trust and University of Birmingham, 2016

⁵³ Executive Summary and Key recommendations to *Care Act for carers one year on: Lessons Learned, Next Steps* Carers Trust and University of Birmingham, 2016

⁵⁴ <https://www.gov.uk/government/publications/carers-strategy-actions-for-2014-to-2016>

⁵⁵ *Carers at the heart of 21st century families and communities* at: <https://www.gov.uk/government/publications/the-national-carers-strategy>

⁵⁶ *Recognised, valued and supported: next steps for the Carers Strategy: Response to the call for views* at: <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy-response-to-the-call-for-views>

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.

The 2010 update to the national carers strategy identified four areas for priority action using the responses received to *Recognised, valued and supported: next steps for the Carers Strategy: Response to the call for views*⁵⁷, as summarised below.

3.2.1 Priority Area 1: Identification and recognition

Key is the identification of carers in order that they can be recognised, valued and supported. Carer UK's survey in 2014 found that over half of respondents had not been consulted, or consulted too late when the person they cared for was being discharged from hospital.⁵⁸ Based on its engagement with carers and carer organisations, NHS England found this to be an emerging theme for carers who wanted their expertise as carers to be recognised by professionals and to be offered help in their caring role.⁵⁹

Despite initiatives to raise awareness among healthcare staff and the development of a toolkit for healthcare professionals,⁶⁰ a snapshot of progress one year on from the implementation of the Care Act,⁶¹ found that many carers were still finding engagement with health services problematic for themselves and the person they cared for. The Carers Trust believes it is essential that local authorities ensure all social workers and assessors are appropriately trained and able to reflect the wellbeing principle in the assessment and support planning.

3.2.2 Priority Area 2: Realising and releasing potential

Key issues are support for young and young adult carers, and for carers of working age. The 2011 Census identified 166,000 young people aged between 5 and 17 with caring responsibilities. A study in 2013⁶² found that less than half (46%) of respondents thought they had received good careers advice that had taken their caring role into consideration. A quarter of those surveyed had also been bullied at school due to their caring role.

⁵⁷ *Recognised, valued and supported: next steps for the Carers Strategy: Response to the call for views* at:

<https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy-response-to-the-call-for-views>

⁵⁸ <http://www.carersuk.org/for-professional/policy/policy-library/facts-about-carers-2014>

⁵⁹ NHS England's Commitment to Carers (May 2014), <https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/>

⁶⁰ NHS England toolkit available: <https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/carers-toolkit/>

⁶¹ Executive Summary and Key Recommendations to Care Act for carers one year on: Lessons Learned, Next Steps; Carers Trust and University of Birmingham, 2016, https://carers.org/sites/files/carerstrust/care_act_one_year_on.pdf

⁶² *Young Adult Carers at School: Experiences and Perceptions of Caring and Education* (2013) Carers Trust and Nottingham University at: http://www.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1_proof_4_final.pdf

In 2013 the Children's Society *Hidden from View* report⁶³ found there was an immediate and lasting effect for young carers on education and future prospects. Young carers had a significantly lower level of achievement at GCSE level than their peers, and also had a greater likelihood of not being in education, employment or training (NEET) between 16 and 19.

In respect of employment, an employer and employee survey in 2014⁶⁴ found a disconnect between employer policy and employee experience. Whilst 83% of employers said they offered flexible working arrangements, only 48% of carers reported that this was available in their workplace. Also, where a third (33%) of employers said they had a specific policy for carers, only 19% of employees reported this.

3.2.3 Priority Area 3: A life alongside caring

The Action Plan 2014-2016 recognises that there is not a 'one size fits all' solution. Personalising support for carers and those they support, and the availability of good quality information, advice and support is key. In the Action Plan, the Government did not see a lack of information as the issue, but rather a lack of awareness of its existence and how to access it and points out that teachers, employers, and health and social care professionals should be active in signposting carers to sources of information and help, including improved legal entitlements.

In the section of the Action Plan, 'Supporting adults caring for adults to have a life of their own alongside caring' - the concept of the 'promotion of well-being' is introduced. Provisions dealing with care and support in Part 1 of the *Care Act 2014* are underpinned by a general duty to promote an individual's wellbeing.

Individual aspects of wellbeing and outcomes are defined in the Action Plan and the Care and Support Statutory Guidance⁶⁵ (as updated September 2016) supporting implementation of part 1 of the *Care Act 2014*. Wellbeing is defined as relating to physical, mental and emotional wellbeing; control over day-to-day life; participation in work, education or recreation; and social and economic wellbeing in particular.

Specific provisions in the legislation make clear that when a local authority is carrying out a carer's assessment they will be required to explore with the carer if they are willing and able to provide care, and taking a 'whole family approach', establishing the outcomes a carer wants to achieve in their daily life, and whether the provision of

⁶³ The Children's Society (2013) *Hidden from View: The experiences of young carers in England*, <https://www.basw.co.uk/resource/?id=2058>

⁶⁴ Report from Carers UK and Employers for Carers (2014) *Supporting employees who are caring for someone with dementia*, <https://www.carersuk.org/for-professionals/policy/policy-library/supporting-employees-who-are-caring-for-someone-with-dementia>

⁶⁵ Department of Health, *Care and support statutory guidance (updated 26 September 2016)* available: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

support the local authority provides to the carer would achieve that outcome (*Care Act 2014*, Part 1).

3.2.4 Priority Area 4: Supporting carers to stay healthy

In Carers UK State of Caring Survey in 2014, 80% of carers reported that caring had a negative impact on their health. As hours of caring increase, carers' health tends to deteriorate. The group most impacted by poor health are young male carers aged up to 24 who care for over 50 hours a week (four and a half times more likely to report poor health than their peers).⁶⁶ Ill health was also prevalent among young carers aged under 18 years of age⁶⁷ when caring for 50 or more hours a week (five times more likely to report ill health than their peers).

The Action Plan 2014-2016 says that carers should be supported to access leisure and sport activities and NHS and local authority public health services for physical and mental health and wellbeing. Gaining a better understanding of the condition or illness of the person they care for can also alleviate stress, as can information about, and access to, equipment and/or technology that could assist them.

4 Scotland – Law and Policy for Carers

4.1 Legislation in Scotland

The Carers (Scotland) Act passed on 4 February 2016 and will be commenced from 1st April 2017. Its key objective was the intention that carers and young carers should be consistently supported in order that, if they wish, they should be able to continue in their caring role. It is also the intention that young carers should be able to have a childhood that is similar to their peers who do not have a caring role.

The Scotland Act 2016 provided for the devolution of Carer's Allowance to Scotland. The Scottish Government plans to increase Carer's Allowance to match the rate of Jobseeker's Allowance, increasing the weekly rate from £62.10 (£62.70 from 1st April 2017) to £73.10. All the main Scottish political parties support this increase, although the Scottish Green Party would increase it further to £93.15 a week. The aim is to compensate carers for the contribution they make to society.⁶⁸

⁶⁶ http://www.ons.gov.uk/ons/dcp171776_310295.pdf

⁶⁷ ONS analysis of 2011 census, <https://www.ons.gov.uk/census/2011census/censusanalysisindex>

⁶⁸ Georghiou, N. and Berthier A. (2016) Scotland Act 2016: Carer's Allowance, Scottish Parliament SPICe briefing, http://www.parliament.scot/./SB_16-52_Scotland_Act_2016_Carers_Allowance.pdf

It is estimated that there are 745,000 adult carers, and 44,000 young carers in Scotland,⁶⁹ with the total value of unpaid care in Scotland estimated at £10.3 billion per annum. In common with the *Carers Act 2014* in England, the *Carers (Scotland) Act*⁷⁰ ('the Act') removes the requirement for the care a carer provides to be 'substantial' and 'regular'. The Act (parts 2-6):

- Replaces the current carer's assessment with a new adult carer support plan (ACSP) and provides a young carer statement (YCS) for all young carers;
- Provides for the establishment of an information and advice service for carers in each local authority, which must include a short breaks services statement;
- Introduces a duty to support carers whose needs cannot be met by general services in the community (including the information and advice service). The carer's needs must meet local eligibility criteria in order for the duty to apply;
- Requires local authorities, in determining which support to provide carers, to consider in particular whether the support should take the form of, or include, a break from caring;
- Requires local authorities to prepare local carer strategies for their area; and
- Requires local authorities and health boards to involve carers in carer services for carers and cared-for persons.

The *Children and Young People (Scotland) Act 2014*⁷¹ recognises the need to promote public awareness and understanding of the rights of children and young people.

Carer organisations in Scotland (Coalition of Carers in Scotland) influenced the direction of the Act through amendments at stage 3 of the Bill. These included ensuring the *Equality Act 2010* is taken into account when planning or providing information or support to carers; promoting the need for short breaks to be provided on 'a planned basis', and a duty on local authorities to promote a wide range of breaks for carers; including information on emergency planning and preventative support in local carer strategies; and extending the provision of information and advice services to bereaved carers.

However, some amendments that were supported by carers organisations failed, including the setting of a national eligibility criteria for carrying out carer assessments. Each local authority will set its own criteria for eligibility when carrying out carers' assessments. In England local authorities apply national eligibility criteria for assessments of adult carers, but not for young carers. In justifying the decision not to apply national eligibility criteria for support in Scotland, the Minister said:

⁶⁹ The 44,000 is an estimate as the Scottish Health Survey uses 16 as the split between young and adult carers and the Carers (Scotland) Bill defines young carers as under 18.

⁷⁰ Carers (Scotland) Act 2016 available: <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>

⁷¹ Children and Young People (Scotland) Act 2014 available: <http://www.legislation.gov.uk/asp/2014/8/contents/enacted>

I do want to ensure consistency of approach across Scotland. I believe this can be achieved through the National Matters which will be set out in regulations and which will underpin local eligibility criteria.

The Coalition of Carers in Scotland stated:

We are disappointed that eligibility criteria will be developed locally. However, we intend to work with the government in relation to the development of the regulations setting out the National Matters. We believe these national matters need to establish a consistent approach in setting out eligibility for support. We will be promoting the use of the National Eligibility Framework developed by the National Carer Organisations and endorsed by carers.

Scottish Ministers will, however, still have powers to set national eligibility criteria, and during the debate the Minister stated:

We will monitor the efficacy of the approach in the Bill of using local eligibility criteria, and I will have no hesitation in using the power and instituting national eligibility criteria if this is found to be necessary.

4.2 Strategy in Scotland

In partnership with National Carer Organisations and COSLA (Convention of Local Authorities Scotland), the Scottish Government published “Caring Together: The Carers Strategy for Scotland 2010-2015”⁷² (‘the Scottish Carers Strategy’) focusing on the identification of carers, information and advice, health and wellbeing, carer support, and participation and partnership.

Also published for the period 2010 – 2015 was *Getting it Right for Young Carers*⁷³, believed to be the first strategy specifically for young carers in Europe. The Scottish Carers Strategy headlined actions to improve outcomes for carers. The main actions include:

- The development of a Carers Rights Charter consolidating existing rights for carers and outlining key principles for the future;
- Steps to improve the uptake and quality of carer assessments and support plans;
- Carer representation on community health partnerships;
- Investment in carer (and workforce) training through a grant to the national carer organisations;

⁷² Caring Together: The Carers Strategy for Scotland 2010-2015 available:

<http://www.gov.scot/Publications/2010/07/23153304/0>

⁷³ Getting it right for Young Carers available: <http://www.gov.scot/Publications/2010/08/16095043/1>

- Local authorities continuing to provide access to short breaks and further investment to provide more innovative short breaks delivered by the voluntary sector;
- Encouragement and support for carer-friendly employment practices; and
- Tackling issues facing carers in remote rural areas.

5 Wales – Law and Policy for Carers

5.1 Legislation in Wales

The Social Services & Well-being (Wales) Act 2014 (in force since April 2016)⁷⁴ provides a single Act bringing together the duties and functions of local authorities with the aim of improving the well-being of people who need care and support, and **carers** who need support. It is still very early days for the implementation of the Act and therefore too early to evaluate much change on the ground for carers.

It provides the statutory framework to deliver the Welsh Government's commitment to integrate social services and support people of all ages as part of families and communities.⁷⁵

In an overview of the Welsh Act⁷⁶ Professor Luke Clements from Leeds University believes that it "will have a profound impact on the provision of social care in Wales", and "will create a quite distinct social care legal jurisdiction in Wales." Clements also points out that the Welsh Act is materially different to the English Act, chiefly because it applies to people of any age deemed to be 'in need', and their carers, while the English Act mainly applies to 'adults in need' and their carers.

Section 3 of the Act replaces previous community care legislation where need derived from age, illness, disability etc. Need now focuses on whether a person 'needs' care and support, or a carer 'needs' support, regardless of the cause of that need. This does not however apply to those caring for a disabled child where 'disabled' must be defined.

Section 3(4) defines a carer as a person who provides or intends to provide care for an adult or a disabled child. This is a change to the previous definition as a carer no longer has to establish that they are providing, or intending to provide a 'substantial' amount of care on a 'regular' basis.

⁷⁴ Social Services and Well-being (Wales) Act available: <http://www.ccwales.org.uk/the-act/>

⁷⁵ Social Services and Well-Being (Wales) Bill Explanatory Memorandum incorporating the Regulatory Impact Assessment and Explanatory Notes, January 2014 available: www.assembly.wales/bus-home/bus-business-fourth...laid.../pri-ld9181-em-e.pdf

⁷⁶ Luke Clements (15 July 2016) *The Social Services & Well-being (Wales) Act 2014: An Overview*; Updated and expanded briefing available: <http://www.lukeclements.co.uk/>

A key principle is to support people who have care and support needs to achieve well-being, and places a general duty on local authorities to promote the well-being of people 'in need' and their carers. In relation to adults this includes giving them 'control over their day to day life', and 'participation in work'.

Assessments of carers of any age must include:

- Whether the carer is willing and able to provide care;
- Outcomes the carer wants in their day to day life; and
- Whether the carer works, or wishes to work (and/or) to participate in education, training or recreation.

Provision is made (sections 28 & 29) for combined assessments dependent on consents. Carers Wales⁷⁷ highlighted that it is important that carers receive clear and distinct assessments in their own right.

National eligibility criteria are to be detailed in regulations for the Act. However, the Welsh Government has made it clear that the intention is for more people to be supported who fall outside the eligibility framework. The national eligibility framework regulations and code of practice determine at what level individuals and carers have an enforceable right to support from the local authority. It will also define the point where a local authority has a legal duty to provide, or arrange the provision of care and/or support. If someone meets the eligibility criteria the local authority must consider what must be done to meet their needs, whether to impose a charge, and if so, the amount this should be.

The Act also places a duty on local authorities (section 16) to promote the development of social enterprises/co-ops/third sector organisations to provide care and support and preventative services, that involve users in their design and operation.

Support for 'not for profits' organisations providing care and support and preventative services is seen as 'imaginative' as such enterprises can re-invest profits in the services they provide. Clements points out that this is in contrast to the English Act where it is likely there will be a significant increase in privatisation of social care provision, particularly in relation to carrying out assessments.⁷⁸

5.2 The Carers Strategy for Wales Delivery Plan 2013 – 2016⁷⁹

⁷⁷Carers Wales is an information, advice and support organisation for carers <https://www.carersuk.org/wales>

⁷⁸ Luke Clements (15 July 2016) The Social Services & Well-being (Wales) Act 2014: An Overview; Updated and expanded briefing available: <http://www.lukeclements.co.uk/>

⁷⁹ Carers Strategy for Wales Delivery Plan 2013 – 2016 available: <http://gov.wales/topics/health/publications/socialcare/strategies/carers-strategy/?lang=en>

“The Carers Strategies (Wales) Measure 2010: Guidance issued to Local Health Boards, NHS Trusts and Local Authorities”⁸⁰ enabled the National Assembly for Wales to require the NHS and local authorities to work in partnership to prepare, publish and implement a strategy for unpaid carers. Supporting legislation⁸¹ came into force in January 2012. The guidance set out minimum requirements for strategies that had to be approved by Ministers.

The Carers Strategy for Wales⁸² had five priority areas: health and social care; identification of carers, information and consultation; young carers and young adult carers; support and a life outside the caring role; and carers and employment.

By the end of 2016 the Carers Strategy for Wales Delivery Plan 2013-2016 wanted to achieve the following for carers:

- That all carers are listened to, treated with respect and achieve proper recognition; and
- All carers are genuinely involved in all decisions that affect them and the people they care for, including decisions about the level of care they are willing and able to provide.

Key themes and priority areas that were to be taken forward were also documented in the Delivery Plan 2013-2016 as:

- Health, social care and well-being;
- Identification, information and consultation;
- Support for young carers and young adult carers;
- Support and a life outside of the caring role; and
- Carers and employment.

Well-being is an important concept in all three jurisdictions. In Wales, where it is included in the title of the Act, the Welsh Government has published a Well-being Statement to set out what well-being is, put together by both the people who deliver, and the people who use social services. It is made up of eight main parts:

- Ensuring you have your rights;
- Being physically, mentally and emotionally happy;
- Protected from abuse, harm and neglect;
- Having education, training, sports and recreation;
- Positive relationships with family and friends;
- Being part of the community;

⁸⁰ Carers Strategies (Wales) Measure 2010: Guidance issued to Local Health Boards, NHS Trusts and Local Authorities available: <http://gov.wales/topics/health/publications/socialcare/guidance1/carers/?lang=en>

⁸¹ The Carers Strategies (Wales) Regulations 2011 available: <http://legislation.data.gov.uk/wsi/2011/2939/made/data.html>

⁸² The carers Strategy for Wales available: <http://gov.wales/topics/health/publications/socialcare/strategies/carers-strategy/?lang=en>

- Having a social life and enough money to live a healthy life;
- Having a good home.

6 EU Strategy and EU Example Case Studies – Policy and Law

Informal and family care is often an ignored sector of the economy, yet 80% of all care across the EU is given by family carers and an overwhelming majority are women. At EU level, the European Parliament has supported direct references to carers under the EU's PROGRESS programme budget lines since 2011 and the *European Parliament Interest Group on Carers* continues to act as a forum for discussion on EU policy. According to Eurocarers, three major initiatives refer explicitly to carers⁸³:

- The European Innovation Partnership on Active and Healthy Ageing - this Partnership explicitly targets carers as one of the main stakeholder groups;
- The Employment Package, particularly the Staff Working Document on the employment potential of household and personal services, which contains a number of relevant statistics on carers and the need to ensure high quality and sustainable care provision; and
- The Social Investment Package and its Staff Working Document on Long Term Care recognises the contribution of carers and acknowledges their main issues and challenges.

With regard to EU policy - the Confederation of Family Organisations in the EU has recommended⁸⁴:

EU strategy carers - the European Commission should, following the *European Parliament Interest Group (2014) demand*, develop a comprehensive strategy on Family and Informal Carers at EU level that will mainstream recognition and support for carers throughout the European Policies and legislation.

EC Recommendation on family and informal carers - The European Commission should initiate a Recommendation on the recognition of family and informal carers and for the adoption of provisions recognising their legal status in Member States. This should be based on the *EU Charter for Family Carers (COFACE, 2007)* and would be the natural continuation of the existing EU policy documents, including the *Social Investment Package* and its *Staff Working Document on Long Term Care*.

Carers' leave directive - The Commission should prepare a directive on this issue, giving an adequate amount of leave to workers who are faced

⁸³ Enabling carers to care, Eurocarers, 2014, Introduction, www.eurocarers.org/ENABLING-CARERS-TO-CARE

⁸⁴ Confederation of Family Carers in the EU, http://www.coface-eu.org/en/upload/ERP/ERP_2015-carers.pdf

with care duties for their family members with disabilities or elderly dependents. This directive should contain recommendations for financial compensation during carers' leave as well as the possibility for family and informal carers to switch from full time to part-time and vice versa. Special attention should be devoted to making it possible for male workers to take up their share of carers' leave as well.

Belgium has been highlighted as a good practice model of legislative and policy development for carers, having commenced a process of reform in this area with a law to give carers a legal status.⁸⁵

Belgium adopted a law in 2014 for the recognition of family and informal carers (2014/203605), recognising the legal status of family and informal carers caring for a person with high dependency needs. The law defines a legal status for carers, which will be granted annually, after a specific application to the social security that will need to be renewed each year. This law is highlighted as the first step of a longer process as it does not provide carers with specific social rights or financial compensation.

In addition, Belgium also now offers Carers' Leave and Time Credit Systems - workers in time credit or carers' leave hold their pension rights and the possibility to get back to their jobs⁸⁶:

Each employee having worked at least 12 months for the same employer, has a right to take carers' leave for a period of 12 months (24 months for single parents to take care for a child up to 16 years old), on the condition of a medical certificate stating that the assistance of the worker is needed for the person that needs care. This leave is remunerated by the government as a lump-sum. There is an additional carers' leave (called "motivated time credit") that can be used for the same purposes, for a maximum period of 24 months, but the conditions are stricter and the remuneration lower. ...Workers in time credit or carers' leave hold their pension rights and the possibility to get back to their jobs. In addition, time-credit can be used not only as a full-time block of leave, but can be spread over years by switching to part-time.

In **France**, carers who drop out of paid employment to be a family carer for at least 30 consecutive months can enjoy full pension rights at the age of 65 and those periods will be assimilated to employment as for pension rights. Informal carers, external to the family, can also benefit from this measure if they care for a person with disability receiving an allowance for supporting a carer.⁸⁷

⁸⁵ Confederation of Family Carers in the EU, http://www.coface-eu.org/en/upload/ERP/ERP_2015-carers.pdf

⁸⁶ Confederation of Family Carers in the EU, http://www.coface-eu.org/en/upload/ERP/ERP_2015-carers.pdf

⁸⁷ As above

In **Italy**, the region of Emilia Romagna approved a regional law in 2014 (*LEGGE REGIONALE 28 marzo 2014, n. 2*) for the recognition and support of family and informal carers. It is a regional law and has, therefore, validity only in that region and for the regional competences like skills recognition and access to training, and access to services like respite, support and care. However, it has no impact on social rights as they are regulated at national level. Despite being regional, it still has a direct impact on citizens' lives and may be a trigger to further legislation at a wider level across Italy.⁸⁸

In the **Republic of Ireland (RoI)**, Carer's Allowance is a means tested benefit paid to people on a low income who are living with, or in a position to provide full-time care to someone over the age of 16, or under 16 and receiving Domiciliary Care Allowance. A carer must not be engaged in employment, self-employment, training or education outside the home for more than 15 hours per week, and during their absence adequate care and attention for the person being cared for must be in place. If a carer is in receipt of certain other social welfare payments, they may be entitled to half-rate Carer's Allowance.⁸⁹

In order to be eligible for Carer's Allowance to be paid, the person receiving care must be so incapacitated as to require continuous supervision and frequent assistance throughout the day to avoid being a danger to themselves, **and** be likely to require full-time care and attention for a period of at least 12 months.

The most recent RoI National Carers' Strategy⁹⁰ was published in 2012. Its vision statement is:

Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life.

The third progress report (September 2014- September 2015) provides an overview of the initiatives and services that are in place for carers.⁹¹ The *Family Carers Ireland Manifesto*⁹² focuses on achieving 'fairness' for carers. In addition to a range of specific actions, such as increasing the hours a carer can work/study from 15-20 hours a week and increasing the funding for the Housing Adaptation Grant Scheme, it asks for the following five commitments for family carers:

- Ensure family carers are not financially burdened as a result of their caring role;

⁸⁸ Confederation of Family Carers in the EU, http://www.coface-eu.org/en/upload/ERP/ERP_2015-carers.pdf

⁸⁹ Citizens' Information available: http://www.citizensinformation.ie/en/social_welfare_payments/carers

⁹⁰ National Carers' Strategy: Recognised, Supported, Empowered (2012); Department of Health available: <http://health.gov.ie/blog/publications/national-carers-strategy/>

⁹¹ National Carers' Strategy Third Progress Report (September 2014 – September 2015) available: <http://health.gov.ie/blog/publications/national-carers-strategy/>

⁹² Family Carers Ireland – Pre-election Manifesto 'Election 2016 Achieving fairness for Family Carers available: <http://familycarers.ie/about-us/publications/>

- Create a more ‘carer friendly’ health service;
- Invest in the futures of young carers;
- Publish phase two of the National Carers’ Strategy with ring-fenced funding for implementation; and
- Commit to supporting issues affecting carers both nationally and locally.

7 Discussion - Key Ways to Support Carers

It is clear that a continuation of family and informal caring roles will be essential given future demographics and cost pressures facing long-term care systems across the UK and wider EU. Continuing to find ways to support and maintain the supply of family and informal care appears to be a necessity and a win/win approach for the carer, the recipient of the care and for the public social care system.

In 2011, the Organisation for Economic Co-operation and Development (OECD) reviewed policies across OECD countries to support family carers. The key policies adopted by countries fall into three main areas⁹³:

- Helping carers combine care responsibilities with paid work;
- Improving carers’ physical and mental-wellbeing; and
- Compensating and recognising carers.

7.1 Helping carers combine care responsibilities with paid work

Flexible working hours and practices may help carers remain in the labour force. As described in section 2.3.2, in the UK from 30 June 2014 the rules for requesting flexible working have improved⁹⁴:

- All employees with 26 weeks service will be able to request flexible working, with the requirement to be a parent or carer removed; and
- The statutory procedure for considering requests has been removed and replaced by a duty on employers to deal with requests in a reasonable manner, considering whether the request can be accommodated on business grounds.

⁹³ Help wanted? Providing and Paying for Long-Term Care, OECD 2011, Chapter 4, Policies to Support Family Carers, <https://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm>

⁹⁴ Supporting Working Carers, a guide to requesting flexible working, Carers UK, <https://www.carersuk.org/for-professionals/policy/policy.../supporting-working-carers>

However, across OECD countries part-time and/or flexible working is more likely to be used to care for children rather than care of the frail elderly, perhaps because carers feel it may have an impact on career prospects and household income.⁹⁵

With regard to **paid 'care leave'** conditions for such leave tend to be limited and paid leave is available in only around a half of OECD countries. As mentioned in section 6, Belgium provides the longest publicly paid carer leave, for a maximum of 12 months, which employers may refuse only on serious business grounds. However, Scandinavian countries tend to pay the most, with Norway and Sweden paying 100% and 80% of salary respectively.

As with requests for flexible working, carers' requests may be limited if carers feel it may have an impact on career prospects and responsibilities often prefer to use holidays or sick leave if they fear endangering their career.⁹⁶

Carers in the UK have advised 'Carers UK' that they often use up annual leave entitlement to provide care for longer periods, for example, to a partner recovering from an operation. When their leave runs out they may feel they cannot cope and give up work altogether. Carers UK has highlighted that the UK is falling behind many other countries in this regard and called for⁹⁷:

*A **statutory entitlement to care leave** would help many carers to juggle their caring responsibilities with work in a more sustainable and manageable way, making them more productive and less stressed, and saving businesses and the economy money in the long run.*

7.2 Improving carers' physical and mental-wellbeing

The provision of **respite care** is key in this area and includes day-care services, in-home respite and institutional respite. In NI, the availability of respite care to an individual is based on a community care assessment of their needs by their HSC Trust. The individual *may be* eligible for care at a day centre to give them or the person who cares for them a break or 24 hour care as respite care for a number of days or weeks.⁹⁸

Policies across the OECD generally include respite care, but legal entitlement is not always clear and does vary. In the **Republic of Ireland** an annual grant for respite care can be used throughout the year, when certain criteria are met; in **Austria** a specific

⁹⁵ Help wanted? Providing and Paying for Long-Term Care, OECD 2011, Chapter 4, Policies to Support Family Carers, <https://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm>

⁹⁶ Help wanted? Providing and Paying for Long-Term Care, OECD 2011, Chapter 4, Policies to Support Family Carers, <https://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm>

⁹⁷ The Case For Care Leave, Carers UK, Research, December 2013, <https://www.carersuk.org/for-professionals/policy/policy-library/the-case-for-care-leave>

⁹⁸ Social care and support, Citizens Advice, NI <https://www.citizensadvice.org.uk/nireland/relationships/looking-after-people/social-care-and-support-ni/>

allowance is available for respite care for up to four weeks a year and in **Finland** the Act on Family Caregiving grants at least three days respite a month for carers who care on a continuous basis.⁹⁹

It is generally thought that well planned and flexible respite care services may improve carer's outcomes and wellbeing and a range of different services is probably most appropriate. It is suggested that these need to be combined with services for planning and transportation as the users of adult day services spend considerable time in travelling and preparations to attend.¹⁰⁰

According to surveys carers would also welcome more **psychological counselling** and information from health professionals regarding the disease or disability of the person they care for. Research has shown that counselling is effective at relieving carer's stress. For example, the **Netherlands** uses a preventative counselling and support method called the POM method. Once enrolled in National Care Plans, individuals are contacted by social workers who carry out house visits and follow-up with phone calls on a quarterly basis to help prevent mental health problems in care givers.¹⁰¹

7.3 Compensating and Recognising Carers

A large number of OECD countries provide financial support to carers through a carer allowance of some sort (see section 2.1.3 for UK details of the carers allowance benefit) and/or direct payments to those in need of care, part of which may be used in some countries to compensate family carers. Both types of payments are available, for example, in the UK, Norway, New Zealand and Sweden.

There are two main approaches with regard to 'carers allowances'- (i) the provision of **remuneration** to family carers who are formally employed or (ii) use of **means-tested allowances/benefits**¹⁰²:

- (i) In **Nordic** European countries the 'carers allowance' is considered as **remuneration**. Municipalities, which are responsible for long-term care services, employ family caregivers directly. Salaries vary across municipalities vary with care needs and are equivalent to the hourly pay received by regular home helpers. The Municipalities are not obliged by law to provide them, possibly to limit their attractiveness to low-wage earners. Carers' allowances tend to be granted to keep the care recipient at home instead of moving to an

⁹⁹ Help wanted? Providing and Paying for Long-Term Care, OECD 2011, Chapter 4, Policies to Support Family Carers, <https://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm>

¹⁰⁰ Help wanted? Providing and Paying for Long-Term Care, OECD 2011, Chapter 4, Policies to Support Family Carers, <https://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm>

¹⁰¹ As above

¹⁰² As above

institution, and when the care performed is extraordinarily heavy or burdensome. In comparison, many more family carers benefit from payments via the care recipient.

Care 'wages' may seem a promising avenue but they remain a relatively costly option and there is a legitimate question as to whether or not more qualified or experienced formal carers should be used instead.

- (ii) **Means-tested benefits** paid directly to carers are found mostly in English-speaking countries (Australia, Ireland, New Zealand, and the UK as already discussed). Allowances are limited to those most in need, with heavy and regular caring duties that result in forgone earnings. In addition, the care recipient must be in receipt of a disability benefit. Their stringent eligibility is linked to low reciprocity rates.

With regard to **direct payments** or cash benefits to the recipients of care (in the UK these are referred to as 'direct payments' – see section 2.1.1), these are often advocated as maximising the independence of the care recipient. In some countries, these payments can be used to employ family members, which may create difficulties with family relationships.

In the UK there are specific rules around employing family members which vary depending on the jurisdiction. In NI, the person cared for cannot usually use the direct payment to pay their spouse or partner, or anyone who lives with them (unless that person is someone who has been specifically recruited to be a live in employee) to provide them with care, unless it is an exceptional circumstance, for example, religious reasons or communication reasons. Carers can use the direct payment to pay a family member who does not live with them as long as the local HSC trust agrees that this family member will meet their needs.¹⁰³

Compensating carers is indeed an important way to recognise their important role but the benefit of such payments and cash or direct payments to those in receipt of care is only maximised in the context of a proper care plan. This includes training for carers, work measures such as flexible working and other forms of support, including respite care.

¹⁰³ Direct Payments, Carers UK, <http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments#sec6>