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# Toward a New Co-Production of Care

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# Executive Summary

Households have shown consistent disinterest in pooling the risk of needing paid care, whether via taxation (e.g. an estate levy), social or private insurance. A key reason is that many individuals would prefer to receive informal care, which they are more likely to receive, but which may impose considerable financial and personal costs on family members. It appears households opt to conserve savings so as to effectively 'insure' at the 'household-level'. This suggests getting the 'offer' to informal carers right is essential if a new settlement on long-term care funding is to achieve wide support.

Individuals struggle to think about the risk of needing care, so policymakers should focus on the potential burden involved in providing high levels of informal care, and give households a clear, tangible and guaranteed 'vision' of informal care-giving which they feel is worth the price of any new settlement on care funding. In the very short-term, the government should raise the earnings-cap on Carer's Allowance and mandate local authorities to offer Carer's Assessments to all carers. In the longer-term, a new settlement on long-term care funding should disregard informal care provided by those under-16 and over-75, guarantee carers at least one day-off per week, and cap the hours of informal care anyone provides at 60 hours per week. A national system of assessment, entitlement and funding should be applied to both care funding *and* cash-based locally-administered entitlements for carers. To ensure that those making contributions under a new long-term care funding settlement can see that they will benefit directly even as providers of informal care, public spending on care-related benefits and the social care system, including support to carers, should be merged with a national financing vehicle providing for receipt of new contributions from households.

Potential reforms to the funding of long-term care in England and Wales will determine the volume of formal care provision across the population and - *by definition* - also determine the volume of informal care provided.

The long-term care funding debate has been characterised by households showing consistent disinterest in pooling the risk of needing paid care, whether via taxation (e.g. an estate-levy), social insurance schemes or private insurance.

A key reason is that households opt instead to conserve savings and wealth, effectively 'insuring' at the 'household-level', rather than the 'population-level'. Many would prefer to receive informal care, which they are in fact more likely to receive, and which may impose considerable financial and personal costs on the person providing care. In this context, it is only logical that households effectively 'self-insure'.

A fundamental challenge in long-term care funding debates is therefore: how to get individuals to pay into a new system they will disqualify themselves from if they receive informal care?

This suggests that getting the 'offer' for informal carers right is essential if a new settlement on long-term care funding is to achieve wide support and participation. This requires ensuring that the balance between formal and informal care in any new long-term care funding settlement is the right one, and ensuring that this is 'communicable' to the public.

The current picture: funding care and support

The key features of the long-term care funding system in England and Wales are universal disability benefits, community care assessment used to ration public funding of care, and evolving trends in the design of care services toward personalisation. The core of this system comprises local authority administered

community care assessments, which are 'carer-sighted' needs-assessments accompanied by a means-test. Individuals must have low levels of wealth, and not be in receipt of informal care, in order to qualify for support.

Carers to those entitled to public support should in theory be doing this voluntarily and sustainably. However, this care provision intersects with the rationing of public funding in the context of an under-resourced system, and there is an incentive for councils to overestimate the provision of informal care. Research from the former Commission for Social Care Inspection identified wide variations in the application of guidance by local authorities, implicit and explicit rationing, and a reliance on individual subjective assessments.

Carers to those too wealthy to receive public support may do so for a number of reasons, including to protect the assets of those needing care from being run down by out-of-pocket payments on care. Others may lack information about the support services available.

Disability benefits are another component of the system, and provide universal low-level universal cash entitlements. However, take-up is variable, and the sums involved are not significant given the levels of need required to claim.

The current picture: informal care policy

Informal care policy comprises welfare benefits (Carer's Allowance), NICs contributions, protection from discrimination, rights to flexible working, the right to request a Carer's Assessment, measures to encourage supportive employers, and an evolving range of local services seeking to support informal care such as information and advice, respite care and health checks.

On various measures, this policy framework is helping many informal carers, for example, by compelling employers to be flexible around the needs of employed carers.

However, some elements of this framework fall short. Carer's Allowance is effectively meaningless as an earnings-replacement benefit: it assumes poverty-level earnings, take-up is low even among those entitled, and it appears many individuals opt to disqualify themselves through paid work, shouldering heavy levels of care provision and paid work. Carer's Assessments by local authorities are a valuable innovation rolled out in recent years, but their application, and any associated support, remain at the discretion of budget-constrained local authorities.

Overall, support for informal carers and the long-term care funding system offers little certainty or guarantees to those contemplating a future involving providing informal care to a partner or relative.

As such, it should not be surprising that households are inclined to conserve wealth rather than contributing to a risk pool for funding paid care. Creating a new 'offer' for carers may be the only way to secure reform. Policymakers must give households a clear, tangible and guaranteed 'vision' of informal care-giving, which households feel is worth the price of any new settlement on care funding.

Taking such an approach may be the only way that policymakers will achieve widespread support for reform to long-term care funding. It has proved consistently difficult to persuade many individuals to think about the risk of needing care in the future. Instead, policymakers should focus on something which individuals find much easier to imagine: the personal burden involved in providing high levels of informal care.

Asking households to think about the outcomes and life they would want as informal carers - and persuading them to participate in a new settlement on long-term care funding on the basis of these outcomes - may be the key to unlocking support for a new settlement on long-term care funding. In effect, a new settlement for care funding can ask individuals to insure against the potential burden of providing 'catastrophic' levels of care.

In the very short-term, the government should therefore:

- ▶ Raise the earnings-cap on Carer's Allowance to £136.54, so carers claiming Carer's Allowance have an income in line with the National Minimum Wage.
- ▶ Mandate local authorities to offer Carer's Assessments to all carers.

As part of a new settlement on long-term care funding, a new 'offer' to carers should comprise:

- ▶ Community care assessments should disregard informal care provided by those under-16 and over-75.
- ▶ Carers should be guaranteed at least one day-off per week through giving equivalent Personal Budgets to all receiving care, regardless of means.
- ▶ A national system of assessment, entitlement and funding of care and support should be implemented giving individuals transparency and predictability in what they will receive, and removing arbitrary geographical variations in local authority support.
- ▶ The government should replace Carer's Allowance with a nationally consistent system of universal cash-based entitlements for carers delivered via local authority carer's assessments.
- ▶ All those in need of care and support, regardless of means, should be given Personal Budgets that ensure no informal carer provides more than 60 hours of care per week.

- ▶ To ensure that those making contributions under a new long-term care funding settlement can see that they will benefit directly even as providers of informal care, public spending on care-related benefits and the social care system, including support to carers, should be merged with a national financing vehicle providing for receipt of new contributions from households.

# 1. Introduction

Any reform of long-term care funding will also determine the volume of informal care provision across the population and within households...

**Like many countries, the UK is grappling with the question of the most appropriate way to fund the care and support of those with long-term conditions and disabilities.**

Although issues of funding and formal care provision dominate such debates, all countries actually display 'mixed economies' of care: formal care co-exists with the provision of informal care by family members, friends and communities. In the UK, unpaid, informal care provision outstrips the 'formal' kind in terms of recipients and the numbers involved in providing care.

Any system for funding care and support will determine the volume of formal care provision across the population and - *by definition* – also determine the volume of informal care provided, as well as unmet need. As such, the policy challenge – “how should we fund long-term care?” – also contains a second question: “how much informal care should society expect families to provide?” Any answer to the first question also involves proposing an answer to the second.

The effective 'answer' to these questions in England and Wales is a policy framework that has evolved over time, but boils down to a stringent means-assessment and needs-assessment that local authorities use to allocate public funding for care and support. Individuals must have low levels of income and savings, and not be in receipt of informal care, before the state targets them with substantial resources. Beyond this entitlement, some families may opt to purchase care privately 'out-of-pocket'.

In short, decisions on allocating public support to those who pass the means-test threshold are 'carer-sighted' – take account of the availability of informal care - but this is set against a growing range of policy interventions and entitlements seeking to support informal carers across the population, developed and

refined in successive carer's strategies from the government. Nevertheless, no government has sought to specify a precise answer to the question: “how much should society rely on carers?”

Potential reform to long-term care funding, which is currently a live policy debate in England and Wales, would inevitably change the mix of formal and informal care again. If England and Wales is to have the right balance between formal and informal care, mechanisms to achieve this will need to be written into the core of any new funding settlement. In evaluating potential reforms to the long-term care funding system, policymakers must ask: what is the right balance between formal and informal care and what sort of long-term care funding system will create it?

## Informal care, risk-pooling and the family

However, the link between long-term care funding and informal care provision runs much deeper than simply mechanisms to allocate public resources: achieving an appropriate balance between formal and informal care may not just be a desirable 'bonus' of a new funding system – it may be a pre-requisite.

At the heart of the policy debate in England and Wales on long-term care funding is a simple question: how to persuade healthy individuals with no care and support needs, particularly older people, to pay into a risk-pool for long-term care funding?<sup>1</sup>

Debates on long-term care funding have thrown up multiple models, whether a 10% estate-tax, an £8000 lump-sum at retirement to cover residential care costs, or models based on income contributions from those below and above the age of 65.

However, individuals and families have consistently shown disinterest in insuring themselves in relation to the potential cost of long-term care, whether via paying

A key reason households consistently reject participation in various reform proposals for long-term care funding may be that many would prefer to receive informal care, so ‘insure’ against the burden this can impose on relatives by conserving their savings...

more into tax revenues (such as a tax on estates), or into state-sponsored or private sector insurance.

Multiple reasons can be cited to explain this disinterest among households.

However, a key explanation of this phenomenon would be that people are – *correctly* – recognising that they are more likely to be recipients of informal care, and perceive – *correctly* – that state support for any family member that provides them with informal care will be limited.

In addition, many people also consider the prospect of receiving care from a family member preferable to receiving care from a paid care worker, and may therefore prefer to plan on the basis of receipt of informal care. Research on this issue is limited, but the most recent survey found that being cared for by a family member in their own home was the most popular choice among healthy individuals for how they would wish to receive care if they required support in the future.<sup>2</sup>

In this context, individuals may choose to conserve and build their savings and wealth, rather than insuring themselves, so as to use their assets to support and help a family member in providing informal care to them in future. Receipt of informal care is more likely than formal care, and in this sense, individuals are only logical to ‘insure’ against the pressures and costs that informal care might impose on their family, rather than the potential cost of formal care.

For example, imagine a retiring couple with an average (mean) level of savings and investments of around £50,000,<sup>3</sup> which they keep for a ‘rainy day’. Both may hope and expect that the other will provide care for them if needed, in conjunction with help from adult children.

The different proposals that have featured in long-term care funding debate give this couple a choice:

- ▶ Pay into a risk-pooling mechanism to meet the potential cost of paid care (taxation/state, social insurance scheme, private insurance);
- ▶ Conserve assets and savings such that they can be used to support one partner in providing informal care for the other, or care by a child.

In effect, people make choices about the ‘closed economy’ of informal care within the family before they consider participation in risk-pooling to hedge against the risk of needing care, whether organised by the state or insurance industry. Assets and savings are used as insurance in case informal care is required from one family member, as well as being available to fund associated costs such as housing adaptations and maintenance. Although few willingly acknowledge it, wealth may also be preserved for the purposes of incentivizing and rewarding informal care provision via gifts and inheritance transfers. In particular, such gifts may provide compensation if an adult child is forced to give up employment (and their income) to provide care for an elderly parent.

This exposes a fundamental challenge in long-term care funding debates: how to get individuals to pay into a new system they will disqualify themselves from if they receive informal care? Individuals may reject state-organised insurance – taxation, social insurance funds – because they will not benefit if, as they hope, they are able to rely on informal care. Individuals may reject private sector insurance because they would prefer to receive informal care, so why pay a premium to an insurance company when they can save this money in case they rely on care and support from a family member.

This tension between informal care and ‘population-level’ insurance was brought into sharp focus in debate surrounding the publication by the then Labour

## Getting the ‘offer’ to carers right is therefore likely to be essential as part of any new settlement on long-term care funding...

government of the social care White Paper *Building the National Care Service* in April 2010.<sup>4</sup> This document proposed abolishing the means-test in the publicly funded social care system, with a mandatory levy on estates the most likely source of the new funding required. However, as the Shadow Secretary of State for Health pointed out at the time, this would have had the effect of imposing a tax on the estates of individuals who had been looked after by their families and had never received formal care funded by the state. The carers involved, who may well have given up paid-work to provide care, would have been left facing a double financial ‘hit’ by the imposition of an estate levy.

Viewed this way, public policy toward informal carers will itself actually determine the effectiveness of any settlement for long-term care funding that emerges, by shaping the willingness of individuals to participate. If individuals do prefer to insure against needing care and support by building assets to support their potential family carer – effectively insuring at the ‘household level’ – they may be unwilling to insure at the ‘population level’ through any form of taxation or insurance. Adult children who expect to provide informal care and to give up work to do so may also encourage their elderly parents to keep hold of their savings.

It is in this context that the absence of concrete statements from the government defining what are and are not acceptable outcomes for informal carers potentially undermines household participation in different types of risk-pooling for long-term care. Policymakers must think about informal care policy as one of the major components of a new settlement on long-term care funding.

Put simply, if the ‘offer’ for informal carers in the context of long-term care funding reform is inadequate, households will continue to hoard their wealth and reject participation in any new funding settlement.

This suggests that rather than informal care being merely a parallel policy issue to the challenge of how to fund long-term care, it is at the very heart of the debate. Until the ‘offer’ for carers is sufficient and gives households confidence about their potential experiences as informal carers, including as ‘working-carers’, many people will opt to ‘insure’ at the household level, undermining attempts to forge a new settlement on long-term care funding. Getting the offer on informal care right will be the first step toward reform of long-term care funding.

This raises a question: what ‘offer’ for carers will facilitate and incentivize individuals to contribute to a new long-term care funding settlement? This requires a review of policy to support carers in terms of outcomes, but also in terms of how ‘communicable’ and compelling such policy is to individuals with no knowledge of the care and support system.

For example, the availability of advice and information is known to be crucial to improving carers’ outcomes and has rightly been a key objective for recent informal care policy. However, as a policy to support carers, is this enough to encourage households to release their savings and to contribute to a new long-term care funding system, for example, by accepting a 10% levy on their estate? If individuals are expected to make large financial contributions to a new settlement on long-term care funding, they will want to know what they will ‘get back’, even as informal carers. Policymakers must examine carer’s policy from the point of view of those with no caring responsibilities, as well as from the point of view of carers.

The questions facing policymakers, which this report seeks to address, are therefore:

- ▶ What sort of long-term care funding system and informal care policies will create the right balance between formal and informal care at both the population and household level?

# This means looking at policy to support informal carers through the eyes of someone with no contact with the social care system...

- ▶ How can this framework make up an 'offer' to households that will overcome their aversion to making a financial contribution to insure against the cost of formal care?

For example, there may be aspects of informal care policy that are actually compelling to individuals outside of social care. One example might be a cast-iron guarantee to carer-breaks and having at least one 'day-off' per week. Alternatively, a revamped, up-rated Carer's Allowance reframed as recognition for unpaid caring may be effective. Another approach would be to merge the budgets of social care and carer support, so that individuals know that the framework they pay into will also support them directly as carers, effectively giving individuals the opportunity to insure against the potential costs and burdens that may be associated with becoming an informal carer.

Such policy ideas need to be examined in terms of effectiveness to support carers, but also in terms of giving confidence to individuals and households that they do not need to conserve and protect their savings in case they become providers of informal care. Individuals need to know that they will receive help in providing informal care, and have a clear understanding of what support will be available.

## Toward a new co-production of care

This report therefore seeks to explore these issues and make recommendations for policy on both informal care and long-term care funding.

The next chapter explores the current long-term care funding system and how it interacts with and determines the provision of informal care.

The third chapter reviews policy to support informal carers, encompassing the varied measures involved, such as welfare benefits and rights to flexible working.

The fourth chapter develops and evaluates some potential new approaches to recasting the interaction between formal and informal care, with particular reference to the kinds of measures that would encourage households to go beyond 'insuring' at the household level.

The conclusion highlights key messages for policymakers.

## Key points

- ▶ Potential reforms to the funding of long-term care in England and Wales will determine the volume of formal care provision across the population and - *by definition* – also determine the volume of informal care provided.
- ▶ Households have consistently shown disinterest in pooling the risk of needing formal care, whether via taxation/state, social insurance schemes or private insurance.
- ▶ A key reason that households opt instead to conserve savings and wealth is to effectively 'insure' at the household level. Many would prefer to receive informal care, which they are in fact more likely to receive, and which may impose various financial and other costs on the person providing care.
- ▶ A fundamental challenge in long-term care funding debates is therefore: how to get individuals to pay into a new system they will disqualify themselves from if they receive informal care?
- ▶ This suggests getting the 'offer' of support to informal carers right is therefore essential if a new settlement on long-term care is to be effective, and achieve wide participation and support.
- ▶ This requires ensuring that the balance between formal and informal care in any new long-term care funding settlement is the right one, and ensuring that this is 'communicable' to households.

- ▶ Individuals need to know that they will receive help in providing informal care, and have a clear understanding of what support will be available.

## 2. Long-term Care Funding Policy: Outcomes for Informal Care and Policy

Part of the big picture for potential carers - the long-term care funding system is built around community care assessments, disability benefits and a growing trend toward personalisation...

**Has the UK got the right balance between formal and informal care? Achieving this balance will be essential if individuals are to engage with a new long-term care funding settlement, rather than ‘self-insuring’ at the household level.**

This chapter therefore reviews and evaluates current long-term care funding policy in England and Wales in terms of:

- ▶ The balance between formal and informal care that results;
- ▶ The ‘offer’ to carers it represents.

### Long-term care funding policy in England and Wales

The key features of the long-term care funding system in England and Wales are universal disability benefits, community care assessments used to ration public funding of care, as well as emerging trends in the design of care services toward personalisation. Public funding of care and support could be described as carer-sighted, means-tested, with a poorly functioning system of low-level universal cash entitlements, and a growing trend toward cash-based entitlement to social care funding. At the heart of this system is the community care assessment, which determines entitlement to public support.

### Community care assessments

Local authorities in England and Wales are responsible for assessing people in their area with disability-related needs, and allocating publicly funded support to them on the basis of a *needs*-assessment and *means*-assessment. Public spending on social

care is around £6.37 billion in relation to those aged 18-64 and £7.39 billion in relation to those aged 65+. <sup>5</sup> During 2007-08, around 1.75 million people of working age and older people used different social care services, either provided by their local council or purchased on their behalf from private and voluntary organisations. Of local authority social care expenditure, 59% was on services for older people in 2007-2008, and 22% on adults aged 18-64 with learning disabilities. <sup>6</sup>

Local authority services for those needing care can include:

- ▶ Personal care, such as help with washing, dressing and using the toilet;
- ▶ Practical help such as cooking or cleaning;
- ▶ Aids and equipment;
- ▶ Adaptations to the home;
- ▶ Telecare alarm systems;
- ▶ Meals delivered to the home.

However, reflecting the *Putting People First* and ‘personalisation’ agendas, the government is keen for many users to receive a cash-based Personal Budget rather than services provided or organised by their local authority.

The critical feature of the needs-assessment within community care assessments is that it is ‘carer-sighted’ rather than ‘carer-blind’, i.e. takes account of care provided by informal carers.

Current guidance for local authorities in England for taking account of informal care is contained in: *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care*. Given its importance, it is worthwhile quoting this guidance in full:

- ▶ “Whilst determination of an individual’s need for assistance should take account of the support

## Community care assessments involve a carer-sighted needs-assessment and a means-test to allocate public funding...

which carers, family members, friends and neighbours are willing and able to offer, the determination of presenting needs should identify all community care needs, regardless of whether and how they are being met.

- ▶ If, for example, an individual cannot perform several personal care tasks, but can do so without difficulty with the help of a carer, and the carer is happy to maintain their caring role in this way, both currently and in the longer-term, then it is reasonable to record these as needs on the care plan, but that they are being fully met by the carer.
- ▶ Where an individual has needs and a carer is willing to meet some but not all of these, then the council should provide a response to address those eligible needs, which are those needs not being met by the carer.
- ▶ However, during assessment, no assumptions should be made about the level or quality of support available from carers.
- ▶ Inappropriate assumptions about how much support carers are willing or able to provide can lead to an underestimation of potentially eligible needs.
- ▶ An individual might be supported by a carer but still be eligible for community care services because of the nature of their needs and the level of support that both the individual and the carer require to maintain their independence and well-being.”

In this way, local authorities carry out ‘carer-sighted’ needs assessments for domiciliary care. The key points are that assessments should record all of a person’s needs regardless of whether they are being met by a carer, and that the receipt of informal care does not mean that individuals should not also receive support from the local authority.

Social workers are employed to undertake a skilful assessment of a family’s individual circumstance, with an emphasis on judgement over merely ‘ticking-boxes’.

Entitlement to home care from local authorities is also assessed on the basis of a person’s *means*, i.e. their income and wealth. In relation to means-assessments, the same Department of Health guidance states:

- ▶ “Once an individual’s needs, and those of their carer(s) where appropriate, have been assessed and a decision made about the support to be provided, an assessment of the individual’s ability to pay charges should be carried out promptly, and written information about any charges or contributions payable, and how they have been calculated, should be communicated to the individual.
- ▶ This means that once a person has been identified as having an eligible need, councils should take steps to ensure that those needs are met, regardless of the person’s ability to contribute to the cost of these services.
- ▶ An assessment of the person’s ability to pay for services should therefore only take place after they have been assessed as having eligible needs.
- ▶ A person’s ability to pay should only be used as a reason for not providing services in circumstances where a person has been assessed as needing residential accommodation, the person has the means to pay for it and if the person, or someone close to them, is capable of making the arrangements themselves.”

Critically, a means-assessment must not precede a full needs-assessment; the emphasis in the guidance is on everyone receiving a needs-assessment. However, a 2008 Commission for Social Care Inspection (CSCI) survey found one third of people who failed to get a needs-assessment reported that they were told they did not meet their council’s financial criteria.<sup>7</sup>

Every local authority has different rules on charging for services, particularly related to income. In relation to capital, means-assessments are required to exclude the value of a person’s home.

Although evidence is limited, various studies have found problems with this system on the ground, such as variations in entitlement and implicit rationing...

The upper capital limit is the same as that used for residential care charging, i.e. £23,250. If a person has more than this amount in assessable capital, they may be asked to pay the full cost (up-front or deferred) of any care organised by the local authority, whether via direct provision or through a personal budget. As with residential charging rules, capital of between £14,250 and £23,250 is assumed for the purposes of the means-assessment to provide an income of £1 per week per £250 of capital.<sup>8</sup> Care users can ask that any capital that is 'earmarked' for a specific purpose be disregarded in the means-test, although this is discretionary.

Disability benefits may be taken into account as part of a person's income when local authorities calculate how much to charge someone for any services received; however, the mobility component of DLA cannot be taken account of, and councils should also take account of disability-related expenditure in assessing disability related income.

Given the direction of travel toward personalisation, it is particularly important to be clear about the interaction of charging with the use of personal budgets. If the financial assessment of someone with need shows that the person has enough income or savings to contribute to their personal budget, the council will tell them what the actual contribution might be. A care plan or support plan will then be prepared, setting out how the person wants their needs to be met using their personal budget. The care user may ask the council to arrange all the care and support they need to meet their needs or they may ask the council to let them have the whole amount of the personal budget paid to them as a direct payment. Alternatively, they might decide to have a mixture of the two with some services arranged by the council and some of the personal budget paid as a direct payment. Once the support plan has been completed the council will confirm the amount of any actual contribution that the budget holder may be required to make.<sup>9</sup>

Community care assessments, comprising both needs and means-assessments, ultimately boil down to subjective interpretation of guidance by an individual. The entire framework and the outcomes for those in need are highly dependent on the effectiveness of this assessment system. Research published by the CSCI in 2008 identified that some staff making judgements may be inexperienced, the willingness and ability of carers to provide care may be insufficiently explored, and people may be screened out too early or not given adequate support.<sup>10</sup> Another study for CSCI in 2008, prior to the publication of the most recent Department of Health guidance, identified:<sup>11</sup>

- ▶ A lack of clarity and transparency in practice, particularly related to the complexity of the framework, so neither professionals nor people using services are confident of their understanding.
- ▶ A lack of fairness in the way criteria are applied, due to variations in professional judgements and different approaches taken by councils.

There is a lack of evidence on the application of needs-assessments in practice. Although anecdotal, a response to a CSCI survey provides a flavour of the inconsistency that can result: "Sometimes I have been made to feel that my son's needs are a mix of either not severe enough, too severe or a burden on services. I feel that unless a family is at crisis point then help is not available."<sup>12</sup>

It is particularly important to emphasise that community care assessments are in effect used by local authorities to ration the availability of publicly funded care and support. Any informal care provided therefore intersects directly with the mechanism used to manage budgets and ration demand among local authorities. As such, there is a clear incentive framework confronting local authorities effectively nudging them to overestimate the availability of informal care, in the context of limited budgets and widely-recognised under-funding of the system.

## Disability benefits – Disability Living Allowance and Attendance Allowance - are universal cash payments to those with care and support needs from the Department for Work and Pensions, which may also be used to support a carer...

Evidence of how this incentive structure influences individual assessments is limited, but should be considered in the context of research from CSCI which found that the number of older people using community and residential services has reduced from 867,000 people in 2003 to 827,000 in 2008, despite the population aged 75 and over increasing by 5% during this period.<sup>13</sup>

The system for allocating public funding of long-term care in England and Wales is therefore characterised by a means-assessment and carer-sighted needs-assessment. What are the advantages and problems of this approach?

### Pros

- ▶ *Targeting* – by assessing means, community care assessments ensure that public resources are dedicated to those most in need.
- ▶ *Rations public expenditure* – applying a carer-sighted needs-assessment is considerably cheaper for the Exchequer than a ‘carer-blind’ framework, in which those willing and able to provide care might nevertheless withdraw support.

### Cons

- ▶ *Means-testing* – the application of means-testing is unpopular and causes some to disengage from the system, including some who would be entitled to public support.
- ▶ *Geographical variations* – the interpretation of means and needs-assessments, particularly charging rules, as well as the funding of care and support, vary by local authority.
- ▶ *Subjective assessments* – assessments are reliant on the subjective interpretation of guidance by a single individual.
- ▶ *Carer inertia* – some carers, including those suffering as a result of unpaid care provision, may not realise they are free to withdraw support when the person they care for is entitled to public support.

- ▶ *Rationing of needs-assessment* – as described, there is evidence to suggest that some individuals are excluded from needs-assessments on the basis of quick means-assessments by local authorities, even though all are meant to be entitled to a needs-assessment.
- ▶ *Asset exposure* – wealthier individuals that do not qualify for public support are exposed to having to run-down their wealth.
- ▶ *Potential for gaming* – individuals and their families may ‘game’ the means-assessments by engaging in so-called ‘deliberate deprivation’ of assets.
- ▶ *Rationing through assessments* – community care assessments should take account of informal care that is provided on a sustainable and voluntary basis. However, this assessment still represents a point at which budget-constrained local authorities have to undertake rationing. As such, the incentive structure and budgetary framework facing local authorities may encourage them to overestimate the availability of informal care.

### Disability benefits

The second pillar of long-term care funding in England and Wales is the disability benefits system. Those in need of significant care and support are entitled to one of two disability benefits. Although not earmarked for informal carers, these benefits are relevant to their outcomes. First, as a financial contribution to the household of someone needing care, disability benefits may fund consumption by both carers and those they care for, such as joint ‘living-costs’ (heating, etc.). Second, entitlement to the principal carer’s benefit - Carer’s Allowance - depends on the recipient of informal care claiming disability benefits. Third, as a benefit payment to meet the costs of care, an increase in the value of disability benefits would potentially reduce demand for informal care and the volume of care some informal carers provide.

# Take-up of Attendance Allowance – the disability benefit for the over-65s – is low and correlated with household wealth...

## Disability Living Allowance

Disability Living Allowance (DLA) is a non means-tested, cash benefit payment for children and working-age adults who have a physical disability, mental disability, need help caring for themselves or someone to supervise them, for their own or someone else's safety, or have walking difficulties. DLA is paid to 1.4 million people at a cost to the Exchequer of £5.5bn per year.<sup>14</sup> DLA has two parts called 'components': a 'care component' and a mobility component'. Some people will be entitled to receive just one component; others may get both. The care component and mobility component are paid at different rates depending on how a disability affects a person.

However, in recognition of its complexity, cost to the Exchequer, administrative burden and insensitivity to changes in people's condition, the Department for Work and Pensions (DWP) has recently proposed replacing DLA with a new benefit: the Personal Independent Payment (PIP).<sup>15</sup> Entitlement to PIP will be based on individual assessments of health conditions and impairments, and will also have a Mobility and Daily Living component. The DWP states that a key feature of the PIP will be an objective assessment by independent healthcare professionals, allowing an in-depth analysis of an individual's circumstances. The DWP also suggests that such assessments may be a route by which individuals will access aids and adaptation. In this regard, the PIP will closely resemble Direct Payments in the social care system.

## Attendance Allowance

Attendance Allowance (AA) is a tax-free, non means-tested, cash benefit for people aged 65 or over who need someone to help look after them because they are physically or mentally disabled. It is paid weekly at a higher rate of £71.40 and a lower rate of £47.80. The

benefit is paid by DWP to 2.16 million people aged over 65 at a cost of £7.5bn per year.<sup>16</sup>

Academic research from the Institute for Social & Economic Research (ISER) has found that there is a higher probability and level of receipt of AA among low-income people, reflecting the higher incidence and severity of disability among poorer people and the lower propensity of higher-income people to claim AA in relation to any given level of disability. It is noted that poorer people are more likely to receive higher-rate awards, possibly given a stronger (income) incentive to apply for up-rating of the award as disability worsens over time. Interestingly, being an owner-occupier substantially reduces the probability that someone will claim AA, regardless of disability.<sup>17</sup> Separate research has tentatively concluded that there exists a significant volume (possibly as high as 30%) of un-pursued but potentially successful AA claims.<sup>18</sup> Importantly, distributional analysis has found that any loss of AA (and DLA) would result in a significant loss of income for older households whose incomes in the absence of these benefits would in fact put them in the lower part of the income distribution.<sup>19</sup>

The benefits system in England and Wales therefore distributes very substantial sums to the disabled population. What are the advantages and disadvantages of this framework?

### Pros

- ▶ *Reduce demand for informal care* – as a direct financial contribution toward the costs of care and support, disability benefits reduce the burden on informal carers.
- ▶ *Absence of means-testing* – it is reasonable to assume that the limited amount of means-testing involved in assessing AA (and DLA) applications has a positive effect on take-up.
- ▶ *Control* – as cash benefits, recipients of disability benefits have total control and discretion over how the money is used, and in that sense, these

# Personal Budgets for care users are ideally suited for households to create the right balance and mix of formal and informal care...

benefits embody the principles of the personalisation agenda in social care.

- ▶ *'Accidental' progressivity* – although the low take-up of AA by wealthier households could be seen as representing a policy (implementation) failure, this does have the effect of making the distribution of AA progressive in terms of outcomes: poorer households benefit more.

## Cons

- ▶ *Adequacy* – the value of disability benefits is not sufficient to purchase significant volumes of personal care given the level of need required to claim.
- ▶ *Take-up* – benefits fail to reach all those entitled to them.
- ▶ *Absence of targeting* – where wealthier households do claim AA (and DLA), this could be seen as wasteful given some households may not need the extra financial support.
- ▶ *Use as income-support* – evidence suggests that some households rely on AA for income. While not a problematic outcome in itself, AA was clearly not designed to act a 'sticking-plaster' in this way.

## Personal Budgets and Direct Payments

Finally, it is worth exploring trends in the delivery of funding within the social care system around the use of Personal Budgets and Direct Payments.

Giving care users personal budgets, and therefore direct control over their services, has become a key policy driver in recent years. The government has set the target of 2013 for giving all eligible individuals personal budgets if they wish for them.<sup>20</sup>

A personal budget is the sum of money that a council decides is necessary to spend in order to meet an individual's needs following an assessment. The budget can be allocated as a Direct Payment or the

council can retain direct control of the budget. An increasing number of councils are putting mechanisms in place that offer older people greater choice over the range of options open to them for having and managing the money in their personal budget, including the ability to mix and match between different options.<sup>21</sup>

It is currently not possible for a personal budget to be taken as a Direct Payment to be used to pay for someone's services if they live in the same household, i.e. their informal carer. However, carers in the same household may be getting support in their own right including a direct payment to meet their needs, and there can be a fine line between the person's and the carers needs.

In many ways, personal budgets are ideally suited for individuals to receive a mixture of informal and formal care and support, whether the care provided is complementary or overlapping in nature. When combined with a well functioning local market in care and support services, personal budgets enable households to choose their own services, mould and shape the formal care received according to the priorities, needs and preferences of the informal carer as well as the person care for.

Nevertheless, it is recognised by the government that carers and those receiving care may not in all instances want personal budgets: some remain concerned about money management and the availability of services. Advocacy and brokerage services provided by local authorities and third-sector organizations are likely to have a key role.

However, it is important to explore how Personal Budgets have the potential to change the dynamics around voluntary informal care provision in important ways, when individuals entitled to public support rely on family carers instead.

# However, the growth of cash-for-care public entitlements may result in some informal carers seeing that their support effectively substitutes cash from the state...

Previously, households choosing to provide informal care were merely substituting their time and effort for statutory services, i.e. a family carer vs. one “sent by the council”. However, the advent of Personal Budgets changes the nature and appearance of this choice for households. Among households that may be entitled to public support, their provision of informal care could effectively displace cash payments from the council to the person they care for. From the point of view of a carer, it may even appear that providing informal care will cost the person they care for money in the form of a lower-value Personal Budget. Indeed, some individuals may be able to estimate with some precision how much their provision of informal care will result in a cash-loss to the person they care for. This brings into focus the need for clearer policy statements regarding what is expected of families, what families will receive for effectively saving money for the state.

As such, it is important to think through the advantages of Personal Budgets and Direct Payments in terms of the balance between formal and informal care.

## Pros

- ▶ *Control* – Personal Budgets and Direct Payments, when taken as cash entitlements, give recipients total control and discretion over how the money is used.
- ▶ *Mixing care* – giving users control over their resources, and the opportunity to plan with their families the care they receive, may be particularly effective in helping informal carers define a role they feel comfortable with.

## Cons

- ▶ *Administration* – some recipients of social care, particularly in the older generation, have raised concerns at the administration and responsibility of overseeing a Personal Budget.
- ▶ *Cash substitution for informal care* – as described above, Personal Budgets and Direct Payments may change the equation around informal care provision

where carers see that the care they provide effectively results in a financial loss for those they care for.

## Comment

The previous sections have outlined the long-term care funding system in England and Wales, identifying the key pillars of community care assessments, disability benefits and personalisation.

How does the long-term care funding system in England and Wales determine the balance between formal and informal care at the macro- (population) and micro- (household) level? Is this balance the right one?

The key feature of the system in this regard is the means-test within community care assessments, which effectively creates two types of informal carer:

- ▶ Carers to individuals entitled to local authority support

Subject to the assessment system working effectively, such carers should be willing and able to provide care on a voluntary and sustainable basis, and accept any financial, health and social toll on their life.

- ▶ Carers to individuals *not* entitled to public support

The factors determining participation in unpaid care among this group may be more complex:

- Some may be willing and able to provide informal care.
- Some may provide care because they are afraid to see their relative’s assets run down to pay charges for care – especially given there is no cap on such expenses until individuals

## This system, built around community care assessments, with their assessment of a person's means, effectively creates two types of informal carer...

are reduced to the threshold of entitlement of means-tested local authority funding.

- Some in this group may be in a position to give up paid work to provide care because of their financial resources; research shows that among the 50+, those caring for a parent are significantly wealthier than equivalent non-carers.<sup>22</sup>
- Others, particularly co-resident older carers, may provide care because, in the absence of state support, they see it as their role.
- For some, illiquid assets, a lack of financial advice and understanding, may also be barriers to spending down resources to pay for care. In reality, the situation of carers and care recipients in this situation can be unstable.

As research undertaken for CSCI observed: "People are resourceful and many will manage to put together a patchwork of support using a combination of friends, family and privately purchased services. However, what often characterises these situations is the fragility of arrangements which may break down when they are really needed."<sup>23</sup>

The system of community care assessments is also defined by several other features reflecting how the system may work in practice, rather than in official guidance:

- ▶ Some carers do not know they are free to withdraw the unpaid care they provide.
- ▶ As described above, research from CSCI identified a number of issues around the implementation of community care assessments on the frontline, particularly in relation to workforce and the quality of assessments.
- ▶ Faced with tight budgets, community care assessments are effectively at the frontline of rationing of public expenditure, and some local

authority staff may feel pressured to overestimate the willingness of carers to provide care.

Community care assessments, with their means-assessment and carer-sighted needs-assessments, define the balance of formal and informal care within society more than any other feature of the system. The low means-tested threshold that determines entitlement to public support also determines the extent of informal care among those not entitled to support. In theory, such households would simply run down their savings and wealth until they qualify for public support: this is effectively the rationale underpinning the system. However, the picture is more complex: at least some carers to this group must provide care out of fear of the financial consequences of care having to be paid for out-of-pocket.

As such, the balance of informal and formal care that results from this system reflects the means-testing of support, and the many, varied decisions taken by individual families regarding the care they are able to provide, and the shouldering of the burden this imposes, whether financial, physical, social or psychological. Households that are outside the safety-net of state support are left to make their own arrangements that result in provision of informal care, even when this may impact negatively upon the carer.

The other side of this picture is the disability benefits system. AA and DLA are designed to contribute toward the costs of living with a disability among those with substantial levels of need. In theory, a recipient could use them to purchase formal care, or 'pay' their informal carer. However, there is a significant absence of evidence on how households use disability benefits, and their effect on the balance between formal and informal care. Given poorer households are more likely to claim AA and pursue up-rating claims, it is likely that a substantial number of households use it to fund general household living costs and expenditure.

# The effective ‘offer’ to carers resulting from this system is characterised by rationing, variability and uncertainty...

## Long-term care funding and the offer for carers

What is the ‘offer’ to carers presented by the long-term care funding system in England and Wales, and how is this perceived by those households without any care needs?

The means-tested threshold for public funding of care and support effectively delineates between carers who – in theory – should be providing voluntary and sustainable care, and carers whose drivers for providing care may be more complex. Some in this latter group may have resources such that they are able to support themselves in the caring role, as well as via transfers from the person receiving informal care. But this is an uncertain outcome, and the policy framework is not well suited to delivering one set of outcomes over the other.

Disability benefits, although a contribution to care costs and potentially a cap on demand for informal care, represent an extremely blunt policy tool, and in practice, are affected by problems of take-up, and appear in many households to provide a form of income-support.

For individuals who may anticipate providing care for a parent or partner too wealthy to receive support from the state, the implied ‘message’ is: make your own provision. As described in the Introduction, families may be encouraged by this system to conserve savings and wealth, which can effectively support and ‘fund’ both informal and formal care. Instead of the burden of informal care being limited by the availability of local authority support – so carers can define a role they are willing and able to take – families in this category must make do: the incentive to preserve wealth is clear.

Another feature of the system is *uncertainty*: the availability of local authority support, and any associated charges, will be hard to predict as this is

determined by both political risk – future priorities of local councils – and fiscal risk, i.e. the fiscal outlook and its effect on public spending. The only guaranteed entitlements in this picture are disability benefits; however, as outlined, these benefits do not appear to be functioning well, and the government has recently indicated they are set for a fundamental overhaul.

For individuals whose relative may be more likely to be entitled to local authority support, the ‘offer’ appears more positive. However, local authority social care budgets are under longstanding pressure owing from rising demand, with implicit and explicit rationing the norm. As such, there is a difference between Department of Health guidance for community care assessments, particularly in taking account of informal care, and how this guidance is applied on the frontline. The incentive structure clearly nudges local authorities to rely on informal care to make-up for financial shortfalls, even as this caring ceases to be entirely voluntary and sustainable. More widely, many individuals providing unpaid care to older people and working-age adults do suffer in terms of physical and mental health, and social networks, suggesting that somewhere, the system isn’t working.

However, the design of the long-term care funding system in England and Wales is only one half of the picture. The balance between formal and informal care, and the offer for carers, is also determined by the evolving policy framework for support informal carers, which is explored in the next chapter.

## Key points

- ▶ The key features of the long-term care funding system in England and Wales are universal disability benefits, community care assessment used to ration public funding of care, and emerging trends in the design of care services toward personalisation.

- ▶ The core of this system are local authority administered community care assessments which are carer-sighted needs-assessments accompanied by a means-test.
- ▶ Carers to those entitled to public support should be doing this voluntarily and sustainably. However, this care intersects with the rationing of public funding in the context of an under-resourced system, and there is an incentive for councils to overestimate the provision of informal care. There is evidence of wide variations in the application of guidance by local authorities, implicit and explicit rationing, and a reliance on individual subjective assessments.
- ▶ Carers to those too wealthy to receive public support may do so for a number of reasons, including to protect the assets of those needing care from being run down. Others may lack information about the support services available.
- ▶ Disability benefits are another component of the system, and provide universal low-level universal cash entitlements. However, take-up is variable, and the sums involved are not significant given the levels of need required to claim.
- ▶ The picture is also evolving: Disability Living Allowance is earmarked for reform, and the growing trend toward Personal Budgets in social care may see carers to those entitled to public support becoming increasingly aware that they are substituting cash entitlements, rather than carers “sent by the council.”

# 3. Informal Care Policy: Outcomes for Informal Carers

Informal care policy – developed in successive strategies – includes universal benefits, individual assessments, rights-based protection and measures targeted at the workplace...

**The previous chapter explored how the functioning of public funding of care and support, built around community care assessments and disability benefits, interacted with informal care provision.**

This chapter outlines and evaluates informal care policy and the effective ‘offer’ to carers that it represents.

Like social care policy as a whole, policy on informal carers is the direct responsibility of three government departments: the Department for Work and Pensions (DWP), the Department of Health (DH) and Communities and Local Government (CLG). Given the prevalence of working carers and child-carers, the Department for Education (DE) and Department for Business, Innovation and Skills are also key stakeholders (BIS).

The demographics of informal care

Informal carers are predominantly from older age groups. Nearly half of carers are aged 65 or over, 44% are aged 45-64 and the remaining 7% are aged 18-44. Two-thirds are female.<sup>24</sup>

Within the 50+ age-group, around 10% provide care: around 39% care for a spouse, 35% for a parent (-in-law), 24% for a relative friend or someone else, and 11% for a child. Among the 50+, the large majority (86.5) care for no more than one person.<sup>25</sup>

The ageing of the UK population and increasing longevity are expected to cause an increase in the numbers of individuals needing care and support. If the proportion of disabled older people by age, gender and marital status receiving informal care were to remain constant, academic projections show that the numbers of disabled older people receiving care from spouses or partners will than double between 2005 and 2041,

while the numbers receiving care from their adult children will increase by around 90%.<sup>26</sup> If the probabilities of providing care by age, gender and marital status remain the same in the future, the numbers of people providing care to older parents are projected to increase by 27.5% between 2005 and 2041, from nearly 400,000 in 2005 to around 500,000 in 2041.<sup>27</sup>

Hours of care

Estimates of average hours of care provision vary. The volume of care provided depends on how the recipient is related to the carer and whether care is provided to a fellow household-member. One survey found 57% of carers spent 35 hours or more per week looking after or helping the person they were caring for, 49% spent 50 hours or more caring and 37% of carers spent 100 hours or more per week caring.<sup>28</sup>

Among the over-50s, those caring for a spouse on average provide 105 hours per week; those caring for child(ren) provided 92 hours, while those caring for a parent or parent in-law provided 32 hours on average. Another survey found that the highest proportion (42%) of providers of more than 20 hours of care per week were providing it to a partner.<sup>29</sup>

Unsurprisingly, volume of informal care provision is a key predictor of the impact of unpaid care. Among the 50+ age group, providers of heavy care (20+ hours per week) report a significantly lower quality of life than equivalent non-carers, even when other relevant factors are controlled for.<sup>30</sup>

The monetary value of informal care provision to society

Academic research from the University of Leeds published by Carers UK, a charity representing carers, suggests that the equivalent financial value of unpaid care provision in the UK was £87 billion in 2007.<sup>31</sup> This

# Carer's Allowance is a universal benefit payment to working-age carers of those entitled to disability benefits...

assumes that one hour of informal care is worth the same as one hour of home care provided formally at £14.50 per hour. At least some of the value of this informal care provision represents a direct saving to public expenditure; however, means-testing rules mean that many of those receiving informal care would not be entitled to state support.

## The evolution of carer's policy

The first national strategy for carers was published in 1999, and represented the first really comprehensive attempt to pull together a coherent, coordinated strategic approach to informal carers.<sup>32</sup> In 2010, the Coalition Government published its carers' strategy: *Recognised, valued and supported: Next steps for the Carers Strategy*.<sup>33</sup> However, the overall policy framework is still characterised by contrasting approaches: for example, universal non means-tested financial entitlements combine with subjective individual assessments of carer outcomes.

The key pillars of the policy framework toward informal care can be identified as: welfare benefits; rights-based protection; employment support, and local authority support for carers.

## Carer's Allowance

Carer's Allowance (CA) is a cash benefit paid to 481,000 carers at a rate of £53.90 per week by the DWP. The cost to the Exchequer was around £1.3 billion in 2007-08.<sup>34</sup> To be entitled to CA, carers must:

- ▶ Earn no more than £100 per week after taking off NI contributions, income tax, pension contributions and other expenses necessary to perform a job.
- ▶ Not receive overlapping benefits such as the State Pension – the principle being that individuals cannot be compensated twice for the same lack of a job.

- ▶ Care for at least 35 hours a week for a person receiving Disability Living Allowance Care Component at the middle or highest rate, Attendance Allowance or Constant Attendance Allowance.

Originally 'Invalid Care Allowance', CA was created as one of two earnings replacement benefits – the other was Severe Disability Allowance - aimed at people who were unable to work for legitimate reasons but were not covered by National Insurance related benefits.<sup>35</sup>

The majority of pension-age carers are affected by the overlapping benefit rules because of receipt of the State Pension. Indeed, were it not for receipt of the State Pension, 478,000 more people would be entitled to CA.<sup>36</sup>

Carers on low incomes who satisfy the Carer's Allowance entitlement rules, whether or not they are paid Carer's Allowance, can also receive an additional payment of £27.75 a week, known as a 'Carer Premium' or 'Additional Amount', in their income-related benefits. It is estimated by the DWP that about 469,200 people receive these payments, costing the Exchequer £677 million.

The National Audit Office (NAO) has estimated that carers receiving carers benefits provide care which, if it were provided as formal care paid for by the state, would cost approximately £23 billion a year.<sup>37</sup>

The principal issues with CA relate to:

- ▶ Suitability, i.e. what is CA trying to achieve and how effective is it?
- ▶ Problems with administration and take-up.

## Suitability

As an earnings-replacement benefit, CA is too low to

## But Carer's Allowance is wholly inadequate as an earnings-replacement benefit, notoriously complex, and take-up is low...

realistically provide a replacement income for an average earner, and does very little to reduce the opportunity cost of high-level informal care provision among those of working age with reduced participation in the job market. By not allowing recipients to have earnings of more than £8000 pa. in net income before they lose entitlement to CA, it can reasonably be argued that CA implicitly assumes poverty-level earnings for those combining paid work with caring.

Indeed, academic research suggests that there are 697,000 people who provide more than 35 hours of care per week to people entitled to disability benefits, but these carers are disqualified from CA due to their economic activity.<sup>38</sup> This suggests that faced with a low-income, many individuals opt instead to hold down substantial levels of employment while still also providing 35 hours of care per week. Indeed, this phenomenon and the maintenance of CA at a poverty-level may explain one of the most interesting trends from administrative (government) data on take-up of CA: although the number of individuals receiving AA or DLA more than quadrupled during the last 20 years, despite limited changes in rates of disability or eligibility thresholds, the growth in take-up of CA was far less.<sup>39</sup>

However, there is a contradiction underpinning Carer's Allowance: it can be claimed by someone with sufficient household income and wealth such that they do not need to engage in paid-work, and are therefore able to provide high levels of informal care. In this way, some claimants of CA could be regarded as not actually needing the money, and CA could be described as poorly targeted.

More widely, the gap between allowable income under CA rules and median net weekly earnings in the UK of around £374.41 could be seen as part of the 'protection-gap' affecting many individuals, i.e. the substantial gap between their income, and what they would receive from the state in welfare benefits if

income is lost due to unemployment, ill-health or caring responsibilities. In this sense, considered as a potential policy tool to reduce the *financial impact* of being forced to give up work to provide informal care, CA is insufficient.

As a tool to prevent financial hardship among informal carers, CA is also too low to be effective; as some commentators argue, working-carers must effectively be in poverty to claim it, unless they have other sources of household income. This is significant given CA is designed to function as an earnings-replacement benefit: unlike unemployment benefits, which arguably incentivise paid work by being set at a low level, CA cannot incentivise paid work because some recipients are providing very high levels of care.

In this context, some carers' groups have sought to frame CA as a state-funded financial acknowledgement of the care they provide. However, by assuming a net income of no more than £153.90 per week, the maximum hourly rate - assuming a carer provided no more than 35 hours of care - that this could represent is £4.40 per hour, far below the average hourly cost of domiciliary care, and below the current minimum wage of £5.93.

### Problems with administration and take-up

In terms of feasibility, it is widely recognized that CA is a particularly complex benefit, and uncertainty remains over whether it is actually reaching its target group. Academic analysis of the Family Resources Survey suggests 1.1 million people provide care for more than 35 hours per week, plus a further 0.5 million between 20 and 34 hours. This totals 1.6 million people who might possibly claim CA. However, it is extremely difficult to know how effective CA is in terms of take-up. The most rigorous academic analysis of this question found that for the core group of individuals providing high-levels of care to fellow household

# Carer's Allowance should be considered ripe for reform, and may be swept up in proposed changes to the benefit system...

members, without overlapping benefits, the take-up rate of CA was 65%.<sup>40</sup>

Research by the NAO of CA recipients showed that while the majority did not experience problems making claims, a fifth of recipients did, with issues highlighted providing some potential explanations of low take-up:

- ▶ Some found it hard to understand the Allowance's eligibility criteria and to understand and complete the application form;
- ▶ Others felt applications took too long to process.<sup>41</sup>

As such, problems with take-up of CA may relate to lack of knowledge, complexity of assessment, stigma, as well as fluctuating patterns of care provision (informal care provided for short-periods).

Against such a complicated picture around its design and take-up, what are the advantages and disadvantages of Carer's Allowance?

## Pros

- ▶ *Control* – as a cash payment, carers have autonomy and control over how to spend CA.
- ▶ *Recognition* - provides a financial recognition, paid for by wider society, of the societal contribution represented by unpaid care.

## Cons

- ▶ *Efficacy* – as an earnings-replacement benefit, it is too low to be meaningful.
- ▶ *Adequacy* – effectively assumes that 'working-carers' live in poverty to receive it.
- ▶ *Take-up* – academic evidence suggests that take-up of CA among its core target group is below levels observable for other benefits.
- ▶ *Ineffective targeting* – some working-age individuals who provide care may be able to claim CA precisely because other sources of household income enable them not to work. Older households

who have retired early but deferred receipt of the State Pension may also be able to claim CA.

- ▶ *Complexity* – CA is widely recognised as one of the most complex benefits to claim and be assessed for.
- ▶ *Pass-ported entitlement* – assessment for CA relies on the efficacy of DLA and AA assessment procedures and their take-up by individuals; however, take-up of these benefits among some groups is low. This may be particularly problematic if a recipient of care refuses to claim disability benefits - for example, because of perceived stigma associated with the welfare system - thereby denying their informal carer the opportunity to claim CA.
- ▶ *Inflexibility* – CA is inflexible in assuming that carers are only unable to work if they are providing at least 35 hours of care; as with Carer Credit, a more flexible approach might more explicitly encourage part-time caring and part-time working.
- ▶ *Potential for fraud* - as commentators note,<sup>42</sup> the CA claim form simply asks the carer and the disabled person each to report that at least 35 hours of care is provided, and there is no independent procedure for validating these reports, even though the disabled person receiving care will have had to show they need care throughout the day or supervision during the night, and a main carer is therefore likely to provide care for at least five hours per day.
- ▶ *Concentration of care* – to reduce the prevalence of 'heavy' care provision among carers, it would be desirable for more individuals to be involved in unpaid care provision within family networks, thereby spreading the burden of care; however, by only allowing one person per AA/DLA claimant to claim, CA implicitly encourages families to see informal caring as the responsibility of one person, which the benefits system classifies as "the carer".

# Carers receiving Carer's Allowance have recently become entitled to National Insurance Contributions. The recent Equality Act also gives carers protection from discrimination...

## Comment<sup>43</sup>

It would not be unreasonable to argue that as an earnings-replacement benefit, CA is meaningless. It is also too low to provide 'recognition' of heavy levels of care provision. As a flat-rate entitlement, it is insensitive to variations in the burden that different types of care impose. The fact that entitlement is reliant on care recipients receiving disability benefits may explain why take-up appears to low among the target-group. Even the government's own research on support for informal carers found that many believe CA to be inadequate, the rules around overlapping benefits are unfair and the earnings limit is a disincentive to work.

As such, CA should be considered ripe for a fundamental re-think and overhaul. Some have argued that the revenue from CA would be more effective and better targeted if it were spent by local authorities.

As part of the 'offer' to households regarding the support they will receive if they become a carer, it is clearly inadequate, being only applicable to working-age carers, and among this group, being far too low for many to impact upon decisions around informal care.

## National Insurance Contributions (NICs)

The 2010 social care White Paper - *Building the National Care Service* - introduced into official documents the idea that it should be possible to receive a full basic State Pension based on caring responsibilities.<sup>44</sup>

Since April 2010, for every week that someone receives Carer's Allowance, the person is credited with a National Insurance contribution. In addition, people who provide care for one or more disabled person(s) for a total of 20 hours or more each week, but do not receive Carer's Allowance, are entitled to Carer's

Credit, which also protects NICs. Carers may qualify for Carer's Credit through the disabled person being entitled to a qualifying benefit (the majority of applications) or through a certification route (Care Certificate).

## Pros

- ▶ *Recognition for care* – alongside the cash-payment of Carer's Allowance, NICs contributions and Carer's Credit provides a notional recognition by society of the contribution of unpaid care.

## Cons

- ▶ *Adequacy of State Pension* – the State Pension is inadequate to live on, and those who have no other income in retirement also receive Pension Credit in order to boost their income to an acceptable level. As such, given long-term carers may be unable to make other provisions for retirement, NICs contributions provide only a notional recognition: even without a State Pension, carers would have received Pension Credit anyway, and the fiscal implications of NI credits for carers is therefore small. Mooted reforms to raise the value of the State Pension may change this picture.

## Equality Act

The Equality Act, which came into force in October 2010, provides protection for carers from direct discrimination. As such, all employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities. An example of the Equality Act in practice would be a restaurant not being able to refuse service to a carer who is accompanied by someone with learning difficulties.

At present, there is no case law in existence in relation to carers and the Equality Act. As with the rest of the Act, the real force of the legislation is to provide

# Various policies seek to support carers engaged in paid-work, notably rights to request flexible working...

transparency and clarity regarding what practices are illegal. Given the legal costs of bringing cases and limited availability of support with legal costs, the number of cases brought by individual carers to obtain compensation is like to be small.

## Pros

- ▶ *Protection from discrimination* – provides comprehensive legal protection from discrimination for carers

## Cons

- ▶ *Absence of case law* – at present, there is no case law in relation to carers.
- ▶ *Cost of bringing cases* – individual cases brought under the Equality Act will always be constrained by the cost of bringing cases, particularly following proposals to reduce the availability of legal aid.<sup>45</sup>

## Employment support

As described above, thousands of carers combine caring with paid work. Retaining contact with the workplace for working-age carers ensures the maintenance of skills, provides income as well as a social identity and networks outside of the caring role.

However, combining paid-work with significant levels of unpaid care provision can be particularly challenging to individuals and families. The attitudes and behaviour of employers will be critical in shaping the experiences of employed carers and decisions by carers regarding whether to combine both types of work.

A survey of carers found that among working-age respondents, although 12% cent were in employment and felt supported by their employer, 4% of carers were in employment but did not feel supported. A further 17% were not working because of their caring responsibilities, 6% did not need support from their employer to combine work and caring, and the

remaining 14% were not in employment for other reasons.<sup>46</sup>

A suite of policies have been deployed to support individuals combining paid-work with unpaid caring.

## Right to request flexible working

Most carers now have the legal right to request from their employer the opportunity for flexible working. A fixed procedure is involved in such requests. Flexible working may take the form of movable start and finishing times, job-sharing, compressed hours, as well as working from home. As well as flexible work, carers have the right to take a 'reasonable' amount of time off work to deal with an emergency involving someone they care for.

However the right to request flexible working is not universal, and around 20% are not covered by the existing BIS definition: "carer caring for a spouse, partner, civil partner or relative, or living at the same address as the adult in need of care. 'Relative' includes parents, parent-in-law, adult child, adopted adult child, siblings (including those who are in-laws), uncles, aunts or grandparents and step-relatives". BIS plans to consult in 2011 regarding a possible extension of the right to request to all employees, regardless of circumstance

An employer can refuse the request where one or more of the following grounds apply:

- ▶ Burden of additional costs;
- ▶ Detrimental effect on ability to meet customer demand;
- ▶ Inability to recruit additional staff;
- ▶ Detrimental impact on performance;
- ▶ Insufficient work during the periods the employee proposes to work;
- ▶ Planned structural changes.

## ‘Working-carers’ who do not feel supported by their employer are among those carers with the worst quality of life...

However, employers do have a duty to consider the request, and must demonstrate clearly why it is against the interests of their business to refuse a request.

Flexible working is clearly important to many carers. However, the government’s own 2010 Carer’s Strategy notes that the growth of flexible working has been uneven among different sectors, and that the process of requesting flexible working may not be effective given a sudden onset of caring responsibilities.

### Employer education and awareness

In addition to the legal right for flexible working, various government programmes have sought to raise awareness among employers about the challenges facing carers as well as to share best practice for working arrangements that support carers.

Such measures are important. A survey of working-carers found that those who are in employment as well as carrying out caring roles have the lowest levels of overall quality of life when they do not feel supported by their employer: 28% of this group stated they their lives were either bad, very bad or could not be worse. In contrast, among carers who do feel supported by their employer, 44% and 50% respectively feel their lives are either good, very good or could not be better.<sup>47</sup>

### Job Centre Plus

Since 2009, new practices have been rolled out across the Jobcentre Plus network to help carers combine caring and paid-work, and support carers returning to work through specialist help and re-training. Care Partnership Managers have been appointed in each area to support Personal Advisers and build partnerships with local organisations that can support carers. Provisions are also promised for paid

replacement care for carers undertaking approved training.

### Pros

- ▶ *Growing entitlements* – rights to flexible working have increased in recent years and may be extended again.
- ▶ *Holistic support* – the government has increasingly involved Job Centre Plus in providing more holistic support to working-age carers seeking more flexible or part-time work, or who are returning to the labour market.

### Cons

- ▶ *Persistent employment practices* – cultures and working-practices among some employers remain unsuited to those also providing informal care.
- ▶ *Current outcomes* – surveys of working-carers do reveal a significant proportion who struggle to combine paid work with unpaid caring.

### Comment

Those who are forced to leave the labour market to provide care lose their income, the opportunity to make retirement provision and see their skills wane through lack of contact with the workplace.

However, combining paid work with informal caring responsibilities is a major undertaking. Policy developments of the last decade, such as rights to flexible working, represent major advancements. The incremental process of changing employer attitudes is a necessary shift if society is to cope with the rising demand for care across the population.

As described in the Introduction, those who combine paid work with informal caring – contributing to economic growth while relieving pressure on public resources - may be among those most averse to being compelled to contribute to a new settlement on funding care and support, unless such a settlement relieves

Carers are entitled to ask for an assessment of their needs by the local authority. However, any response from the council is ultimately discretionary, reflecting local political choices...

the burden from them. Such carers may feel they are being expected to contribute twice; through providing unpaid care and through accepting a significant financial contribution to a settlement from their household or family.

### Carer's assessments

Informal carers who provide, or intend to provide, a substantial amount of care on a regular basis have a right to request an assessment by local authorities of their needs *as carers*, independent of the needs of the person they provide care to. Assessments should look at:

- ▶ How the carer feels about their caring role;
- ▶ Whether the carer is coping;
- ▶ Help needed to carry on providing care;
- ▶ Health outcomes;
- ▶ Aspirations and interests

Carers can request assessments independently of whether the person they care for has been assessed by the local authority. In 2006-2007, 198,000 carers aged 18-64 and 189,000 aged 65 and over were offered an assessment. Around one adult in four who received a community service from a local authority in 2006-2007 had a carer who was offered an assessment. Around 178,000 carers received a service following their assessment or review.<sup>48</sup> However, the picture is mixed, and one study found that only 17% of 'new' carers had a carer assessment.<sup>49</sup>

Department of Health guidance advises that carers' assessments have two principal purposes. The first is to consider the sustainability of the caring role. The second is to consider "whether or not the carer works or wishes to work and whether or not the carer is undertaking or wishes to undertake education, training or leisure activity, and the impact that their caring role

might have on these commitments or aspirations."<sup>50</sup> Practice guidance advises adult social care departments to grade the 'extent of risk to the sustainability of the caring role' into one of four categories – namely 'critical, substantial, moderate and low'. These categories are listed in full in the Appendix.

Following an assessment, local authorities have a duty to consider whether or not to provide services to the carer. However – *crucially* – local authorities retain discretion as to whether or not they will in fact provide support to a carer.

Nevertheless, if the sustainability of the caring role is categorized as 'critical', i.e. "vital social support systems and relationships cannot or will not be sustained", this denotes a critical need for the person receiving care, and in this situation, the council is therefore obliged to act, most likely by providing support services to the person needing care. A carer's critical needs may also require the provision of services either to the cared-for person or the carer themselves under the European Convention on Human Rights.

### Pros

- ▶ *Independent entitlement* – carers are entitled to assessments regardless of whether the person they care for has been assessed.
- ▶ *Gateway to support* – assessments may lead to local authority support for carers.
- ▶ *Personalised assessment* – to the extent that services are provided to carers, they follow individual assessments that may enable personalised, tailored support.

### Cons

- ▶ *Take-up* – it is not mandatory for local authorities to undertake carer assessments; carers themselves must usually request them. However, many carers are not aware of this right.

# The design of local services to support carers has advanced significantly in the last ten years, particularly at the intersection of health and social care...

- ▶ *Absence of follow-up* – although carers can request an assessment, local authorities have no statutory obligation for either following up the assessment with services, nor for the outcomes of carers.
- ▶ *Subjective* – assessments ultimately come down to subjective interpretations of official guidance.
- ▶ *Geographical variations* – given the role for local discretion, geographical variations exist in the rates of carers' assessments and whether these assessments result in services to carers.

## Comment

In historic terms, carers' assessments – an individual assessment by the state of how someone is coping in their caring role - are a relatively new innovation. In theory, a carer's assessment could result in a precise, personalised assessment of a carer's needs and aspirations leading to appropriate and personally tailored support that helps them in their caring role. However, local authorities are not obliged to undertake assessments, inform carers of their right to request them, nor follow up an assessment with the provision of services to the carer or the person receiving care. In this context, various changes could be conceived, such as making carers' assessments mandatory and giving local authorities statutory responsibility for carers' outcomes.

## Services, support and innovation

Carers and those they care for may use a range of support services whether provided directly by a public body, or from third- or private-sector providers. Services may be of benefit to both carers and the person they care for, and not just by providing relief for a carer.

In terms of publicly-provided services, of particular interest are the 25 National Carers Strategy Demonstrator Sites, which are exploring the ways in

which the NHS can provide better support to carers, support breaks, as well as testing the efficacy of health and well-being checks focusing on carers.

The most common type of support or service used by carers is information and advice, with 56% of carers using this service. Around 30% of carers get support from carers groups or an adviser, while 6% of carers report receiving training for their caring role. A recent survey of carers found that 54% were either extremely or very satisfied with the support or services they and the person they cared for had received in the last 12 months from social services; a further 29% said they were fairly satisfied, 9% were neither satisfied or dissatisfied and the remaining 8% were either extremely, very or fairly dissatisfied.<sup>51</sup> There is evidence to suggest satisfaction is higher among carers caring for people with certain conditions (dementia, longstanding illness) than those caring for individuals with mental health problems or learning disabilities.<sup>52</sup>

The government's own research with carers into priority areas has also identified that carers:<sup>53</sup>

- ▶ Need better and timely access to information;
- ▶ Can often feel excluded by clinicians;
- ▶ Find accessing assessments overly bureaucratic and slow;
- ▶ Often feel forced to give up work to care;
- ▶ Need breaks from caring in order to sustain their role as a carer.

It is worthwhile identifying and exploring some of the key types of services and support that have developed and become a focus of policy in recent years.

## Information and advice

The provision of information and advice to carers has been found to be of such importance in successive consultations that it has taken on the status of being

## Local support services can include information and advice, breaks, and telecare...

an independent measure to support carers. This is because many informal carers may be caring for the first time, and as such, many need information on employment rights, benefit entitlements, local authority support as well as the services available to them from third- and private-sector providers of care and support services.

Local authorities and charities typically run information and advice services, with local authorities retaining an oversight role. In a survey of carers, around a quarter reported that they found it very easy to find the information and advice they needed, half stated they found it fairly easy to get this information, but 19% found it fairly difficult and 7% found it very difficult. Most information received by carers is felt to be useful, although a very small minority (8%) feel the information they received was unhelpful.<sup>54</sup>

### Breaks

A key measure to support carers is the provision of breaks by local authorities, whether short one-day breaks or longer breaks that enable a carer to take a holiday.

However, the use of breaks is not universal among carers, for a variety of reasons. A survey of carers found that 29% were using support or services to enable them to take a break lasting longer than 24 hours and 35% took shorter breaks lasting less than 24 hours. But, for longer breaks, 16% were not using breaks because they were not available, a further 6% were not using breaks because they did not feel the services available were suitable, and the remaining 48% were not doing so for other reasons. In relation to shorter breaks, 15% of carers reported they were not available, around 5% were not using breaks because they did not feel the services available were suitable and the remaining 46% were not using breaks for other reasons, potentially including the provision of support from other family members.<sup>55</sup>

Recognising difficulties around the design of break provision, in particular, 'one-size-fits-all' provision such as a sitting service, the government's carers strategy highlights that the majority of carers who had experienced a good break had it organised them themselves using direct payments.<sup>56</sup> Innovations such as "Book your own break" services seek to provide a more personalized provision of breaks for carers.

### Telecare and telehealth

Telecare and telehealth are devices and services used in social care to enable individuals to live independently, reduce hospital appointments and enable remote oversight of some vulnerable individuals. The government has recognised the potential of telecare and telehealth to help informal carers, particularly in providing care while engaging in paid employment.<sup>57</sup> Some local authorities offer telecare and telehealth services to carers, while others signpost where such services can be accessed privately, and it is expected that this form of technology will play a growing role in supporting carers in future.

### Whole-family approach

The 2010 Carer's Strategy promoted a 'whole-family approach' in needs assessment and service design for households providing informal care. It argued that "a whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes, is much more likely to result in individual care packages that can be sustained effectively."<sup>58</sup> This approach is particularly felt to be appropriate when carers provide care for more than one person, and for carers that are non co-resident.

### Carer-designed services

The government has recently argued that carers and the people they support "should have the opportunity

Overall, despite increased rights for carers, the current ‘offer’ to carers is characterised by variability of support services, a poorly functioning benefits system and an uncertain experience for those mixing paid work and caring...

to play active roles in the design, development, delivery and review of innovative and personalized care and support arrangements in order to maximise choice and independence and to utilize the widest range of resources. Co-production with carers should be integral to the delivery of all care services.”<sup>59</sup>

#### Personal Budgets for Carers

A recent extension of Personal Budgets has been to give some carers who receive support from local authorities their own personal budget to buy services that support them in their caring role, besides simply procuring more support.

#### Comment

Policy to support informal carers has evolved enormously in the last decade, since the publication of the first Carer’s Strategy, and now encompasses Carer’s Allowance, rights to flexible working, protection from discrimination, rights to carer’s assessments and a growing range of new and innovative support services for carers.

This policy framework does not determine the balance of informal and formal care at a population- and household-level, but does support carers and may influence decisions around how much informal care to provide. Informal care policy enables care, and maintains the outcomes of carers, rather than seeking to explicitly cap or boost the volume of informal care provision within society. There is no data available that tracks how the outcomes of informal carers have changed over the last decade. However, recent cross-sectional surveys have found, for example, good levels of satisfaction with services such as respite care.

Nevertheless, considered as an ‘offer’ to carers and – importantly – from the perspective of those who don’t

provide informal care but may do so in the future, what are the key characteristics of informal care policy?

- ▶ Carer’s Allowance is effectively meaningless to most households: pensioners cannot claim it and working-age individuals looking ahead to high levels of care provision would consider it far too low to help them, and would exclude it from their decision-making.
- ▶ Carer’s Assessments represent an important innovation – the right for carers to be requested for their own needs – however, they are discretionary. They create little obligation on local authorities, particularly in the context of tight budgets and rationing, to address carers’ needs.
- ▶ Local support services are improving and being refined through repeated cycles of policy design, piloting, evaluation and implementation. However, there is variability in the level and form of services available among local authorities. As such, few anticipating informal care provision in the future would be likely to assume that they can rely on support services from the local authority in providing unpaid care; the availability of such services will depend on the choices and priorities of local authorities and the wider fiscal conditions framing public spending.
- ▶ Employment support and rights to flexible working have improved the experience of many combining paid work with unpaid care. However, employer behaviour is variable, and policy is limited in the guarantees it can make to those who may have to provide informal care while remaining in the labour market.

#### Key Points

- ▶ Informal care policy comprises welfare benefits (Carer’s Allowance), NICs contributions, protection from discrimination, rights to flexible working, the right to request a Carer’s Assessment, measures to

encourage supportive employers, and an evolving range of local services seeking to support informal care, such as information and advice, respite care and health checks.

- ▶ On various measures, this policy framework is helping many informal carers, for example, by compelling employers to be flexible around the needs of employed carers. However, some elements of this framework fall short.
- ▶ Carer's Allowance is effectively meaningless as an earnings-replacement benefit: it assumes poverty-level earnings, take-up is low even among those entitled, and it appears many individuals opt to disqualify themselves through paid work, shouldering heavy levels of care provision with paid work.
- ▶ Carer's Assessments by local authorities are a valuable innovation, but their application, and any associated support, remain at the discretion of budget-constrained local authorities.
- ▶ Overall, the policy framework offers little certainty to those contemplating a future involving providing informal care to a partner or relative.

## 4. Creating a New Offer for Carers

The current ‘offer’ for carers features divergent sources of support, means-testing, unpredictability and local variations, all of which encourage households to ‘insure’ by conserving their savings and wealth...

### **The previous chapters have examined the long-term care funding system in England and Wales, and the evolving policy framework to support informal carers.**

Despite progress in advancing the rights of carers - flexible work and innovation in the design of carer support services - viewed from the perspective of the long-term care funding debate, the choices presented to prospective informal carers are not compelling. The associated ‘offer’ to informal carers is defined by variable and ultimately unpredictable local authority support, and poorly targeted and inadequate benefit payments. Crucially, even policy interventions with proven effectiveness for carer outcomes, such as information and services, and telecare, are unlikely to be enough to overcome the tendency for households to ‘insure’ against the risk of informal care provision by conserving savings and wealth.

This chapter explores what could be changed in this picture, particularly if allied to fundamental reform of long-term care funding, with the potential for new funding to be directed at supporting the outcomes of carers. The chapter does not propose fundamental changes to many existing policies seeking to support carers: within the budgetary and other constraints confronting policymakers, there is little that would be changed around equality protection, rights to request flexible working and the ongoing design, piloting and evaluation of locally-delivered measures to support carers. In particular, getting the offer to ‘working-carers’ right is likely to be key given the anxiety many people feel about the implications of having to withdraw from paid work to provide care. However, besides moving further and faster, and better communicating the rights of working-carers, there is no obvious new approach that could be applied to specifically support working-carers.

Instead, building on current policy frameworks, and the ‘infrastructure’ provided by elements such as Carer’s

Assessments and Personal Budgets, this chapter explores ideas that might fundamentally improve the offer to carers in England and Wales in a way relevant to achieving participation in a new settlement on the funding of care and support.

In order to think about a new ‘offer’ on informal care, it is first worthwhile characterising the offer to carers represented by the overall framework of current long-term funding and informal care policy.

#### Divergent sources of support

- ▶ Public spending to support carers and those they care for is spread across three government departments: the Department for Work and Pensions (DWP), Department of Health (DH) and Communities and Local Government (CLG), resulting in divergent sources of support that carers themselves have to join together.

#### Means-testing creates more pressure on carers in wealthier households

- ▶ Carers of individuals entitled to public support can – in theory - care voluntarily: local authority needs-assessments will look at whether informal care provided is sustainable.
- ▶ For households too wealthy to qualify for public support, although some informal care may be entirely voluntary, some carers may feel pressured – carers may be afraid of seeing a family members forced to run down their wealth in order to pay for care.

#### Rationing and uncertainty

- ▶ The range of locally coordinated carer support services has leapt forward in the last decade. However, support of carers and those with disabilities is discretionary, varies by local authority

# A new balance between formal and informal care could be conceived of in multiple ways...

and ultimately relies on an individual's subjective interpretation of local entitlement criteria.

- ▶ All carers are entitled to an assessment – but the response of local authorities is discretionary and therefore unpredictable.
- ▶ Local government spending on care and support, including for carers, may be cut as part of public spending squeezes and cannot be relied upon in the long-term.

## Informal care intersects directly with the rationing of public resources

- ▶ Local authorities have limited budgets and have to ration the support they provide. However, informal care intersects right at this 'pressure point' in the system: faced with under-resourced budgets, local authorities confront an incentive structure that may sometimes nudge them to overestimate the availability of informal care in a household.

## Poorly-performing universal entitlements

- ▶ Care-related benefits – CA, DLA, AA – fail to meet their objectives, are poorly targeted and experience low take-up.

## Cash for care

- ▶ Personalisation is transforming the experiences of many people with care and support needs. However, personal budgets and direct payments may see carers increasingly aware that the care they provide results in a financial loss to the person they care for, potentially undermining the motivation to provide care, and exposing policymakers to the accusation exploiting carers.

In this context, any household facing up to a future potentially involving informal care provision would clearly be incentivised to retain assets and wealth within the household, rather than participating in any

'population-level' risk-pooling against the costs of formal care.

In this way, the balance between formal and informal care, and the offer for carers, inevitably defines the potential success of long-term care funding reform. This may be particularly true of long-term care funding models that invite individuals to focus their resources on one of the associated risks associated with social care, for example, residential care 'hotel-costs', while ignoring other risks, such as the risk of being expected to provide very high levels of informal care. From the point of view of households, there are a bundle of risks associated with the onset of care needs in the household, and these include the potential negative effects of high levels of informal care provision, as well the potential costs associated with various types of formal care.

## What should be the balance between informal and formal care?

By creating a situation in which many households appear incentivised to only pool risk at the 'household-level', leaving them exposed to pay for formal care, it appears current care funding and informal care policy frameworks are failing to achieve an appropriate balance between formal and informal care.

Besides incentivising greater risk-pooling against the potential costs of formal care, how else can an appropriate balance between informal and formal care be characterised?

- ▶ A *public spending* perspective would be that the cost savings to the state of informal care provision should be equivalent or more than the cost of policy to support carers, as well as healthcare to carers made ill, means-tested benefits for those left in poverty by informal caring, etc. On this approach, transferring as many costs of meeting the demand

However, unpredictable and uncontrollable variations in the outcomes experienced by carers make it difficult for policymakers to specify precisely what the balance of formal and informal care should be...

for care in society to households makes sense: this leaves greater scope for (limited) tax revenue to be allocated to other things.

- ▶ A purely *normative* perspective would limit the burden on carers to reflect common expectations across the population as to what is an acceptable burden and outcome of informal care, for example, specifying precisely how much families should have to contribute in time, effort and associated financial costs.
- ▶ A *role-based* perspective might focus on the nature of the caring role for carers, particularly as this is determined by the needs of the person receiving care. On this perspective, low-level and general support – cooking, cleaning – might be the responsibility of families, with the state/formal care providing more intensive and specialised care. In effect, social protection would protect individuals from the most challenging of informal caring roles.
- ▶ A *limited-liability* approach might seek to cap the burden of informal caring, whether in terms of financial cost, duration of care, etc.
- ▶ A *rights-based* approach might create a balance between informal and formal care by asserting the rights of informal carers, not just to protection from discrimination – as laid out by the Equality Act - but to have the opportunities and capabilities associated with non-carers.

However, while different perspectives on the balance of formal and informal care at the macro- and micro-level can be identified and discussed, the implications for policymakers and policy design are limited by the practical feasibility of what can be achieved across different households. This is particularly true given:

- ▶ The impact of informal care on a carer varies by the characteristics of the recipient. For example,

research has found that caring for someone with dementia is associated with a significantly lower quality of life than caring for someone with a longstanding physical illness or condition.<sup>60</sup>

- ▶ The impact of informal care on a carer varies according to the financial, psychological, physical, and social 'capital' that carers can bring to the caring role, which varies enormously across the population of unpaid carers.
- ▶ The impact of informal care depends on the behaviour of a range of other actors, notably employers of 'working-carers' and other family members.

For these reasons, despite the considerable literature that exists on care as a responsibility of families vs. the state, in terms of policy design and outcome, the balance of formal and informal care that is the objective of policy may be driven by the practical limitations of what policy can achieve. Indeed, conceived in terms of an individual's carer's outcomes, it is not clear that policy can specify a delineated set of outcomes that would represent an appropriate balance of informal and formal care, and an appropriate reliance on family care by society. Indeed, arguably policy would not want to specify such outcomes: the outcomes that people value are subjective, and it is not for policymakers to dictate what a person should find important.

#### **What would be desirable for a new 'offer' to carers?**

Nevertheless, as described in the Introduction, it appears that households reject participation in risk-pooling mechanisms – taxation, social insurance, private sector insurance – in relation to long-term care, and instead opt to conserve wealth, potentially to support informal care provision. Any new settlement on

Nevertheless, a new ‘offer’ to carers, in contrast to the current system, should be communicable, value-for-money, guaranteed, provide something-for-something and recognition for caring...

long-term care funding reform therefore needs to incorporate an improved balance between informal and formal care and an associated ‘offer’ for carers that overcomes the inclination to ‘insure’ purely at a household level.

In light of the characteristics of the current system, in terms of the ‘offer’ to carers it represents, and given the difficulties in specifying and achieving a particular balance between formal and informal care, what would be desirable characteristics of a new offer to carers?

▶ Communicable

The offer should be understandable and communicable to those who have had no contact with social care. The offer needs to take the form of a ‘currency’ that people can relate to such as: money, time and the type of care provided (bathing, shopping, cooking, etc.).

▶ Value-for-money

At present, much support for carers, such as the provision of information and advice, would be unlikely to encourage individuals to contribute financially to a new long-term care funding system, for example via a 10% estate charge. An offer to carers therefore needs to be high-impact, tangible and to appear to represent ‘value-for-money’ to those with no experience of the social care system.

▶ Guaranteed

The offer should give individuals guarantees about what will be on offer and when as part of the ‘care-journey’, and not over-expose them to ‘political-risk’ – that local and national politicians will decide to spend money on other things – and ‘fiscal-risk’ – that public spending will not be able to afford to support carers when a person comes to need support.

▶ Something for something

Financial contributions should, as much as possible result in something back, including when individuals do not actually receive publicly funded care and support. Having paid into a new settlement, if someone becomes an informal carer, they should also receive something back to support them and in recognition of their unpaid work.

▶ Recognition for caring

Where care is unpaid, it would be desirable for this to be subject to formal recognition, for example, through an unrestricted universal payment.

▶ Personalised

Personalised support for carers enabling choice and control is likely to result in better outcomes. It would also not be tenable for personalisation in informal care not to keep pace with the progress of personalisation in formal care and support services, even as this potentially makes it more difficult to construct an offer around fixed, defined guarantees for individual carers given the drive toward personalised solutions.

### **The policy toolkit for a new co-production of care**

The previous chapters described the frameworks for long-term care funding and informal care policy. Before looking at alternative ways of defining and framing an offer to carers, it is worthwhile identifying the existing ‘toolkit’ available to policymakers:

▶ Community care assessments

Local authorities routinely assess individuals against pre-defined criteria of need and risk. This is significant because the net of care users given

## Multiple ideas for a new offer to carers can be developed building on the infrastructure of the current system: community care assessments, needs assessments and Personal Budgets...

community care assessments could be expanded, even if they do not receive public support, as part of a process to assess the role and support requirements of an informal carer.

### ▶ Carer assessments

Local authorities now have experience of identifying and assessing informal carers in relation to multiple criteria.

### ▶ Personal Budgets

The use of Personal Budgets by recipients and providers of informal care creates greater scope for choice and control. Importantly, Personal Budgets create scope to give individuals resources while ensuring their use is restricted, i.e. spent on care and support.

It is also worth highlighting some wider potential systemic changes which long-term care funding debate has explored, and which has featured in previous government publications:

### ▶ The transfer of care-related benefits into the social care funding system.

Some commentators continue to argue that relevant benefits, including Disability Living Allowance, Attendance Allowance and Carer's Allowance, should be re-directed from the DWP to the social care system, while remaining as 'cash' entitlements delivered via Personal Budgets. Such a change would save on administration, enable improved targeting and coordination.

### ▶ The application of nationally consistent assessments for needs, means and a national scale of entitlement.

Various publications, for example, CSCI's assessment of the application of community care assessments by local authorities and the previous Labour government's social care White Paper, have made this proposal.<sup>61</sup>

### Creating a new offer for carers: toward a new co-production of care

The rest of this chapter outlines and evaluates different ideas for creating a new offer for carers that would result in a new co-production of care. Some ideas represent small changes to current carer's policy; others involve a fundamental overhaul to the entire long-term care funding system in England and Wales.

The ideas developed in this chapter are summarised below. The next chapters draws together some of these approaches to create a proposed new offer for carers.

<b>Changes to Carer's Allowance</b>	
<b>Raise the value of Carer's Allowance</b>	Raise the value of Carer's Allowance to £90.44.
<b>Raise the earnings-limit on Carer's Allowance</b>	Net-income cap determining eligibility to Carer's Allowance increased to £136.54.
<b>Index the value of Carer's Allowance</b>	To ensure it is meaningful as an earnings-replacement benefit, up-rate the value of CA and then index it to changes in average earnings.
<b>Remove State Pension from list of over-lapping benefits for Carer's Allowance</b>	Receipt of State Pension no longer a bar to receipt of Carer's Allowance.

These ideas could involve changes to Carer’s Allowance, carer’s benefits directed to the social care system, broader changes to the social care system, measures to limit the impact of informal care and measures that seek to create a new balance of formal and informal care...

<b>Social care benefits for informal care</b>	
<b>Flexible Carer’s Allowance administered by local authorities</b>	In conjunction with mandatory carer’s assessments (see below), local authorities become responsible for administering Carer’s Allowance in the form of a Direct Payment or a Personal Budget for carers.
<b>Carer-needs related universal entitlement: Carer Budget</b>	Replace Carer’s Allowance with a non means-tested all-age universal entitlement based on a local authority assessment of need, and distributed by local authorities.
<b>Care-needs universal entitlement: “Family Care Credit”</b>	Carer’s Allowance is replaced with a “Family Care Credit”, with the value determined directly by the volume of informal care provided.
<b>Changes to the social care system</b>	
<b>National assessment and entitlement criteria for local authority support</b>	Arbitrary geographical variations in local authority support to those in need of care and support replaced by nationally consistent assessment and entitlement.
<b>Mandatory carer’s assessments</b>	Local authorities given a statutory duty to offer a carer’s assessment to every carer known to them, rather than relying on carers’ making a request.
<b>Personal Budgets payable to Family Carers</b>	Individuals in receipt of Personal Budgets entitled to use them to pay their informal carer.
<b>Nationally consistent levels of</b>	Arbitrary geographical variations in local authority support to carers replaced by

<b>carer support</b>	nationally consistent assessment and entitlement, enabling portability of entitlements, and working-age carers to move home without fear of losing support.
<b>Limiting the impact of informal care</b>	
<b>Age limits on informal care</b>	Cap the age-range within which individuals are expected by society to provide informal care to 16-75.
<b>Weekly time-caps on informal caring</b>	Regardless of the nature of informal care provision and its impact on a carer, a cap is put in place on the amount of care that any carer has to provide of 60 hours per week.
<b>Universal one-day respite for carers</b>	All individuals requiring some amount of care on a daily basis are given funding for at least one day’s worth of care, regardless of their means, so that every informal carer is guaranteed one day-off per week.
<b>Cap the duration of informal care in retirement</b>	Cap the duration of heavy care (35+ hours per week) that retired informal carers have to provide to no more than two years.
<b>Creating a new balance of formal and informal care</b>	
<b>Abolish the means-test in community care assessments</b>	Local authorities no longer undertake means-testing in relation to community care assessments.
<b>Carer-blind ‘Partnership’ model</b>	A ‘carer-blind’ version of the ‘Partnership model’ proposed by the Wanless Review of Social Care, <sup>62</sup> in which all households would get a

	minimum level of public support regardless of informal care provision, and matching contributions encourage households to ration demand on the basis of resources <i>and</i> availability of informal care.
<b>'Matching care contributions'</b>	Where informal care is provided by households, any private out-of-pocket care purchased receives a matching contribution from the state, with the generosity of the matching ratio – 4:1, 3:1, 2:1 etc. – proportional to the percentage of a person's needs met through the informal care provided.
<b>Insuring against informal care</b>	
<b>Merged revenue streams via a national care fund</b>	Public spending on care and support for informal carers, as well as new contributions from households, all routed via a single national financing vehicle.

## Changes to Carer's Allowance

### Raise the value of Carer's Allowance

*Summary:* Raise the value of Carer's Allowance to £90.44.

*Why?* Someone earning the National Minimum Wage of £5.93 per hour working a 37.5 hour week has gross annual pay of £11,563.50, which equals net weekly earnings of £190.44. Increasing the value of Carer's Allowance to £90.44 would at least imply that a carer achieved National Minimum Wage equivalent income under current CA entitlement rules.

### *Pros*

- ▶ *Carer income* – enabling carers to earn more would directly benefit the outcomes of carers.
- ▶ *Take-up* – increasing the value of CA may improve take-up rates.

### *Cons*

- ▶ *Cost* – increase in cost of CA to Exchequer of around £18 million.
- ▶ *Targeting* – some of those who would benefit would not need the extra allowance.

### Raise the earnings-limit on Carer's Allowance

*Summary:* Net-income cap determining eligibility to Carer's Allowance increased to £136.54.

*Why?* Individuals providing at least 35 hours of care per week are not unemployed and Carer's Allowance lacks a meaningful rationale. Everyone providing 35 hours or more of care per week while also working should at least be able to have an income equivalent to the minimum wage.

*How would it work?* A worker on £5.93 per hour doing a 37.5 hour week has gross annual pay of £11,563.50, which equals net weekly earnings of £190.44. Assuming Carer's Allowance is £53.90, raising the income-cap on Carer's Allowance to £136.54 would see individuals combining paid work with high levels of care receiving an income at least equivalent to the minimum wage.

### *Pros*

- ▶ *Carer income* – enabling carers to earn more would directly benefit the outcomes of carers.
- ▶ *Public expenditure* – raising the earnings cap would not cost the government anything, and in fact, would increase GDP by increasing the volume of paid work.

#### Cons

- ▶ None.

#### Index the value of Carer's Allowance to average earnings

*Summary:* To ensure it is meaningful as an earnings-replacement benefit, up-rate the value of CA and then index it to changes in average earnings.

*Why?* To have a clear purpose, CA must be meaningful as an earnings-replacement benefit to the average earner. Indexing the value of CA to average earnings would help to achieve this.

#### Pros

- ▶ *Rationale for CA* – as the only earnings-replacement benefit under which individuals do actually provide (unpaid) work, the rationale for CA would be bolstered if its value was tied directly to changes in average earnings.

#### Cons

- ▶ *Cost* – expensive at a time of public spending cuts.

#### Remove State Pension from list of over-lapping benefits for Carer's Allowance

*Summary:* Receipt of State Pension no longer a bar to receipt of Carer's Allowance.

*Why?* Individuals providing at least 35 hours of care per week are not retired from meaningful work and should be supported. Might be a quick and simple mechanism for making any reform of long-term care funding more attractive to older people.

*How would it work?* Amending the current criteria on claiming Carer's Allowance would be straightforward.

#### Pros

- ▶ *Take-up* – extra incentive for older households to claim Attendance Allowance by enabling their carers to claim Carer's Allowance.
- ▶ *Support* – would support pensioners whose retirement is dominated by the provision of informal care.

#### Cons

- ▶ *Cost* – expensive at a time of public spending austerity.
- ▶ *Targeting* – some older households would not need the extra support.

#### Social care benefits for informal care

These potential reforms would see the role of universal cash allowances for carers, as well as public spending on Carer's Allowance, redirected to the social care system.

#### Flexible Carer's Allowance administered by local authorities

*Summary:* In conjunction with mandatory carer's assessments (see below), local authorities become responsible for administering Carer's Allowance in the form of a Direct Payment or a Personal Budget for carers, with entitlement criteria remaining broadly the same.

*Why?* Carer's Allowance is overly complex, take-up is low and dependent on the DLA/AA assessment system. Retaining CA in its current form, but transferring administration to local authorities would provide an incentive to individuals to make themselves known to local authorities, and avoids any stigma associated with the welfare system. Using Carer's Assessments undertaken by local authorities would represent an improvement on the current system of

asking CA claimants on a form how much care they provide, which is potentially open to abuse.

*How would it work?* Local authorities would allocate CA revenues to working-age carers on the basis of Carer's Assessments of carer-need, hours of care, and their participation in the labour market.

#### *Pros*

- ▶ *Take-up* – receipt of Flexible Carer's Allowance would not rely on the person cared-for claiming DLA or AA, which evidence shows can be patchy.
- ▶ *Self-identification* – gives carers an extra incentive to make themselves known to local authorities and be subject to a Carer's Assessment, thereby connecting them with support services, such as information and advice.
- ▶ *Flexible* – enabling local authorities to allocate CA revenues on the basis of an individual Carer's Assessment will enable the benefit to much more closely reflect the needs and situation of individual carers.

#### *Cons*

- ▶ *Potential diversion of funds* - unless strongly ring-fenced, local authorities may re-allocate revenues to other parts of their social budgets.

#### Carer-needs related universal entitlement: "Carer Budget"

*Summary:* Replace Carer's Allowance with a non means-tested all-age universal entitlement based on a local authority assessment of carer need, and distributed by local authorities.

*Why?* Carer's Allowance is an extremely blunt tool for supporting carers, taking no account of variation in need among carers, or the type or nature of care provided.

*How would it work?* Local authorities would distribute revenue currently spent on Carer's Allowance directly to carers following an assessment of need. This support could be provided in the form of a Direct Payment or Personal Budget so that carers retain control over how the money is spent.

#### *Pros*

- ▶ *Support for carers* – would align existing public spending on carers to the ability of local authorities to help carers plan how best to spend their money.
- ▶ *Targeted* – local authorities would be able to target support on those most in need, unlike CA.
- ▶ *Recognition* – a better value-statement and 'recognition' for unpaid carers than current CA.
- ▶ *Multiple carers* – could be allocated to more than one carer, thereby encouraging families to spread the burden of care, unlike current CA.

#### *Cons*

- ▶ *Targeting* – absence of means-testing may see some claiming support without need.

#### Care-needs universal entitlement: "Family Care Credit"

*Summary:* Carer's Allowance is replaced with a "Family Care Credit", with the value determined directly by the volume of informal care provided.

*Why?* Carer's Allowance is a 'cliff-edge' benefit: it assumes that individuals providing 34 hours of care per week do not deserve support, but those providing 35 hours do. A new benefit more closely determined by the volume of care provided relative to the need of the recipient would be preferable.

*How would it work?* With local authorities mandated to offer community care assessments to all, regardless of means, it would be possible to identify precisely how much informal carers were contributing, and to distribute a universal cash entitlement on this basis.

### Pros

- ▶ *Recognition* – the level of cash entitlement carers received would be much more closely aligned to the volume of care they provide.

### Cons

- ▶ *Inadequate compensation* – assuming the value of Family Care Credit was below the market rate for paid personal care, families may object to what might appear to be inadequate and insulting compensation.
- ▶ *Absence of targeting* – in the absence of a means-test, some individuals would receive Family Care Credit who had no need for the extra income.

## Changes to the social care system

### National assessment, entitlement and funding for publicly funded care and support

*Summary:* Arbitrary geographical variations in local authority support to those in need of care and support replaced by nationally consistent assessment and entitlement.

*Why?* Families need predictability to be able to know what support they will receive in the future. Current system of local authority discretion results in too much implicit rationing and unpredictable variability. Within this system, informal care provision intersects directly with the mechanisms used to ration public spending on care and support.

*How would it work?* A national scale of need and entitlement would be applied by local authorities, with levels of funding determined at a national level, removing the scope for current problems around variation and unpredictability in support.

### Pros

- ▶ *Portability of entitlement* – those in receipt of support would be able to move home without fear of losing entitlement.
- ▶ *Predictable and transparent* – even those outside the care system would be able to identify what kind of support they would receive under different scenarios.
- ▶ *Location of rationing* – informal care would no longer intersect directly with the rationing of public spending on care and support.

### Cons

- ▶ *Transition costs* – moving to a national system of assessment and entitlement would be costly, particularly given the associated need for reform of local government financing.
- ▶ *Less scope for judgement* – moving to a national system of assessment and entitlement would reduce the scope for local authorities to exercise judgement.

### Mandatory carer's assessments

*Summary:* Local authorities given a statutory duty to offer a carer's assessment to every carer known to them, rather than relying on carers making a request.

*Why?* Information barriers will always prevent new carers knowing their rights, and not all local authorities offer assessments. Data from assessments could be used to measure aggregate need, design services and prod local authorities to offer more support to carers.

### Pros

- ▶ *Carer outcomes* – making carer's assessments mandatory will result in far higher usage of support services, improving carer outcomes.
- ▶ *Demand projections* – mandatory assessments would improve the data available to local authorities to project demand and manage services.

- ▶ *Economies of scale* – greater usage of support services may see decline in marginal cost of supporting a carer.
- ▶ *Identifying recipients of care* – making it mandatory for local authorities to offer assessments of carers' needs will increase the incentives for households to make themselves known to local authorities.

#### *Cons*

- ▶ *Cost* – increase in take-up of carer's assessments will impose costs on local authorities.

#### Personal Budgets payable to Family Carers

*Summary:* Individuals in receipt of Personal Budgets entitled to use them to pay their informal carer.

*Why?* Individuals should have total control in the use of their Personal Budgets, and this means being able to pay the person who principally provides care to them, even if this is a family member.

*How would it work?* Change to existing regulation regarding Personal Budgets and Direct Payments.

#### *Pros*

- ▶ *Choice and control* – takes away a restriction on how individuals can use their Personal Budget.
- ▶ *Supporting carers* – new financial transfers to informal carers would support their outcomes.

#### *Cons*

- ▶ *Cost* – would effectively turn informal care into formal care, adding pressure to limited funding systems.
- ▶ *Carer-cared for relationship* – encouraging changes to the relationship between a family carer and recipient to one of employer-employee, which many households may find undesirable.

#### Nationally consistent levels of carer support

*Summary:* Arbitrary geographical variations in local authority support to carers replaced by nationally consistent assessment and entitlement, enabling portability of entitlements and working-age carers to move home without fear of losing support.

*Why?* Families need predictability to be able to know what support they will receive in the future.

*How would it work?* The government would set out a clear scale of need and entitlement for local authorities to apply in relation to informal care. This could take the form of guarantees to certain types of service, or as cash payments – effectively Personal Budgets – for carers.

#### *Pros*

- ▶ *Guarantees* – those anticipating informal care responsibilities would be able to know with a much greater degree of certainty what support they will be entitled to under different scenarios.

#### *Cons*

- ▶ *Available support* – existing local variations in available support to carers may make it difficult to produce defined guarantees.
- ▶ *Gaming* – current 'discretion'-based system enables local authorities to exercise judgement as to how much support carers need. However, a national entitlement scale may enable some households to effectively 'game' this needs-assessment.

## Limiting the impact of informal care

### Age limits on informal care

*Summary:* Cap the age-range within which individuals are expected by society to provide informal care to 16-75.

*Why?* Although responsibility for care may be a partnership between families and the state, it is undesirable for the social care system – and by implication, taxpayers - to rely on care provided by children and the elderly.

*How would it work?* By disregarding care provided by those under-16 and over-75 in local authority community care assessments, local authorities would effectively become ‘carer-blind’ to care provided by those in these age-groups. Carers in these age-groups would be free to continue to provide care; however, levels of support made available by local authorities would assume they were not providing care. To avoid unnecessary or wasteful spending, funds could be made available in Personal Budgets and restricted to the purchase of care and support services, with unused funds reclaimed every 12 months.

#### Pros

- ▶ *Value-statement* – a statement, as well as a guarantee, that no one will be expected to provide informal care as a child or in late old age.
- ▶ *Reliance on children* – recent studies have shown excessive reliance on informal care provided by children.

#### Cons

- ▶ *Cost* – in line with population ageing, it might be expensive to disregard informal care provided by the over-75s.
- ▶ *Arbitrary thresholds* – age cap of 75 does not reflect socio-economic variations in when people retire

and their capacity to provide care, and would likely have to be periodically revised upwards.

- ▶ *Cliff-edges* – for example, young people may suddenly be expected to provide care when starting their A-levels.

### Weekly time-caps on informal caring

*Summary:* Regardless of the nature of informal care provision and its impact on a carer, a cap is put in place on the amount of care that any carer has to provide of 60 hours per week.

*Why?* Evidence suggests a clear link between hours of care per week and quality of life. For those caring between 0-9 hours per week almost two-thirds (64%) stated their lives were either good, very good or could not be better. Quality of life then declines as the length of time per week spent caring increases with just over a quarter (28%) of those who care for 100 hours or more per week reporting the same level of quality of life.<sup>63</sup>

Providing a cap on the amount of care provided each week, e.g. 60 hours, that carers could ever be expected to provide would send a clear message as to how much society should rely on informal care provision. Given many individuals have low-level needs, and require less than 60 hours of care per week, the cap would only affect individuals with high-level needs, who would otherwise have relied on ‘excessive’ informal care provision or had to purchase care out of pocket.

*How would it work?* Regardless of means, every individual with very high levels of need of care and support would be given a Personal Budget that assumes no more than 60 hours of informal care is provided. To avoid wasted spending, funds could be made available in Personal Budgets and restricted to the purchase of care and support services, with unused funds reclaimed every 12 months.

### Pros

- ▶ *Value-statement* – a clear statement that no one should have to provide more than 60 hours of care per week.
- ▶ *Support to carers* – effectively removes ‘catastrophic’ informal care from the system.

### Cons

- ▶ *Arbitrary threshold* – 60 hours may represent too high a limit for some informal carers.
- ▶ *Variations in ability to cope* – the ability to cope with high-levels of informal care provision varies enormously by carer and the person receiving care, so a weekly cap on caring would be an arbitrary limit in terms of the outcomes of individual carers.

### Universal one-day respite for carers

*Summary:* All individuals requiring some amount of care on a daily basis are given funding for at least one day’s worth of care, regardless of their means, so that every informal carer is guaranteed one day-off per week.

*Why?* Society should not expect any carer to provide informal care every day of the week, even if the person they care for is too wealthy to qualify for means-tested public support.

*How would it work?* Following a community care assessment, and regardless of means, all those in need of care and support would be given funding in a Personal Budget equivalent to at least one day’s worth of the care they require.

### Pros

- ▶ *Support for carers* – ensures all carers would be guaranteed at least one day-off per week.
- ▶ *Flexibility* – use of personal budgets enables carers to access breaks in other ways if they prefer, for example, two consecutive days per fortnight.

### Cons

- ▶ *Targeting* – would be most of benefit to the carers of those with means above current entitlement-thresholds.

### Cap the duration of informal care in retirement

*Summary:* Cap the duration of heavy care (35+ hours per week) that retired informal carers have to provide to no more than two years.

*Why?* There appear to be links between the length of time people care for and their overall quality of life. Quality of life appears to be slightly higher among carers who have been caring for shorter periods of time and decreases as the length of time spent caring increases although there is an improvement for those who have been caring for over 20 years who reported similar levels of quality of life (both good and bad) to those who have been caring for shorter periods.<sup>64</sup>

As such, no one in retirement should have to provide high-volume care (35+ hours per week) for more than two years. This approach would effectively limit the liability or exposure at the household level of individuals to the risk of providing informal care for an extended period, potentially making them more likely to engage in risk-pooling at the population level.

*How would it work?* Where a carer’s assessment records that someone has provided high-level care to someone in receipt of AA for two years, the care recipient should then be reassessed on a carer-blind, non means-tested basis, and given a Personal Budget that reflected this assessment.

### Pros

- ▶ *Value-statement* – recognises that all have an interest in a retirement that is not dominated by high-levels of informal care provision for an extended period.

- ▶ *Means-test* - caps how much informal care households too wealthy to qualify for state support would have to provide.

#### Cons

- ▶ *Arbitrary cap* – the accumulated impact of care provision varies enormously by the nature of care provision and the person receiving care. So, some individuals may be entirely happy to provide 35+ hours of informal care per week for more than 2 years.

### Creating a new balance of formal and informal care

As described in the second chapter, one effect of the use of Personal Budgets may be that carers become increasingly aware that their informal care provision substitutes cash-support that would have been received by the person they care for. This underscores the potential role of alternative mechanisms that seek to balance public funding for formal care – in the form of cash – and informal care provision.

#### Abolish the means-test in community care assessments

*Summary:* Local authorities no longer undertake means-testing in relation to community care assessments.

*Why?* Universal free care, still incorporating a carer-sighted needs-assessment, represents the ultimate measure to remove from the system carers who provide care under pressure, because the person they care for is not entitled to local authority support.

Evidence from other countries, notably Scotland, suggests that most informal carers would carry on providing care even given the availability of fully-funded free care.<sup>65</sup>

*How would it work?* Means-test abolished in community care assessments, with carer-sighted needs-assessment retained.

#### Pros

- ▶ *Voluntary care provision* – should ensure all care provision is fully voluntary and sustainable right across the income scale.

#### Cons

- ▶ *Cost* – even if prevalence of informal care provision were to continue at similar levels, cost likely to be substantial.
- ▶ *Efficiency* – although not the experience of countries such as Scotland, this option may see some carers withdraw from informal care provision despite being willing and able to provide care.
- ▶ *Rationing* – even under ‘free care’, budgets have to be managed and resources rationed, as shown by the experience of Scotland, with informal care likely to be relied upon to meet any unmet demand.

#### Carer-blind ‘Partnership’ model

*Summary:* A ‘carer-blind’ version of the ‘Partnership model’ proposed by the Wanless Review of Social Care,<sup>66</sup> in which all households would get a minimum level of public support regardless of informal care provision, and matching contributions encourage households to ration demand on the basis of financial resources *and* availability of informal care.

*Why?* Matching contributions applied under a ‘carer-blind’ model encourage households to ration their demand for public resources on account of both the availability of financial resources in the household to purchase care out-of-pocket, and the availability of voluntary and sustainable informal care. This creates potential for an ‘optimal’ consumption of formal care, balancing public support, private spend and the availability of informal care.

*How would it work?* Following a community care needs-assessment and means-assessment, all individuals would receive at least a portion of their care costs paid for, proportional to their means, and regardless of whether informal care is available. Beyond this, the local authority would match out-of-pocket payments by the household on formal care.

#### *Pros*

- ▶ *Spend-down* – matching contributions seek to encourage wealthier households to spend down their wealth on care.
- ▶ *Balance of formal vs. informal care* – scope to create an optimal consumption of care that balances public and private spending on formal care with the willingness of households to provide informal care.

#### *Cons*

- ▶ *Means-testing* – households dislike and resent means-testing, and universal application of means-testing may see some simply disengage from system.
- ▶ *Gaming* – the application of means-testing will see some households engage in ‘deliberate deprivation’ of wealth in order to ‘game’ the means-test.
- ▶ *Costs* – likely to be considerably more expensive than the ‘carer-sighted’ version of the Partnership model.
- ▶ *Administration costs* – depending on the level of technology underpinning the system, the administrative costs of matching contributions could be significant.
- ▶ *Uncapped liability* – even under a ‘carer-blind’ approach, the Partnership model leaves those households paying for care out of pocket or providing high levels of informal care exposed to ‘longevity-risk’, i.e. the risk that private payments will accumulate into ‘catastrophic costs’, or the risk that informal carers will be left providing care for many years.

#### *‘Matching care contributions’*

*Summary:* Where informal care is provided by households, any private out-of-pocket care purchased receive a matching contribution from the state, with the generosity of the matching ratio – 4:1, 3:1, 2:1 etc. – proportional to the percentage of a person’s needs met through the informal care provided.

*Why?* Matching contributions – e.g. £1 transfer into a Personal Budget for every £2 privately spent on care – is one mechanism for rationing demand for public funding. To both reward and incentivize informal care provision, ‘matching care contributions’ would see the matching ratio of public to private spending on care linked to the volume of informal care provided to a person. Those households providing low levels of care would receive a low-match, e.g. £1 contribution for every £5 of out-of-pocket payment. If a high level of informal care is provided, the generosity of the match would increase to £1 contribution for every £2 out-of-pocket payment, or even a match of £1 to £1 for those providing, for example, 40+ hours of care per week.

*How would it work?* Following a community care needs assessment, a carer agrees with local authority the volume of care they are willing to provide. If high level of informal care is offered, local authority says it will match £1 for £1 (up to a limit) any private spending on care by the household. If a lower level of informal care is offered, local authority says it will match £1 for every £5 of private spending on care.

As well as reflecting the percentage of care needs met through informal care provision, the generosity of the match could also be determined by other factors, such as the type of care provided by and the total hours of care per week.

#### *Pros*

- ▶ *Rewards households for informal care* – provides a mechanism to balance public and private spending

on formal care with the willingness of households to provide informal care, while rewarding and incentivizing high levels of informal care.

#### Cons

- ▶ *Complexity* – variable matching contribution rates may be difficult for many households to understand.
- ▶ *Administration costs* – depending on the level of technology underpinning the system, the administrative costs of matching contributions could be significant.

### Insuring against informal care

#### Merged revenue streams via a national financing vehicle

*Summary:* Public spending on care and support for informal carers, as well as new contributions from households, all routed via a single national financing vehicle.

*Why?* By bringing together revenue streams on formal and informal care into a single risk-pool, everyone who participated in a risk-pool for long-term care funding at the ‘population level’ would get something back directly if they provide or receive informal care rather than formal care. Would provide a key incentive to go beyond simply insuring at the household-level.

*How would it work?* All current care-related benefits (DLA, AA and CA), and public funding on social care routed via a national financing vehicle, such as a national care fund, which would also provide a vehicle for receipt of new contributions from households. The fund would allocate spending on social care as well as funding to support for carers.

#### Pros

- ▶ *Something for something* – would ensure that everyone who participated in a risk-pool for long-

term care funding at the ‘population level’ would get something back directly if they provide or receive informal care rather than formal care.

- ▶ *Guarantees* – if the national financing vehicle was held at arm’s length from HM Treasury, households could be confident their contributions would not be diverted for other purposes, for example, to pay off public debt.

#### Cons

- ▶ *Resource drift* – risk that support for carers would be restricted as resources drifted across to focus on the care and support of those with the highest needs.

### Key Points

- ▶ Despite progress in advancing the rights of carers, flexible work and innovation in the design of carer support services, viewed from the perspective of the long-term care funding debate, the choices presented to prospective informal carers not compelling.
- ▶ Current long-term care funding and informal care policy frameworks are characterised by divergent sources of support, means-testing creating pressure on carers in wealthier households, rationing and uncertainty, informal care intersecting directly with the rationing of public resources and poorly-performing universal entitlements.
- ▶ However, in the context of the long-term care funding debate, and building on current policy frameworks and the ‘infrastructure’ provided by elements such as Carer’s Assessments and Personal Budgets, a new ‘offer’ on informal care is required.
- ▶ Different perspectives on the balance of formal and informal care at the macro- and micro-level can be identified and discussed, but the implications for policymakers and policy design are limited by the

practical feasibility of what can be achieved across different households.

- ▶ This is particularly true given the impact of informal care on a carer varies by the characteristics of the recipient, and the financial, physical, support, and psychological resources that carers can bring to their caring role.
- ▶ Desirable characteristics of a new 'offer' to carers would be: communicable; value-for-money; guaranteed; providing of 'something for something'; providing of recognition for caring; and personalised.
- ▶ Given the current system, the policy 'toolkit' available includes community care assessments carer assessments, personal budgets, as well as potential reforms discussed in various government publications such as the transfer of care-related benefits into the social care funding system, and application of nationally consistent assessments for need, means and a national scale of entitlement.
- ▶ Potential reform options centre around: changes to Carer's Allowance; changes to the social care system; limiting the impact of informal care; social care 'benefits' for informal care; creating a new balance of formal and informal care; and creating a settlement that enables people to insure effectively against the burden of providing informal care.

## 5. Conclusion: Toward a New Co-Production of Care

Given the reluctance of individuals to consider their future potential care needs, politicians may be more successful in promoting a new settlement on funding care and support by focusing on people's potential experience as an informal carer...

**The starting point for this report was a recognition that governments have repeatedly failed to persuade households to make provision for the risk of needing care by paying more into taxation (e.g. an inheritance tax), into a state-sponsored insurance scheme, or into private sector insurance.**

The vast majority of individuals simply do not wish to think about the risk of needing care and many hope they will be taken care of by those closest to them.

Significantly reducing the burden on informal carers may be seen as prohibitively expensive, unnecessary and low-priority in the context of a difficult fiscal environment. However, for as long as individuals and households are inclined to conserve wealth rather than contributing to a new settlement for long-term care funding, creating a new 'offer' for carers may be the only way of unlocking a settlement on long-term care funding reform.

Policymakers must give households a clear, tangible and guaranteed 'vision' of informal care-giving, which households feel is worth the price of any new settlement on care funding. A real partnership in relation to care, and a true co-production of care in the face of rising demand, would see households pay into a risk-pooling mechanism that funds the care of those reliant on formal services, but which also supports those that provide informal care.

Taking such an approach may be the only way that policymakers will achieve widespread support for reform to long-term care funding. It has proved consistently difficult – even impossible – to persuade many individuals to think about the risk of needing care in the future. Time and again, individuals struggle to imagine themselves living a life of diminished physical and cognitive capability. This mental barrier in many

ways explains the long-term care funding crisis confronting England and Wales: politicians struggle to convey to people the risk of needing care and, therefore, the imperative for reform.

Instead, policymakers should focus on something which individuals find much easier to imagine: the personal burden involved in providing high levels of informal care. Asking households to think about the outcomes and life they would want as informal carers - and persuading them to participate in a new settlement on long-term care funding on the basis of these outcomes - may be the key to unlocking support for a new settlement on long-term care funding. A new settlement can effectively ask individuals to insure against the potential burden of providing 'catastrophic' levels of care. Politicians should seek to 'sell' long-term care funding reform to the public on this basis.

### A New Co-Production of Care

This report has ranged widely across multiple policy domains, encompassing the long-term care funding system and informal care policy.

Building on the analysis of the previous chapters, the key recommendations for policymakers are as follows.

In the very short-term:

- ▶ The government should raise the earnings-cap on Carer's Allowance to £136.54 per week, at no cost to the Exchequer, giving 'working-carers' the chance to have a net income equivalent to the National Minimum Wage.
- ▶ Local authorities should be mandated to offer Carer's Assessments to all informal carers.

In the long-term the government, should create a new offer to carers as part of a settlement on long-term care funding:

## Key features of a new offer should include a weekly cap on informal care provision, geographical consistency in support for carers and those receiving care, and a guaranteed day-off each week...

- ▶ Community care assessments should disregard informal care provided by those under-16 and over-75.
- ▶ All requiring care, regardless of means, should be given a Personal Budget equivalent to at least one day's worth of their assessed care needs, thereby guaranteeing all informal carers at least one day-off per week.
- ▶ A national system of assessment, entitlement and funding of care and support should be implemented giving individuals transparency and predictability in what they will receive, and removing arbitrary geographical variations.
- ▶ The government should provide for a nationally consistent system of universal cash-based entitlements for carers delivered via local authority carer's assessments.
- ▶ All those in need of care and support, regardless of means, should be given Personal Budgets that ensure no informal carer provides more than 60 hours of care per week.
- ▶ Public spending on care-related benefits and the social care system, including carer support, should be merged with a financing vehicle providing for receipt of new contributions from households, ensuring that those making new contributions under a new long-term care funding settlement can see that they will benefit directly even as providers of informal care. This financing vehicle should be strongly ring-fencing so that household contributions are not subject to the 'political-risk' of politicians subsequently reallocating funds to other uses.
- ▶ A cash payment for the person you care for, regardless of their means, proportional to their need, which they can spend as they wish.
- ▶ Entitlements for you and the person you care for, set by a transparent, national scale.
- ▶ Guaranteed 1-day off per week.
- ▶ No more than 60 hours of care per week.
- ▶ No care for under-16s or over-75s.
- ▶ Assessments from the local authority for you and the person you care for.
- ▶ Choice and control over the resources you get to support you.
- ▶ Use your money to shape your responsibilities to ones you feel happy with.
- ▶ Confidence that your contribution will be there for you if you need to support.
- ▶ Replacement care you are happy with.
- ▶ If you're sharing care responsibilities with another family member, you will both be entitled to support.

And for those in employment:

- ▶ Help for you and your employer
- ▶ Money for your employer to purchase telecare and other related services.

### Key Points

- ▶ The vast majority of individuals simply do not wish to think about the risk of needing care and many hope they will be taken care of by those closest to them. However, for as long as individuals and households are inclined to conserve wealth rather than contributing to a new settlement for long-term care funding, creating a new 'offer' for carers may be the only way to secure reform.
- ▶ Policymakers must give households a clear, tangible and guaranteed 'vision' of informal care-giving, which households feel is worth the price of any new settlement on care funding. Taking such an approach may be the only way that

Allied to parallel reforms in the social care system, particularly around the National Market Development Forum and changes to Job Centre Plus, such reforms would make up a tangible offer to carers, which would provide a clear answer to the question "what do I get for my money?":

policymakers will achieve widespread support for reform to long-term care funding. It has proved consistently difficult to persuade many individuals to think about the risk of needing care in the future.

- ▶ Instead, policymakers should focus on something which individuals find much easier to imagine: the personal burden involved in providing high levels of informal care.
- ▶ Asking households to think about the outcomes and life they would want as informal carers - and persuading them to participate in a new settlement on long-term care funding on the basis of these outcomes - may be the key to unlocking support for a new settlement on long-term care funding. A new settlement can effectively ask individuals to insure against the potential burden of providing 'catastrophic' levels of care.

- ▶ All those in need of care and support, regardless of means, should be given Personal Budgets that ensure no informal carer provides more than 60 hours of care per week.
- ▶ Public spending on care-related benefits and the social care system, including carer support, should be merged with a financing vehicle providing for receipt of new contributions from households, ensuring that those making new contributions under a new long-term care funding settlement can see that they will benefit directly even as providers of informal care.

In the very short-term:

- ▶ Raise the earnings-cap on Carer's Allowance to £136.54.
- ▶ Mandate local authorities to offer Carer's Assessments to all carers.

As part of a new settlement on long-term care funding:

- ▶ Community care assessments should disregard informal care provided by those under-16 and over-75.
- ▶ Carers should be guaranteed at least one day-off per week through giving equivalent Personal Budgets to all receiving care, regardless of means.
- ▶ A national system of assessment, entitlement and funding of care and support should be implemented giving individuals transparency and predictability in what they will receive, and removing arbitrary geographical variations.
- ▶ The government should provide for a nationally consistent system of universal cash-based entitlements for carers delivered via local authority carer's assessments.

# Appendix: Carers and Disabled Children Act (2000)

The descriptions of the four levels of risk for carers contained in the guidance to the *Carers and Disabled Children 2000 Act* are summarised in the table below:

## **CRITICAL**

Critical risk to sustainability of the caring role arises when:

- ▶ Their life may be threatened;
- ▶ Major health problems have developed or will develop;
- ▶ There is, or will be, an extensive loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- ▶ There is, or will be, an inability to look after their own domestic needs and other daily routines while sustaining their caring role;
- ▶ Involvement in employment or other responsibilities is, or will be, at risk;
- ▶ Many significant social support systems and relationships are, or will be, at risk.

## **SUBSTANTIAL**

Substantial risk to sustainability of the caring role arises when:

- ▶ Significant health problems have developed or will develop;
- ▶ There is, or will be, some significant loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- ▶ There is, or will be, an inability to look after some of their own domestic needs and other daily routines while sustaining their caring role;
- ▶ Involvement in some significant aspects of employment or other responsibilities is, or will be, at risk;

- ▶ Some significant social support systems and relationships are, or will be, at risk.

## **MODERATE**

Moderate risk to sustainability of the caring role arises when:

- ▶ There is, or will be, some loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role;
- ▶ There is, or will be, some inability to look after their own domestic needs and other daily routines while sustaining their caring role;
- ▶ Several social support systems and relationships are, or will be, at risk.

## **LOW**

Low risk to sustainability of the caring role arises when:

- ▶ There is, or will be, some inability to carry out one or two domestic tasks while sustaining their caring role;
- ▶ One or two social support systems and relationships are, or will be, at risk.

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- <sup>1</sup> Commission on the Funding of Care and Support (2010) *Call for Evidence on the Future Funding of Care and Support*, Department of Health, London
- <sup>2</sup> In 2004, CSCI commissioned MORI to undertake a survey of people's preferences for social care, which asked if they needed care and support looking after themselves (when older, if not already). 62% said they wanted to stay in their own home with care and support from friends and family, while 56% wanted to stay in their own home but with care and support from trained care workers.
- <sup>3</sup> ONS (2010) *Wealth in Great Britain*
- <sup>4</sup> Department of Health (2010) *Building the National Care Service*
- <sup>5</sup> Commission on the Funding of Care and Support (2010) *Call for Evidence on the Future Funding of Care and Support*, Department of Health, London
- <sup>6</sup> CSCI (2009) *The State of Social Care in England 2007-08*, CSCI, London
- <sup>7</sup> CSCI (2008) *Cutting the care fairly: CSCI review of eligibility criteria for social care*, CSCI, London
- <sup>8</sup> Department of Health (2010) *Fairer Contributions Guidance 2010 - Calculating an Individual's Contribution to their Personal Budget*
- <sup>9</sup> Ibid.
- <sup>10</sup> Henwood M and Hudson B (2008) *Lost to the system? The impact of Fair Access to Care: a report commissioned by CSCI for the production of 'The state of social care in England 2006-07'*, London, CSCI
- <sup>11</sup> CSCI (2008) *Cutting the care fairly: CSCI review of eligibility criteria for social care*, CSCI, London
- <sup>12</sup> Ibid.
- <sup>13</sup> CSCI (2009) *The State of Social Care in England 2007-08*, London
- <sup>14</sup> Commission on the Funding of Care and Support (2010) *Call for Evidence on the Future Funding of Care and Support*, Department of Health, London
- <sup>15</sup> Department for Work and Pensions (2010) *Public Consultation: Disability Living Allowance reform*
- <sup>16</sup> Commission on the Funding of Care and Support (2010) *Call for Evidence on the Future Funding of Care and Support*, Department of Health, London
- <sup>17</sup> Pudney S (2010) *Disability Benefits for Older People: How Does the UK Attendance Allowance System Really Work?*, Institute for Social & Economic Research, University of Essex
- <sup>18</sup> Pudney S (2009) *Participation in disability benefit programmes*, Institute for Social & Economic Research, University of Essex
- <sup>19</sup> Hancock R & Pudney S (2010) *The distributional impact of reforms to disability benefits for older people in the UK*, Institute for Social & Economic Research, University of Essex
- <sup>20</sup> HM Government (2010) *Recognised, valued and supported: Next steps for the Carers Strategy*
- <sup>21</sup> Department of Health (2010) *Personal budgets for older people - making it happen*, London
- <sup>22</sup> Ross A et al. (2008) *Living and Caring? An Investigation of the Experiences of Older Carers*, ILC-UK, London
- <sup>23</sup> Henwood M and Hudson B (2008) *Lost to the system? The impact of Fair Access to Care: a report commissioned by CSCI for the production of 'The state of social care in England 2006-07'*, London, CSCI
- <sup>24</sup> NHS Information Centre (2010) *Personal Social Services Survey of Adult Carers in England, 2009-2010*
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- <sup>26</sup> Wittenberg R et al. (2007) *Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care for Older People in England*, PSSRU Discussion Paper 2514
- <sup>27</sup> Pickard L (2008) *Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041 in England*, PSSRU Discussion Paper 2515
- <sup>28</sup> NHS Information Centre (2010) *Personal Social Services Survey of Adult Carers in England, 2009-2010*
- <sup>29</sup> Berthoud R (2010) *The take-up of Carer's Allowance: A feasibility study*, Department for Work and Pensions
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- <sup>31</sup> Yeandle S (2007) *Valuing Carers - calculating the value of unpaid care*, Carers UK, London
- <sup>32</sup> HM Government (2010) *Caring about carers: A national strategy for carers*

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- <sup>33</sup> HM Government (2010) *Recognised, valued and supported: Next steps for the Carers Strategy*
- <sup>34</sup> NAO (2009) *Supporting Carers to Care*
- <sup>35</sup> Berthoud R (2010) *The take-up of Carer's Allowance: A feasibility study*, Department for Work and Pensions
- <sup>36</sup> Ibid.
- <sup>37</sup> NAO (2009) *Supporting Carers to Care*
- <sup>38</sup> Berthoud R (2010) *The take-up of Carer's Allowance: A feasibility study*, Department for Work and Pensions
- <sup>39</sup> Ibid.
- <sup>40</sup> Ibid.
- <sup>41</sup> NAO (2009) *Supporting Carers to Care*
- <sup>42</sup> Berthoud R (2010) *The take-up of Carer's Allowance: A feasibility study*, Department for Work and Pensions
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- <sup>45</sup> Ministry of Justice (2010) *Proposals for the Reform of Legal Aid in England and Wales*, London
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- <sup>58</sup> Ibid.
- <sup>59</sup> Ibid.
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