



# Living and Caring for All

James Lloyd

September 2008

ILC-UK

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**This report was first published in September 2008.**

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## About this Report

This discussion paper is based on and responds to research published simultaneously by the ILC-UK in collaboration with NatCen called *Living and Caring? An Investigation of the Experience of Older Carers*.<sup>1</sup>

The purpose of this report is to provide accompanying policy analysis and discussion to *Living and Caring?* for both a general and specialist readership. Its primary purpose is to provoke discussion.

## Acknowledgements

This report and the *Living and Caring?* research would not have been possible without the generous support of the Nuffield Foundation.<sup>2</sup> The Nuffield Foundation is a charitable trust established by Lord Nuffield. Its widest charitable object is 'the advancement of social well-being'. The Foundation has long had an interest in social welfare and has supported this project to stimulate public discussion and policy development. The views expressed are however those of the author and not necessarily those of the Foundation.

The analysis for *Living and Caring?* was undertaken by Andy Ross, Michael Weinhardt and Hayley Cheshire of the National Centre for Social Research (NatCen).<sup>3</sup>

This report has also benefited from the comments of Primrose Musingarimi of the ILC-UK.

The author is extremely grateful to all parties for their time, support, enthusiasm and dedication.

All opinions expressed in this report are the author's own and should not be attributed to any of the aforementioned organisations or individuals.

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<sup>1</sup> Ross A et al. (2008) *Living and Caring? An Investigation of the Experience of Older Carers*, ILC-UK, London

<sup>2</sup> <http://www.nuffieldfoundation.org/>

<sup>3</sup> <http://www.natcen.ac.uk>

## Executive Summary

There is wide recognition that commensurate with population ageing, demand for social care will increase in coming decades. The majority of care provision is likely to remain unpaid care, and it is older people themselves who are expected to meet a large share of this rising demand.

For policymakers, these trends create numerous strategic questions, such as: where should the burden of care fall? How appropriate is unpaid care? What are the negative effects of unpaid care provision by older people for public policy? How can the negative outcomes experienced by older carers resulting from care provision be eliminated or reduced?

What can be termed the 'social construction of unpaid care' in society results from multiple factors, including: the availability of alternative sources of formal care and unpaid care; family relationships and preferences; logistical factors; the opportunity-cost of care provision for carers; and, social and cultural norms and values. Looking at the actual provision of care within the older population that results from the 'social construction of unpaid care', it is clear that unpaid care is slanted toward lower socioeconomic groups, and that for older carers for a spouse or adult child, care provision is characterised by a 'heavy' burden of care. Most carers of an elderly parent provide 'light' care.

Across different policy domains such as quality of life, income, health and housing, there are wide variations in the outcomes older carers experience. However, it is clear that the provision of care, locus and burden, and the outcomes carers experience are all influenced by the characteristics and outcomes of carers prior to an episode of care. This suggests that the objective of public policy should be to reduce or eliminate the differences in outcomes that carers experience as a result of caring. However, improving outcomes in one area of a carer's life may involve improving other outcomes over and above what they would experience. For example, high levels of income may be required to eliminate the effect on quality of life for someone providing an extremely high volume of spousal care. Value judgements, targeting and trade-offs will still therefore have to characterise policy toward carers.

Various outcomes in different domains are associated with changes in the quality of life of carers, particularly health, access to services and income. The Government is right to put health and healthcare at the forefront of policy to support carers. Although relatively few older carers appear to struggle with access to services, their vital role in influencing quality of life suggests that related assessments should be made of carers and appropriate support services provided. In addition, the striking association between the level of memory functioning of the person receiving care and a spousal carer's quality of life points to the need to incorporate assessments of such memory functioning in assessments of carers' needs, and the circulation of such information to all professionals involved in supporting older carers.

Across multiple measures, it is clear that for many older carers, too much unpaid care is being provided by too few people for too many hours. Unpaid care provision does not itself cause ill-health, poverty or lower quality of life; rather, it is the burden, incidence and patterns of unpaid care observable among older cohorts resulting from the social construction of unpaid care that leads to such outcomes.

These facts suggest that the overarching objective of public policy must be to increase the supply of care provision within society. This means increasing the supply and availability of formal care through greater risk-sharing and a larger share of the country's public and private wealth allocated to the task of formal care provision. It also means increasing the number of unpaid carers so that the burden of care is better dispersed, through improving support for carers, addressing the gender balance in unpaid care provision and helping families make decisions and choices around allocating the burden of unpaid care within families.

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# Chapter 1: Introduction

## *Background*

The UK population is ageing. It is projected that by 2031, the UK population will include 3 million people aged over-85 compared with 1.2 million in 2006 and around 0.6 million in 1981. The ratio of the number of people of working age for every person above the state pension age will reduce from 3.32 in 2006 to 2.91 by 2031.<sup>4</sup>

Commensurate with population ageing, the demand for long-term care is forecast to increase. It has been projected that the number of disabled people aged 65 and over will increase from 2.3 million in 2002 to 4 million in 2031. The number of disabled people aged 85 and over is expected to increase from 0.6 million in 2002 to 1.3 million in 2031.<sup>5</sup>

The provision of long-term care to older people can take different forms. Care can be 'formal', i.e. provided by paid carers. Alternatively, care can be 'informal'/'unpaid' when it is provided by a family member or friend.

It is widely projected that the majority of long-term care will continue to be provided as unpaid care. Almost one third of unpaid carers in England are aged 60 or over and the growing demand for long-term care is expected to be met increasingly by older cohorts.<sup>6</sup> Most unpaid care for older people is provided by a spouse or adult child. However, it is expected that care by spouses will be increasingly important in future given various long-term trends including the declining elderly support ratio, improvements in male (healthy) life expectancy, the decline of parent-child co-residence and increasing participation by women in the labour force. It is projected that by 2031, 1.2 million people over 65 will receive care from a spouse, up from 0.6 million in 2002. The number of people receiving care from an adult child is expected to increase from 0.7 million in 2002 to 1.1 million in 2031.<sup>7</sup>

## *Strategic Questions for Public Policy*

Taken together, these trends suggest that growth in unpaid care provision among older cohorts is inevitable. This key emergent societal trend creates a set of critical strategic questions for policymakers and society:

- *Where should the burden of care fall?*

If the growing demand for care is to be met in part by older cohorts, which older groups represent the optimal providers of care given the objectives of public policy? From the perspective of policy, who should provide care and how much? Although the choice or decision to provide care is ultimately personal and individual, is it preferable for unpaid care provision to be limited to certain age or socio-economic groups? Are there optimal limits to the duration of care that someone provides, both in terms of hours per week and the duration of the 'care episode', i.e. one month or one year? How should the burden of care be distributed?

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<sup>4</sup> ONS (2008) *Population Trends*, No. 131, London: HMSO,  
[www.statistics.gov.uk/downloads/theme\\_population/Population\\_Trends\\_131\\_web.pdf](http://www.statistics.gov.uk/downloads/theme_population/Population_Trends_131_web.pdf)

<sup>5</sup> Pickard L et al. (2007) "Care by Spouses, Care by Children: Projections of Informal care for Older People in England to 2031" in *Social Policy & Society*, Vol. 6, No. 3, p353-366

<sup>6</sup> Pickard L et al. (2000) "Relying on care in the new century? Informal care for elderly people in England to 2031" in *Ageing & Society*, Vol. 20, p745-772

<sup>7</sup> Pickard L et al. (2007) "Care by Spouses, Care by Children: Projections of Informal care for Older People in England to 2031" in *Social Policy & Society*, Vol. 6, No. 3, p353-366

- *How appropriate is unpaid care?*

Considered as a form of provision, variations inevitably exist in the nature of unpaid care provided by older cohorts. Just as most formal care is evaluated and 'quality-rated', variations exist in the quality and appropriateness of unpaid care provided by carers. Unpaid care provision can involve a set of skills and responsibilities that carers may have to learn and adapt to, and will do so to varying degrees. It is therefore important to consider how appropriate is the care provided by older carers. In the context of unpaid care provision, public policy has an interest in ensuring that this care is as appropriate as possible.

- *What are the negative effects of unpaid care provision by older people for public policy?*

It is routinely observed that unpaid care provision effectively boosts public expenditure given the care provided by family and friends to individuals who would otherwise qualify for means-tested state-funded care.<sup>8</sup> However, such 'savings' to the state clearly need to be offset by other potential costs, in particular:

- The costs of mental and health care for carers in relation to conditions brought on or exacerbated by their provision of care.
- Lost productivity (both skills and labour contribution) and tax receipts for the economy associated with the absence of working-age carers from the labour force. Carers may subsequently require re-training if they re-enter the labour force after an extended period of care provision.
- Subsequent support required by carers; for example, when working-age carers are forced to cut their participation in the labour market this may reduce their pension saving and ultimately result in their reliance on means-tested benefits in retirement, such as Pension Credit.

- *How can the negative outcomes experienced by carers resulting from care provision be eliminated or reduced?*

There is widespread consensus regarding the normative imperative for public policy to reduce or eliminate the negative influence on the outcomes of carers that result from the unpaid care they provide. This has been reflected in Government publications such as the 2008 'Carers Strategy', which stated:

"Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen."<sup>9</sup>

The challenge for public policy lies both in the wide range of negative outcomes that may result from unpaid care provision – from immediate economic effects (loss of income) to more general effects on quality of life – and the wide variations in the effect of care provision on outcomes in the lives of carers. Policy debate and innovation continues to focus on how public policy can best reduce or eliminate differences in outcomes among carers and (comparable) non-carers. In addition, in the context of limited resources and the likelihood that there will always be individuals experiencing negative outcomes

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<sup>8</sup> In fact, some studies that seek to calculate savings to the state resulting from the provision of unpaid care assume that all unpaid care substitutes for state-funded care, which is not the case, particularly given the means-testing of state-funded care to older people.

<sup>9</sup> HM Government (2008) *Carers at the heart of 21st-century families and communities*, HMSO: London

because of their provision of unpaid care, how should the resources of the state in this area be targeted and prioritised?

*Living and Caring? An Investigation of the Experience of Older Carers*

Each of these strategic questions for public policy requires evidence. Comparatively little quantitative research comparing the lives of carers and non-carers in the UK has been undertaken due, in particular, to the dearth of suitable data sources. Research has tended to focus on the physical and mental health effects of caring on carers of all ages. Hirst used the *British Household Panel Survey* to explore the incidence of 'carer distress', i.e. symptoms indicative of anxiety and depression, social dysfunction, loss of confidence and self-esteem.<sup>10</sup> Analysis found that increased distress was associated with the provision of intense care over long-periods, although more so for women than men. The study also found that several groups of carers experienced psychological health inequalities compared to non-carers, in particular those looking after a spouse or partner, and mothers caring for a sick or disabled child.

An earlier study by Singleton et al. looked at the incidence of neurotic symptoms among carers.<sup>11</sup> The research found that female carers (21%) were more likely than males (12%) to be assessed as having high levels of neurotic symptoms. When compared to the general population using age-standardised ratios, female carers were found to be 23% more likely to have neurotic symptoms than women in general. The same comparison for men found no significant difference between carers and men in general.

The *English Longitudinal Study of Ageing* (ELSA) is a bi-annual longitudinal survey of a representative sample of around 10,000 individuals aged 50+ in England and Wales, and one of the newest UK surveys providing data that can be generalised to population level. ELSA provides an excellent resource to study the effect of care provision on the 50+ population since it contains questions to identify individuals providing care as well a broad range of multi-dimensional variables relating to income, well-being, housing and leisure, etc.

Following a grant from the Nuffield Foundation, the ILC-UK and NatCen collaborated on a research project using ELSA to explore the effect of care provision on the lives of people aged 50+, focusing in particular on quality of life and outcomes in domains directly relevant to local authority policy and service design. The resulting research – *Living and Caring? An Investigation of the Experience of Older Carers* – was published simultaneously to this report, which seeks to use the findings of the *Living and Caring?* research to explore the strategic questions for public policy identified above.

Chapter 2 of this report considers the multiple factors that shape the provision and patterns of unpaid care and relates this discussion to the actual provision of care by the older population identified in *Living and Caring?*.

In Chapter 3, the principal evidence of *Living and Caring?* is reviewed in relation to the outcomes that older carers experience. Differences in the experiences of carers and the relationship of these outcomes to the pre-care characteristics of carers is discussed.

Chapter 4 summarises the evidence provided by *Living and Caring?* regarding the quality of life of older carers, relating to both the characteristics of the person receiving care and the association between quality of life and outcomes in various other domains.

In Chapter 5, the future of carers policy is considered. The current experience of older carers is related to the wider shortage of funding and risk-sharing in the supply of formal care. The critical importance of increasing the volume of unpaid and formal care provision is emphasised along with the need to better 'disperse' the burden of care.

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<sup>10</sup> Hirst M (2005) "Carer distress: A prospective, population-based study" in *Social Science & Medicine*, Vol. 61, Issue 3, p697-708

<sup>11</sup> Singleton N et al. (2002) *Mental health of carers*, Office of National Statistics

## Chapter 2: Carers and Caring – Making Sense of Care Provision

In both specialist and lay discourse, “carers” is used to denote the population of individuals providing unpaid care, but masks the huge variations that exist both among carers, their outcomes and in the form and type of care that is provided. Carers and care provision are highly *heterogeneous*. Why is this the case? Why do some individuals become carers and not others? How do families make decisions about who will provide unpaid care and how much?

*Living and Caring?* found that by far the most important reason that older carers cite for the provision of care is that “they are needed”. Significant minorities of older carers also cite feeling obliged, wanting to be useful and enjoyment as reasons for providing care. However, behind such personal explanations of the factors causing unpaid care provision, what can be termed the ‘social construction of unpaid care’ is extremely complex and subject to multiple competing drivers and causal factors at both the micro and macro levels.

### *The Social Construction of Unpaid Care*

*Living and Caring?* found that most older carers provide care “because they are needed.” However, it is crucial to analyse and understand the systems and mechanisms that lead carers to report “being needed” as the reason they provide care. The decision or choice to provide unpaid care is personal and unique to every individual carer and their situation. However, there are many different factors and motivations that result in provision of unpaid care in society. Extensive academic research has sought to explore and measure the effect and incidence of some of these drivers, although others remain beyond scientific measurement. These factors determine not just how the burden of care is distributed, i.e. who provides care and who does not, but in addition, how much care individual carers provide and the type of care. These factors can be roughly grouped as follows:

- *Alternative sources of formal care*

The interaction of the availability of formal care and unpaid care provision has long been a key interest for policymakers and researchers.<sup>12</sup> The provision of unpaid care may be determined by:

- The ability of the cared-for or other family members to pay for care privately either ‘out-of-pocket’, or through the use of an immediate needs annuity insurance product or possession of a pre-funded long-term care insurance product.

Unpaid care provision may be closely related to the quality, cost, affordability and availability of privately funded and purchased formal care. However, it is important not to assume the existence of a simple ‘substitution effect’ between the provision of formal and unpaid care, i.e. that unpaid care only arises from the non-availability of (affordable) formal care. For example, a US study found that the availability of unpaid caregivers had no statistically significant effect on the purchase of long-term care insurance or intentions to purchase such insurance.<sup>13</sup> Nevertheless, it can be supposed that some unpaid care provision among older

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<sup>12</sup> Greene V (1983) “Substitution between formally and informally provided care for the impaired elderly in the community” in *Medical Care*, Vol. 21, No. 6, p609-619

<sup>13</sup> Mellor J (2001) “Long-term care and nursing home coverage: are adult children substitutes for insurance policies?” in *Journal of Health Economics*, Vol. 20, Issue 4, p527-547

people results from the cost/un-affordability of paid care, or a desire to preserve assets and wealth within a family.

- The availability of state or charitable-funded care.

At present, free personal care funded by the state is only available to individuals in England and Wales who have total assets worth less than £21,500. However, once again, it is important to recognise that there is no simple or straightforward 'substitution effect' between unpaid care provision and the availability of 'free' formal care. A study of Scotland following the introduction of a benchmark value of universal free personal care funded by the state found that although unpaid carers had not withdrawn from care provision, there was some evidence that their activities were changing in nature, for example, tending toward performing different, non-personal forms of care.<sup>14</sup> Scandinavian studies have found no substitution effect between statutory and voluntary sector provision of care<sup>15</sup> but a substitution effect between statutory formal care and unpaid care.<sup>16</sup> Research in the Netherlands found evidence of both 'compensatory processes', i.e. informal care substituting for professional care, and 'bridging processes', i.e. informal care facilitating professional care.<sup>17</sup> Cross-national research has found evidence of 'mixed responsibility' whereby countries with more formal care provision saw more unpaid care provision.<sup>18</sup> Overall, evidence on the substitution effect between state-funded free care and the provision of unpaid care is inconclusive. Personal satisfaction gained from unpaid care provision and the bridging effect of formal care, are just two of many factors that may reduce the impact of any 'substitution effect' between formal care and unpaid care.

- *Alternative sources of unpaid care*

The provision of unpaid care by one family member (or friend) will depend on the availability of unpaid care from other family members and any associated 'family bargaining' that occurs. In particular, it is crucial to recognise that the provision of spousal and parental care can be closely interrelated. The provision of spousal care may be determined by the availability of adult children to provide parental care, and vice versa. How families arrive at decisions around who will provide unpaid care and how much can be surprising. For example, one study emphasised "time pressures and the idiosyncratic factors that constrain the work and care timetables that families are able to construct".<sup>19</sup>

- *Family relationships and preferences*

Sibling-sibling and child-parent relationships within a family may determine who provides care. In addition to the preferences of the potential carer, the person requiring care is likely to have preferences. For example:

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<sup>14</sup> Bell D et al. (2007) *Free Personal Care in Scotland: Recent Developments*, Joseph Rowntree Foundation, York

<sup>15</sup> Dahlberg L (2004) "Substitution in statutory and voluntary support for relatives of older people" in *International Journal of Social Welfare*, Vol. 13, p181-188

<sup>16</sup> Johansson L et al. (2003) "State provision down, offspring's up: the reverse substitution of old-age care in Sweden" in *Ageing & Society*, Vol. 23, p269-280

<sup>17</sup> Geerlings S et al. (2005) "Predicting transitions in the use of informal and professional care by older adults" in *Ageing & Society*, Vol. 25, p111-130

<sup>18</sup> Motel-Klingebiel A et al. (2005) "Welfare states do not crowd out the family: evidence for mixed responsibility from comparative analyses" in *Ageing & Society*, Vol. 25, p863-882

<sup>19</sup> Baldock J & Hadlow J (2004) "Managing the Family: Productivity, Scheduling and the Male Veto" in *Social Policy & Administration*, Vol. 38, No. 6, p706-720

- Preferring that an adult child provide care rather than a spouse, or indeed, vice versa;
- Preferring one potential family carer to another on the basis of their legacy relationship, personality or gender.
- Preferring unpaid care to formal care. Some research has found evidence that as many 42% of those new to caring said that the person for they cared did not want to receive formal care services.<sup>20</sup>

Potential family carers will also have preferences, which may include a preference to become a carer. Indeed, it is important not to overlook the satisfaction and 'returns' which can result from care provision.<sup>21</sup>

- *Logistical factors*

The provision of unpaid care will depend on multiple logistical factors, such as potential carers living in reasonable geographical proximity or the availability of space within a private home to accommodate someone requiring care. Where these practical factors are a constraint to care provision, the availability of logistical resources to address them will also determine care provision, such as the availability of liquid wealth to move house or expand a property.

- *The opportunity-cost of unpaid care provision*

For many individuals, the most important potential opportunity-cost of unpaid care provision is the loss of salary. Beginning or continuing to provide unpaid care may be associated with reductions in hours worked or withdrawal from the labour market, as well as the gradual obsolescence of skills, i.e. future earning-power. However, it is important to recognise the different dynamics and motivations that are involved. Some individuals may reduce their labour activity to provide care because they can afford to, i.e. they have sufficient alternative sources of income and retirement saving, such as the presence of a spouse who can continue to work, or household wealth that has already been accumulated. In other cases, individuals may reduce their labour activity because the income foregone is low, for example, because of low salary/earnings potential or part-time work. However, the opportunity-cost of reducing labour participation to provide care is not purely an economic decision, as research has shown.<sup>22</sup>

Families may also make such opportunity cost decisions across households. For example, spouses may provide unpaid care because of a wish not to interrupt the career of an adult child, with the effects that would result on the adult child's pension saving, future potential earnings, acquisition of skills and child-rearing.

- *Social and cultural norms and values*

It is easy to analyse decisions and choices around unpaid care provision in terms of 'rational actors' and economics. However, the allocation of care burden and responsibilities may also have little to do with rational decision-making and bargaining, but in fact mostly result from social and cultural norms and values. The effects of such norms and values are particularly observable through comparisons of unpaid care provision across different ethnic and religious groups.<sup>23</sup> The consistent tendency for more

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<sup>20</sup> Yeandle S et al. (2007) *Stages and Transitions in the Experience of Caring*, Carers UK, London

<sup>21</sup> Kuuppelomäki M et al. (2004) "Family carers for older relatives: sources of satisfaction and related factors in Finland" in *International Journal of Nursing Studies*, Vol. 41, p497–505

<sup>22</sup> Arksey H et al. (2005) *Carers' aspirations and decisions around work and retirement*, Department for Work and Pensions Research Report No 290, HMSO: London

<sup>23</sup> Sudha S & Mutran E (1999) "Ethnicity and Eldercare Comparison of Attitudes Toward Adult Care Homes and Care by Families" in *Research on Aging*, Vol. 21, No. 4, p570-594

women than men to be unpaid carers can also be linked to the effect of social and cultural values.

### Unpaid Care by Older People

This brief review demonstrates the complexity of the 'social construction of unpaid care'. Individual decisions that result in unpaid care provision are likely to incorporate multiple factors identified above, whether or not these factors are explicitly recognised by a carer. Changes in any one of these factors could be expected to affect the provision of unpaid care by an older person, both in whether they provide care and how much.

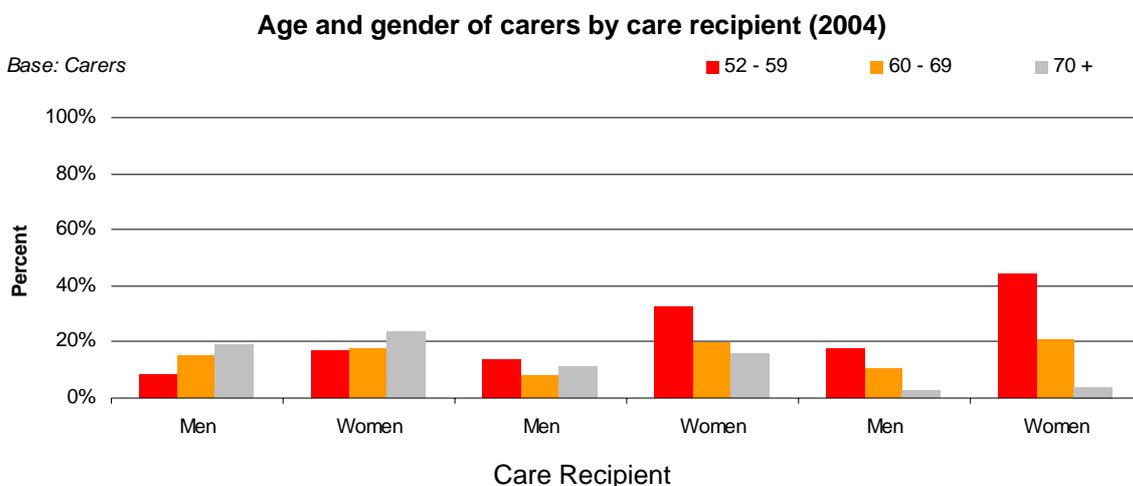
Nevertheless, across the population of carers - and older carers - patterns in care provision and outcomes do emerge. The 'social construction of unpaid care' leads to particular patterns of care provision in the population, which can be observed in research.

*Living and Caring?* compared outcomes for older carers and non-carers, and analysed differences among carers for the *locus* of care (care for a spouse, for a parent or for an adult child, i.e. not 'childcare') and for the *burden* of care (more than or less than 20 hours of care per week). The analysis controlled for gender, age, marital status and education.

Around 10% of individuals aged fifty-two and above were providing some form of unpaid care in the year 2004. Of these, 39% cared for a spouse or partner, 11% cared for a child with specific care needs, 34% cared for their parent(s) or parent(s) in law, and 24% for another category of person (and hence were not included in the study). *Living and Caring?* found consistent differences in outcomes and characteristics of carers. For example:

- As expected, women provide the bulk of care, but this effect is far stronger in relation to parental care compared to care for a spouse. Around 10 per cent of women aged 50+ provide parental care. Among the 70+, men are more likely to be spousal carers than women.<sup>24</sup>
- Locus of care provision varies with age. As individuals age, they are less likely to be providers of care to a parent or adult child, but more likely to be spousal carers.
- Carers are diverse in their characteristics. For example, individuals providing light (up to 20 hours) parental care had non-pension wealth significantly above the mean for non-carers.<sup>25</sup> For providers of heavy spousal care, the opposite is true.

These variations and patterns in care-giving can be seen by comparing the age and demographic profiles of the different groups analysed by *Living & Caring?* within the 50+ age group:



<sup>24</sup> However, this may be the result of a 'selection effect', i.e. rates of mortality among men.

<sup>25</sup> This finding controls for age so is not simply a function of lifestage or cohort membership.

The typical characteristics of different types of carer in the 50+ population, compared to an average non-carer, can be summarised as follows:

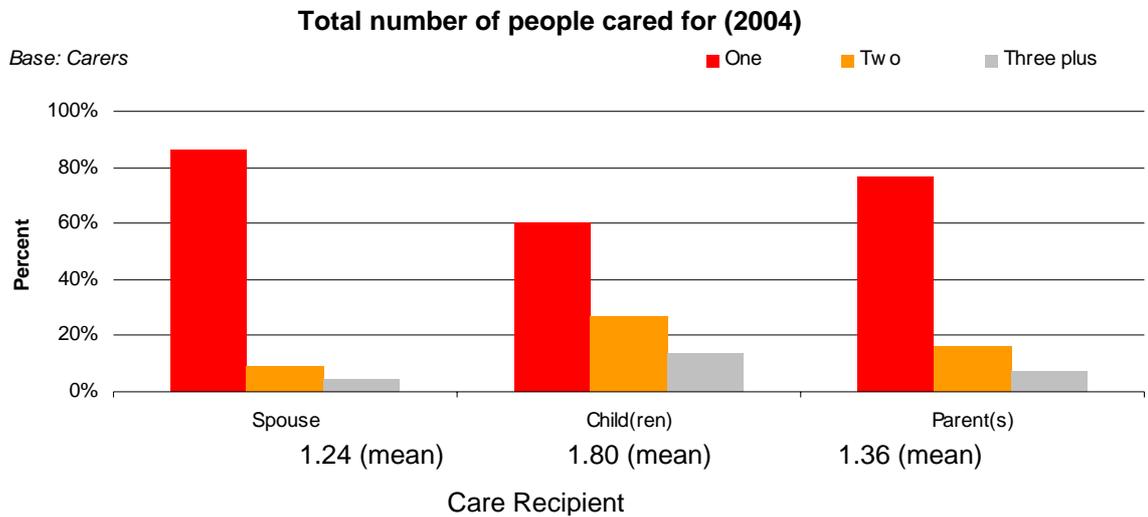
*Non-carers:* 52% female, average age 68, 34% single, 44% no qualifications, 48% low supervisory, semi-routine & routine.

*Spousal carers:* 58% female, average age 68, all married, 46% no qualifications, 54% low supervisory, semi-routine & routine.

*Parental carers:* 69% female, average age 59, 20% single, 24% no qualifications, 37% low supervisory, semi-routine & routine.

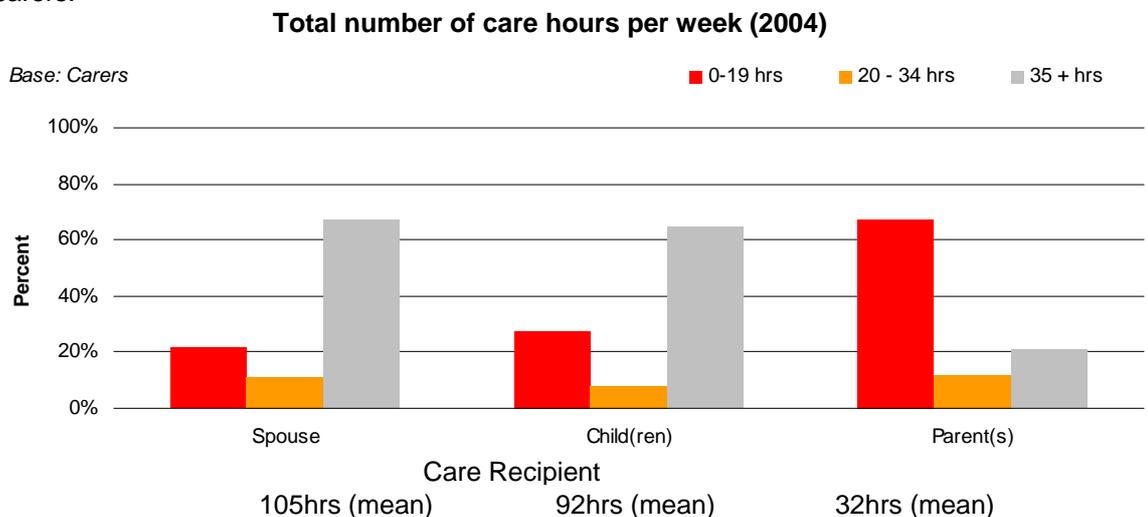
*Adult child carers:* 68% female, average age 63, 22% single, 42% no qualifications, 47% low supervisory, semi-routine & routine.

Living and Caring? also found that variations exist in the number of people cared for by older carers:



This charts show that although the majority of older carers only provide care to one person, individuals can have multiple caring roles.

Wide variations also exist in the average number of hours of care provided each week among carers:



Providers of parental care typically provide far fewer hours of care per week than other types of older carer and the majority of parental carers provide up to 19 hours of care per week. Among older carers of spouses and adult children, the situation is reversed: care provision is clearly skewed toward 'heavy care'.

These patterns in carers and care provision are reflected in other characteristics of carers:

- Spousal carers consistently report worse outcomes than non-carers, for example, in income, total non-pension wealth, functioning and quality of life.
- Conversely, parental carers consistently display better outcomes than both spousal carers and carers of adult children. This can be related to the fact that the hours of care provided by parental carers are typically lower, and that fewer parental carers (20%) live with the person they care for, compared to spousal (100%) and child (70%) carers.

## **Discussion**

How do older carers come to be older carers? Why do older carers provide the type and volume of care they provide? This chapter has reviewed the multiple factors that determine patterns of care provision, including volume of care, within the population. Many different patterns of care provision in the older population could be imagined; any number of different scenarios for the allocation of the burden of care unpaid care to the older population could be conceived. However, *Living and Caring?* shows that clear patterns of care provision by the older population exist:

- Care provision is gendered: women are consistently more likely than men to provide unpaid care.
- Care provision is skewed: relatively few of the older population provide spousal or care to an adult child and this care is skewed toward heavy care. Care provision is effectively *concentrated*, not dispersed.
- Care provision varies by the *locus* of care: parental carers typically provide far fewer hours of care each week than other types of older carer.
- Care varies with socio-economic group: overall, care provision among the older population appears slanted toward lower socio-economic groups. This effect is most noticeable with spousal carers. This supports previous research findings that individuals from lower socio-economic groups are more likely to be caring for a spouse than their wealthier peers: a tendency which can be explained in part because of the higher prevalence of disability and illness among these groups,<sup>26</sup> and the purchase of formal care by wealthier older groups.

So, among the many ways in which the burden of caring could fall on the older population, the actual 'social construction of unpaid care' reveals carers and care provision with the characteristics and patterns outlined above. It would be reasonable to expect this 'social construction of unpaid care' by older cohorts to be associated with different outcomes among carers. This is indeed the case and is explored in more detail in the next chapter.

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<sup>26</sup> Glaser K & Grundy E (2002) "Class, caring and disability: evidence from the *British Retirement Survey*" in *Ageing & Society*, Vol. 22, p325-342

## Chapter 3: Are Older Carers Living and Caring?

The previous chapter has shown the diversity among older carers and their experience of care provision. In particular, differences among carers are observable in age, socio-economic characteristics and whether someone lives with the person cared for.

Given this diversity, how does care provision impact upon the lives of older carers? It would seem likely that the effects of caring will vary among different types of carers. What differences in outcomes can be observed both among older carers, and between carers and non-carers? This chapter explores the evidence provided by *Living and Caring?*.

The *Living and Caring?* research explored differences in outcomes associated with care provision, i.e. it compared the outcomes of carers and non-carers, controlling for age, gender, education and marital status. *Living and Caring?* analysed the outcomes of carers among different 'policy domains', such as housing and health, to explore how care provision was associated with differences in outcomes in these domains compared to non-carers. The research also explored the association between care provision and quality of life. The key findings of *Living and Caring?* are summarised below and identify both 'negative' outcomes associated with care provision, and findings that are 'positive' or simply interesting for the absence of negative outcomes.

### *Quality of Life*

*Living and Caring?* analysed the responses of older carers to a set of 19 questions used in surveys such as the *English Longitudinal Study of Ageing* which have been designed to collectively provide a scientific measure of quality of life and well-being. These questions include feelings of being in *control*, having *autonomy* to pursue personal goals, as well as experiences relating to *self-realisation* and *pleasure*. *Living and Caring?* found that:

- Providers of 'heavy' (20+ hours per week) spousal, child and parental care report a significantly lower quality of life than non-carers. The importance of this finding is underlined by the fact that the vast majority of care by older people for spouses and adult children is 'heavy' care.
- + Providers of light child and parental care have the same quality of life as non-carers.

### *Income and work*

*Living and Caring?* considered multiple aspects of income and work for older carers, including consideration of individual and family income.

- Among working-age older carers, providers of heavy care of all types are significantly less likely than non-carers to be in paid work. The total earnings of older carers in employment are lower than non-carers, particularly for providers of heavy care to a parent and adult child.

Family income from employment is higher for non-carers than carers. Overall equivalised family income (i.e. from employment and other sources) for older carers is generally lower than non-carers (£215pw.). For example, equivalised total weekly family income for light spousal carers was £188pw.<sup>27</sup>

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<sup>27</sup> To put this figure in perspective, it is worth noting that in 2004, Pension Credit, the means-tested income guarantee for older people sought to ensure everyone aged 60 and over received an income of at least £105.45 for single people and £160.95 for couples.

Longitudinal analysis found that individuals providing care in both 2004 and 2006 had overall non-pension wealth significantly below non-carers.

Providers of heavy care to a spouse or adult child have total non-pension wealth significantly below that of non-carers. In fact, rates of property ownership - which accounts for the bulk of non-pension wealth - among spousal carers are significantly below that of non-carers.

- + Providers of light parental care had total non-pension wealth significantly above the average for non-carers.

Older carers of all types are no more likely to report that they are in financial hardship than non-carers, despite variations in income within the population of carers, and the lower income experienced by some older carers, compared to non-carers.

Across multiple factors, carers in paid employment – or who remain in paid employment following the start of caring - do not report significantly more problems at work than non-carers in relation to job satisfaction, recognition at work, job promotion prospects, job security, time pressure, adequate support and feelings of control in work. However, these finding may reflect 'selection effects', i.e. carers leaving work to provide care, or moving to lower-skilled and lower-paid less-demanding jobs in order to balance care responsibilities with paid employment.

#### *Access to services and mobility*

The importance of carers having mobility outside the home and access to services is generally acknowledged. *Living and Caring?* explored whether there were differences between older carers and non-carers in relation to mobility, access to services and use of a car.

- Compared to non-carers, spousal and parental carers report more difficulty getting to hospital services (around 25% compared to 10% of non-carers), as well as more difficulty getting to a GP.
- + Older carers providing light parental care were more likely to have access to a car than non-carers; all other older carers report no difference in car access to non-carers. Similarly, there are no significant differences between older carers and non-carers in the use of public transport.

When controlling for car access and individual mobility, older carers are not particularly more like to have difficulty getting to local shops, dentists, and the post office.

#### *Leisure and Community Activities*

Care provision could be expected to be associated with disengagement with the community or less participation in leisure activities, such as taking a holiday. *Living and Caring?* found:

- Perhaps reflecting lower income and wealth, spousal carers are less likely to holiday abroad or in the UK, or take day-trips. Indeed overall, older people that begin caring become less likely to take a holiday abroad. Older carers are more likely to wish they could go to the cinema more often than non-carers. Providers of heavy spousal carers wished that they could eat out more often and are likely to be a member of fewer organisations than non-carers.
- + There are no differences between carers and non-carers in relation to having a hobby or pastime. Parental and adult child carers report no difference to non-carers in taking

holidays and day-trips. Providers of light parental and adult child-care are likely to be members of more organisations than non-carers.

### *Health*

The effect of care provision on the health of carers has long been a key interest for researchers and policymakers. *Living and Caring?* explored both the health of carers and their 'functioning', e.g. mobility and ability to carry basic tasks of daily living.

- Longitudinal analysis found that those caring in both 2004 and 2006 were consistently more likely to report poor subjective health than non-carers, although the difference was extremely small.

Providers of heavy spousal care are more likely to have poor mobility than non-carers.

- + The proportion of carers reporting that their health is excellent or very good is no different to the non-carer population (around 39%). There is no difference between carers and non-carers in the likelihood of being troubled by pain.

Providers of light parental care are likely to have better mobility than non-carers. Heavy spousal carers and parental carers are more likely to have a higher capability for carrying out 'activities of daily living'.<sup>28</sup> Similarly, heavy spousal carers and providers of light child and parental care have a higher capability for 'instrumental activities of daily living'.<sup>29</sup> Carers providing heavy spousal and heavy parental care also appear to have a higher level of 'executive function' than non-carers.

### *Housing*

Given most older carers live with the person they care for, housing will be critical in determining a person's experience of caring. *Living and Caring?* explored patterns of tenure, housing problems and housing adaptations among older carers.

- Spousal carers are significantly less likely to be 'owner-occupiers' than non-carers (around 70% compared to 85%). This is likely to reflect the higher incidence of spousal care provision among lower socio-economic groups. Indeed, providers of spousal care are more likely to have housing problems such as lack of space, vermin and noisy neighbours.

Providers of heavy care to an adult are more likely to live in overcrowded accommodation.

- + Spousal carers are more likely than non-carers to live in homes adapted for frailty and disability. The number of adaptations to a home increases for individuals moving into care, suggesting the deployment of adaptations in response to the start of caring responsibilities.

## **Discussion**

Are older carers living and caring? Perhaps the most critical finding of *Living and Caring?* was that the majority of older carers do experience significantly lower quality of life than equivalent non-carers. It bears repeating that since most care provision by older people for a spouse or

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<sup>28</sup> 'Activities of daily living' or so-called ADLs include: dressing, walking across a room, bathing and eating.

<sup>29</sup> IADLs include preparing a hot meal, shopping for groceries, making telephone calls and doing work around the house or garden.

adult child is heavy care, this means that a very large proportion of older carers are experiencing a significantly lower quality of life as a result of their care provision.

However, it is interesting to note that providers of light care to adult children and parents report no difference in their quality of life, demonstrating again that providing any care is not itself associated with poorer quality of life; rather, variations in the *locus* and *burden* of care are the factors that seem to be associated with older carers experiencing a poorer quality of life.

However, linked to this finding, a key theme that emerges from *Living and Caring?* is that although variations in the locus and burden of care are associated with different outcomes for carers, variations among older carers in the burden and locus of care are themselves the result of the 'social construction of care' and the demographic, socioeconomic and other characteristics of a carer prior to their care provision.

In short, the experience of care-giving is not homogenous and depends in large part on a person's outcomes – health, wealth, socio-economic status etc. – *prior* to their provision of care. Although care provision seems to cause reduced outcomes among some carers, relatively poor outcomes also seem to be factors associated with care provision among some groups. In this sense, both the care and the outcomes that an individual experiences as a result of caring are *path dependent*.

This can be seen by contrasting outcomes for providers of light parental care and heavy spousal care:

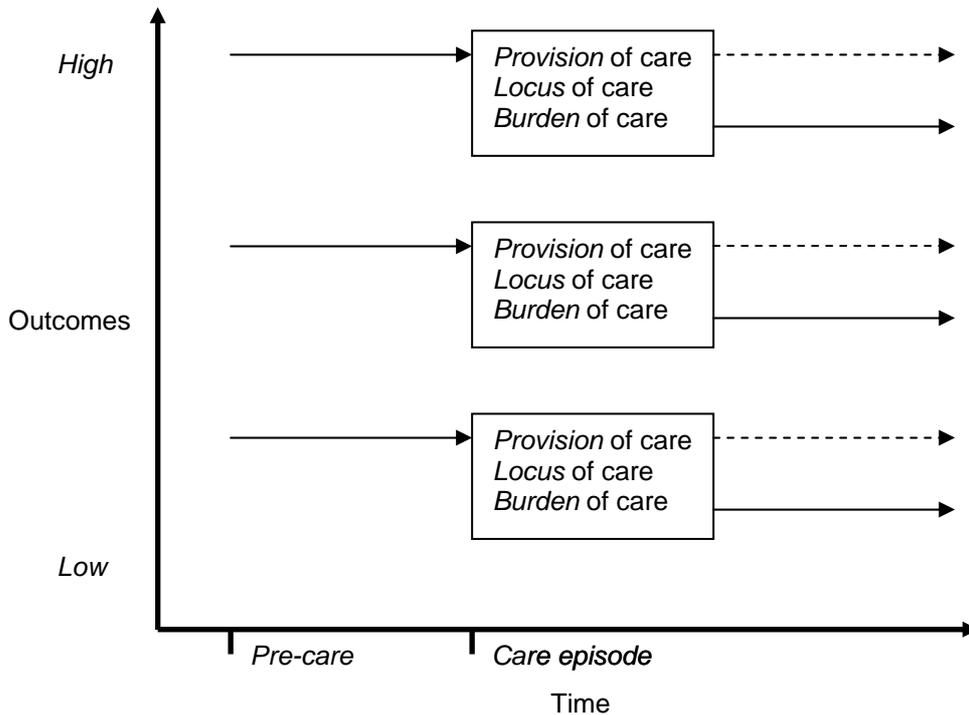
- Light parental carers have the same quality of life as non-carers; heavy spousal carers experience significantly poorer quality of life;
- Light parental carers have total non-pension family wealth significantly above the average for non-carers; heavy spousal carers have significantly less non-pension family wealth than non-carers resulting, in particular, from lower rates of property ownership among spousal carers.

*Living and Caring?* also provides evidence of differences among carers in adaptations and coping with unpaid care provision:

- Light parental carers are more likely than non-carers to have access to a car;
- Spousal older carers are significantly less likely to have taken a holiday abroad in the last 12 months than all other types of older carer.

There is also evidence that some characteristics of individuals prior to their care provision may result in their 'selection' to provide care. For example, providers of heavy spousal care have higher 'executive function' than non-carers and similarly higher capacity to carry out various activities of daily living. Such capacities may have developed in response to care provision, but may also be the very reason that, for example, a spouse chose to take on care responsibilities rather than relying on an adult child.

This *path dependency* in carer outcomes is crucial to understanding the effects of care provision. The relationship between an older person's initial pre-care outcomes, the influence of these outcomes on whether they become a carer and the locus and burden of that care, and ultimately the outcomes they experience as a carer, can be conceptualised in the following form:



This graph shows that prior to an episode of care, individuals can experience a range of outcomes. These outcomes influence:

- Their *provision* of care, i.e. whether they become a carer;
- The *locus* of care, i.e. who they provide care to;
- The *burden* of care, i.e. how many hours of care per week;
- The outcomes that a carer experiences as a result of caring.

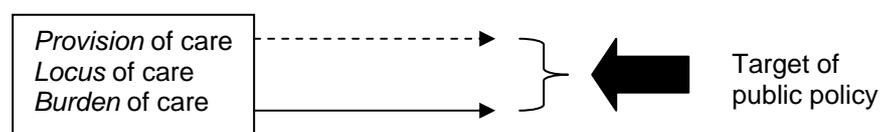
The majority of older carers experience reduced outcomes in some form as a result of their care provision. This is represented above as the difference between the single and dotted lines on the right of the graph.

#### Outcomes, Care and Public Policy

This approach for conceptualising how pre-care outcomes and care provision itself influence a carer's outcomes provides a useful framework for thinking about the scope and objectives of public policy toward carers.

Clearly, 'carers policy' carers cannot affect the outcomes of carers prior to their episode of care provision. It also appears beyond the scope of carers policy to seek to target outcomes that principally result from an individual's outcomes prior to their provision of care. For example, carers above pension age may be in poverty because of multiple factors that occurred during their working life, rather than the beginning of a care episode in retirement.

This suggests that public policy directed at supporting older carers should seek to reduce and eliminate differences in outcomes for carers that result from caring. These differences in outcomes can be presented as:



This approach is already reflected in attempts to monitor the health of carers and ensure that they do not suffer ill-health as a result of caring responsibilities. It is also reflected in calls to fully compensate carers who are forced to reduce their activity in the labour market through extra pension contributions paid on their behalf. This reflects the fact that the effect of caring on the outcomes of carers can be short-term/immediate (stress and ill-health), or long-term (retirement poverty or gradual obsolescence of skills).

Nevertheless, it is important to recognise that for carers in lower socio-economic groups, whose lower pre-care outcomes influence the chances of providing care and its locus and burden, unpaid care provision can be considered just one more factor that amplifies and multiplies the adversity they experience during the life-course.

This point has been made in relation to the health outcomes of carers by Hirst (2005) who recommends that unpaid care provision be considered an integral part of the health inequalities agenda – i.e. as another social determinant of health outcomes and health inequalities - given the potential health effects of unpaid care provision and its association with certain socio-economic groups.<sup>30</sup>

So, does this approach of reducing or eliminating the negative effects of care provision on carer outcomes provide a clear framework for the development of public policy toward carers? Not necessarily. Reducing the negative effects of caring in one domain of a carer's life (e.g. health) may mean raising outcomes in another domain of a carer's life over and above what such a person would have experienced in the absence of care (e.g. income).

For example, for carers providing the heaviest and most intense forms of care, extremely high compensatory incomes may be required to achieve a quality of life equivalent to what they would have experienced without the responsibility of care provision.

In addition, commentators and social discourse often view certain outcomes for carers as being unacceptable because of their care provision and perceived contribution to society. For example, there is less tolerance of income poverty among carers than non-carers, regardless of whether it is the provision of unpaid care that results in income poverty.<sup>31</sup>

So, while reducing or eliminating the negative effects of care provision on the lives of older people provides a guiding framework for the development of public policy toward carers and indeed, has done so for some time, it does nevertheless appear that value judgements, targeting and trade-offs will still be required. This points to a vital need to understand what factors influence the outcomes that carers experience.

*Living and Caring?* found that that the effect of care provision on carers was most pronounced in relation to their quality of life. The analysis therefore sought to explore what outcomes, in domains such as income, leisure and housing, were associated with variations in the quality of life of an older carer. These findings are outlined in the next chapter.

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<sup>30</sup> Hirst M (2005) "Carer distress: A prospective, population-based study" in *Social Science & Medicine*, Vol. 61, Issue 3, p697-708

<sup>31</sup> The dilemma this issue poses for policymakers is demonstrated by the commitment in the 2008 UK 'Carers Strategy' to support carers "so they are not forced into financial hardship by their caring roles", but not to take carers out of financial hardship.

## Chapter 4: Improving the Quality of Life of Older Carers

A key priority for policymakers is improving the quality of life of carers. What factors improve quality of life for older carers? The *Living and Caring?* research explored two crucial questions: how are the characteristics of the person receiving care associated with the carer's quality of life? How are variations in outcomes across different domains of a carer's life associated with variations in their quality of life?

### *Quality of Life and the Receiver of Care*

Clearly, the characteristics of the person receiving care will have a significant influence on their carer's quality of life. *Living and Caring?* explored this relationship by looking at the characteristics of older individuals receiving care and analysing how variations in these characteristics were associated with the quality of life of their spousal carer. *Living and Caring?* analysed multiple different characteristics of the person requiring care:

- Ability to undertake 'activities of daily living' (ADLs);
- Ability to undertake 'instrumental activities of daily living' (IADLs);
- Self-reported (subjective) health;
- Experience of severe pain;
- Executive function such as literacy, numeracy;
- Memory functioning.

The research looked at how variations in these characteristics are associated with the quality of life of the carer, and undertook this analysis controlling for the effect of other variables such as hours spent caring and age. The analysis showed that one characteristic of the person requiring care had a far stronger association with variations in the carer's quality of life than all the others: *memory functioning*.

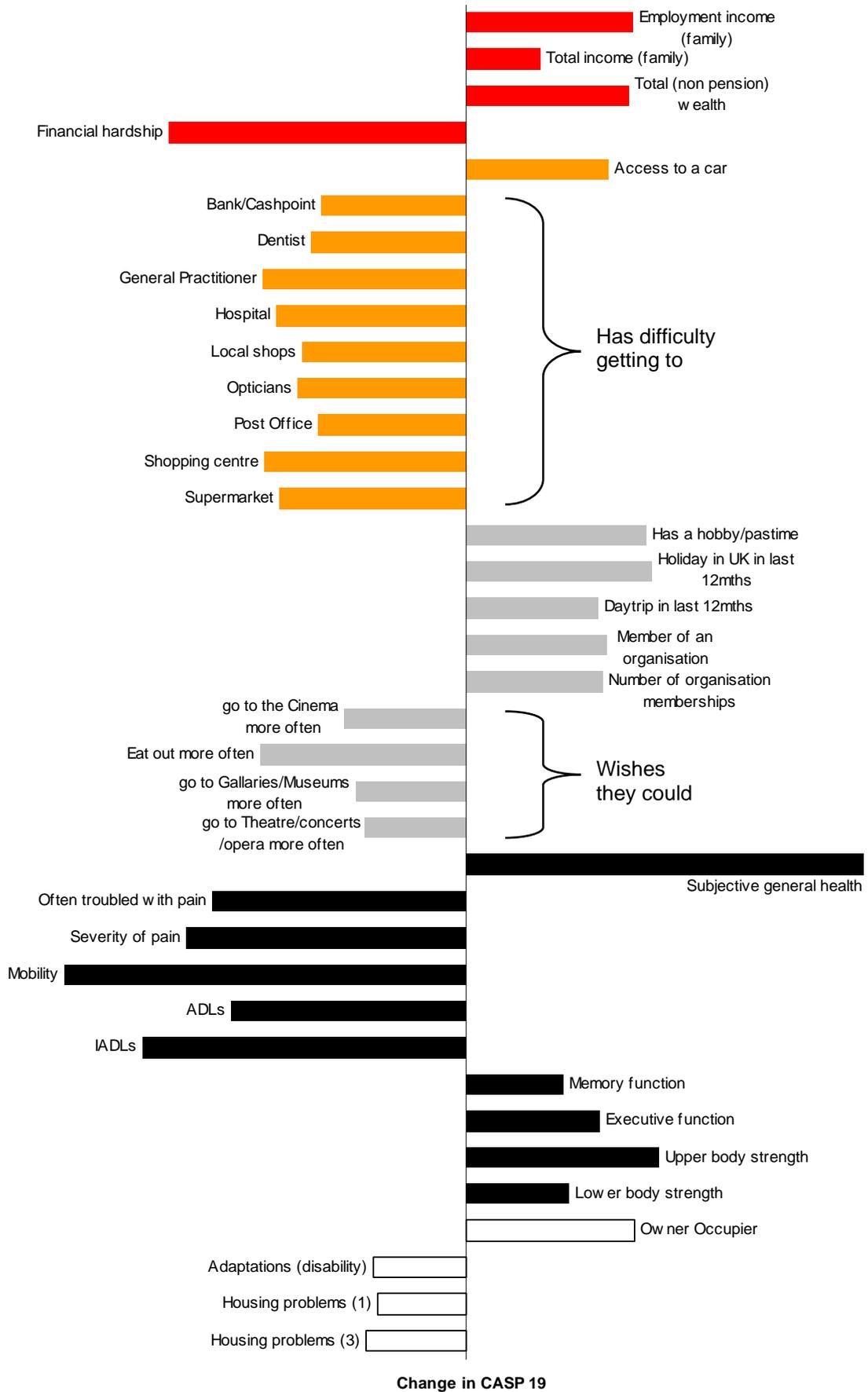
Memory functioning relates to time orientation (knowing the time and date), word recall (recalling information immediately and after a delay) and prospective memory (remembering to do something). Variations in memory function of the person requiring care are strongly associated with their carer's quality of life.

These findings were drawn from data on spousal carers, the vast majority of whom live with the person they are caring for. It can be surmised that the effect of memory function would apply to other types of care provision; however, its effect on parental carers is likely to be diluted by the fact that only 20% of this group of carers live with the person cared-for.

### **Influences on the Quality of Life of Carers**

The preceding chapter showed variations in the outcomes of older carers across key policy domains such as access to services and income. Clearly, variations in these outcomes among carers will influence their quality of life. *Living and Caring?* therefore compared how variations in these factors were associated with variations in the quality of life of older carers, and 'standardised' the effects of these variations so that the influence of different factors could be compared directly. The results are shown below:

**Comparative Significant Influences on Quality of Life Using Standardised Results**



This analysis of factors influencing the quality of life of older carers provides some interesting insights, for example, the overall importance of health outcomes for the quality of life of carers, despite the fact that *Living and Caring?* did not uncover significant differences in the health of carers compared to non-carers. Similar comments could apply to access to local services and facilities.

## **Discussion**

*Living and Caring?* found that far more than any other characteristic, the memory functioning of an individual receiving care has a significantly negative effect on the quality of life of their spousal carer. The implications of this finding are sobering when it is considered that there are currently about 700,000 people in the UK with a form of dementia but, commensurate with population ageing and increasing longevity, this will increase to 940,000 by 2021 and 1.7 million people by 2051.<sup>32</sup>

How then to improve the quality of life of older carers? The *Living and Caring?* research suggests the following recommendations for policymakers:

- *Incorporate memory functioning in assessments*

The importance of memory functioning of the person receiving care for the quality of life of an older carer suggests that measures of memory functioning should be incorporated into all assessments of individuals receiving care, and the results circulated among all related professionals (GPs; care brokers) involved in supporting their carers. The impact of poor memory functioning for those providing care should be included in efforts to educate medical professionals about carers. Policymakers should also review the scope and merit in specific support services for those providing care to people with poor memory functioning, including as part of the Government's 'dementia strategy'.

- *Put healthcare at the forefront of policy to support carers*

More than any other 'domain', an older carer's quality of life is influenced by their health, for example, whether they are troubled by pain or have difficulties carrying out daily activities. Many health conditions among carers are likely to pre-exist their caring responsibilities and indeed, *Living and Caring?* found little evidence of differences in health outcomes among older carers and comparable non-carers. However, these findings suggest that for older carers, improvements in health status have the biggest influence on quality of life. Indeed, although *Living and Caring?* found limited evidence of older carers experiencing poor health, the findings raise questions about the appropriateness of any individual providing care who is in ill-health or has a low capacity to carry out daily activities.

The 2008 Carers Strategy recognises the importance of healthcare in supporting carers and sets out various measures the Government will explore including greater support for carers at GP practices and hospitals, the development of a full training package for GPs, and the rolling-out of annual health checks for carers nationally.

However, the *Living and Caring?* research suggests that further measures could be deployed. In particular, the singular importance of mobility on the quality of life of an older carer suggests that assessments and resources should be targeted at identifying older carers with lower mobility and the provision of products and services that will compensate for poor mobility.

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<sup>32</sup> Knapp M et al. (2007) *Dementia UK*, Alzheimer's Society, London

- *Access to Services*

Those representing the interests of carers often emphasise the importance of accessing services. Although *Living and Caring?* found that only a minority of older carers have problems accessing services, difficulties in accessing services do indeed have a significant influence on quality of life. This suggests that access to services should always be included in assessments of carer's needs, and local authorities should explore how access to services can be improved for those otherwise struggling. This may include the provision of subsidised public transport.

- *Total family income*

Total family income has a surprisingly small influence on the quality of life of an older carer compared, for example, to being able to get to a supermarket, having a hobby or access to a car. This perhaps demonstrates that it is the scope for sufficient *consumption* (of goods, services, etc.) rather than *income* that truly matters for older carers. This is underlined by the fact that although carer's are not particularly more likely than non-carers to report financial hardship, the incidence of financial hardship is however among the strongest influences on an older carer's quality of life. This points to the need for policymakers to again explore the interaction of carer's benefits and means-tested benefits for retirement income poverty, recognising in particular, the fact that care provision may impose costs which reduce the adequacy of Pension Credit as an income supplement.

- *Leisure*

Those representing the interests of carers regularly emphasise the importance of breaks and respite care. The evidence of *Living and Caring?* is surprising for the strength of the influence of various types of leisure activity on the quality of life of the carer, particularly having a hobby or pastime, or holiday in the UK during the last 12 months.

## Chapter 5: The Future of Carers Policy

At present, demand for social care is met by formal care and unpaid care. However, some demand remains unmet. It is widely recognised that demand for social care will increase in coming decades in line with population ageing and increasing longevity.

Defining the future of public policy toward carers requires taking account of the broad picture of demand and supply of social care within the population, in particular, the interaction of unpaid care and unmet need.

The Commission for Social Care Inspection has estimated that the total number of older people who receive no formal care services and no unpaid care despite having high support needs is around 6000 older people, and 275,000 older people with less intensive needs.<sup>33</sup> In the current UK system, 1.5 million older people (60% of the total number of older people with any disability or impairment) have some shortfall in their care if it is assumed they do not receive any informal care. This number goes down to 450,000 people if the support of family carers is assumed.

Unpaid care therefore sits between the provision of formal care and unmet need.<sup>34</sup> One reason that so many carers provide 'heavy care' is that it is the very flexibility and informality of unpaid care that results in the capacity of carers being stretched to meet the difference between demand and the supply of formal care, whether paid for privately or by the state. Unpaid carers are forced to be the 'spare capacity' in the system who struggle to meet demand for social care, albeit at considerable cost to the individual carers involved.

Such is the nature of the 'social construction of unpaid care' among older people: too much unpaid care is provided by too few people for too many hours. Unpaid care provision does not itself cause ill-health, poverty or lower quality of life: rather, it is the burden (hours of care), incidence and patterns of care observable among older cohorts resulting from the 'social construction of unpaid care' that leads to such outcomes.

Where the provision of unpaid care results in extra costs for the state (healthcare for carers, reliance on pension credit, etc.), there is clearly a logical imperative for public policy intervention. However, political consensus has rightly concluded that public policy should go further: to reduce or eliminate as far as possible the negative effects of caring on outcomes for carers. The previous chapter explored and provided recommendations for improving public policy to support carers in relation to quality of life. This chapter looks at the wider transformations across public policy and society that are required to define a future for carers policy. What recommendations can be made?

### **Increase the supply of care in society**

*Living and Caring?* repeatedly demonstrates better outcomes for individuals providing light (up to 20 hours each week) care compared to providers of heavy care. Given such tendencies and the fact that much care provision by older carers is heavy care, it is clear that the overarching objective of policy toward carers must in fact be to increase the supply of care within society and to distribute and disperse more widely the burden of care which is currently concentrated among so few people. This can be done in two ways:

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<sup>33</sup> CSCI (2008) *The State of Social Care in England 2006-2007*, CSCI, London

<sup>34</sup> It has been estimated that 10% of care to older people is privately purchased, 25% is purchased by the state, and 65% of care to older people is unpaid. See: Deloitte & Touche (2008) *Mapping Care of Older People*, Resolution Foundation, London

- *Increasing the supply and availability of formal care*

It was observed in Chapter 1 that some unpaid care provision results from the non-availability of formal care, due in particular to cost factors. In addition, market failures, lack of brokerage and advice, and aversion to paid care are all barriers to the supply of formal care.

To truly relieve the burden on unpaid carers, the UK population will have to allocate a much greater proportion of its total national public and private wealth to the task of formal care provision, thereby massively increasing the supply of formal care. This will involve not just turning over a much larger volume of wealth to the production of formal care, but also transferring productive capacity in the economy to the task of care provision, in particular, transferrals of labour from other parts of the economy to the care industry.

Although there is general recognition across the political spectrum that the UK needs to spend more on care provision, how this reallocation of national wealth will occur is a source of ongoing debate. Discussion centres on the balance of contributions between the individual and the state, the role for redistribution, the extent of risk-pooling and how the risk-pool for long-term care should be drawn, in particular, across the older cohort only or across all age-groups.

Simple out-of-pocket payments for formal care are inadequate as shown by the current system; un-affordability and liquidity constraints result in unmet need and excessively concentrated provision of unpaid care. Universal free state-funded personal care is viewed as unaffordable given the costs that would be imposed on the state and taxpayers, and is increasingly recognised as having pernicious effects for intergenerational equity and wider societal inequality. Other funding models have been proposed that seek to incorporate the risk-sharing embodied by state-funding, but through alternative risk-pooling mechanisms that allow older individuals to insure themselves for the risk of long-term care using wealth that would otherwise be left as inheritance.<sup>35</sup>

Whatever funding model or models are preferred, and however political discourse is able to achieve consensus and form a new narrative and 'bargain' with the voting population, improving outcomes for unpaid carers and relieving their burden will involve a far larger portion of the UK's wealth being allocated for this purpose. The preponderance of both demand for care and provision of heavy care among lower socio-economic groups also points to the inevitability of redistribution within the system. A truly meaningful 'strategy for carers' will only be possible when a new long-term care funding system has been implemented in the UK.

- *Increasing the number of unpaid carers*

Unpaid care represents the bulk of care provided and ultimately fills the gap between formal care provision and unmet need. Yet relatively few individuals provide unpaid care with the result that care is *concentrated*: as *Living and Caring?* has shown, the provision of a heavy burden of care is associated with negative outcomes for carers. This burden and its negative effects on the outcomes of carers could be reduced if more individuals were to provide unpaid care. Although increasing the number of individuals who provide unpaid care may appear counterintuitive as an objective of public policy or as part of a 'carers policy', it is clear that if the burden of unpaid care was better *dispersed*, all unpaid carers would experience better outcomes.

How can the Government increase the supply of unpaid care? Ultimately, every decision to provide unpaid care is personal, unique and results from multiple factors. Nevertheless, as is clear from the exploration of the 'social construction of unpaid care' in Chapter 1, multiple factors and drivers lead to current patterns of unpaid care provision, and several

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<sup>35</sup> Lloyd J (2008) *A National Care Fund for Long-term Care*, ILC-UK, London

approaches could be conceived for the Government to increase the number of unpaid carers:

a) Improve support for carers

More individuals are likely to become carers if there is support available to them in their caring role. Advances in Government policy to support carers and clarify their rights therefore represent the correct approach, both for supporting existing carers and ultimately encouraging more individuals to become carers. Indeed, it is not just important to inform existing carers about their rights and available support; everyone should be informed of this so that individuals can be encouraged to become carers. As the Government has recognised, this needs to be part of wider changes in societal attitudes that recognise and value the contribution of carers. It will also involve recognising at an institutional and policy level that several individuals may be involved in providing unpaid care to someone and each individual carer may require support.

b) Decision-making tools for families about unpaid care provision

While the Government cannot intervene in private family decisions about care provision, the Government could help families make these decisions. As reviewed in Chapter 1, both the decision to provide care and the volume of that care reflect a complex constellation of factors that is both individual and personal, but also reflects the multiple factors associated with the 'social construction of unpaid care'.

Where families confront a member's need for care and consider unpaid care provision, decision-making tools could be provided to help different members of a family evaluate how much care they can provide. More information could be provided, especially through the work-place, to help all family members understand the effects, consequences and rewards of unpaid care provision. This could particularly focus on the *burden* of care, i.e. the fact that an increasing volume of care provided is associated with increasingly negative outcomes. Information and literature could be made available and targeted at individuals within the kinship networks of older carers to help them understand the effects of care provision and consider their own potential role in supporting a carer, or indeed, providing care. Although caring for children is a common experience that most individuals have at some point, caring for an older individual with specific needs and conditions, such as Alzheimer's disease, is far less common and understood. Most people have a conception of parenting and child-rearing; far fewer have a conception of care provision. This lack of knowledge affects the support structures that form around carers in families and how the burden of unpaid care provision is allocated.

c) Improving the gender balance in care provision

Unpaid care provision is frequently the result of normative and behavioural factors. This is nowhere more visible than in the gendered nature of care provision among older cohorts. Caring roles have traditionally been female, particularly for the cohorts currently entering and in retirement. Where a need for care and support emerges, both male *and* female family members may therefore assume that care will and can only be provided by female family members. Such cultural and social norms can and should be challenged by public policy and publicity campaigns with the purpose of increasing the availability and supply of unpaid care.

### **Achieving the right approach for targeting and means-testing**

In the context of limited public budgets, Governments often seek to target resources either by focusing resources on outcomes that will produce the biggest 'return' for the objectives of public policy, or on targeting resources at those most in need.

However, in relation to supporting carers, such simple guiding principles are thrown into confusion by the complexity of unpaid care provision. In relation to unpaid carers, public resources to fund support for carers could be allocated in multiple ways proportional to:

- The volume of care that individual carers provide;
- The private resources of the carer;
- The private resources of the carer's household;
- The private resources of the person requiring care;
- The private resources of the household of the person receiving care;
- The care needs and condition of the person receiving care;
- The needs and outcomes of the carer;
- The 'cost' of care provision to the carer, e.g. income foregone, reduced pension contributions, etc.

Unpaid care effectively represents a transfer of resources (time, energy, income and leisure foregone) from the carer to the person receiving care. However, it is far from clear that carers expect or receive monetary transfers in-kind in the opposite direction. There is huge variation in the extent to which families 'commodify' caring exchanges within the family, either through the exchange of actual cash or non-monetary goods, e.g. use of a car.

If resources to support carers ignore their household resources or that of the person receiving care, public policy risks transfers to individuals who do not require such support. Indeed, a useful insight from *Living and Caring?* is that the influence of individual carer income on quality of life is not significant; rather, it is family work status and level of income that is significant. Transferring resources to carers in wealthier households clearly therefore risks being wasteful and undesirable to the extent that it limits the resources available to support carers who truly do need support.

From the perspective of public policy, complicating matters further is the personalisation agenda in social care and 'individual budgets' for individuals with care needs, which provide such individuals with an amount of money that they can spend on their care and support as they wish, which may or may not include paying their carer directly or paying for services that support their carer.

In addition, many commentators argue that the societal benefit of unpaid care provision should be recognised through a universal entitlement for carers as opposed to an 'income-replacement' benefit. Finally, it is also generally recognised that it is difficult enough to induce individuals to identify themselves as carers; any means-testing will only further increase the likelihood that people will not claim care-related benefits.

What then is the right approach for targeting and means-testing resources to support carers? As is argued above, the environment for carers policy will change radically if a new and appropriate long-term care funding system emerge. Put simply, whereas *Living and Caring?* found over 80% of carers citing "being needed" as the primary reason for providing unpaid care, this figure should drop dramatically if a sufficient and appropriate share of national wealth is allocated to the production of formal care following reform of the long-term care funding system. In such a scenario, the volume of care that carers provide should drop, with many providing only complementary, 'bridging' and top-up care. Indeed, the experience of Scotland is that in the context of readily available formal care, the nature of care provided by carers changes.<sup>36</sup>

Even under such a new system, it is still likely that some form of universal recognition for carers would be desirable. For example, if for whatever reason, an older carer is providing 35 hours of unpaid care per week, some form of carer's allowance would provide recognition of this contribution, particularly if this unpaid care provision reduced demand for formal services or improved the outcomes of the person receiving care.

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<sup>36</sup> Bell D et al. (2007) *Free Personal Care in Scotland: Recent Developments*, Joseph Rowntree Foundation, York

Beyond this, resources for carers could be targeted by focusing on outcomes and seeking to support those carers experiencing negative outcomes while engaged in unpaid care provision. To the extent that unpaid care provision would lead to poverty or ill-health, carers could be helped through existing assessment-based welfare and health systems. Such an approach could apply to both older carers beyond retirement age and working-age older carers.

## **Conclusion**

In one sense, society is still only learning to adapt to the growing demand for social care it faces. Although families have provided child care and child-rearing since the inception of the human race, it is only relatively recently in historical terms, because of increasing longevity and improvements and in healthcare, that societies, and the families within them, are fully contemplating and comprehending the current volume of demand for long-term social care and that which will emerge during the coming decades of demographic change, as well as learning to adapt and cope with long-term care provision. As a result, the social and cultural norms around unpaid care provision, as well as the institutional and policy framework, are arguably still in a 'catch-up' phase. This is particularly observable in the lack of funds and risk-sharing which exist in the UK long-term care funding system.

In future decades, today's current system that allows millions of individuals to suffer poor outcomes as a result of unpaid care provision and insufficient national spending on formal care may come to be seen as an historical aberration, when society, public policy and debate struggled to adapt to changes in dependency and need within the population. Most of all, today's system reflects the lack of redistribution that occurs in relation to long-term care needs: demand for and provision of unpaid care is focused on lower socioeconomic groups with the associated poorer outcomes that result. This has always been the case, but as advances in healthcare and longevity see the incidence of care needs rise up the social scale, the pressure for reform is unsurprisingly growing. If the pool of unpaid carers can be expanded, and a proper system of new funding and risk-sharing for long-term care is implemented, as well as better targeted and delivered support for carers, then there really will be the opportunity for living and caring for all.

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