# Policies for Carers in Australia and the UK

## Social policy ideas, practices and their cross-national transmission: social movements, parliamentary inquiries and local innovations

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# Introduction

This paper offers a comparative analysis of policy developments in relation to carers – those who provide unpaid care for a family member, friend or neighbour who needs their support because of long-term or terminal illness, disability or frailty associated with old age. It considers how, in Australia and the UK in the past decade, demographic, economic, political, labour market and gendered social processes have brought policies for carers on to the agendas of parliamentarians, policymakers and social movements, refocusing how carers and their contribution are conceptualised, regulated and supported. It argues that in the UK, and specifically in England, the wellspring for policy change has been a combination of: socio-economic/demographic imperatives; an active but non-partisan carers' movement; employer engagement at strategic moments; and a strong evidence base, giving voice to carers' own perspectives and marshalling robust statistical data to expose the size, scale and range both of carers' contribution to the health and social care system and of the challenges ahead. These factors culminated in the enquiry of the *House of Commons Work and Pensions Committee* which released its report *Valuing and Supporting Carers* in 2008, producing a raft of recommendations emanating from the UK evidence-base, from consumer representative organisations and other agency submissions, from a large number of public hearings and interviews with relevant ministers and civil servants, and from international visits, including to Australia.

In Australia, the major influences shaping policy changes with respect to carers are similar: political responses to socio/economic/demographic imperatives, specifically population ageing and increased female labour force participation - increased participation which has been mandated by activation policies in the social security system. There is a linked policy discourse stating that increased old age dependency ratios will entail an increased demand for community care services to enable ageing in place. Accompanying this projection, there is official recognition that since the 1980s the policy shift from institutional care to care in the community for people who are aged or with disability has relied heavily on the availability and willingness of informal carers to take on caring responsibilities (AIHW, 2003). This recognition has been coupled with the expressed anxiety that the supply and willingness of informal carers will not be sufficient to meet the increased demand (AIHW, 2003). In addition, there has been and continues to be an active, non-partisan and politically astute Carers Association network with strong advocacy skills which has spearheaded economic valuations of the financial contributions made by informal carers to families, communities and economy, assessing the cost of informal care, including replacement costs if care was provided by formal services, and opportunity costs incurred by carers' reduced workforce participation and loss of market earnings (Access Economics, 2005). In light of this, a series of developments over the last several decades in the social security system have linked carers' pension rates and entitlements to age pension rates and entitlements, in the process safeguarding income support policies for carers from activation requirements and providing these payments with a legitimacy less accorded to other income support arrangements for people of workforce age. There is also an increasingly robust evidence base highlighting the contributions made by informal carers to the health and social care of children and adults with disability, long-term illness and for the frail aged, and in particular documenting and analysing the impacts of care-giving on carers' labour force participation, income, health and well-being (ABS, 2008; Ganley, 2009; Edwards et al, 2008; Hill et al, 2009; Hill and Thomson, 2008). This accumulation of evidence and advocacy culminated in an Australian Government Parliamentary Inquiry (2008-09) into *Better Support for Carers* (House of Representatives Standing Committee on Family, Community, Housing and Youth (HRSCFCH&Y), 2009).

The dissimilarities with the UK lie in particular in the relative absence of engagement with employers or the introduction of national government-mandated workplace policies for carers, while policies of this nature have increasingly been focused on employment leave arrangements and flexible workplace benefits for parents caring for young children.

The Paper examines the similarities and differences across the two countries in policy responses at the levels of social care services, financial support, employment-based policies, highlighting the significant interventions and advocacy of carers representative organisations, and the robust roles of parliamentary inquiries, which have brought the circumstances of informal carers, the supports and services required and the significant gaps in policy centrally onto the policy agendas of both countries. What are the circumstances in which this accelerated concentration of policymaker inquiry and activity has occurred; who are the key policy players; and what has been the cross-national fertilisation of policy ideas? Finally, what has been the impact of these inquiries and investigations at the level of policy developments?

## The policy contexts In the UK and Australia

In both the UK and Australia, the salient socio-demographic-economic and health service trends that have framed the increased emphasis given to informal carers include: demographic ageing and increased longevity; increased rates of age-related disability; increased trends to 'ageing in place' supported by community-based social care provision; developments in health care technology; increases in female labour force participation; and public policy agendas by governments in both countries which have altered substantially the framework and logic of the welfare state.

### *UK: Demographic ageing, increased longevity, increased rates of disability*

In the UK, rising awareness of continuing demographic and social change has been critical in pushing carers and the provision of care at home up the agenda in both social and employment policy. The contextual issues include:

- **Population ageing**, with an expected increase (2000-25) in the numbers of people aged 75+ (up 50 per cent), and 85+ (up 75 per cent).
- The preference among older and disabled people for **independent living**[1], with greater dignity, choice and autonomy. As very few older people in the UK live with their extended families[2] this development makes home-based care ever more important.
- **Developments in healthcare provision and medical technology** which are now enabling many more people to live at home with disability, dementia, arthritis, stroke or other long-term conditions (including younger people being cared for outside hospital despite serious illness or disability).
- **Changes in female labour force participation,** comprising increases which are signalling a shift from a 20th Century male breadwinning/female homemaking ideal to a normative 21st Century

expectation that women, like men, will be active in the labour market throughout adult working life - with important consequences for employment systems, patterns and arrangements.

- **A New Labour political agenda** that through three administrations (since 1997) has set out to implement a reform agenda affecting the welfare state (including social security, pensions and the health service); the education, skills and employment system; and the co-ordination and priorities of local and regional government.

There is a growing awareness that, to support more older, sick and disabled people, many more unpaid carers (an estimated 3 million more by 2025) and additional paid care workers[3] will be needed - at the same time as the UK economy is likely to need 2 million more workers (to fill positions primarily in managerial, technical and health and social care occupations[4]). This has been important in sharpening the policy focus on carers of working age. Key policy initiatives set in place by government – on work-life balance and 'support for hard-working families'; on labour market activation and welfare reform (emphasising the need for all 'who can' to participate in the labour market); new policies on education and pensions which will both delay and extend the timing of working life in the average life-course; health and social care reform (emphasising personalisation, choice, independent living, efficiency and cost containment); housing policies focused on 'supporting people' and assisted living – have all underscored the expectation that for most citizens, working and caring will be fundamental features of their everyday lives, needing to be managed, balanced and facilitated.

## *Australia: Demographic ageing, increased longevity, increased rates of disability*

A similar picture pertains in Australia, where there is a rising awareness of continuing demographic, economic and social change which has been influential in positioning carers and the provision of elder care and disability care at home onto the political and policy agenda, predominantly in social policy but less so in employment policy. The contextual issues include:

- **Population ageing**. The most recent *Intergenerational Report* (Commonwealth of Australia, 2007), produced by the Australian Government provides population projections which show that the proportion of the population aged 65 and over was 13.4 per cent in 2007 projected to rise to just over 25 per cent by 2047. Even more pertinently, the proportion of the very old population aged 85 and over is projected to rise from 1.7 per cent in 2007 to 5.6 per cent in 2047 (Commonwealth of Australia, 2007:16).
- **Preference for independent living and policy priorities toward home and community care.** The expressed preference among older people and people with disability for independent living, in home and community has been reinforced by a significant shift in Australian policies since the mid 1980s from residential care in institutional settings to formal home and community care policies, in which informal carers are often conceptualised as “partners in care” (Borowski et al; 2007; HRSCFCH&Y, 2009). Also in train, but as yet to a significantly lesser extent than in the UK and other European countries, is a trend to consumer-directed care policies and individualised funding models, emphasising greater levels of independence and decision-making over care choices for people with disability; a trend likely to have as yet unidentified impacts on the circumstances and responsibilities of carers (Cass and Thompson, 2008).
- **Developments in healthcare provision and medical technology** These developments are now enabling many more people not only to live longer, but also to live at home with physical, mental and developmental disability, and other long-term health conditions (including children and younger people requiring assistance and support outside institutional settings because of serious illness or disability) (HRSCFCH&Y, 2009). Although the literature notes a significant trend to healthier more active ageing for longer periods of the older life-course, this has not yet resulted in clear evidence that age-specific disability rates are falling in Australia (Mathers, 2007). This is so because the overall prevalence and severity of disability will

continue to increase due to population ageing, since higher proportions of the older population will be in older age groups where disability levels are higher. This raises the questions of how will care be provided, by whom; and how are care policies being framed, with what claims made for the recognition and redistribution of care (Williams, 2009)?

- **Changes in female labour force participation**

  Increased rates of female labour force participation signal, as in the UK, a shift from a male breadwinning/female homemaking normative ideal, which was subject to significant change from the 1980s, to a normative expectation that women, like men, will be active in the labour market throughout adult working life - with important consequences for employment systems, patterns and arrangements. However, in Australia, the predominant trend for female labour force participation has been a significant increase in part-time employment, with a much less pronounced increase in full-time employment (House of Representatives Standing Committee on Family and Human Services (HRSCFHS); 2006). This trend has influenced the shaping of income support activation policies for parents with children towards mandating part-time employment, since recipients of support are predominantly mothers. This constitutes not so much a full adult worker model as a *one-and-a-half earner family model,* with women retaining the major share of childcare responsibilities (Craig and Mullan, 2009) - a trend which spills over into women's significantly higher levels of provision for disability and elder care, compared with men (Cass, 2008).

- **A bi-partisan political agenda for welfare state restructuring**

  From 1996 – 2007 under the Howard Coalition government and since 2007 under the Rudd Labor government there have been significant policy changes towards an 'activation' model in social security which is prioritising and strongly mandating market participation; increasing incentives for remaining in the labour force at older ages, in particular through changes to the retirement incomes system based on the entrenchment of an occupational superannuation scheme which

> renders a longer life-course of (full-time) paid employment increasingly desirable (Borowski and Olsberg, 2007); and the recently announced increase in the age of eligibility for receipt of age pension from 65 to 67, over a phasing-in period. Juxtaposing these changes in the welfare state with the issue of informal care provision for an ageing population with higher levels of disability highlights the gendered nature of these trends: employment and care are increasingly brought into a complex web of contradictions.

There has been a significant emphasis, indeed a sense of demographic crisis generated in Australia on the potential effect of population ageing on the reduction of the labour supply, since labour force participation rates currently fall significantly for those aged over 55 years, and participation is negligible after the age of 70 years. The Commonwealth Government's Productivity Commission Report on *Economic Implications of an Ageing Australia* (2005) however also stressed that the labour force behaviour of cohorts of people depends on educational achievement, attitudinal changes and changes in policy settings, and that these have already had a substantial impact on labour force behaviour in older ages. Cohort effects on participation rates are especially strong for women, especially for women with post-school education and training.

The *Intergenerational Report* (2007: 23) projects that labour force participation rates over the period 2001-2045 will stay at around 80 per cent for men aged 55-59 and around 60 per cent for men aged 60-64, and that they will increase for men aged 65-69 (from 20 to 30 per cent). For women, the projected rates of increase are strong: from 48 per cent to 72 per cent for women aged 55-59; from 30 to almost 40 per cent for women aged 60-64; and from 5 to about 15 per cent for women aged 65-69. From age 70, participation rates for both men and women are projected to remain low, at around 5 per cent for men and no more than 2 per cent for women.

The OECD *Report on Ageing and Employment Policies in Australia* (2005) notes that in some respects Australia is better placed than many other OECD countries to cope with the economic and labour supply challenges of population ageing. Over the ten years in the OECD analysis Australia recorded above-average rates of employment and economic growth, which helped to put a brake on the trend decline in the labour-force participation of older men, and reinforced the rising trend for older women, as evident in the projections above. The problem of providing elder care and disability care (for a spouse, older parent or offspring with disability) is not noted in the official reports on the priority to increase labour force participation rates in the context of demographic ageing, for women as well as men, accompanied by a phased in raising of the age for receipt of age pension to 67 years and the phasing out of more liberal non-activity-tested income support arrangements in the decade prior to pension age. It is in this context that the dual demands on informal carers are brought starkly into focus.

In Australia in 2003, the Australian Bureau of Statistics *Survey of Disability, Ageing and Carers* (SDAC) a nationally representative sample survey estimated that there were 2.5 million carers who provided any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people (aged 60 and over). This assistance had to be ongoing, or likely to be ongoing, for at least six months (ABS, 2008). This represented 16 per cent of the population, with the proportion of women who were carers being higher (at 17 per cent), than the proportion of men (at 14 per cent) (ABS, 2008). Using the *Census of Population and Housing 2006* as another data source, it is estimated that there were approximately 1.6 million people, or 11 per cent of the Australian population aged 15 years and over, who provided informal care to a person with disability, long-term illness or problems related to old age (ABS, 2008). The Census data are considered to provide a less reliable estimate because of the self-reported nature of the population census methodology and because of the wording of the question which asked for information on unpaid care provision over the last two weeks. The data for the SDAC survey, on the other hand are gathered through computer assisted face-to-face interviews and the time-frame for the question on care provision was much longer, over at least the last six months or likely to continue for the next six months. Nevertheless, the census data are useful for making comparisons between population groups which are too small to be well represented in the SDAC. Using Census data, rates of informal caring were higher in the Aboriginal and Torres Strait Islander (Indigenous) population, with 32,600 Aboriginal and Torres Strait Islander people aged 15 years and over identified as informal carers, a rate of 13.2 per cent (ABS, 2008). Among both Indigenous and non-Indigenous people, the rate of informal care-giving was higher for women than for men: with prevalence rates of 15.7 per cent for Indigenous women, and 13.4 per cent for non-Indigenous women (ABS, 2008). The issue of higher prevalence rates of self-reported care provision by Indigenous people in Australia is an important issue which indicates a difference in two liberal welfare states, UK and Australia, where Australia as a post-colonial country has an Indigenous population which has sustained, since post-European contact, dispossession, poverty, loss of land, languages and cultures, which have had resultant harsh impacts on health and levels of disability (Sutton, 2009; Stanley, 2008).

The numbers and rates of care-giving are considered very likely to underestimate the extent of caring in the Australian community, partly due to the self-administered nature of Census data collection methods, and partly due to the hidden nature of care-giving, which also affects estimates based on the SDAC data. The provision of informal care is usually deeply embedded within the everyday responsibilities and duties of family life, and people providing support, help and assistance to family members or friends with a disability, chronic illness or frailty associated with old age may not identify themselves as a “carer” – a significant issue with respect to social care policies, their framing and the making/or not making of claims on the system of social care.

## Trends in social care provision in the UK and Australia

### *Trends in the UK*

Over the past 20 years, starting with the 1989 *NHS and Community Care Act,* UK trends in social care provision have been remarkably consistent. They include:

- A strong *shift towards a mixed economy of care*, with most publicly funded care provision now outsourced to independent sector providers, through systematic changes in procurement and commissioning.
- A move towards more *intensive packages of care*, with more total hours of care delivered to fewer households, and stricter eligibility criteria, with those receiving state-supported care becoming increasingly needy.
- A gradual (but now accelerating) *process of individualisation*, emphasising independence and choice for care users as consumers, using Direct Payments and Individual Budgets as the main mechanisms. The aim has been to move from a 'fixed menu' service provision approach, towards more flexible, responsive and imaginative support – although in practice IBs and DPs have often been used (especially by older people) to purchase fairly traditional home care services[5].
- A focus on the need for *better integration of the health and social care systems*, with progress on this rather slow and uneven across the country.
- A *growing attention to carers* – with a focus on their need for better information/advice and more and better opportunities for respite, the introduction of carers' assessments (to identify their own support needs), new attention to young carers and to emergency planning for carers, and in some localities strong partnerships with voluntary sector bodies supporting carers.

Already in 2001 there were almost 6m unpaid carers in the UK, some 12-13 per cent of the adult population; one million regularly provided 50 or more weekly hours of care[6]. In addition, in England alone, paid care workers, already 9 for every thousand in the population across the country[7] support 600,000 clients who receive homecare organised by local authorities, delivering over 4m hours of homecare each week[8]. The prevalence of unpaid caring in the UK peaks in the 45-59 age group, with women outnumbering men in their propensity to care until the mid 60s (a situation which reverses around age 70, as older men are more likely than older women to be carers). Almost 4 million carers are people of working age; among them, 75 per cent of men and 60 per cent of women combine their unpaid care with paid work. The strong statistical evidence base available on carers in the UK, documenting the scale and ubiquity of caring, has been an important influence on official thinking (as shown below). The pressures on carers, including working carers, are now well documented in the UK[9]. They include: *poorer health* (stress, exhaustion, anxiety and physical strain, plus a tendency to neglect their own health while the care of others is prioritised); a negative impact on *personal finances* (because of reduced pay and pension entitlements and low benefits; the largely unrecognised additional costs of caring also leave some poorer carers struggling with debt); and *social exclusion* (isolation, loneliness, difficulty in going out to work, education, or leisure, etc., often because services are not sufficiently adequate, flexible or reliable).

As indicated, most of the care and support needed by older, sick and disabled people living at home in the UK is supplied by two specific groups of people: their unpaid carers[10], many struggling to combine paid work and unpaid care (some having to give up jobs, careers or educational opportunities); and workers in health and social care personal service occupations, who supply to those in the greatest need (additional) personal care, services and support. Both groups are predominantly female – 58 per cent of all unpaid carers and 88 per cent of paid care workers, are women.

Unpaid carers who give up work to care receive only modest replacement income benefits in the UK. Carers Allowance (maximum payment of £53.10 p.w.[11]) was paid to just over 400,000 people in England in November 2008 (less than 10 per cent of all carers), about 74 per cent of them women. Most carers receive no state benefits[12], however; the real cost of their unpaid care is in personal incomes foregone, pension contributions not made and taxation lost to the public purse, because carers become clustered in lower paid occupations, cannot achieve their career potential, or need to reduce their working hours or leave the labour market, often retiring prematurely[13].

## *Trends in Australia*

Australian developments in formal and informal care services are characterised by:

- *A significant shift to home and community care for older people and people with disability*, away from formal care in institutional settings.
- A gradual (but much less marked and well developed than in the UK) *focus on individualisation of aged and disability service provision*, emphasising independence and choice for people with disability as consumers, using Direct Payments and other case-managed packages of care (Cass and Thompson, 2008). Nevertheless, the major part of disability, aged care and carers services remain within the traditional service delivery model.
- Some attention paid to the *integration of health and community care systems*, but starting later than in the UK and remaining predominantly at the level of planning, rather than implementation (Fine, 2007).
- *Significantly increased attention paid to carers*, with a focus on their need for better information and advice, improved access to appropriate and affordable respite and other support services, and access to appropriate forms of income support, with increased attention given to the responsibilities and needs of young carers.

In terms of public policy changes in aged care provision: in the period from the 1950s to the late 1970s the major form of care for the aged was in Commonwealth Government financed, non-government operated nursing homes, a policy and practice described as 'institutional domination'. This was superseded by the Aged Care Reform Strategy introduced by the Hawke Labor Government from the early 1980s, with the intention to restrain nursing home costs, and better recognise the preferences of older people which were documented in a number of public inquiries. The strategy resulted in the diversion of people who did not need nursing home care into alternative home and community care provision (Fine, 2007). The period saw a marked shift in Australian policies towards assessment, targeting of services, and better regulation: predominantly supply-side measures concerned with meeting increases in demand for care associated with demographic ageing within affordable budgetary limits (Howe, 1997). This policy shift to care in the community is clearly underpinned by support provided by informal carers (AIHW, 2003; 2007; ABS, 2008; HRSCFCH&Y, 2009). The Australian Institute of Health and Welfare Report on *Australia's Welfare* (2007) emphasises that assistance from a carer is an important enabler of community care, without which formal in-home services would not be sufficient to enable older people with significant impairment to remain at home in the community with maintained quality of life (AIHW, 2007, p 98). The role of informal carers as enablers of community care provision could indeed be seen as a significant hidden cost, given the well documented costs to carers' health, labour force participation, market earnings and sense of well-being (Access Economics, 2005; AIHW, 2007; Cummins and Hughes et al.; 2007; Ganley, 2009).

With respect to aged care, informal care remains the predominant form of care: in 2003-4 only 5 per cent of the population aged 65 and older were in residential aged care services, either in high or low care services; while 24 per cent were receiving a range of Home and Community Care or other community aged care packages.  A further 13 per cent were living at home with unpaid care only, although it is well recognised that many older people receiving at-home formal services also receive support and assistance from informal carers (Fine, 2007: p 273). There was therefore a further 58 per cent of the population aged 65 and over who did not require assistance, or, in some cases, required assistance but did not receive it.

The issues with respect to disability care are similar to those for aged care. However, whereas aged care is predominantly a Commonwealth responsibility, disability care services are delivered through a federal structure, the Commonwealth and State/Territory Disability Agreement (CSTDA) which allocates funding to employment services, housing services, community access services and respite services, most of which are provided by non-government organisations. There has been a significant increase in the prevalence of living in community settings among people with a severe or profound disability and, as with aged care, de-institutionalisation has been a policy driver in the disability policy field since the 1980s. This began with the provision of group homes, and has been increasingly supplemented by home-based support services and individualised funding packages (AIHW, 2007). The increase in the number of people living in the community was markedly greater in the period 1981-2003 than the decrease in people living in cared accommodation –

an increase of 156 per cent and a decrease of 40 per cent respectively. This suggests that the trend to community living is mainly due to new service users in community-based living arrangements.

Based on projected trends in population ageing, the population of people with a disability who will require services under the CSTDA has been projected to grow substantially from 2006 to 2010. Other factors contributing to the projected increase include: increases in the prevalence of some long-term health conditions related to disability; increases in levels and types of need for assistance, due to the ageing of the population with a disability and the ageing of their carers; the ongoing trend towards community-based living arrangements (AIHW, 2007). Further, unmet demand for disability support services has been estimated, identifying in particular unmet demand in the fields of accommodation and respite services, and community access services (AIHW, 2007, p192).

The administrative data indicate that many people using disability services also rely on informal carers: of people utilising respite services, 90 per cent reported having an informal carer, as did 55 per cent of those accessing community support services. In addition, over 90 per cent of people aged under 65 years in need of ongoing assistance with self care, mobility or communication received support from family or friends, compared to 26 per cent who received assistance from formal care providers (AIHW, 2005: 249). With respect to people of all ages requiring care, informal carers provide 77 per cent of all the care that enables people with disabilities and older people to remain in their homes rather than enter residential care (Bittman, Hill and Thomson, 2007)

It is apparent that the infrastructure of formal support services for people with disability depends to a very considerable extent on the support and assistance of informal carers, and the trends to population ageing, de-institutionalised forms of care, community-based living and evidence of unmet need for services will continue to generate increased demand for informal carers.

As in the UK, the provision of care in Australia is gendered. Among informal carers, women comprise 55 per cent of all carers, but 71 per cent of primary carers, those who provide the most amount of care to a person with a disability, long-term health condition or frailty due to ageing (ABS, 2008). In addition, women are more likely to commence caring at young ages than men, with women in the age range 15-59 having higher rates of informal care than their male age counterparts. Over the age of 60, rates of care for women and men become equivalent, with male rates surpassing women's rates by age 70. This is predominantly because most informal care at older ages is spouse care, and with increased ageing, a higher proportion of women than men are widowed (ABS, 2008). Commencement of caring at younger ages for women, predominantly during workforce age, has a significant impact on labour force participation, with respect to being outside the labour force, unemployed or reducing the hours of paid work with consequent lower earning, and vulnerability to income poverty (Ganley, 2009; Carers Australia, 2003; Hill, Thomson, Bittman and Griffiths 2008). The associations between lower labour force participation rates, lower earning and vulnerability to income poverty are applicable to male as to female carers, but the situation is gendered because of the higher prevalence of caring among women of working age and especially among primary carers, who comprise the category of carers most likely to have low rates of labour force participation. The ABS *Survey of Disability Ageing and Carers* (ABS, 2008) data show that in 2003, 63 per cent of all carers aged 15-64 were employed, compared with only 48 per cent of primary carers, and both rates are lower than the employment rate for people who do did not have caring responsibilities, at 73 per cent. Further, part-time employment was higher for employed carers and especially primary carers, compared with people not providing care: comprising 38 per cent of all employment for carers, 54 per cent of all employment for primary carers compared with 29 per cent of all employment for people not providing care (ABS, 2008, p 56). This is associated with the household income circumstances of carers: in 2003, about one third of carers and 44 per cent of primary carers were living in low income households, compared with 17 per cent of people not providing care and the proportion of all carers living in low income households was higher than for non-carers in all age groups (ABS, 2008, p 52). Further, Australian research has demonstrated higher rates of disability, mental and physical ill-health, and lower rates of subjective well-being among informal carers, compared with people of similar ages without care responsibilities (ABS, 2008; Cummins and Hughes et al, 2007; Edwards et al, 2008).

Turning to the gendered nature of formal care providers: there are few reliable sources of data which disaggregate various types of employment in community services providing various forms of care, but analysis of ABS Labour Force Surveys for 2006 shows a significantly gendered profile. Among welfare and community workers, 79 per cent are female; among social workers, 81 per cent are female; and among welfare associate professionals, 68 per cent are female. These proportions may be compared with other occupations where 43 per cent of the workforce are female (AIHW, 2007, p 335). Also of importance is the relatively low earnings of community services workers (with the exception of social workers) and this is especially the case for those employed in the community services industry (AIHW, 2007, p 335). Care provision, both informal care and waged employment, appears to intertwine two salient characteristics: an over-representation of women and a low-income penalty.

There is one dedicated income support payment for informal carers in the Australian social security system: *Carer* P*ayment* is an income and assets-tested income support payment paid to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. Carer Payment is paid at the same rate as age pension and disability support pension ($546.80 per fortnight for a single person and $456.80 each for a couple, at July 2008, with an annual bonus payment of $1,000), and the rates of withdrawal on receipt of other income are similar to other pension payments. These rates are higher and conditions more liberal than those which pertain to most other forms of income support for people of workforce age (in particular Newstart allowance for unemployed people). In addition, carer payment is not subject to activity-testing and has not been included in the ‘activation’ policies applied to most other forms of income support for people of workforce age. There is also a Carer Allowance, which is neither income nor assets-tested, and paid to people who provide daily care and attention at home to a dependent child or adult with a disability or medical condition. The rate of Carer Allowance is $100.60 per fortnight, and may be received by recipients of Carer Payment, other forms of income support or people who receive no government income support.  An annual bonus payment of $600 is paid to recipients of Carer Allowance. Notwithstanding these payments, for people whose main source of income is Carer Payment or other forms of income support, and who have no or little additional income, the outcome is usually living in a low-income household with consequent vulnerability to poverty (ABS, 2008).

In 2008 there were 131,000 recipients of carer payment (Ganley, 2009), which represents a very small proportion of all carers, and more pertinently of primary carers. Although the calculation is approximate, the number of carer payment recipients is about 28 per cent of the number of all primary carers (474,600 in 2003), and about 5 per cent of all carers. However, carer payment is not the only form of government income support which carers receive: the proportion of all carers receiving government income support as their main source of personal cash income in 2003 was 40 per cent and 57 per cent for primary carers; compared with 24 per cent of people not providing care (ABS, 2008, p 53). The other forms of income support which carers receive, depending on eligibility criteria, may include age pension, parenting payment or disability support pension (given that a higher than average proportion of carers have a disability themselves).  The high proportion of carers reliant on government income support as their main source of income is a reflection of their lower rates of labour force participation, and greater propensity when employed to work part-time.

The conditions of carer payment permit participation in paid work, unpaid work, education or training for less than 25 hours per week, but an analysis of carer payment recipients of workforce age in 2006 showed that only a small proportion of recipients (23 per cent) had earnings over at least two weeks while in receipt of payment (Ganley, 2009, p 39). The reasons identified for the low rate of carers earning additional income were a complex combination of factors:  predominantly the strain of caring responsibilities, exacerbated for some by lack of skills and training, and in 40 per cent of cases not being in employment prior to the commencement of caring and/or receipt of carer payment; and the carer’s own health problem or disability (Ganley, 2009, p 46).

The network of Carers Associations across the States and Territories and the national peak body, Carers Australia, have successfully placed the issue of the circumstances and needs of carers onto the political agenda in a bipartisan way. They have themselves commissioned research and liaised with research organisations to highlight the costs and the value of informal care (Access Economics, 2005); and carers' subjective levels of well-being across the domains of health, personal relationships, safety, standard of living, community connectedness and sense of future security (Cummins and Hughes et al, 2007). Governments at various levels, often with strong advocacy from Carers Associations, have placed the circumstances and needs of young carers and young adult carers (aged up to 24 years) and identification of supportive policies appropriate for young people onto the research and public policy agendas, commissioning research that has contributed substantially to the building of comprehensive and extensive sources of evidence (Hill, Smyth, Thomson and Cass, 2009; Cass, Smyth, Hill, Blaxland and Hamilton, 2009 forthcoming).

Most significantly, a coalescing of some parliamentarians' interests in the circumstances and needs of carers in the context of socio-demographic changes, urged on by carers association advocacy, culminated in the establishment by the Rudd Labor Government of the *Inquiry into Better Support for Carers*, undertaken by the House of Representatives standing Committee on Family, Community, Housing and Youth, which reported in 2009 (HRSCFCH&Y, 2009). The Commonwealth Government has yet to respond to the 50 recommendations which range across: extension of the information base through nationally representative surveys on a more regular basis; community education campaigns; development of a nationally consistent carer recognition framework and carer strategy across all jurisdictions; review of the adequacy of care coordination or case management for carers and care receivers across aged care, disability care and mental health services; examination of the restructuring of carer payment to better reflect differences in the levels of care provided, to improve the base rate and reduce disincentives to earn supplementary income; fund a survey to measure the financial costs to households of caring for people with disability; address the shortage of health and community care services in regional and remote locations; examine the adequacy of culturally appropriate community care services for Indigenous carers; increase funding for respite care services, paying attention to availability and accessibility, affordability, and responsiveness to the needs of carers and care recipients in regional, rural and remote areas; undertaking pilot studies to re-allocate funding of respite care and home assistance through individualised funding programs or consumer-directed care; extending the right to request flexible working arrangements to all employees with care responsibilities, including those caring for adults with disabilities, mental illness, chronic illness or who are frail aged; considering the needs of carers seeking employment and supporting employers to provide employment opportunities; implementing programs to support the needs of people seeking to enter or re-enter the workforce; develop flexible education policies for students to combine education and caring; (amongst others).

There is no doubt that such issues of enhanced service provision and accessibility, adequacy of income; promotion of and support for employment, education and training; the right to request flexible employment arrangements; and a move towards individualised funding models and consumer-directed care have been identified in research with carers and people with disability (Cass, 2008; Cass and Thompson, 2008; Hill, Thomson, Bittman and Griffiths, 2008). It is not yet apparent how the government will respond in a period of fiscal stringency; either to better support individual carers (as has been the current policy focus); or to enhance the infrastructure of flexible, individually-tailored social care services; or to extend the right to request flexible work arrangements to carers, who have not been recognised in employment and workplace policies to nearly the same extent as carers of young children – or a mix of all three.

## Debates about combining paid work and unpaid care in Australia and the UK

Debates about combining paid work and unpaid care (care of children and, in this case, care for people with disability, long term illness or frailty associated with old age) have featured strongly in feminist studies of care provision over the last 20 years, and were more recently placed on the policy agenda in both the UK and Australia. To mention only a few of the most recent accounts: the three part ‘social care’ construct of Daly and Lewis, (2000); Mahon’s comparative analysis of the OECD work/family reconciliation agenda in an environment which accepts the adult worker model as established, or at least normative (Mahon, 2006); Orloff’s questions about the extent to which maternalist policies have been fundamentally overturned by the policy priority given to the ‘adult worker model’ in the liberal democracies, or whether feminist claims in the policy domain might be framed around the recognition of care (Orloff, 2008); and a review essay by Lewis (2006) about the key domains in which policies to reconcile employment and care are located.

Unlike many of the feminist accounts of care and employment and struggles to reconcile them, the analysis in this present paper focuses not on care of children but on care of frail aged people and people with disability, including children with disability, which has less often been the subject of the work/care reconciliation debate in policy agendas (Brennan, 2007a; Hill and Thomson et al, 2008).

Debates about the reconciliation of employment and care, and policies to promote reconciliation are situated in an education, labour market, demographic and policy framework in which the labour force participation rates of partnered women and mothers are increasing, and demographic ageing has been framed as a key issue for maintaining sustainable health and social care policies. As noted by Ungerson and Yeandle (2007, p. 4), these important demographic processes, which began in the twentieth century and have accelerated in the twenty-first, have resulted in a diminishing pool of women of workforce age wholly committed to unpaid performance of domestic and caring labour. Government policies in the UK and Australia, and the trends are similar across other OECD countries, are focused on further increasing the overall level of labour force participation, particularly that of women, older people and people with disability (Cass, 2003; Brennan, 2007b; Annesley, 2007). Very often such policy priorities ignore the nature and worth of care, moving rapidly (yet often ambivalently) from a ‘male breadwinner’ model of family life to an ‘adult worker’ model, without full consideration of how care-giving might best be provided, supported, and the costs of care shared through public and private provision, and between women and men (Giullari and Lewis, 2005; Williams, 2009).

## *Employment/family reconciliation and policies to support care in the UK and Australia*

Building on the 'social care' construct of Daly and Lewis (2000), to develop a four-part social care framework:

- *Care is labour*: Informal, unpaid care of children, care of adults who are frail elderly, have a disability or long-term illness involves time that in every sense involves work. In Australia, Bittman et al (2005) using the ABS *Time Use Survey* found that most caregivers undertake the equivalent of a part-time job to assist and support a family member or friend. Over a quarter of Australian informal carers provide the equivalent of a full-time employee's labour (40 hours or more per week), and another quarter work between 20-39 total weekly hours to provide informal care.
- *Care is located within a normative framework of obligations and responsibility*. Care tends to be initiated and provided under conditions of social, usually familial relations and responsibilities, making it inappropriate to consider the labour aspects of care alone.
- *Care is an activity with financial and emotional costs*. The costs involved are reduction of labour force participation and greater likelihood of part-time, rather than full-time employment; reduction of household income; increased experience of various indicators of deprivation compared with people who do not provide care; emotional and health-related costs (Bittman, Hill and Thomson, 2007; Hill, Thomson et al, 2008; Ganley, 2009; Arksey et al, 2005; Moullin, 2007). These are not just point-in-time costs, but may have life-course impacts on employment and income, difficulties with labour force re-entry and reduced retirement incomes.
- *Informal care-giving and employment are combined (juggled or reconciled) in different ways and to different extents,* depending on the

> type of care provided - child care, elder care or disability care, and quite often dependent on combinations of several forms of care being provided by the same caregiver, predominantly women with child care and elder care responsibilities; the stage of the carer's life-course, and the labour market and employment circumstances and conditions in which the care-giver is located. Care-giving may in some circumstances displace employment entirely both while it is being carried out and when care-giving responsibilities cease, or be more or less satisfactorily reconciled with employment, often through part-time employment, supported by carer-friendly workplace arrangements and the availability of appropriate support services for the care recipient (Hill and Thomson, et al, 2008; Arksey et al, 2005). Point-in–time and over-time analyses of the *Household, Income and Labour Dynamics in Australia* (HILDA) data for people caring for a disabled or sick family member have found a significant 'caring penalty'. Similarly, analysis of UK Census data for 2001 shows a significant reduction in employment rates for working-age carers providing care for 20-49 hours per week, and this is especially the case for carers who are caring for more than 50 hours a week (Moullin, 2007).

The loss of income that occurs for informal carers is significant and this may have sustained effects over the carer's lifetime, compromising return to employment when caring responsibilities cease or ease (Cass, 2006; Glendinning and Kemp; 2006). In particular, the circumstances and needs of children and young people who provide care have been placed on the research and policy agendas in the UK and Australia, with the recognition that young carers educational attainment may be compromised and their employment interrupted or constrained (Cass et al, 2009; Hill et al, 2009; Becker, 2007; Yeandle et al 2007).

Debates about policies to reconcile employment and care are located in several key public policy domains. A review essay by Jane Lewis (2006), analysing the recent literature on policies to reconcile 'work and family' states that policies tend to be located and debated in two separate domains:

- *The domain of statutory policy* which may include payments recognising care through the income support system; the mandating of paid maternity, parental and other carer leave provisions; the right to request variation in employment hours to accommodate caring responsibilities as has been introduced relatively recently in the UK and has been a long-term feature of Swedish work/family policy; public provision or subsidisation of formal care services which are accessible, affordable and of high quality (Glendinning and Kemp, 2006; Fine, 2004; Brennan, 2007b; Mahon, 2006).
- *The domain of workplace and employment relations*, where the balancing of employment and care is expected to be part of employee/employer negotiations, in some cases within over-arching statutory frameworks which set the parameters of negotiation (Baird and Williamson, 2009).

In both Australia and the UK, the key factors identified in the employment/care research with respect to impacts on remaining in employment and maintaining workforce attachment are: the intensity of care provided; carers' physical and mental health; the nature of the carer's employment (full-time or part-time; casual or secure); level of earnings; availability of formal and informal support services; and access or lack of access to flexible workplace arrangements, in particular flexible start and finish times, ability to take time off in emergencies or for planned health and hospital visits  (Arksey, 2005; Hill and Thomson, et al, 2008). From a multivariate analysis of the Australian Household Income and Labour Dynamics (HILDA) Survey over a number of Waves (HILDA is a longitudinal survey), Hill andThomson et al (2008: p. 31) found that a variety of characteristics of the mode of employment increase the probability of employees leaving employment in response to the onset of caring responsibilities. These are: being a casual rather than a permanent employee; working part-time; having no supervisory responsibilities; not belonging to a union; and working for a smaller firm. In addition, lack of access to any carer-friendly workplace arrangements also predict that employees are likely to leave their jobs when they become carers. These carer-friendly workplace arrangements include: special leave for caring, permanent part-time work, flexible start and finish times; or home-based work. Access to at least one of these arrangements improves the odds of staying in employment.

These findings from the UK and Australia point to both statutory policies and the domain of workplace and employment relations as salient in carers maintaining their workforce attachment (cf Lewis, 2006). However, while the research in each country points to similar issues for carers attempting to juggle employment and care or return to employment after a period of care provision, the public policy and employer responses in Australia and the UK differ, as will be shown below.

## Policies and strategies for carers and impact at the level of Practice in the UK

In the UK, carers' representative organisations[14] have campaigned over the past four decades for carers to be accorded new rights/entitlements and for policy changes which recognise carers and give them better support. Originating 40 years ago in a much narrower focus on 'single women and their dependants[15], their approach has evolved into a conceptualisation of carers as a diverse group[16] of women and men of all ages, who need recognition, rights and support to care while continuing to participate in the 'normal activities of everyday life'.

Comprised of a range of organisations, the UK carers' movement has steadily grown in influence, ambition and impact, playing a significant role in shaping carers' policy, including the *National Carers' Strategies* (1999, 2008)[17]. Drawing attention to carers and 'naming' them as deserving of policy attention, the movement has taken debate (within and outside government) well beyond its original focus on carers' 'isolation' and 'public ignorance' of their situation[18]. Its increasingly confident agenda has:

- called for policies addressing carers' health, financial and social situation;
- laid claim to carers' right to a life outside caring;
- linked the campaigning agenda for carers with other public policy objectives – equalities, social inclusion, work-life balance, social cohesion, and human rights;

- developed innovative local projects to support carers;
- built a strong evidence base on carers' situation and perspectives;
- engaged employers in active policy-making around 'making work work' and opening up access to jobs and flexible working for carers; and
- taken its agenda into EU policy-making, through *Eurocarers* (launched 2007) and the *MEPs' Interest Group on Carers* in the *European Parliament*.

Its campaigning has yielded significant if modest new rights and entitlements for carers: the right to leave from work to deal with emergencies and caring crises; the right to request flexible working arrangements; the right to a Carers Assessment which respects a carer's desire to work as well as to care; and the right to access education, leisure, training and employment[19]. These developments have been supported by an all-party group of MPs[20]; and most new legislation affecting carers has had all-party support during its passage through both Houses of Parliament[21]. Policy-makers and social care professionals have mostly welcomed the shift to a more explicit focus on carers' situation; and (over time) employers' representative organisations (such as the CBI[22]) have become supportive of the limited new rights carers have in the workplace, with some prominent employers joining together as *Employers for Carers* (an employer-led forum, launched in 2008[23]), calling for stronger policies, initiatives and services to support those combining work and care.

Carers' limited but enforceable rights in the UK[24] are linked to certain statutory obligations on local authorities, employers and others to support them, although progress has been held back by resource constraints and some organisational inertia. For example, only a small minority of carers with significant caring roles have had their needs assessed, as they are entitled[25]; only about 10 per cent of carers receive Carers Allowance[26]; and while it is too early to assess the impact of carers' 'right to request' flexible working arrangements (available to most working carers only since April 2007), this offers merely a limited right to 'request' flexibility, without compensation for loss of earnings to carers who reduce their working hours[27]. Nevertheless review of local authorities' initiatives shows that almost all now take carers' rights under the *Carers (Equal Opportunities) Act 2004* seriously, and are actively developing both policies and activities to enhance support for carers[28].

Early in the first New Labour administration, government Ministers made their position on carers clear, through the introduction of *National Strategies for Carers* in England (1999), Scotland (1999) and Wales (2000) which took UK policy-making forward by acknowledging carers' need for greater support. In England this led to *Carers Grant* funding (to all 150 local authorities with social services responsibilities), triggering the development of new local support services for carers, often developed in partnership with voluntary sector agencies[29]. New inspection, accreditation and regulatory frameworks in social care were also put in place, with the key agencies – the *Commission for Social Care Inspection* (CSCI), the *Social Care Institute for Excellence* (SCIE) and the regulatory bodies (the *General Social Care Council,* social care workforce regulator in England; *Care Council for Wales; Scottish Commission for the Regulation of Care*) - all having specific responsibilities for carers[30]. The CSCI (replaced in 2009 by the *Care Quality Commission*) carried out regular inspections of social care services/performance, publishing its results and taking action where shortcomings were found, and producing an annual report '*The State of Social Care*', drawing specific attention to carers and their need for improved support[31].

In 2006, a wide-ranging Department of Health White Paper - *Our Health, Our Care, Our Say* – again demonstrated Ministerial support for carers, and (in response to heavy lobbying by carers' organisations) promised a *New Deal for Carers* in 2007[32], and a major review of the 1999 *National Strategy for Carers.* Four 'Task Forces' (focused on carers' Incomes, Employment, Health and Social Care, and Equalities) were set up in autumn 2007, engaging representatives of most central government departments and (unusually) drawing in external agencies, including the main national carers' organisations. In spring 2008 each Task Force produced recommendations for the Carers' Strategy (later published as separate documents[33]). These were subjected to an impact assessment by civil servants and used to develop the main strategy document, '*Carers at the Heart of 21st Century Families and Communities*' published in June 2008, and endorsed by the Prime Minister and cabinet ministers at the head of seven government departments[34].

The vision set out in the 2008 strategy reflected the influence and lobbying of the carers' movement, and drew on the strong evidence base it had helped to assemble[35]. The vision was for all carers, by 2018, to:

- Have access to the integrated /personalised services they need
- Be respected as expert care partners
- Be able to have a life of their own
- Be financially supported, not forced into hardship
- Be supported to stay mentally / physically well and treated with dignity
- When young, be protected from inappropriate caring roles

The strategy also set out Government's short-term agenda, underpinned by additional funding (£255 million). New commitments included: £150 million towards planned short breaks for carers; piloting of annual health checks for carers to help them stay well; and training for GPs to recognise and support carers. £38 milion was also promised towards supporting carers to enter or re-enter the job market, including the introduction, in every Jobcentre Plus district, of a new Care Partnership Manager post, and a fund to enable carers accessing return to work support to purchase alternative care services[36]. The role the NHS could play in achieving better outcomes for carers through more integrated and personalised support was also identified, and targeted training for key NHS professionals, to raise awareness of carers' contribution to the delivery of care following hospital discharge and in the management of chronic illness was also promised.

During the preparation of the 2008 Strategy, carers' incomes, benefits, access to information and advice and other key aspects of the support they need were also taken up in a separate initiative by the *House of Commons Work and Pensions Committee* at Westminster. This influential (cross party) Select

Committee - with powers to summon Ministers for questioning and to call on the Department of Work and Pensions and other agencies (including carers' organisations) to supply both written and oral evidence – chose in its 2007-8 session to conduct an *Inquiry on Carers*, and to include in the evidence it assembled an investigative visit to Australia during which it explored how carers there were supported, to see whether policies adopted in Australia might offer any guidance to the changes needed in the UK[37].

Calling its report *Valuing and Supporting Carers,* the Committee published its findings in August 2008[38], making detailed recommendations re: 'Information, Advice and Guidance'; 'Carers' Income and Benefits'; 'Support for Caring'; 'Employment and Training Strategy for Carers'; and 'Equality, Recognition and Discrimination'. Its aims were to: 'support adults who become carers during their working lives to combine work and care'; 'enable carers to return to paid work when caring ends'; 'secure adequate financial support for carers'; 'compensate them for the extra costs of caring'; 'provide adequate income replacement /pensions protection'; 'protect the interests of young carers, ensuring they suffer no disadvantage in accessing education, training, employment'; 'provide adequate support for older carers, mitigating any financial strain if their pensions are affected by caring'; and 'to ensure carers are supported in the social care system by informing them of their rights and entitlements and helping them to access appropriate support and services'.

The Committee was much impressed by the evidence it saw about how carers were supported in Australia. Its report drew attention to Australian carers' access to a different system of benefits and allowances: Carer Payment (an income-replacement benefit), Carer Allowance (an income supplement, which could be claimed for each person cared for), Carer Adjustment (*ex gratia* payment), and Carer's Bonus. Noting the contrast between these arrangements and those in the UK, the Committee, highly critical of the 'outdated' UK Carers Allowance, called on the Department of Work and Pensions to 'give urgent and detailed consideration to replacing Carers' Allowance with a two-tiered benefit for carers, proposing both a 'Carer

Support Allowance' and a 'Caring Costs Payment', which it asked the department to cost and investigate as a matter of urgency[39].

### *Impact on policy and practice*

As noted, growing attention to carers' issues in the UK has begun to have significant impact on policy and practice, through new legislation, changes in social care policy and local initiatives. The legislation and rights already mentioned have become an important focus for voluntary sector agencies supporting carers; for example the charity Carers UK has published three editions of its comprehensive assessment of carers' legal rights. The latest (Clements 2009) draws attention to recent changes affecting carers in the UK (noting some differences between the different legislatures in England, Scotland, Wales and Northern Ireland):

> 'the coming into force of the *Work and Families Act 2006*, the growing momentum of the personalisation agenda and the European Court of Justice's decision in *Coleman v Law* (2008)'.

The latter legal judgment is expected to have wide-reaching ramifications, as the UK government has responded by including in its *Equality Bill 2009* (currently going through parliament) a clause outlawing discrimination of the type experienced by Sharon Coleman (discrimination at work arising from her care of her disabled son) in relation to employment, goods, services, housing and some other fields.

Other national level developments are also beginning to have a significant impact on carers at the level of practice. In England, virtually every one of the 150 local authorities with social services responsibilities now has in place its own Carers Strategy, funded in part by Carers Grant (see below) in which it makes commitments to local carers and offers various forms of support, commonly including respite care and sitting services, emergency planning arrangements, information and advice and targeted support for carers in specified categories (often with a particular focus on young carers).

Local authorities have also been actively developing a 'personalisation' agenda in social care in recent years, including promoting Direct Payments and Individual Budgets, with carers explicitly and actively involved in decision-making and care planning in many of these cases. All local authorities have a legal obligation to offer carers providing regular and substantial care an assessment of their own needs, and to report on the number of these assessments carried out each year, and whether or not information or services were provided as a result.

Over the past three - four years many authorities have also been experimenting with a new form of support which is proving important for carers – the introduction of telecare services and equipment, which are proving popular with (and beneficial for) carers as well as for those they care for. Principally of value to carers because they offer greater peace of mind, and enable carers to leave the person they care for, knowing that in an emergency or if there is an accident assistance can be immediately summoned, many telecare installations have been funded through the national *Preventative Technology Grant*, provided in 2004-2008 to stimulate local developments and encourage the introduction of new services which are both cost-effective and enhance the wellbeing of users and carers.

### *Carers Grant to Local Authorities*

Through their local Carers' Strategies and the creation of Carers' Lead Officer posts, many local authorities have recently enhanced their local provision, often working closely with local voluntary agencies and with health sector providers, and actively engaging carers in the development of their plans and policy/ practice reviews. An assessment of the impact of this funding (Fry, Price and Yeandle 2009 in press) shows that it was being used to:

- Develop more flexible and innovative services – e,g, discretionary payments to individual carers; telephone help-lines; and emergency cards to identify carers
- Improve arrangements for Carers Assessments, through joint working with local health services, new Carer Development Worker posts targeting carers at hospital discharge; self assessment forms and Carers Registers at GP surgeries
- Increase the range of breaks services available to support carers

- Introduce additional support for young carers - sitting services, outreach in schools, Young Carers Worker posts
- Engage local stakeholders in the development of local Carers Strategies and Plans.

## Policies and strategies for carers and impact at the level of Practice in Australia

Carers Associations operate in all Australian States and Territories and are connected as a national Carers network through the Canberra-based office of Carers Australia. Carers Australia articulates its objectives as:

> Carers Australia and the network of carers associations in each state and territory's purpose is to improve the lives of carers. Together we provide important services like counselling, advice, advocacy, education and training. We also promote the recognition of carers to governments, businesses and the wider public. (Carers Australia website, 2009a)

This quote is instructive in pointing to the dual purposes of the network of associations, concerned with both advocacy (directed to Commonwealth and State/Territory governments) and service provision funded predominantly by governments to provide information, referrals and direct services to carers. In keeping with these aims, Carers NSW states that its core business is to:

- Deliver **services direct to carers** including providing information, referrals, emotional support, and counselling.
- Provide **leadership and develop policy** on major issues affecting carers.
- Provide **strategic input and systemic advocacy** into key government, non-government, academic and corporate sector initiatives related to carers.
- Develop, pilot and deliver **education and training** to assist carers, service providers, health professionals and other stakeholders.
- Develop, promote and distribute **information, resources and publications** to carers and other stakeholders.
- **Promote carer issues** through events, media and other public activities.
- Build **partnerships and alliances** and provide expert advice on ways to better support carers.

- Foster **research, and collect and analyse data** to provide a sound evidence-base on which carer issues can be progressed. (Carers NSW website, 2009)

As can be discerned from this statement, Carers Associations work within a set of contradictions, both independently of, but dependent on government, as advocates and lobbyists whose vigorous claims for better carer recognition, financial resources and services are directed to governments and other stakeholders (education, community services and health services in particular), through submissions to government inquiries, and public critiques of the inadequacies of service provision. At the same time, they receive both Commonwealth and State/Territory government funding to provide information and services to carers, while also acting as the conduit for claims, as an organisation of civil society. To cite just one instance of this complex intermeshing: Joan Hughes, the CEO of Carers Australia, while launching the Report of the Young Carers National Forum *(Bring It! Young Carers Forum 08*, Carers Australia*,* 2009*)* which was organised in Parliament House in 2008 with funding predominantly from the Australian government and several industry bodies, stated that ‘The national program for Young carers in Australia is in crisis’ (Carers Australia website, 2009b). She noted that the Report of the Forum set out strategies for providing supports and assistance to young carers (up to age 25) to meet their urgent needs, if ‘they are to have the same rights, choices and opportunities as other young Australians’.

Carers Associations constituted a concerted voice lobbying the Commonwealth Government for the establishment of the Parliamentary *Inquiry into Better Support for Carers,* which was referred to the House of Representatives Standing Committee on Family, Community, Housing and Youth on 14 May 2008, and which reported in April 2009 (HRSCFCH&Y, 2009). More than 1,300 written submissions were received by the Inquiry, of which 1,200 were from individuals, most of whom were or had been carers. The detailed submissions presented by Carers Associations from all States and Territories and Carers Australia were quoted liberally throughout the Report, and their advocacy contributed to shaping the Report’s 50 recommendations, to which the Government will respond by the end of 2009.

Further, Carers Australia was a vigorous advocate for the recognition of carers' voices and rights in the deliberations of the National Health and Hospitals Reform Commission, established by the Prime Minister and the Minister for Health and Ageing in 2008 to consider the future design of Australia's health system. The final Report of the Commission described unpaid carers as the 'invisible health workforce, who may dwindle in the future as more people age and rely on family members to participate in the paid workforce' (National Health and Hospitals Reform Commission (NHHRC), 2009). It is noteworthy that, in the deliberations of this high level Commission, the contribution of carers was placed on the agenda of health policy reforms, whereas the issue of carers has usually been framed in official policy debates within disability and aged care services frameworks. The NHHRC Report (2009) acknowledged the vital role of informal/family carers in supporting and caring for people with chronic conditions, mental disorders, disabilities and frailty. The Commission went on to recommend that carers be supported through educational programs, information, mentoring, timely advice and, subject to the consent of those they care for, suitable engagement in health decisions and communications. The Commission further recommended improved access to respite care arrangements to assist carers to sustain their role and that the health of carers should be a priority of primary health care services. Government has yet to respond to the raft of recommendations made by the NHHRC, however, it is of considerable interest that two areas of Australian government portfolio responsibility, community services and health, have turned their gaze to the roles and responsibilities of informal carers, set against the framework of population ageing, labour market changes involving the increased participation of women, and health care reform in the context of anticipated increases in the prevalence of chronic illness, frailty and disability.

The House of Representatives *Inquiry into Better Support for Carers* was established explicitly in the context of other major reviews of government policy established by the Rudd Labor Government: the Inquiry into Australia's Future Tax System (yet to report); and a Review of the Pensions System, which reported in February 2009 (Harmer, 2009). Both reviews have potential repercussions for carers, with respect to government income support, the interactions of the tax and benefit systems in producing effective marginal tax rates for carers' income support payments and tax treatments of formal services and service costs. The *Pension Review Report* treated carers in the same context as Age Pension and Disability Support Pension recipients with respect to 'measures to strengthen the financial security of seniors, carers and people with disability' (Harmer, 2009, p. xi). This intermeshing of carers with seniors and people with disability was done with reference to the adequacy of the rate of pension; indexation arrangements for pensions; the design and delivery of pension payments; the concessions and services that support the pension system; the targeting and long-term sustainability of the pension system. The Report found that Age Pension, Carer Payment and Disability Support Pension should be paid at the same basic rate; while other specific costs associated with health and disability should be addressed by targeted services rather than differential rates of income support. In addition, it recommended that for older people of age pension eligibility age, it was preferable for carers and people with disability to receive Age Pension, leaving Carer Payment and Disability Support Pension as payments for people of workforce age who meet the relevant criteria (Harmer, 2009, pp. xiii-xvii). The overall message of this Report reinforces the treatment of income support for carers within the pensions framework, safeguarded from the activation policies and lower rates of payment which apply to most other income support payments for people of workforce age. This effectively places carers within the framework of sustaining and supporting informal care provision within the overarching priorities generated by population ageing and increased prevalence of disability and chronic illness. However, other issues such as reconciling care and employment, and redistributing care from informal provision to formal health and community services are not addressed in this Report, nor were they part of its Terms of Reference.

The Parliamentary *Report of the Inquiry into Better Support for Carers* does address those issues, noting that the key themes emerging from the Inquiry were:

- lack of recognition of the role and contribution that carers make to society and absence of a national and strategic approach to supporting carers and their families;
- difficulties in accessing necessary and relevant information on supports and services available to carers and lack of assistance for carers to develop the range of skills needed to support them in their role;
- financial stresses facing many carers and their families as a consequence of opportunity costs, the level of government financial assistance and the additional costs of disability and caring;
- dissatisfaction with the community care system. Specifically, evidence highlighted significant concerns in relation to the complexity of systems, the level of unmet need, the costs of accessing services, inflexible delivery of services; and in some cases, the questionable quality of care;
- lack of choice for carers in relation to participation in the workforce and/or education, primarily due to shortages of respite or alternative care options for the care receiver and inflexible workplace practices; and
- the physical, emotional and social impacts of caring on the health and wellbeing of carers and families. (HRSCFCH&Y, 2009, p. 29)

## *Impact on Policy and practice*

Whereas campaigning by carers representative organisations in the UK has yielded significant (if modest) rights and entitlements in the domains of flexible employment arrangements, the right to access education, training, employment and leisure, and more flexible service delivery, policy developments in Australia cannot be considered commensurable, although these issues have been placed on policy agendas. Emphasis on statutory rights is less evident than in the UK: within Australia’s federal structure of government there is no overarching national legislative framework for carers (with the major exception of income support which is a Commonwealth responsibility). The eight States and Territories have different systems of specific Carer Recognition legislation and/or Carer Strategies/Action Plans, with only four jurisdictions – Western Australia, the Northern Territory, Queensland, and South Australia having Carers Recognition Acts, introduced over the period 2004-2008; while seven jurisdictions have Carers Action Plans in place. Tasmania is the only jurisdiction with neither (HRSCFCH&Y, 2008, p. 55). The Report states:

> The introduction of state and territory based carer recognition legislation and amendments to broader human rights and anti-discrimination legislation suggest that recognition of carers is increasing. However, inconsistencies between jurisdictions have prompted calls from carers and organisations for a legislative framework that is both more robust and consistent between the jurisdictions. (HRSCFCH&Y, 2009, p. 57)

This is followed by a Recommendation calling on the relevant Commonwealth Government Minister and cross-jurisdictional ministerial council to develop a nationally consistent carer recognition framework which complements state and territory legislation; and a national carer strategy which builds on and complements state and territory policies. It is considered by the Parliamentary Inquiry, by Carers Associations and other representative organisations that a national approach is required to set down robust statutory rights, and more effective health and community care policies recognising carers. It is apparent that the issue of national legislative and policy consistency has been placed firmly on the political agenda, with outcomes yet to be negotiated and determined.

Another point of difference in Australia in comparison with policies in the UK is the less well-developed system of flexible workplace arrangements as a statutory right. Australian research has documented the constraints on remaining in employment, especially full-time employment, which carers experience, and difficulties of workplace return after a period of care provision (Hill and Thomson et al, 2008; Edwards et al, 2008; Ganley, 2009). Despite the challenges, carers provided evidence to the *Inquiry into Better Support for Carers* indicating that they strongly value the benefits of employment in improving their financial security and their health and well-being (HRSCFCH&Y, 2009, p 198). Constraints to remaining in employment identified in the Report include: lack of access to alternative, suitable and affordable formal care arrangements; difficulty of arranging working hours; lack of flexible employment options; loss of skills from being out of the workforce. In addition to recommending increased investment in extended respite care and support services, the Report turned its attention to flexible workplace arrangements, arguing that the case for carer-friendly working arrangements is now well established, but far from being widely available. A number of submissions to the Inquiry, including from the Australian Congress of Trade Unions (ACTU), called for the provision of a legislative framework extending carers rights into the workplace, reducing the potential for direct or indirect discrimination. In addition, several submissions (including from Carers NSW, Carers Victoria and the Australian Human Rights and Equal Opportunity Commission) called for the safety net of fair minimum legislated conditions in the National Employment Standards (NES) for employees in the *Fair Work Bill 2008* (then before Parliament) to include extension of the right to request flexible working arrangements and for the strengthening of personal/carers leave. The Report notes that the focus of the right to request flexible working arrangements currently relates to parents and carers of pre-school aged children and children under the age of 18 with a disability, to the exclusion of employees with other caring responsibilities. The ACTU submission and others recommended that the right to request flexible working arrangements should be extended to all carers, including those who care for disabled or elderly or chronically ill people. The Report of the Inquiry endorsed the importance of a robust legislative foundation which extends carers rights in the workplace and recommended that this be done through amendment to the *Fair Work Act 2009,* 'to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including to those who are caring for adults with disabilities, mental illness, chronic illness or who are frail aged.' (HRSCFCH&Y, 2009, pp 210-215). It is evident that this issue has been placed on the workplace legislation and policy agenda, again to be the subject of negotiation between the trade unions, employer organisations and the Commonwealth Government.

With respect to income support arrangements in Australia, the UK Select Committee Report *Valuing and Supporting Carers, 2008* noted favourably the Australian system of benefits and allowances for carers and recommended changes to strengthen the UK system (as set out above). As noted previously, the Australian system consists of an income and assets-tested *Carer Payment*, paid at the same flat rate and under similar conditions to pension payments, whose rationale is ‘an income support payment for people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation’; and a *Carer Allowance* at a considerably lower rate which is not income or assets tested and whose rationale is ‘an income supplement available to people who provide daily care and attention at home to a person with disability or a severe medical condition’ (Ganley, 2009, p 35). Only a small proportion of carers receive the dedicated carer payment, even though about 40 per cent of all carers and 57 per cent of primary carers rely on government benefit as their main source of income (ABS, 2008). Other types of income support received by carers include Age Pension, Disability Support Pension, Parenting Payment and Newstart Allowance (the latter for unemployed people), depending on the circumstances of the carer.

While Carer Payment is exempt from the activation agenda of other payments for people of workforce age, evidence provided to the *Inquiry into Better Support for Carers* indicates other matters of concern to carers and representative organisations: in particular the rate of payment which is seen as not recognising adequately the indirect costs of care (foregone employment and loss of market income), or the additional direct costs of care (HRSCFCH&Y, 2009, p 118). The report recommended a review of carers’ income support arrangements to examine how carer payments might be restructured to better reflect differences in the levels of care provided (HRSCFCH&Y, 2009, p. 127).  If implemented, this would constitute a fundamental departure from the current logic underpinning income support for carers, tied as it is to the flat-rate, income and assets-tested Australian pensions system.

Further, submissions brought forward evidence of difficulties and frustrations associated with the complex assessment procedures involved in applying for income support, which may result in carers not proceeding with claims or being denied legitimate entitlements. The report recommended a review of assessment procedures for carer payment/allowance so as to streamline and simplify procedures, and give greater recognition in assessment to carers of people with intellectual disability and mental illness (where claims are currently seen as most likely to be rejected) (HRSCFCH&Y, 2009, pp 136-137).

Despite the criticisms made of the system of carers' income support, it has been nevertheless one of the bulwarks of Australian policy support for carers, constituted as an element of the pension system since the mid 1980s, and accorded bipartisan political legitimacy. *Carer Pension* was introduced in 1985, as a component of changes to age pension, designed to replace both the wife's pension (then in the process of being phased out) and the spouse carer's pension, which had been introduced previously for men caring for a spouse in receipt of invalid or age pension who was in need of constant care and attention. Carer Pension was more comprehensive in its coverage than both of the payments which it replaced, providing income support for people providing constant care (understood as the equivalent of a working day, every day) for a spouse, parent, other close relative, offspring or friend with disability, chronic illness or the frailty of old age. Renamed *Carer Payment* in 1996, the payment continues to provide income support for people unable to maintain substantial employment participation because of full-time caring responsibilities. It is the close connection with both Age Pension and Disability Support Pension which has given carer income support its strength and legitimacy, no doubt in the context of population ageing and the projected impacts on health and social care provision, and the expressed official concerns that the supply of family carers will diminish as the demand for care increases.

One of the salient questions to be asked is why policy emphasis in Australia has been placed predominantly on income support, rather than on legislated rights to flexible workplace arrangements? Part of the answer may be found in the fact that national legislation of rights to paid parental leave for the care of very young children for 18 weeks after birth or adoption (announced in 2009 for implementation in January 2011) and for the right of parents to request flexible workplace arrangements for the care of young children and children with disability under the age of 18 (legislated in 2009) came relatively late in Australian public policy compared with similar liberal and social democracies, in particular the UK and other European and Nordic countries (Brennan, 2009). Recognition of the rights of carers of people with disability, chronic illness and the frail aged to flexible workplace arrangements has lagged further behind, but is now at least visibly on the policy agenda following the Report of the Parliamentary *Inquiry into Better Support for Carers*, supported by an increasingly robust evidence and research base. The fact that rights with respect to the care of children now have a national legislative base, and that advocacy is strong for extension of these rights to all carers, promoted by Carers Associations, various cross-party parliamentarians and the peak trade union body the ACTU, suggest that the extension of rights to request flexible employment arrangements may succeed.

Another policy and practice trend of considerable importance in the UK has been embarked upon to a limited degree in Australia, and only very recently. This is the significant expansion in the UK of flexible service delivery through the development of a ‘personalisation’ agenda in social care, including Direct Payments and Individual Budgets, with carers explicitly involved in decision-making and care planning in many instances. By comparison, in Australia the introduction of consumer-directed funding and personalised packages of care and support for people with disability and frail older people has been more recent and more tentative across the various jurisdictions (Cass and Thompson, 2008). At the level of the Commonwealth government, in November 2005 the then minister for Ageing in the Howard Coalition government called for the exploration of consumer-directed care to meet the needs of the ‘new old’ of the baby boomer generation (people born after 1945) whose higher incomes and awareness as consumers had, she stated, opened a market for more diverse, more specialised and more innovative customised care (Aged and Community Services Australia, 2008). More recently, the Report of the *Inquiry into Better Support for Carers* noted that they had received submissions from proponents of ‘individualised funding’ or ‘consumer-directed care’, which argued that this funding model provides greater control to carers and care receivers over the services which they receive (HRSCFCH&Y, 2009, p 183). Indicating bipartisanship on this issue, the cross-party Report recommended that the various responsible Ministers of Community Services and Health and Ageing undertake pilot studies to test the potential for the Australian Government’s funding for carer respite and in-home assistance to be re-allocated directly to carers through ‘individualised funding programs’, also known as ‘consumer-directed care’ and ‘self managed funding’ (HRSCFCH&Y, 2009, p186).

Measures of this nature have been implemented in a number of States and Territories over the last decade to varying degrees, with the explicit intention of improving the flexibility of disability services and providing people with disability with greater decision-making and control over the range and types of services which they access. It is salient to note that in Australia the circumstances and needs of carers are less often addressed in these programs and their evaluation, the focus being on the person with disability as the recipient of consumer-directed care. It should also be recognised that in all current Australian programs of consumer-directed care, it is explicit policy that informal family carers may not be the recipients of cash reimbursement for care: in other words, they may not be recipients of carer payments under these State and Territory programs. This may presumably be attributed to the existence of a national income support program of Carer Payment, and the decision not to complicate further the intersections of federal jurisdictions in carer policies.

Evaluations of various manifestations of the consumer-directed model of care in place in some Australian States (NSW, Western Australia and Victoria) have shown them to be effective in increasing client choice and control and clients’ level of satisfaction with their support and care. The New South Wales ‘Direct Funding’ pilot project as part of the Attendant Care Program had a strongly positive response from participants. Respondents found their outcomes improved in all domains, as did their relationships with their paid carers. They also had more stability and consistency of care, and could provide their carers (who could not be family members) with better pay and conditions (Fisher and Campbell-McClean, 2007). In addition, the NSW Department of Ageing, Disability and Home Care is currently implementing and piloting several programs of consumer-directed packages of support for people with disability, in some cases involving direct funding. These programs include a Community Participation program for young people with disability, which involves the young person and their family carer/s in developing and reviewing their personalised support plan with individualised and portable funding. A pilot program of support for older carers of people with disability is planning to offer a case-managed package of support which requires carers in the pilot to develop an individualised plan for service provision, which follows a brokerage model. In both of these cases, the programs are in very early stages of planning and implementation.

Evaluation of the Victorian Government's *Support and Choice* program was shown to be to be a significant shift in policy towards actively promoting consumer control, flexibility and community participation (Lime Management Group, 2005). However, its success depended not only on the actual program itself, but on other factors external to the program such as participants' abilities, the broader service system, and the wider community. The Western Australian program, Local Area Coordination (LAC), provides an organisational framework for the development of support networks, linking people with services and resources in local communities, both urban and rural/remote, and disbursing individualised funding. Each LAC serves only a limited number of people and hence is able to be individually tailored. The LAC system is regarded by government as a cost-effective way of delivering community-based support, and is stated to be popular with service users (WA DSC, 2007, pp 53-4).

In comparison with direct payment models, case management remains a central part of the community care system in Australia, in particular for people with multiple and complex disabilities. A review of models of support across a range of community services in NSW for people with high and complex support needs referred to case management as ‘person-centred planning approaches’. When the person with a disability cannot direct their own case management, this role would be taken by their carer or person responsible. The review found that case management, together with specialist services, played a critical role in service provision and that it was a vital component of most models of support (McVilly, 2004).

However, the use of case management in the Australian community care sector is only sporadic, and few Home and Community Care organisations for older people are funded to provide case-management services (Allen Consulting Group, 2007). The Allen Consulting Group in its report on the *Future of Community Care* (2007) recommended making case management available to a wider range of community-care clients than at present, at the very least, to all those with higher care needs. The three main models of consumer-directed care elaborated in the *Future of Community Care* report:

- ‘cash or vouchers’ (individualised funding/direct payments);
- assisted choice of provider’ (brokerage); and
- ‘monitored choice of service and provider’ (case management).

vary in the extent to which decision-making, control and autonomy have been shifted from professionals and agencies to clients (The Allen Consulting Group, 2007). The Allen Consulting Group argued that a case-management approach is likely to be more beneficial for clients with high and complex needs who require coordination of multiple services; while an opt-in system of direct cash benefits or vouchers might be more suitable for people with less complex needs and those whose socio-demographic and personal characteristics and resources equip them to take beneficial advantage of direct payment models of consumer-directed support. There is no doubt that the predominant mode of service provision for frail older people and people with disability in Australia retains the characteristics of more traditional patterns of funding, delivery and management, predominantly under the control of government or government-funded not-for-profit NGO agencies.

However, many of the Australian jurisdictions are implementing or at least piloting consumer-directed care programs, indicating a slow but accelerating change of direction. The impact on carers is not yet evident. The Report of the *Inquiry into Better Support for Carers* sounds a precautionary note, while nevertheless going on to recommend that the Australian Government investigate the potential for its services to be re-allocated through consumer-directed care:

> -----there are risks with individualised funding. It may place more responsibility on care receivers and carers than they wish to take on. Thus any system should allow care receivers to achieve the level of self sufficiency they are comfortable with or allow carers or guardians to choose on their behalf. For service providers and agencies it would also mean a move away from contestable and tender driven funding of service delivery to an income model driven by consumer demand. (HRSCFCH&Y, 2009, p 185)

This cautious approach has been the key characteristic of aged and disability care services in Australia, possibly relating to multi-jurisdictional program developments across the Commonwealth and State/Territory departments and the roles of large service-provider agencies within the structure of tender-driven funding. But the trends toward consumer-directed care and individualised funding are now part of future service delivery options, geared much more overtly towards enhancing flexible choices for people with disability, without, in many cases, addressing as a central issue the roles and responsibilities of informal carers in their diverse care relationships.

## The emergence of a supranational policy agenda on carers

### *The UK in Europe*

In Europe, the emergence of supranational debates and bodies owes much to the pressure and influence of the voluntary sector carers’ movement, and to the leadership of key voluntay agencies in Ireland, the Netherlands and the UK. In November 2004, representatives from carers' organisations and from research and development groups from eight countries met in Maastricht

(Netherlands) to explore how they could establish an EU-wide organisation - Eurocarers - to represent and provide a voice for carers[40].

Supported between 2004 and 2007 by a secretariat funded through ACE (led by Carers UK), Eurocarers' has agreed on collective aims which include ensuring that care is valued, and that unpaid care is recognised as central to the sustainability of health and long term care systems in Europe. It seeks to raise the profile of carers across Europe, identifying them as a group at risk of poverty, social exclusion and discrimination, highlighting issues which affect them and trying to ensure their interests are addressed in EU policy developments. The only EU level network specifically working to support carers, Eurocarers (which now has members in over 20 EU member states) aims to:

- Promote recognition of carers and carers' interests, irrespective of their age or the particular health needs of the person they are caring for.
- Advocate carers' interests at EU and national policy level.
- Campaign for EU and national policies which take carers and their issues into account.
- Promote the social inclusion of carers.
- Promote the development of services that can support carers.
- Stimulate and support the development of carers' organisations in countries and regions where they do not exist.

Eurocarers was launched officially in 2007, at an event in the European Parliament which also saw the launch of a new cross-party European Parliamentary Interest Group on Carers[41]. This latter group works to ensure EU policy development takes Europe's estimated 100 million carers into account, checks policies for their impact on the situation of carers, and aims to raise the awareness of MEPs of carers and their situation. In an official communication in November 2007[42], on "Opportunities, access and solidarity: towards a new vision for the 21st Century in Europe", it stressed that '*enabling a better balance between work and family life is the key to unpaid care provision, and policy measures to facilitate this are urgently needed'*.

It pointed out that '*carers run the risk of being left with insufficient pension and social security rights, as a result of having to leave paid employment because of caring responsibilities*' and that '*while women are more likely to provide* *substantial care, a growing number of men across the EU provide significant levels of care to their families, partners or relatives, and their contribution must also be acknowledged and recognised'.* Its concluding message was that '*carers form the bedrock of our health and social care systems, but at a wider level are critical to the future economic and social sustainability of Europe'.*

While carers issues are still often neglected in key EU policy documents, the growing awareness of long-term care issues across Europe has begun to give more prominence to their situation (although health and social policy matters are not part of the EU's formal remit). As an example, Health-EU (the public health portal of the European Commission) now has a section on carers on its web-site[43], which states:

> "Informal carers are people who give care or support to persons who are dependent because of long-term physical or mental ill-health or disability, or problems related to old age, usually at home and typically unpaid. These carers can be relatives of the person who needs care and support, or other volunteers. As they deal with serious matters and often under difficult circumstances, carers need particular attention and support from national, regional and local authorities to help them with their tasks. In general, to carry out their duties smoothly and efficiently they require a mix of suitable supporting services for the social and medical care to the person who needs care, as well as some financial support (including for instance contribution payments to social insurance systems) and flexible working conditions in their own profession."

The European Commission has also begun to note the situation of carers in policy-making on social inclusion, like the European Parliament Interest Group and Eurocarers, highlighting the reconciliation of work and family life, social protection and the importance of services as mechanisms for supporting carers:

> "Member States are committed to increasing access to quality services. The right balance needs to be struck between public and private responsibilities and formal and informal care. Provision in a residential or community setting is preferred to institutional care but for many Member States providing such quality services remains a challenge. The same goes for improved care coordination and ensuring support for informal carers. ….

> … The improvement of working conditions and formal recognition of informal carers in social security schemes are ways to ensure high level of quality in informal provision."[44]

### *The Australian situation*

The situation in Australia is substantially different to the UK with respect to participation in a supranational policy agenda, predominantly because Australia is not included in supranational carers networks like those that are active and organised in Europe, in which Carers UK is a key player. Australian carers associations look predominantly to the UK and other European countries for effective models of care provision, especially with respect to policies for young carers where UK policies are seen as the way forward based on the research and policy analysis of Saul Becker and other academics (Carers Australia, 2009c; Becker, 2007). In addition, with respect to proposals for direct funding of care provision, carers associations and other consumer and welfare organisations look to UK and other European models (HRSCFCH&Y, 2009, p 184-185). In addition, the ACTU and carers association advocacy for extending the right to request flexible employment arrangements for employees with caring responsibilities is influenced by the UK legislation. However, there are no supranational institutions through which such models or proposals are promulgated or mandated; rather, international policy ideas may be seen as influencing and framing advocacy group lobbying. Thus policy-making is located in the national political arena at multiple levels of government, subject to lobbying and negotiations between consumer organisations and carers advocates, political parties and governments at Commonwealth, State and Territory levels.

## Conclusions

While there are many similarities between the situation of informal carers and policy responses in the two liberal democracies, the UK and Australia, there are also distinct differences in the type of policy responses and the domains in which they are situated. As noted in the Introduction: demographic, economic, political, labour market and gendered social processes have brought policies for carers on to the agendas of parliamentarians, policymakers and social movements, refocusing how carers and their contribution are conceptualised, regulated and supported. In the UK, the wellspring for policy change has been a combination of: socio-economic/demographic imperatives around population ageing; increased labour force participation of women and the demise of the normative male breadwinner model towards a dual earner (or adult wage earner model) with strong implications for the availability of female informal care-givers; an active but non-partisan carers' movement; employer engagement at strategic moments; and a strong evidence base, giving voice to carers' own perspectives and marshalling robust statistical data to expose the size, scale and range both of carers' contribution to the health and social care system and of the future policy challenges. There has been in particular concerted research and policy debates about workplace arrangements and legislation to foster and support carers' continuation in employment and the balancing of their employment with care responsibilities; robust debate and lobbying from carers' representative organisations and within government about more appropriate and adequate forms of financial support; strong developments in social care provisions for carers and people with disability, with an accelerating trend to the implementation of models of consumer-directed care for people with disability and carers. These policy responses and lobbying for them have taken place often within the context of supranational institutions, increasingly through the advocacy work of Eurocarers within the European Union.

In Australia, the major influences shaping policy changes with respect to carers are similar: political responses to socio/economic/demographic imperatives, specifically population ageing and increased female labour force participation signalling the demise of the male breadwinner model and the consolidation of a normative one-and-a-half earner family model. There is an official policy discourse stating that increased old age dependency ratios will entail an increased demand for health and community care services to enable ageing in place. Accompanying this projection, there is official recognition that since the 1980s the policy shift from institutional care to care in the community for people who are aged or with disability has relied heavily on the availability and willingness of informal carers to take on caring responsibilities, as ‘partners in care’ in health and social care services delivery. This recognition has been coupled with the expressed anxiety that the supply and willingness of informal carers will not be sufficient to meet the increased demand. In addition, there is, as in the UK, an active, non-partisan and politically astute Carers Association network with strong advocacy skills which has spearheaded economic valuations of the financial contributions made by informal carers to families, communities and economy, assessing the cost of informal care, including replacement costs if care was provided by formal services, and opportunity costs incurred by carers’ reduced workforce participation and loss of market earnings. These carers associations have been assiduous in preparing submissions to major government inquiries, most recently and notably to the House of Representatives Standing Committee *Inquiry into Better Support for Carers*.

In light of these trends, in particular population ageing and the increased prevalence of disability and chronic illness associated with ageing, the strong trend away from institutional care to care in the community, and the consequent reliance on informal carers, a series of developments over the last several decades in the social security system and in community service provision have impacted substantially on the circumstances of carers, introducing and enshrining the premise that carers must be supported to maintain their caring responsibilities. Of particular importance, carers’ pension rates and entitlements have been linked to age pension rates and entitlements, in the process safeguarding income support policies for carers from activation requirements and providing these payments with a legitimacy much less accorded to other income support arrangements for people of workforce age.

An increasingly robust evidence base, with substantial contribution from the Australian Bureau of Statistics, has highlighted in particular the deleterious impacts of care-giving on carers’ labour force participation, income, health and well-being, and more recently focusing on the employment arrangements required to support and maintain carers' workforce participation. It is evident from these developments that carers' double, usually contradictory responsibilities of care and employment are expected to be maintained, an aspiration increasingly shared by carers themselves in their everyday struggles.

Emphasis on statutory rights is less evident in Australia than in the UK: within Australia's federal structure of multi-level governments there is no overarching national legislative framework for carers (with the major exception of income support which is a Commonwealth responsibility). The Report of the *Inquiry into Better Support for Carers* has recommended the development of a nationally consistent carer recognition framework and a national carer strategy which builds on and complements state and territory policies. It is evident that the issue of national legislative and policy consistency has been placed on the political agenda, with outcomes yet to be negotiated and determined.

Other dissimilarities between the UK and Australian policy responses lie in particular in the relative absence of engagement with employers or government-mandated workplace policies for carers. There is a considerably less well-developed system of flexible workplace arrangements in Australia established as a statutory right, although the issue is now on the policy agenda with strong advocates. This may well be related to the relatively late introduction by the Australian government of paid parental leave and the right to request flexible employment arrangements for employees with early childcare responsibilities (compared with the UK). The winning of such rights has spearheaded calls for the provisions to be extended to all carers and for the better implementation of carer-friendly employment practices.

Another policy trend of considerable importance in the UK has been embarked upon to a limited degree in Australia and only very recently. This is the significant expansion in the UK of flexible service delivery through the development of a 'personalisation' agenda in social care, including Direct Payments and Individual Budgets, with carers explicitly involved in decision-making and care planning in many instances. By comparison, in Australia the introduction of direct funding and personalised packages of care and support for people with disability and frail older people has been more recent and more tentative across the various jurisdictions. Australia has followed a more cautious approach in aged and disability care services, possibly relating to multi-jurisdictional program developments across the Commonwealth and State/Territory departments and the roles of large service-provider agencies within the structure of tender-driven funding. But the trends toward consumer-directed care and individualised funding are now part of future service delivery options, geared much more towards enhancing flexible choices for people with disability, without, in many cases, addressing as a central issue the roles and responsibilities of informal carers.

Finally, there is a salient dissimilarity between Australia and the UK with respect to participation in a supranational policy agenda, because Australia is not included in supranational carers networks like those that are active and organised in Europe, in which Carers UK is a key player. Australian carers associations and other key players and researchers look predominantly to the UK and other European countries for effective models of care provision, especially with respect to policies for young carers where UK policies are seen as the way forward; and with respect to proposals for consumer-directed funding of care provision. In addition, the ACTU and carers associations' advocacy for extending the right to request flexible employment arrangements for employees with caring responsibilities is influenced by the UK legislation. Since there are no supranational institutions through which such models or proposals are promulgated or mandated in Australia, international policy ideas may be seen as influencing and framing advocacy group lobbying. Thus policy-making is located in the national political scene at multiple levels of government, subject to lobbying and negotiations between consumer organisations and carers advocates, political parties and governments at Commonwealth, State and Territory levels. This is much more about the diffusion of policy ideas, to be adapted to Australian practices within a political arena, rather than the direct influence, authority and lobbying strength of a supranational body like the EU with its influence on carer policy development in the UK.

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[1] Poole, T (2006) *Telecare and Older People*, Wanless Social Care Background Paper, London: The Kings Fund, p16.

[2] In the 85+ age group, 91% of men and 93% of women in England live alone, in a older couple household or in a residential establishment (calculations prepared by L Buckner, derived from UK 2001 Census Sample of Anonymised Records, ONS 2006).

[3] Carers UK, written submission, *House of Commons Work and Pensions Committee* (2008), HC 485-II. The number of workers in health and social care personal service occupations is expected to rise to 1,129,000 by 2017, from 438,000 in 1997, Wilson, R, Homenidou, K and Gambin, L (2008) *Working Futures 2007-2017: Evidence Report 2*, UK Commission for Employment and Skills, p281.

[4] Wilson et al, op cit. The 2008/9 global financial crisis/recession is expected to affect the estimates about labour demand in the short, but much less in the medium-longer, term. Given the shifting balance in the structure of the population between working age and older population groups, the pressure both men and women of working age to participate in paid employment, generating a pension entitlement for a longer retirement, is likely to be acute.

[5] Yeandle, S & Stiell, B (2007) 'Issues in the Development of the Direct Payments Scheme for Older People in England' in Ungerson, C and Yeandle, S (eds) *Cash for Care in Developed Welfare States*, London: Palgrave Macmillan; Glendinning, C, Challis, D, Fernandez, J, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M & Wilberforce, M (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*, York: Social Policy Research Unit: University of York.

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[6] 2001 Census data, Crown copyright.

[7] Data from 2001 Census: Buckner, L and Yeandle, S (2005) *We Care: Do You* London, Carers UK; and Yeandle, S, Shipton L, & Buckner, L (2006) *Local Challenges in Meeting Demand for Domiciliary Care: synthesis report* Sheffield: Centre for Social Inclusion, Sheffield Hallam University. Care worker data include those identified as 'care workers and home carers'.

[8] *Community Care Statistics 2008: Home Care Services for Adults, England* Health and Social Care Information Centre, 2009; Yeandle, S, Shipton, L and Buckner. L (2006) *Local Challenges in Meeting Demand for Domiciliary Care: synthesis report* GELLM Report Series, Sheffield: Centre for Social Inclusion, Sheffield Hallam University.

[9] See volume of evidence assembled by the House of Commons Work and Pensions Committee in 2008 *Valuing and Support Carers, Volume II* London: House of Commons 485-II, and Yeandle,S et al (2007) *Carers Employment and Services Report Series* London: Carers UK, particularly reports 2 and 6 in the CES series, and the references to other literature within them.

[10] The value of their unpaid contribution estimated to be worth £87bn per annum (Buckner, L and Yeandle, S (2007) *Valuing Carers – calculating the value of unpaid care*, London Carers UK – calculating hours of care at a unit cost per hour of £14.50, as quoted by the NHS Information Centre (for 2005-6).

[11] DWP website, http://83.244.183.180/100pc/ca/cnage/ccsex/a_carate_r_cnage_c_ccsex_nov08.html

[12] In evidence to the *House of Commons Work and Pensions Committee*, DWP reported that 222,000 people in the UK received the carer premium with Income Support in 2008, and that over 221,000 carers over age 60 received the additional amount for carers with their Pension Credit payments, HC 485-II, (2008), Ev. 106, para 3.12.

[13] Yeandle, S and Buckner, L (2007) *Carers, Employment and Services: time for a new social contract?* London: Carers UK.

[14] The national charity *Carers UK* (formerly the *Carers National Association*) has campaigned prominently for legislative/policy change, supporting Westminster MPs to bring forward three Private Members' Bills which have successfully passed into law: the *Carers (Recognition and Services) Act 1995*; the *Carers and Disabled Children Act 2000*; and the *Carers (Equal Opportunities) Act 2004*. With other carers' organisations (e.g. *Contact a Family* [which supports families with disabled children, registered as a charity since 1979] and *Counsel and Care* [which supports carers of older people] it has lobbied government, parliamentarians and policy-makers at the highest level. Two carers' organisations, *The Princess Royal Trust for Carers* [formed in 1991] and *Crossroads Caring for Carers* have built extensive networks of local agencies, some of which have considerable influence on local level carers' policies and strategies. Ad hoc campaigning around specific issues and political developments is regularly enhanced through activities undertaken in *Carers Week* (organised annually by *Carers UK, Counsel and Care, Crossroads Caring for Carers, Independent Age, Macmillan Cancer Support, MS Society, Parkinson's Disease Society, The Princess Royal Trust for Carers, Vitalise* and *WRVS*, working in partnership); and on the annual Carers Rights Day, organised by *Carers UK* working with over a thousand local carers' groups.

[15] The *National Council for the Single Women and their Dependants* was formally established in 1965.

[16] A *National Black Carers Network* was set up in the late 1990s, for example.

[17] See Cook, T (2007) *The History of the Carers' Movement* London: Carers UK for a detailed account.

[18] Cook, T (2007) *The History of the Carers Movement* London, Carers UK.

[19] For details of relevant legislation see CES Report 4 Table 4.2.

[20] The listed membership of the *All Party Parliamentary Group for Carers* includes Conservative, Labour, Liberal and Plaid Cymru members. The group was established to '*ensure the equality of opportunity for carers in the UK by liaising with carers organisations, lobbying Government and promoting legislation on their behalf; to promote awareness amongst members of both Houses of the needs of carers and former carers; to liaise with members of the devolved administrations within the UK in order to share best practice; and to link with appropriate bodies, including carers organisations, on an international basis.*' It has members in both the House of Commons and the House of Lords.

[21] All-party support for carers led to the success of two Private Members' Bills [later the *Carers & Disabled Children Act 2000* and the *Carers (Equal Opportunities) Act* 2004]. Other legislation affecting carers includes: *Employment Relations Act 1999; Employment Act 2002; Work & Families Act 2006; Pensions Act 2007* (all applicable throughout the UK), plus (in England & Wales only)

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*Children Act* 2004; *Childcare Act 2006*; and (in Scotland only) *Community Care & Health (Scotland) Act 2002.*

[22] The CBI is the Confederation of British Industry.

[23] Building on the work done between 2002 and 2007 by the group of employers engaged in the Action for Carers and Employment project, led by Carers UK – see Yeandle, S and Starr, M (2007) *Carers, Employment and Services: Impact of the ACE partnership 2002-7,* CES Report 5 London: Carers UK.

[24] Clements, L (2009, 3rd edition) *Carers and their Rights – the law relating to carers* London: Carers UK.

[25] CSCI (2006) op. cit.

[26] Yeandle, S (2009 in press) 'Telecare: a crucial opportunity to help save our health and social care system', pamphlet, Bow Group publication, London.

[27] This is provided for in the *Work and Families Act 2006.* Research into the impact of the right to request flexible working available to working parents of young children (up to age 6) and of disabled children (up to age 18), provided for in the *Employment Act 2002*, is encouraging. Early research showed that only 13% of women and 23% of men who negotiated about flexible working arrangements with their employer had their request refused. [Fitzner, G and Grainger, H (2007) *The Right to Request Flexible Working: a review of the evidence*, DTI Britain at Work Seminar Series, March 2007].

[28] Fry, G, Price, C and Yeandle, S (2009, in press) *Local Authorities' Use of Carers Grant*, report prepared for the Department of Health, London, England.

[29] Fry, G *et al* (2009 in press) *op. cit*. The slightly different arrangements for Carers Grant in England, Scotland and Wales are explained in Yeandle, S Bennett, C et al (2006) *Carers Employment and Services in their Local Context* CES Report 4 London: Carers UK.

[30] Since 1998, devolved government in Scotland and Wales has led to a degree of differentiation in the legislative and policy contexts affecting carers, with some variations in outcomes for carers (Yeandle et al 2007 CES4). Notable is free personal care for older people in Scotland, introduced in 2002.

[31] CSCI (2005) *The State of Social Care in England 2004-5;* and (2006) *The State of Social Care in England 2005-6* London: Commission for Social Care Inspection.

[32] The *New Deal for Carers* announced in spring 2007 made commitments to a national helpline for carers, an expert carer support programme and additional funding for emergency planning support. The helpline went live in 2009 as *Carers Direct*, with a target of 100,000 call responses in the first year of operation; the *Caring with Confidence* programme, operating through 25 providers of face-to-face support throughout England, and with on-line and self-study versions also available, began mainstream operation in 2009, with a target of reaching 37,000 carers in the first three years of its contract. Emergency planning support for carers has been arranged through 150 English local authorities.

[33] The reports of the four Task Force created to help in developing the Carers Strategy are available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086585.

[34] The seven departments were: Department of Health; Department of Communities and Local Government; Department for Work and Pensions; Department for Business, Enterprise and Regulatory Reform; Department for Children, Schools and Families; Government Equalities Office; and Department for Innovation, Universities and Skills.

[35] For example, Carers UK had commissioned a major programme of academic research (from a research team at the University of Leeds using EU funding available through its *Action for Carers and Employment* project (2002-7) and other funding streams. This produced both new empirical studies (on carers of disabled children, on the social and business benefits of supporting carers at work, and on *Carers, Employment and Services*- a series of 14 reports), as well as extensive and well publicised analysis of the 2001 Census (which had, for the first time, included a question on carers, thereby creating new opportunities for statistical work at the level of local geography, adding to understanding of carers' households, economic activity, occupations, educational level , etc. . Available at either: http://www.carersuk.org/Policyandpractice/Research/CarersEmploymentandServices; or http://www.sociology.leeds.ac.uk/research/care-employment/care-labour-equalities/

[36] The new Care Partnership Managers were recruited from spring 2009; the Department of Work and Pensions has made a formal commitment to making the new financial support for alternative care available to carers from December 2009.

[37] The report of their visit is available as Annex A 'Committee Visit Notes' in House of Commons Work and Pensions Committee (2008) *Valuing and Supporting Carers*, Fourth Report of Session 2007-8, Volume 1, pp 99-113. The Committee met with politicians, officials, academics and voluntary organisations in Sydney and Adelaide during their visit, 12-16 May 2008.

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[38] The Committee appointed two ‘Special Advisers’ for this inquiry. Dr Hilary Arksey (University of York) and Prof. Sue Yeandle (University of Leeds) reviewed all written evidence, attended the public sessions at which oral evidence was given, made presentations to the Committee *in camera*, and accompanied the Committee on its UK visit to Harrogate Carers Resource in Yorkshire. They also assisted the Committee and its secretariat by providing additional written evidence, including data from the Carers, Employment and Services study conducted at the University of Leeds in 2006-7.

[39] House of Commons Work and Pensions Committee (2008) *Valuing and Supporting Carers*, Fourth Report of Session 2007-8, Volume 1, p 94, ref. HC 485-1.

[40] Through ACE, Carers UK was able to support the development of Eurocarers providing a secretariat, resourcing a series of events to raise the profile of the issue in Europe, and engaging policy expertise to place carers’ issues on the European policy stage.

[41] http://www.eurocarers.org/userimages/special_interest_group_carers_jan2008.pdf

[42] http://ec.europa.eu/citizens_agenda/social_reality_stocktaking/contributions/docs/contrib87.pdf

[43] http://ec.europa.eu/health-eu/care_for_me/carers/index_en.htm

[44] European Commission (2008) *Joint Report on Social Protection and Social Inclusion,* Council of the European Union, document 7274/08