The challenge of caring, now and in the future: learning from across the world

- Around the world, growing attention is being given to finding ways of responding to the challenges of population ageing and of living longer with disability or frailty
- These challenges must be met alongside the need to increase employment rates and adjust arrangements for health, care and welfare so they are equitable, sustainable and sufficient to meet need
- In the English-speaking world, Australia, Canada and the UK have played a notable role in identifying and researching these challenges and in exploring options for addressing rapidly changing needs
- In this Discussion Paper we take a comparative look at how support for carers of older, sick and disabled people has developed in these three countries, aiming to stimulate debate about appropriate steps and new policy options
In this Discussion Paper, we consider how the challenges of population ageing - more very frail older people living alone or as frail couples, often at considerable distance from other family members - and growing numbers of people living with long-term conditions and disabilities are being addressed in three countries.

In each country a focus on carers and a recognition that most care is provided by people of working age, usually managing their caring roles alongside workplace responsibilities and the need to earn a living, has been fundamental. And in all three, carers’ organisations and other NGOs have in different ways played a significant part in shaping and progressing debates about policy and practice.

We argue that it's necessary to move beyond debates about whether the state or the family should meet growing care needs. Better and more sustainable policy options are needed for the future so that everyone in our societies can be supported and empowered to play a part in delivering care. The essential framework for these policy options, based on our research and policy analysis, is set out in Figure 1.

How far these different elements have been developed in each country is shown in the following pages, which outline key developments in Australia, Canada and the UK / England and highlight some of what is distinctive and innovative in each. The paper also presents analysis of newly commissioned 2011 Census data for England (page 3) which shows recent rapid growth in the numbers of older workers combining caregiving with paid work, highlighting this key challenge. We then present a summary of progress and developments in each country, concluding the paper with a focus on progress, innovation, challenges and opportunities, designed to stimulate dialogue and debate.
The 2011 Census showed England had 5.4 million carers. This included 4 million working age carers (aged 18-64), among whom 1.3 million cared for 20+ hours per week. Between 2001 and 2011 the proportion of women and men caring rose in all age groups over 55, but fell a little among men and women aged 25-54. Here newly commissioned data from the 2011 Census are compared with data from the 2001 Census / Census SAR. Strikingly, the number of carers aged 45-64 rose by 257,900 between 2001 and 2011, with big increases in the proportion of carers combining care with paid work. These changes make work-care reconciliation policy even more vital, as pressures on women and men in this age group intensify.

Caring increased among older workers for three main reasons: (i) more people were aged 45-64; (ii) more, especially among those aged 60-64, were caring (probably because people in the generation above, and others needing care, were living longer); and (iii) as employment rates for older workers rose, more men and women aged 45-64 combined caring with paid work. Tables 1 and 2 show the detailed changes.

Table 1 Change in caring among people aged 45-64: England, 2001-2011

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Additional people</th>
<th>Carers 1-19 hours</th>
<th>Carers 20-49 hours</th>
<th>Carers 50+ hours</th>
<th>Carers all</th>
<th>Non-carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women 60-64</td>
<td>+396,800 +33%</td>
<td>+82,000 +53%</td>
<td>+17,500 +61%</td>
<td>+17,600 +29%</td>
<td>+117,100 +48%</td>
<td>+297,700 +29%</td>
</tr>
<tr>
<td>Women 45-59</td>
<td>+505,400 +11%</td>
<td>+11,700 +2%</td>
<td>+25,000 +20%</td>
<td>+23,000 +13%</td>
<td>+59,800 +6%</td>
<td>+445,600 +13%</td>
</tr>
<tr>
<td>Men 60-64</td>
<td>+379,900 +33%</td>
<td>+53,700 +41%</td>
<td>+10,900 +55%</td>
<td>+14,700 +38%</td>
<td>+78,900 +42%</td>
<td>+301,000 +31%</td>
</tr>
<tr>
<td>Men 45-59</td>
<td>+482,800 +11%</td>
<td>-36,800 -6%</td>
<td>+22,800 +33%</td>
<td>+16,000 +15%</td>
<td>+2,100 +0%</td>
<td>+480,700 +13%</td>
</tr>
</tbody>
</table>


Table 2 Percentage of carers in paid work: England, 2001-2011

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Carers 1-19 hours</th>
<th>Carers 20-49 hours</th>
<th>Carers 50+ hours</th>
<th>Carers all</th>
<th>Non-carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women 60-64</td>
<td>of whom employed PT</td>
<td>28</td>
<td>41</td>
<td>14</td>
<td>23</td>
</tr>
<tr>
<td>Women 45-59</td>
<td>of whom employed PT</td>
<td>73</td>
<td>81</td>
<td>36</td>
<td>42</td>
</tr>
<tr>
<td>Men 60-64</td>
<td>of whom employed PT</td>
<td>53</td>
<td>61</td>
<td>25</td>
<td>33</td>
</tr>
<tr>
<td>Men 45-59</td>
<td>of whom employed PT</td>
<td>85</td>
<td>86</td>
<td>47</td>
<td>53</td>
</tr>
</tbody>
</table>


Table 2 shows that by 2011, among carers aged 60-64, 54% of men and 36% of women were in paid work, the figures rising especially sharply for women (up from 24%). Among carers aged 45-59, by 2011 the vast majority of men and women were in paid work (women 72%, men 79%). These changes reflected labour market trends towards more part-time working and higher employment rates for both sexes and age groups.
Australia: the situation and context for carers in 2014

In 2012, 12% of Australia’s population (2.7 million people) were carers. Around 2 million of these carers were people of working age (15-64 years). Australia first recognised carers in income support payments in the 1970s; by the mid-1980s, unpaid family care had emerged into Australian public policy. From 1985, the Carer Pension (later renamed Carer Payment) has been a key component of the pensions system for carers of working age; it was also at this time that Australian and State / Territory funded community services recognised carers in the Home and Community Care program. This change signalled a shift from residential to home care in funding priorities in elder care and disability care.

Over 30 years, a strong network linking Carers Australia and carers’ associations in all states and territories has emerged, providing advocacy, research, services, information and representation on government bodies. In 1988 the Australian Bureau of Statistics recognised carers in national data collection, when it introduced the Survey of Disabled and Aged Persons (from 1993 the Survey of Disability, Ageing and Carers). In 2006 and 2011 Australia’s Census of Population and Housing included an item on unpaid care, creating a population database for demographically and regionally sensitive policy development, and recognising carers’ diversity.

In 2010 Australia introduced a National Carer Recognition Framework. Supporting carers’ aspirations to combine employment and care, the National Employment Standards in the Fair Work Act 2009 (Cth) provided some employed carers with the right to receive short periods of paid and unpaid carer leave and to request flexible work arrangements, a right subsequently extended to all carers in 2013.

---

**FINANCIAL SUPPORT**

- Wife’s Pension, Domiciliary Nursing Care Benefit, Handicapped Child Allowance 1970s
- Carer Pension 1985 (renamed Carer Payment 1997): income support (income/ assets tested) for carers of relatives Extended to carers of nonrelatives 1988, extended to carers enabling them to work, study or train < 25 hrs p.w. 2005

**WORK-CARE RECONCILIATION**

- Fair Work Act 2009 (Cth) National Employment Standards: Right to request flexible work, carers of disabled children <18 (extended to all carers, reasonable business grounds for refusal defined, 2013) - 10 days paid leave p.a. if family / household member needs care - 2 days unpaid leave on other occasions

**SERVICES FOR USERS & CARERS**

- Home and Community Care Act 1985
- National Respite for Carers Program 1996-7
- Living Longer Living Better Aged Care Reform 2012, National Disability Insurance Scheme 2013
- Young Carers Respite and Information Services Program
  - Some carers eligible for LM programmes via Job Services Australia

**CARER RECOGNITION & RIGHTS**

- Parliamentary Friends of Carers founded 2007
- National Carer Recognition Framework 2010-11 encompassing:
  - Carer Recognition Act 2010 (Cth) recognises carers’ rights, choices and opportunities
  - National Carer Strategy 2011 better support so carers have more options to participate in paid work
- Investing in Care 2013 Australian Human Rights Commission report

---

Figure 2 Delivering support for carers in Australia

---

1 Prepared by Bettina Cass and Trish Hill, UNSW Australia.
Canada has a history of multidisciplinary research on caregiving which goes back more than 30 years. The first policy initiatives to explicitly target caregivers date from about 1984; the first nationally representative data on social support (which included help received with daily living needs) were collected in 1985. By 2012 more than 8.1 million Canadians (26% of all men and 30% of all women aged 15+) had caring for one or more family members or friends with a long term disability, illness or age-related condition during the previous year. Caregiving is even more common when life course experiences are examined. In 2012, 13 million Canadians (45%) had been a caregiver at some time during their lives. The sub-group of mid-age and older caregivers aged 45+ grew by 20% between 2007 and 2012, and the number of Canadians needing assistance is forecast to double over the next 30 years.

Most Canadian caregivers spend modest amounts of time on care tasks (< 10 hours p.w. for 74%), although 10% spend 30+ hours p.w. caregiving, with those caring for a spouse (31%) or a child (29%) most likely to do so. Most caregivers are also employed, most full time, and spend the equivalent of one full work day p.w. on care tasks with resultant employment related consequences (see figure above). These competing demands mean many caregivers must accommodate their paid work in order to cope; these accommodations threaten the well-being of caregivers, workplaces and the labour market.6

---

**FINANCIAL SUPPORT**
- Nova Scotia Home Life Support Program provincial 1984; max $400 benefit to caregivers; suspended 1988
- Nova Scotia Caregiver Benefit, provincial 2009; cash benefit; any caregiving >20 hrs p.w.; means tested
- Compassionate Care Benefit federal 2004; end-of-life care, 55% income replacement to a maximum.
- Federal & provincial tax credits including 1997 federal Caregiver Tax Credit, co-residential carers; Family Caregiver Tax Credit 2012

**WORK-CARE RECONCILIATION**
- Family Responsibility Leave federal since 2000, most provinces and territories; 3-12 days p.a. unpaid leave
- Compassionate Care Leave federal from 2004; all provinces / territories by 2014; 8 wks leave over 26 wks; end of life care; may be shared by multiple caregivers
- Employers for Caregivers Plan federal 2014; employer panel to identify promising workplace practices to maximise caregivers’ LM participation

**SERVICES FOR USERS & CARERS**
- Home and continuing care services for the care receiver mainly provincial / territorial responsibility; cost shared and means tested

**CARER RECOGNITION & RIGHTS**
- Caregiver Recognition Act 2011 (Manitoba) creates general principles for how caregivers should be treated; establishes Caregiver Advisory Committee to provide Minister with information, advice, recommendations and bi-annual progress reports evaluating caregiver needs and supports
- Human Rights Acts federal and provincial; prohibit discrimination on the basis of family status; recent tribunal decisions and case law extend protection against discrimination to employees with family care responsibilities

---

5 Prepared by Janet Fast and Norah Keating, University of Alberta, Canada.
The UK first recognised carers in national policy on taxation and income support in the 1960s and 70s, when pioneering work in the voluntary and academic sectors began to establish a sound evidence base. Led by Carers UK, carers’ NGOs have campaigned on carers’ issues for almost fifty years. Carers acquired their first limited rights in the UK’s systems for social care and employment in the 1990s and 2000s. Official data has been collected on carers since the 1980s, with a question on caring included in the 2001 and 2011 Censuses. In a first National Carers’ Strategy (NCS) in 1999, government acknowledged carers’ need for services and support, noting their difficulties in reconciling work and care and introducing ‘carers’ grant’ funding to local authorities. In 2008 a revised NCS focused strategic policy aims and some new resources on carer’s health, incomes and rights and on carers who wished to combine work and care. Its approach was broadly supported by the incoming government (2010); a focus on carers fulfilling their educational and employment potential was maintained, although the 2008 commitment to end financial hardship for carers was dropped. The financial pressures carers face are nevertheless barely touched by the modest benefits Carer’s Allowance and other state social welfare support offers, a persistent problem highlighted in several decades of research evidence.

The UK has seen strong employer advocacy of the benefits of supporting employees to combine work and care, exemplified in the work of Employers for Carers, but carers still lack any rights to paid leave from work, and have no entitlement to a period of planned time off to make care arrangements when care needs arise.

---

**Figure 4** Delivering support for carers in the UK / England

---

Prepared by Sue Yeandle, University of Leeds, UK.
Ongoing issues and challenges in developing support for carers

Here we note innovation and challenges of interest for policy-making which have received attention in the three countries. Topics are highlighted as an aid to discussion about how learning from across the world can be applied to address the challenge of caring, now and in the future, in a changing and ageing world.

Establishing and maintaining a strong voice for carers and maintaining awareness of carers

- Strong platforms exist at the national / sub-national level and are well-established in UK and Australia
- Scope for significant development, especially at the national level, in Canada
- Awareness campaigns well established in UK/Australia e.g. Carers Week, Care Aware, Carers Rights Day
- Scope for better and more formalised ‘nudge’ mechanisms in health, social care and with employers

Social inclusion and ‘a life of their own’

- Inadequate emphasis on carers’ risk of exclusion from full participation in the normal activities of society
- Evidence of the ‘triple penalty’ carers pay - poorer health and financial circumstances; social exclusion
- Research in all three countries shows how material insecurity - a hallmark of exclusion – affects carers
- Out of pocket expenses can deplete savings and jeopardise carers’ financial security and futures
- Isolation from friends and tensions in families can arise from carers’ lack of time, energy or health
- Accessible, multi-generation housing, pension schemes and carers’ allowances all offer some protection

Securing an appropriate service mix

- Ensuring carers’ own needs and aspirations are addressed in service systems is a challenge everywhere
- Some large scale projects have shown what can work in supporting carers’ health and well-being
- Progress in providing services which enable carers to work or negotiate multiple activities is being made
- Carers still bear the major costs of most options which support combining work and care
- Using scarce human resources and emerging technology to best effect is entering the policy debate
- Challenges are faced everywhere in ensuring a sufficient supply of suitable services

Reconciling work and care

- Support from employers and managers is vital, as is identifying work-care champions and role models
- There is evident need for greater trade union involvement in developing carer support at work
- Leave options for carers which address financial risk are beginning to emerge but remain very limited
- At work, long hours cultures need to change, adapting expectations to life course circumstances

Minimising and addressing the financial penalties of caring

- Addressing the pension penalty carers experience is vital as this stores up problems for the future
- Combating ‘working below potential’ needs collaborative employer / employee action
- Current policies do not adequately address the costs and financial risks of caring

Maintaining and expanding the evidence base

- Progress in securing data on carers at both national and local levels needs to be sustained
- Care histories over the life course can identify care trajectories and the long term impacts of caring
- Evidence on the social, economic & business case for supporting carers at work is well-established, but additional research on ‘at risk’ groups, pressure points and successful innovation needs development

---

8 Scharf and Keating [2012].
9 Identified in Yeandle et al’s Carers, Employment and Services study for Carers UK (2007).
AUSTRALIA

SPRC Social Policy Research Centre
UNSW Australia
Web:  https://www.sprc.unsw.edu.au/
Email: p.hill@unsw.edu.au

The Carers and Social Inclusion: new frameworks, evidence and policy lessons project is supported under the Australian Research Council's Linkage Project funding scheme (LP110100460), with research partners: University of Leeds; Carers Australia; Australia Government Department of Employment; Office for Carers in NSW Department of Families and Community Services; NSW Health; SA Department for Communities and Social Inclusion. The views expressed herein are those of the authors and not necessarily those of the Australian Research Council or the above departments or the responsible Ministers.

CANADA

Research on Aging, Policies and Practice [RAPP], Department of Human Ecology University of Alberta
Web:  http://www.rapp.ualberta.ca/
Email: janet.fast@ualberta.ca / norah.keating@ualberta.ca

Research on Aging, Policies and Practice is an IAGG (International Association of Gerontology & Geriatrics) Collaborating Centre committed to making a meaningful difference in the lives of older adults and their families by bridging research, policies and practice. Led by Dr Janet Fast & Dr Norah Keating, RAPP’s research focus is on care and support of older adults and adults with chronic illness or disability; costs incurred by family / friend caregivers; social inclusion; and age-friendly rural communities. Norah Keating also directs the IAGG’s Global Social Initiative on Ageing.

UK / ENGLAND

CIRCLE Centre for International Research on Care, Labour and Equalities
School of Sociology and Social Policy, University of Leeds
Web:  http://www.sociology.leeds.ac.uk/circle
Email: CIRCLEadmin@leeds.ac.uk

The Older Workers and Caregiving Project is funded by an award to Professor Sue Yeandle from the Worldwide Universities Network’s Fund for International Research Collaborations. CIRCLE is a theoretically informed and policy relevant research centre directed by Professor Sue Yeandle. CIRCLE carries out research, evaluation and bespoke consultancy on contemporary issues and debates on care, labour and equalities issues and works in partnership with Carers UK on a variety of projects.

Carers UK

Making life better for carers
Web:  carersuk.org
Email: info@carersuk.org

Carers UK is here to make life better for everyone who cares, unpaid, for family and friends who are older, disabled or seriously ill. Over nearly half a century of history, we have campaigned with carers for lasting change and have carried out research, including with academic partners, to provide evidence for that change. We also give expert advice, information and support and innovate to find new ways of reaching out to and support carers. Carers UK established and supports Employers for Carers, a leading employers forum.