POLICIES TO SUPPORT ‘INFORMAL’ CARERS:
DO THEY DO IT BETTER ELSEWHERE?

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Overview

- **Carers in the UK:** concept and contribution
- **Policies supporting carers:** how we got here, types of support
- **Learning from elsewhere**
  - Australia, Canada
  - Sweden and Finland
  - Japan
- **Challenges ahead**
A short history - a ‘head start’?

- First carers’ organisation formed in 1965
- 1986 ‘Carers’ first mentioned in UK legislation on disability (Clements, 2007: 11)
- 1990, Parker speaks of an ‘explosion of research on carers’ (Twigg & Atkin, 1994: 1)
- 1995 first Act of Parliament on carers defines them:
  - ‘provide a substantial amount of care on a regular basis’, giving their care to family members or friends - but NOT as part of ‘a contract of employment’ or as a ‘volunteer for a voluntary organisation’

  *Carers (Recognition & Services) Act 1995*
A campaigning carers’ movement

- **1965** National Council for the Single Woman & her Dependents estd. to campaign on carers’ practical difficulties, isolation, financial problems
- **1967** Dependent Relatives Tax Allowance, first tax concessions for carers
- **1970s-80s** Many local, grassroots carers’ groups sprang up
- NCSWD’s *The Costs of Caring* report led to financial help for carers in **1976**
- From **1980s** onwards, several other national carers’ organisations formed
- **1987** NCCED Chief Exec Jill Pitkeathley* invited to join Roy Griffiths and Herbert Laming to work on national Community Care report.

- ‘Going anywhere we were asked to talk about it and how important it was. I would go endlessly to social services conferences. Fringe meetings at Party Conferences.’
- *Jill Pitkeathley still says: ‘Always be willing to work in partnership’; ‘Policies have to be achievable – ask for them in small bites!’* (interview with SY, March 2015)

- https://www.youtube.com/channel/UCYOGF6dAlRbXzhV-oaZcuLw
Key Achievements of UK carers’ movement

- Invalid Care Allowance 1976 – later ‘Carers Allowance’
  - Cost £1.8bn pa., c.600,000 carers, 35 hrs pw for recipient of a disability benefit
  - Married women entitled following European Court of Justice ruling (J. Drake case)
- Three successful Private Members’ Bills placed duties on local authorities
  - The Carers (Recognition and Services) Act 1995 (Malcolm Wicks MP)
  - The Carers and Disabled Children Act 2000 (Tom Pendry MP)
  - The Carers (Equal Opportunities) Act 2004 (Hywel Francis, MP)
- Coalitions, partnerships, research, statistics
- Carers, employment and flexible working
- Carers Week (started 1969), Carers Rights Day, media campaigns
- All Party Parliamentary Group, Westminster - since 2005
- International profile and activities, 1990s onwards
- New and long-sought rights for carers, Care Act 2014
Defining carers today (UK)

What carers’ organisations say:

- In the UK there are 6.5m people caring unpaid for an ill, frail or disabled family member or friend. These people are called carers but they would probably say "I'm just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a good neighbour"

http://www.carersweek.org/about-us/about-caring

The Care Act 2014:

- “A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation.” DH Factsheet


- 'Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?’ Office for National Statistics
Carers in the population: age structure 2001 & 2011

% Males who are carers


% Females who are carers
Contribution to UK’s health & social care system

- 12% of population provide unpaid care
- In 2015 valued at £132 billion p.a.*
  - Equals total cost of NHS
  - Over 4 times annual UK LA expenditure on social care services
- Following Health Act 2009, NHS Constitution recognises role of families and carers and includes them in its values, rights and pledge statements
- Care Act 2014, Children & Families Act 2014 strengthened rights and recognition of carers in the social care system – wider definition, legal right to receive support, personal budget statements

*Valuing Carers 2015: the rising value of carers’ support, L. Buckner & S. Yeandle
Four kinds of policy focus:

1. Financial support in the social security system

Carer’s Allowance (at first ‘ICA’)
- 1976 financial help for carers unable to fully support themselves through paid work *married women excluded until 1986*
- Claimed by 109,000 in 1988
  (McLaughlin, 1991)
- **Carer Premium** – additional payment for low-income carers claiming certain social security benefits
- **Carer’s credit** giving better state pension to carers, *Pensions Act 2007*

People receiving Carers Allowance 2003-12
Four kinds of policy focus:

2. Services for carers

- **Carers (Recognition & Services) Act 1995**
  - Introduced the concept of a local authority carer’s assessment

- **Carers and Disabled Children Act 2000**
  - Gave stronger rights to assessment and access to ‘direct payments’

- Large DH programmes tested new support for carers:
  - *Caring with Confidence* 2008-10, Demonstrator Sites** 2009-11

- **Children and Families Act 2014**
  - Clarified and improved parent carers’ rights to local authority support

- **Care Act 2014** - consolidated previous social care law
  - LAs must meet assessed needs of eligible carers

- **Voluntary sector services**
  - Widespread, innovative, not universal, fragile funding

* [http://www.sheffield.ac.uk/polopoly_fs/1.552512!/file/training-support-carers.pdf](http://www.sheffield.ac.uk/polopoly_fs/1.552512!/file/training-support-carers.pdf)

Four kinds of policy focus:

3. Workplace support and rights for carers

- **Employment Relations Act 1999**
  - Unpaid time off for family emergencies

- **Employment Act 2002**
  - Right to request flexible working (RRFW) parents of disabled/young children

- **Work and Families Act 2006**
  - Extended RRFW to most carers of adults

- **Children and Families Act 2014**
  - Removed the requirement to be a carer from RRFW legislation
  - ‘Supporting Working Carers’ (2013)

- **Care Act 2014**
  - Includes a duty on LAs to plan care services to enable carers to work
Four kinds of policy focus:

4. Recognition and rights for carers

- Based on the **economic, social and moral case** for treating care to others as a contribution to citizenship
- ‘Recognising’ carers means **valuing** what they do, **respecting** them for giving care to others, and developing ‘**socially inclusive**’ arrangements for carers
- **Carers (Equal Opportunities) Act 2004**
  - Required local authorities to consider carers’ wish to work or learn when conducting carer’s assessments
- **National Carers’ Strategy 2008**
  - Focused on services, social inclusion, income and employment, health and well-being, and young carers
  - The strategy included new support via government Jobcentres to enable carers to access training for work (later discontinued)
- **Equality Act 2010**
  - Protects carers from discrimination because they are caring for a disabled person
Framework for policy options*:
Model for delivering sustainable and inclusive support for carers

- **Financial Support**: Measures to prevent financial hardship for carers
- **Work-Care Reconciliation**: Workplace and life course flexibility for employees, employers, labour force
- **Services for Users and Carers**: Reliable, flexible, affordable, accessible and technology-enabled
- **Carer Recognition and Rights**: The economic, social moral case ➔ value, respect, inclusion

*Figure developed by Yeandle & Fast: [http://circle.leeds.ac.uk/files/2014/05/Challenge-of-Caring-v6-low-res-WEB.pdf](http://circle.leeds.ac.uk/files/2014/05/Challenge-of-Caring-v6-low-res-WEB.pdf)

**Evidence**
- rationale, scale, focus, targeting, efficacy

**NGOs**
- Voice of older and disabled people and their carers, listening, envisioning, innovating
Development of support for carers: three liberal democracies

<table>
<thead>
<tr>
<th></th>
<th>Australia</th>
<th>Canada</th>
<th>UK</th>
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| **Recognition and Rights for carers** | Carer Recognition Act 2010  
National Carer Strategy 2011  
Investing in Care Human Rights Commission 2013 | Caregiver Recognition Act 2011*  
Human Rights Acts | Nat Carers Strats 1999  
Carers (EO) Act 2004  
Equality Act 2010  
Care Act 2014 |
| **Services for users and carers** | Home & Comm. Care Act 1985  
Respite for Carers Program 1996  
Aged Care Reform 2012  
NDIS 2013 | Canada Health Act  
Home and continuing care services | Carers (R&S) Act 1995  
Carers & Dis Ch Act 2000  
Care Act 2014 |
| **Work-care reconciliation** | Work Choices  
Fair Work Act 2009  
Nat. Employment Standards  
Fair Work Amend’ Act 2013 | Family Resp’ty Leave 2000  
Compass. Care Leave 2004  
Employers for Caregivers Plan 2014 | Emplt Rel’s Act 1999  
Emplt Act 2002  
Child & Fams. Act 2014 |
| **Financial support for carers** | Carer Payment from 1985  
(init. ‘Carer pension’) | Compassionate Care Benefit 2004: EoL care, 55% inc. rep. Tax Credits (from 1997) | Carers All’ce /ICA 1976  
Pensions Act 2007 |
Australia’s Federal Carer Recognition Act 2010

Statement on Carers states that they: should .....  

1. Have the **same rights, choices and opportunities** as other Australians 
2. *(if children)*. Have the same rights as all children and young people and be supported to reach their full potential 
3. Be recognised / supported **for the social & economic contribution they make** to society 
4. Be supported to enjoy optimum health and social wellbeing and participate in family, social and community life 
5. Be **acknowledged as individuals with own needs**, within & beyond the caring role 
6. **Relationship between carers/persons cared for** should be recognised /respected 
7. Be considered as **partners with other care providers** in the provision of care 
8. Be treated with **dignity and respect** 
9. Be **supported to achieve greater economic wellbeing** and sustainability and, where appropriate, to participate in employment and education 
10. **Support for carers should be timely, responsive, appropriate and accessible** 

**BUT**: *“This Act does not create rights or duties that are legally enforceable in judicial or other proceedings”*
Support for carers in Canada

- **Compassionate Care Leave** - Part III of Canada’s Labour Code
  - Leave of up to 28 weeks in 52-week period to care for a gravely ill family member, available to all employees.

- **Employment Insurance Compassionate Care Benefits**
  - 26 weeks, when caring for a gravely ill family member, if worked 600 hrs in past year and earnings fall by at least 40%
  - 55% of salary [threshold $50,800pa (£27,834)] – max. $537pw (£294)
  - Can also earn max. $50pw; pilots are in place testing other options
  - Can be shared with another family member
  - UE claimants can also apply for CC benefits

- **Canada Health Act**
  - Does not mandate social care services
  - Wide variation across provinces in support for carers
## Carers’ entitlements today in three liberal democracies

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<tr>
<th></th>
<th>Australia</th>
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<tbody>
<tr>
<td><strong>Care leave rights</strong></td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>(excl. short emergency leave Paid care leave)</td>
<td>✓ 10 days p.a.</td>
<td>✓ EOL &lt;180 days</td>
<td>X</td>
</tr>
<tr>
<td><strong>Carers’ benefits</strong></td>
<td>✓ From 1985 $874 fortnightly* 1/3 primary carers</td>
<td>✓ Varies Some provinces only</td>
<td>✓ From 1976 £62.10 pw 1/3 carers 20+ hrs pw</td>
</tr>
<tr>
<td><strong>Value</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>Coverage</strong></td>
<td></td>
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<tr>
<td><strong>Flex. working rights</strong></td>
<td>✓ Excl. casual workers ✓</td>
<td>X</td>
<td>✓ 6 months’ service In 2004-14 only</td>
</tr>
<tr>
<td><strong>Carer specific right</strong></td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Services for carers</strong></td>
<td>✓ No Not usually</td>
<td>✓ some provinces No Varies</td>
<td>✓</td>
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<tr>
<td><strong>Legal right to receive</strong></td>
<td></td>
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<tr>
<td><strong>Chargeable</strong></td>
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*Single rate; couple (combined) rate max. is $1,317 per fortnight

Sources: Aus: Centrelink; Can: Govt of Canada; UK: DWP.
Support for carers in Sweden and Finland

**SWEDEN**
- **2009 Social Services Act** obliged municipalities to offer support
- Most have a dedicated ‘family care adviser’ liaising with H&SC staff & vol. orgs. and giving info.
- Carers **entitled to an assessment** of their support needs
- **Municipal discretion** on time / money is spent on carer support
- **No legal right** to support for carers
- **Care Leave Act 1989** (1994, 2010) paid leave (80% of income), 100 days for family needing terminal care.

**FINLAND**
- Eligible for LA help if care intensive, demanding, in recipient’s home
- **Municipality and carer make agreement** with care & service plan
- Support may be an **allowance** (min. €387 p.m.) and / or **services**
- Carer usually accumulates pension rights during support
- Carers **may have right to leave**, with LA providing substitute care
- **Employment Contracts Act 2011**: right to unpaid care leave
- **Job Alternation Leave**: 100-180 days, if 20yrs emplt. history, 70% of UE benefit, right to return
Japan: LTC and the ‘socialisation of care’*

- **LTCI model** from 1997, reformed 2006, 2010; fees reviewed every 3 years
  - Policy funded through insurance system, covers 65+ and 40-64 age groups
  - Administration decentralised to LAs, local committees of health/care professionals establish eligibility, based on qualitative and computer-aided data and a document completed by the GP.
  - Uses **care service market model**, with commercial and non-profit providers

- Expectation that contracted services would lead to *self-determination and choice for older people and their family carers*

- Municipalities became administrators not providers of LTC. Issues:
  - Conflict between profit-making and good services
  - Fragmentation of community resources
  - High turnover among care workers

## Japan: assessment by type of policy support

<table>
<thead>
<tr>
<th>Support type</th>
<th>Measure</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Recognition and Rights</td>
<td>Long-standing <strong>obligation</strong> in Japanese law, based on Confucian notion of <strong>filial piety</strong> <strong>R&amp;R concept emerging</strong> in discourse of Carers Japan / Aladdin Foundation, but as yet no policy recognition</td>
<td><em>Personal interview</em></td>
</tr>
<tr>
<td>Services for users and carers</td>
<td>LTCI covers <strong>home &amp; community services</strong> (home help &amp; bathing, AT, short-term inst. care), group homes, <strong>institutional services</strong>. No carers’ services; some LAs run carer support training progs.</td>
<td>3m users 840,000 users</td>
</tr>
<tr>
<td>Work-care reconciliation</td>
<td>Employees entitled to <strong>paid family care leave</strong> (reformed 2016) up to <strong>93 days</strong>, at 65% of usual salary (40% until 2015) <strong>Employers must offer 1 of 3 types of flexibility</strong>: reduced working hours; flexi-time; limit on extra working hours</td>
<td>Reform tackles 100,000 LF quits</td>
</tr>
<tr>
<td>Financial support</td>
<td>LTCI <strong>does NOT include cash payments to carers</strong></td>
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<td>No national entitlement, though at local discretion, a handful of municipalities provide a family caregiver benefit</td>
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Towards convergence in policy choices?

- **Common rationales:**
  - Demography
  - Gender Equality
  - Sustainability
  - Employer interests
  - Managing care costs
  - 21st century care:
    - Care outside hospital
    - Care outside institutions
    - Independent living
    - ‘Bedrock’ of carers’ support

- **Policy options:**
  - Develop local services
  - Fund carers to quit work
  - Carers’ leave
  - Flexible employment
  - Support in the workplace
  - Emergency support
  - Discrimination law
  - Human rights approach
Reflections on policy and practice exchange

**Issues and observations:**
- Importance of ‘fit’ with political systems
- Significant links with supranational charities
- Universality of issues
- Cultural context / difference
- Convergence
- Transfer of policy ideas

**Key informant data show:**
- ‘Common cause’
- Transnational learning
- International mentoring
- Empowerment
- Inspiration
- Sharing of ideas
- Raising the profile
Some references for further reading

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