



UNIVERSITY OF LEEDS

SUPPORTING CARERS OF WORKING AGE IN THE UK'S WELFARE SYSTEM: RESEARCH EVIDENCE AND ITS IMPLICATIONS FOR THE FUTURE

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Overview of presentation

- **The *Carers, Employers and Services* study**
- **Carers – selected official statistics**
- **Developments in publicly-funded support for carers**
- **Some evidence from evaluating carer support programmes**
- **Implications for the future**
- **Comments, questions and debate**

The Carers, Employers and Services (CES) study

- **Funded at Univ. of Leeds** by ESF award to Carers UK '*Action for Carers & Employment*'
- **Methods**
 - Purposive survey of 1,909 carers
 - Qualitative interviews with 134 survey participants on attitudes, experiences and aspirations regarding care, employment and support services
 - Mapping of developments in carer support in 10 LAs
 - Statistical analysis of Census 2001, including SARs and other datasets (Dr Lisa Buckner)
- **Dissemination**
 - CES Report Series (2007, Carers UK), presented at conferences / events in 2007-09
 - Work and Pensions Committee Inquiry 2008; Employment Report for 2008 National Carers Strategy 2008; Coalition Carer's Strategy 2010 (Appendix)
 - Informed new research on WA carers in Australia, Canada, Finland, Japan, Sweden, Taiwan
 - T Kröger and S Yeandle (eds) *Combining Paid Work and Family Care* Policy Press, 2013

*812 employees and 56 self-employed; 400 had left work to care; 50 were unemployed

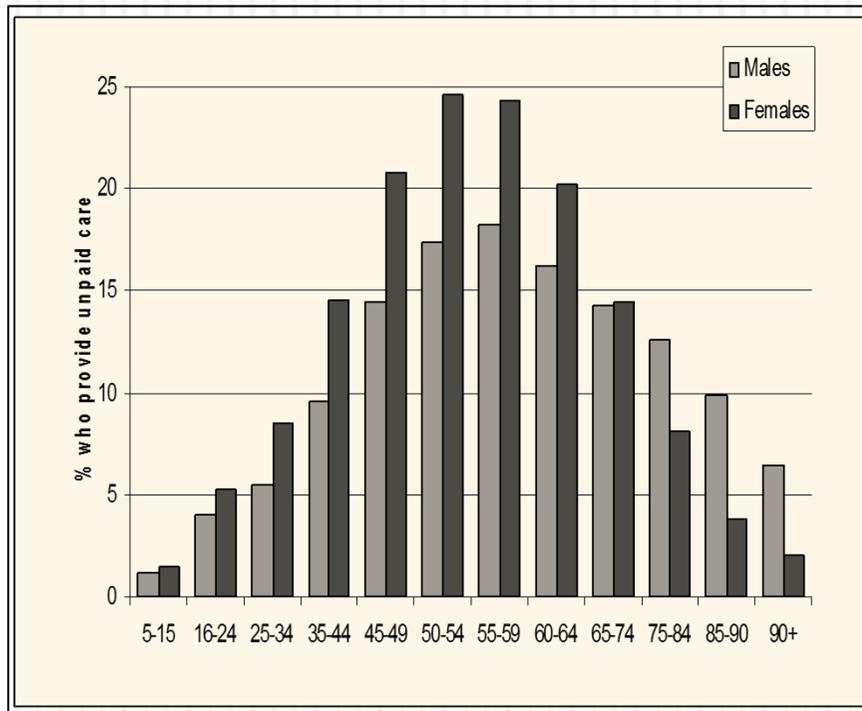
Some examples of what the CES study found

- **Over 40% of new* carers were supporting someone whose needs had not been assessed and who had no support from any service**
 - Highlighted the importance of ‘hidden’ carers , weakness in LA / voluntary support
 - Drew policy attention to the potential roles of GPs and hospitals in:
 - supporting carers
 - developing new services
 - improving carers’ access to information
- **Flexibility at work was crucial, but inadequate**
 - Inflexible /unresponsive services the key barrier to combining work and care
 - Potential benefit of extending right to request flexible working to carers of adults
 - Identified working carers as a target for LAs’ spending of the DH ‘carers’ grant’
- **66% of male and 32% of female carers of working age held FT jobs**
 - Many such carers struggled to cope
 - Male, working age and ethnic minority carers needed more support

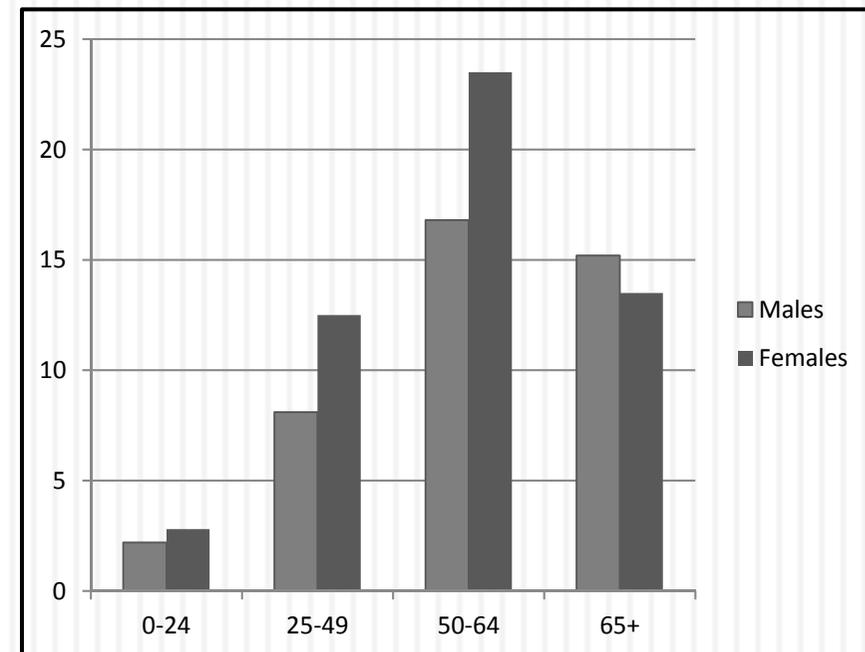
* People who had begun caring within the past two years, n=214 in CES sample



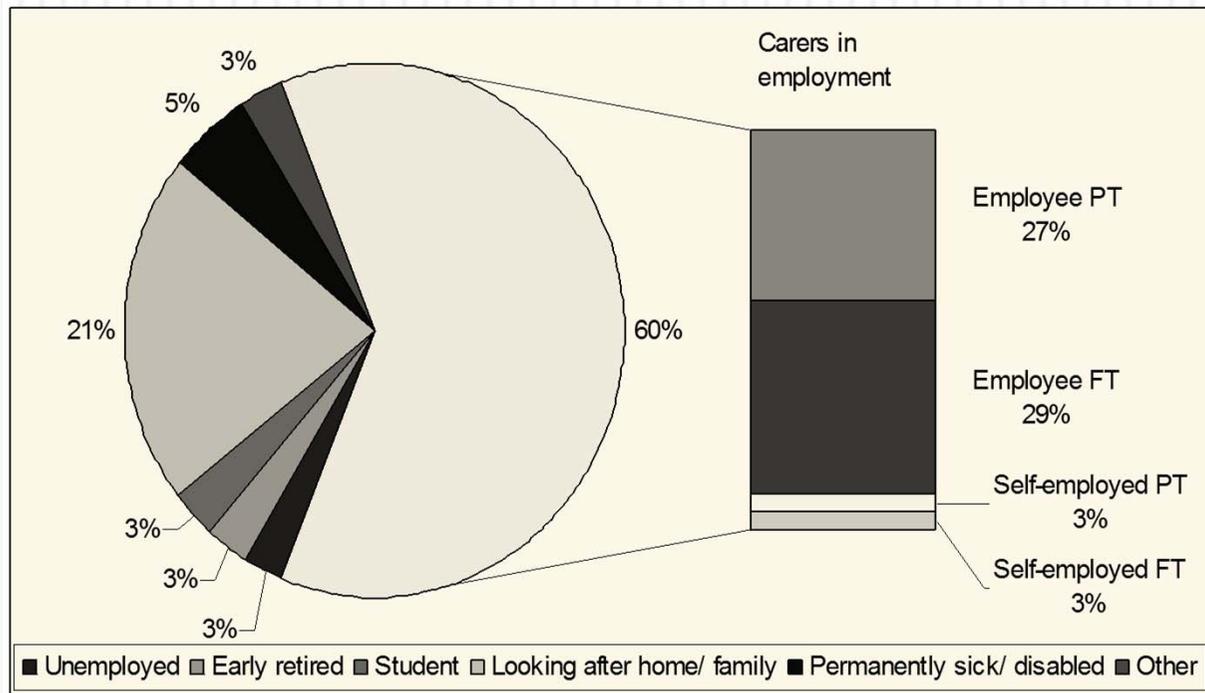
Carers by age and sex: 2001 and 2011



Source: 2001 Census Standard Tables, GB, Crown Copyright

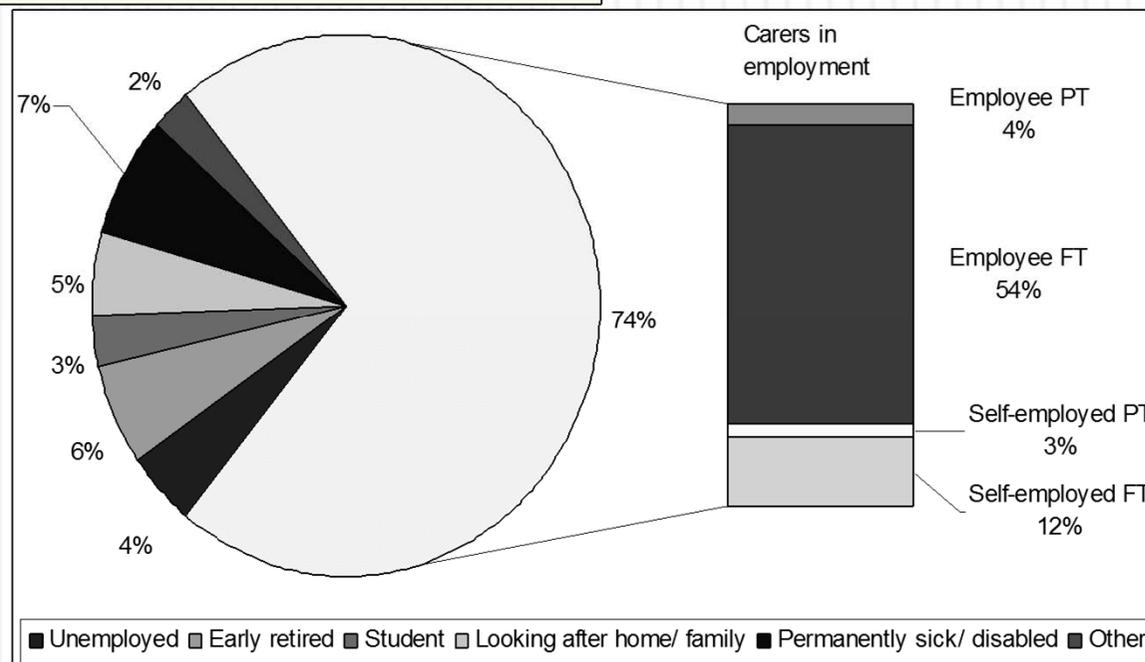


Source: 2011 Census Standard Tables, England, Crown Copyright



Female carers of working age by economic activity status, GB, 2001

Male carers of working age by economic activity status, GB, 2001

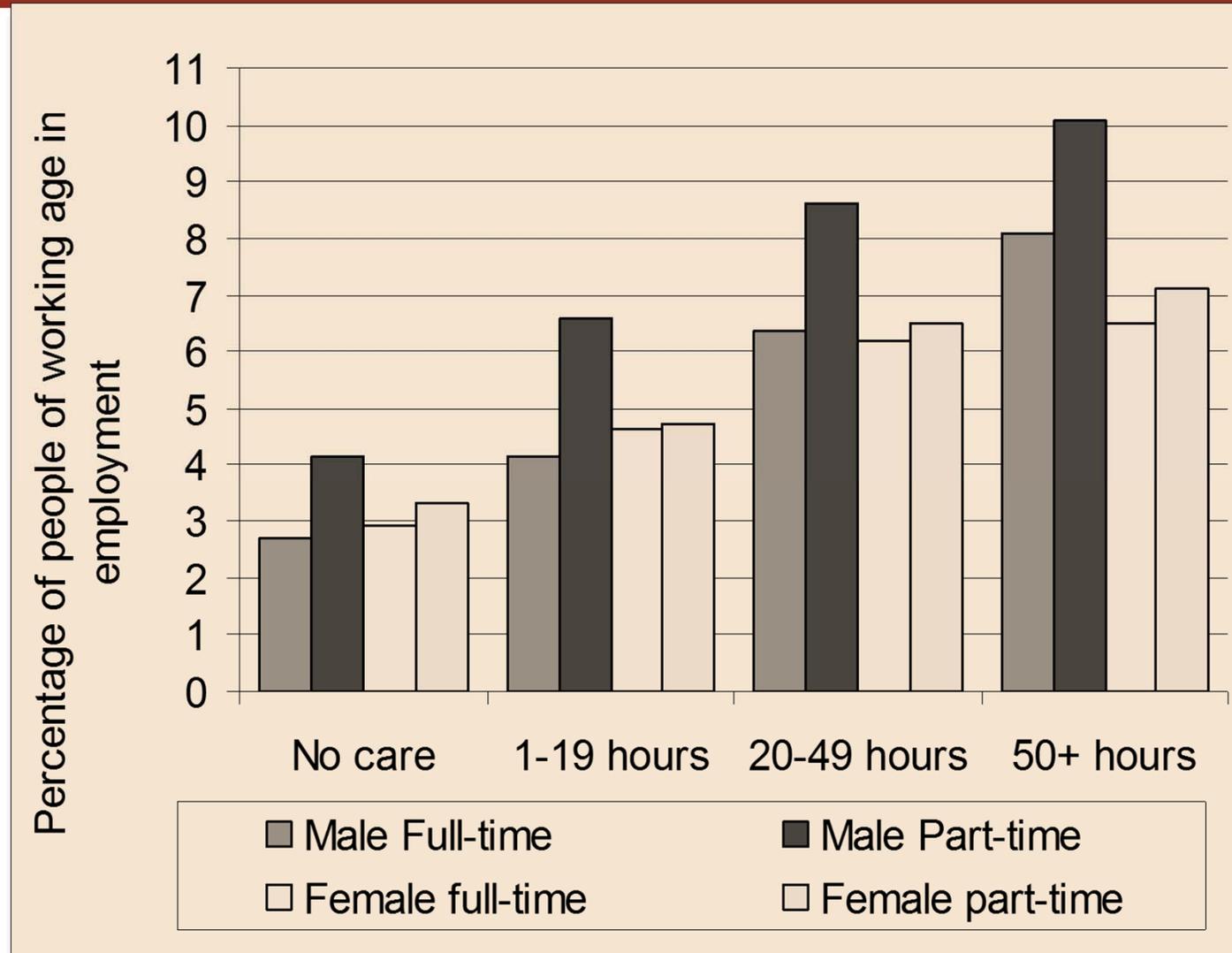


Source: 2001 Census SARs, Crown copyright



Employees whose health is 'not good' by employment status and caring responsibilities

Source: 2001 Census SARs, Crown Copyright 2004. This work is based on the SARs provided through the Centre for Census and Survey Research of the University of Manchester with the support of ESRC and JISC



Relationship of carer to main cared for person

Relationship <i>person cared for is the...</i>	Where care provided		Time spent caring each week		All carers
	Same household	Other household only	< 20 hours	20+ hours	
Parent	19	48	39	26	33
Parent-in-law	3	12	10	4	7
Grandparent	1	7	6	2	4
All the above	23	67	55	32	44
Spouse / partner	51	1	13	41	26
Child	22	3	7	19	13
Other relative	3	11	10	4	7
Friend / neighbour	1	18	14	3	9
Other	1	1	1	1	1
Base: All	1,100	1,100	1,100	1,100	2,200

Source: Health & Social Care Information Centre. **Survey of Carers in Households, 2009-10**
 Copyright © 2010, Health & Social Care Information Centre, Mental Health & Community Care Team. All rights reserved.

State support for carers: overview of developments

- **Services and support shaped by National Carers Strategies**
 - 1999, 2008, 2010 – plus **local** strategies in some LAs
 - Growing focus on work - care reconciliation
- **Legislation relevant to carers and work/care reconciliation**
 - Carers (Recognition and Services) Act 1995
 - Employment Relations Act 1999
 - Carers and Disabled Children Act 2000
 - Employment Act 2002
 - Carers (Equal Opportunities) Act 2004
 - Work and Families Act 2006
 - Care Bill 2013
 - Children and Families Bill 2013
- **Carers' benefits: Carer's Allowance**
 - Moderates the financial impact of caring
 - Mainly supports those who drop out of or are not participating in the labour force
 - Can, in effect, only be combined with low paid, short hours working

Publicly-funded support and services available to carers (England)

Right to a LA Carer's Assessment For some carers from 2000; services at LA discretion.

- *Care Bill 2013* indicates this will change in future

LA - funded carer's services* - respite, training, health checks, direct payments

- 198,000 carers aged 18-64 were supported by their LA in 2011-12
- 48% received 'carer-specific' services, 52% 'information only'; 46,025 carers got a Direct Payment

Carers supported by LAs: up 74% in 3 years to 2011-2, but **LAs only supported 5.6% of WA carers**

LAs' discretionary power to provide carers' services dates from 1995; since 2000 DH Carers Grant helps funds these. From 2011, LA duty to provide '**short breaks**' for carers of disabled children

Local carers centres - advice lines, online forums, training and other services for carers

- Offered through network of 280 local carers' organisations, almost all independent charities
- In 2006-7, partial data showed about half of LAs were part-funding local carers' organisations, supporting 35,000 carers in a sample week (CSCI, 2009)

DH-funded programmes implementing the Carers Strategy in England have included:

Caring with Confidence - training programme for carers, supported **10,238 carers** in 2009-10

- CwC was evaluated at the University of Leeds:

<http://www.nhs.uk/CarersDirect/carers-learning-online/Pages/resources-for-training-providers.aspx> (online programme)

<http://circle.leeds.ac.uk/projects/completed/supporting-carers/evaluation-of-the-caring-with-confidence-programme/> (Evaluation)

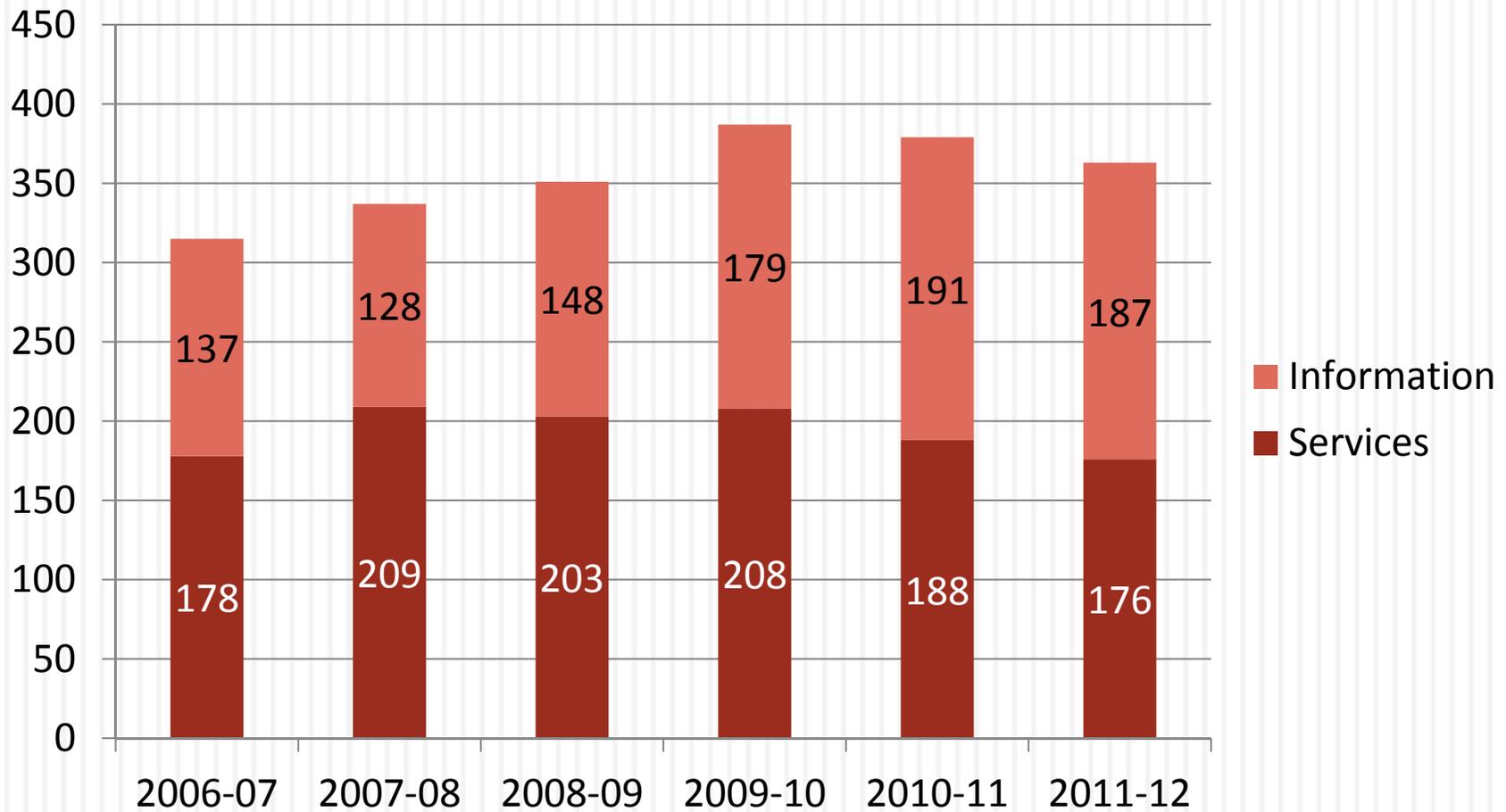
NCS Demonstrator Sites programme 25 projects, each involved Health, LA and Voluntary Sector partners

- Offered Carers' Breaks; Health Checks; NHS Support - provided services to **18,653 carers:**
- 5,655 in Carers' Breaks sites; 5,441 in Health Checks sites; 7,557 in NHS Support sites

<http://circle.leeds.ac.uk/projects/completed/supporting-carers/evaluation-of-the-national-carers-strategy-demonstrator-sites-programme/>

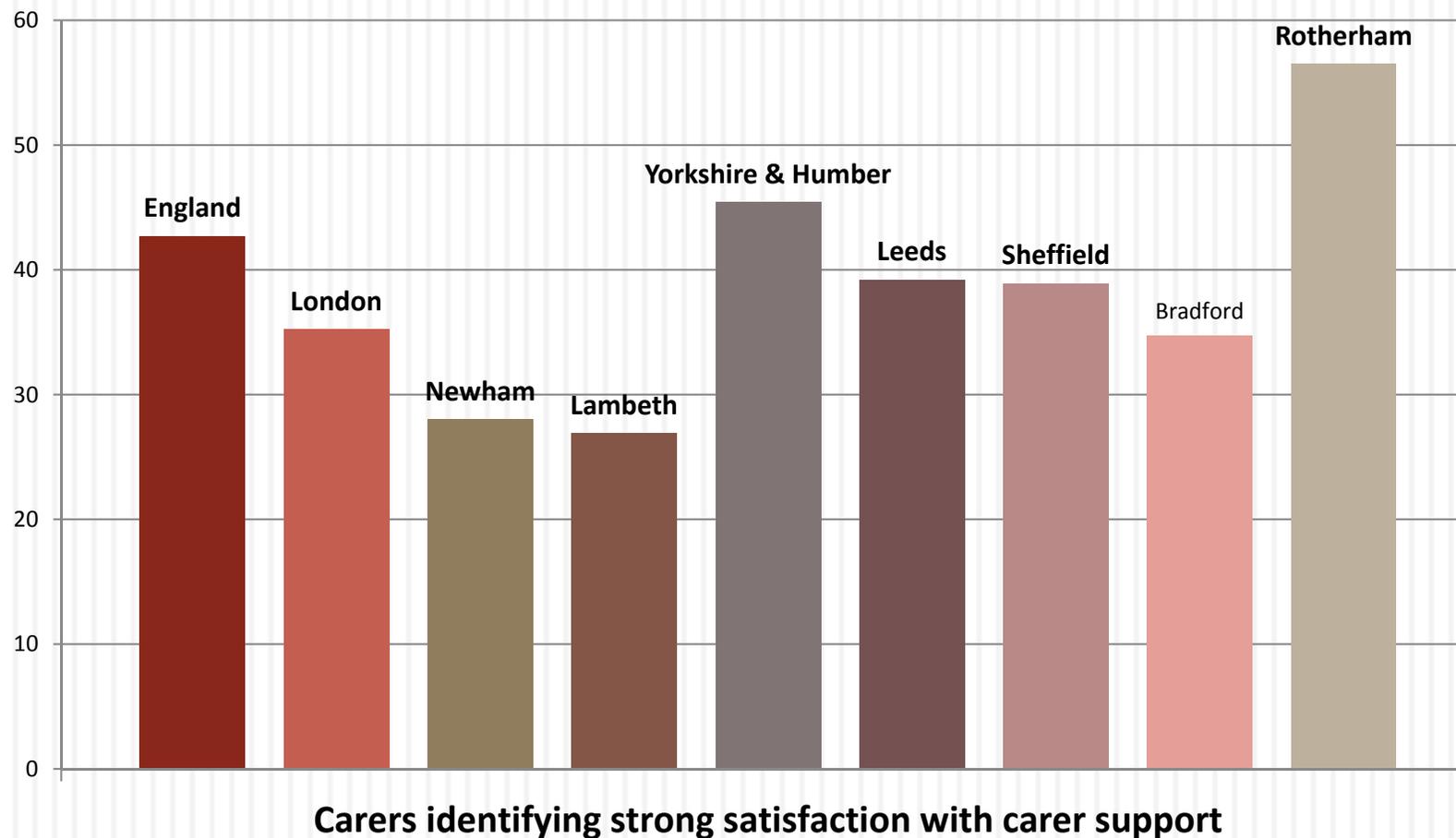
Number of carers receiving services, by type of service received: 2006-07 to 2011-12

Thousands



Source: 2013 Health and Social Care Information Centre

Adult Social Care outcomes: carer satisfaction with care and support in selected localities, 2012-13



Source: HSCIC 2013

Employment support for carers in the UK

Employment rights

No paid leave rights, though some employers offer this, usually on time-limited basis

Emergency short-term unpaid leave to care for a family member (employment protection measure)

Legal right to request flexible working, employees with 26 weeks service, employer can refuse.

Availability, take-up and attitudes to flexible working*

74% of all employees (78% of carers) aware of carers' right to request flexible working

Many employees say flexible working options *are available where they work* :

Part-time work: 80%; Temporary reduced hours: 56%; Flexi-time: 48%; Job-share: 43%

Compressed working week: 39%; Term-time only: 34%; Working regularly from home: 30%

Many employed carers say they are able to work flexibly:

48% of those working full-time; **62%** working part-time

For all types of flexible working (except compressed hours):

A higher % of employees WITH than without a legal right to request FW took up the option

In the past 2 years, 30% of carers of an adult (22% all employees) made a request to work flexibly

- **66%** had request accepted; **17%** had it accepted after negotiation, compromise or appeal
- **11%** had request declined; **6%** were awaiting a decision

29% of carers took time off work to care for dependants in the past 12 months

- **19%** of all employees; **23%** of parents

Dissatisfaction with their current working arrangements expressed by:

- **11%** of employed carers; **8%** of all employees

*Figures from *Fourth Work-Life Balance Survey, 2012*

Financial support available to carers in the UK

Carer's Allowance

- **£58.45 per week (2013)** - taxable
- Not means tested, but **carer's personal income from paid work cannot exceed £100** after tax
- Carer must **care for 35+ hrs pw**, but does NOT need to live with / be related to person cared for
- Carer must be **caring for a person who is receiving a state disability benefit**
- **Only one person** can receive CA in relation to a disabled person
- Carers **must be 16 or older** and have lived in the UK for 26 weeks in the year prior to the claim
- Carers are **NOT eligible if studying for 21+ hours pw**
- CA 'overlaps' with State Retirement Pension and most income support benefits

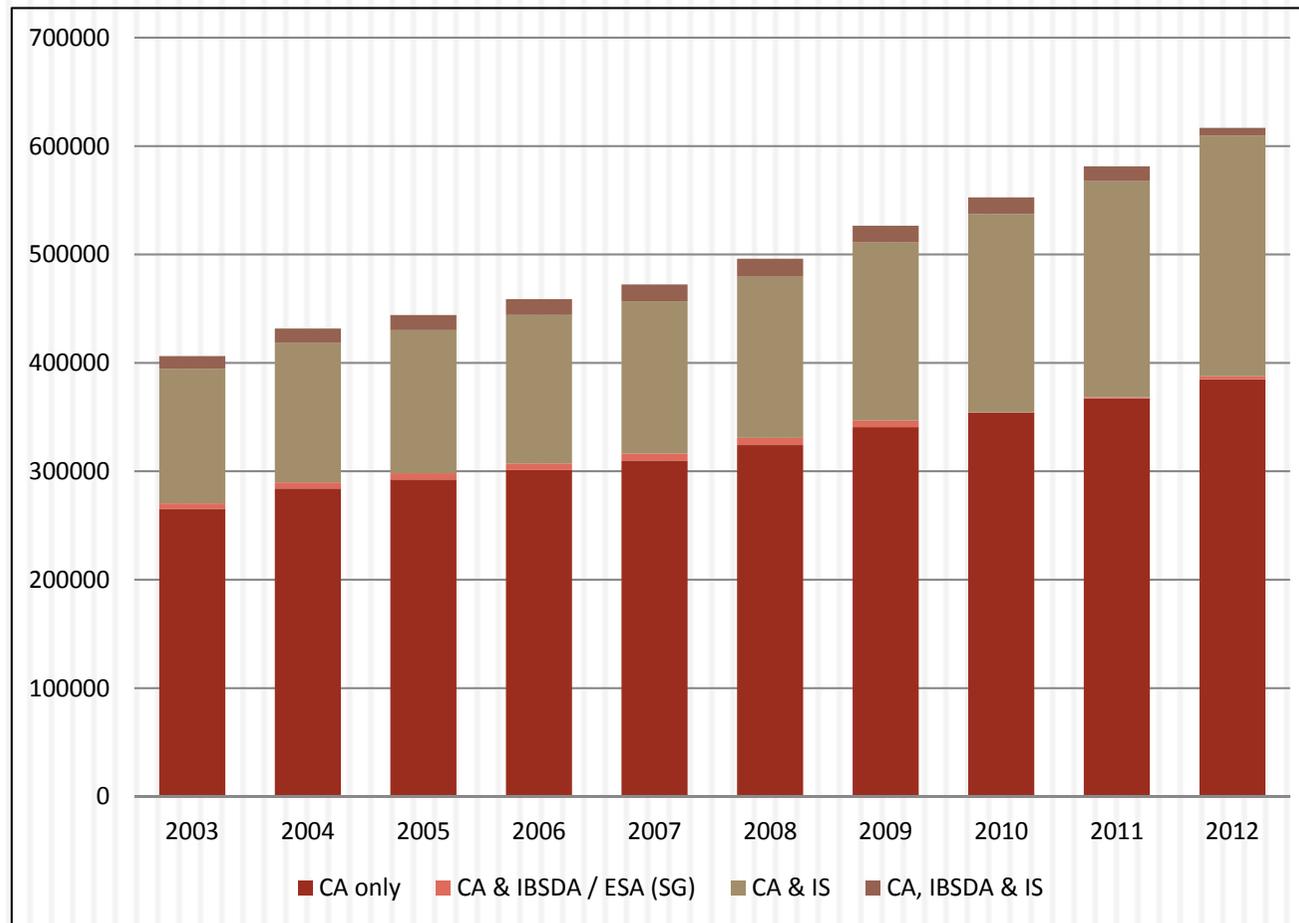
Carer Premium

- **up to £31** - means tested against income and savings
- available within some forms of income support, to people with 'underlying entitlement' to CA

Carer's Credit

- **Credit towards National Insurance contributions** (re State Pension/additional State Pension)
- Carer must be **aged 16+ and under state pension age**
- Carer must be caring for one or more people **for at least 20 hours per week**
- **Person cared for must receive a state disability benefit**
- Payable **even if there is short break from caring** (up to max. of 12 consecutive weeks)

People receiving *Carers Allowance* and those also receiving other benefits



Source: DWP Information, Governance and Security, Work and Pensions Longitudinal Study – www.gov.uk

The Caring with Confidence programme

16

- **Caring with Confidence registered almost 14,000 carers:**
 - ▣ 10,238 attended at least one CwC module; 59% were ‘fully trained’
 - ▣ Participants reasonably representative of all carers; some ‘hard-to-reach’ groups targeted effectively
- **Most had very positive experiences of CwC, such as:**
 - ▣ learning new skills; meeting other carers in a supportive environment; greater knowledge of how to access support; improved health and wellbeing; help to care more effectively; more confidence
- **Some used the financial guidance / information to identify benefits they had not previously claimed or to access additional support / services**
- **Substantial minorities of carers took up new social, leisure or health activities; some commenced training or found paid work**
- **6 months later, many reported benefits affecting their caring role**

The National Carers Strategy Demonstrator Sites

- **25 Demo Sites supported 18,653 carers**
 - 5,655 in Carers' Breaks sites
 - 5,441 in Health Checks sites
 - 7,557 in NHS Support sites
- **Target groups of carers** included: ethnic minority carers; carers of people with dementia; Gypsy and Traveller carers; carers of people with substance misuse problems
- Carers supported were mainly older, female carers
- Breaks and Health Checks Sites succeeded in engaging carers from EM communities
- Carers of people experiencing dementia, mental ill-health, long-term / terminal illness, learning disabilities, substance misuse also well represented

Demonstrator Sites – some outcomes and responses

Breaks sites:

- 80% had no previous break of more than few hrs

Accessing the breaks service enabled some to:

- **Have more of a 'life of their own' / build confidence**
- **Adopt behaviour beneficial to well-being / health**
- **Start new leisure activity**
- **Improve communications with professionals**

NHS Support sites provided:

- **Direct carer support in hospital settings**
- **Staff to work with carers in GP practices**
- **Benefits advice**
- **Befriending, peer support, carers' cafés**
- **Assessment and support workers**

Health Checks sites:

Carers welcomed the well-being emphasis, more holistic approach, and feeling listened to / supported.

4 months later:

- **1 in 4 said how they looked after their health / amount of exercise they took had improved**
- **Most had been signposted to additional services**
- **A few said signposting had been unhelpful; needed more careful referral or follow-up**

Breaks: *"It has helped me **feel valued** as a carer. (We ..) are like an invisible army, often doing care work for family 24 hrs a day, 7 days a week, 365 days a year, year after year. We deserve recognition and financial help; **the scheme has also boosted my self-confidence and mental and physical wellbeing.** ...breaks service is excellent .., it **gives the carer a chance to unwind and do their own thing.**"*

Health Checks: *".. an excellent service **as it checks on the carer who often does not check their own problems.** (My) carer's health check .. at my own GP surgery was a great help. ... It's given me **help and support on my doorstep.** I will now access the services pointed out to me, and **they are helping me put together an emergency plan** for the future.."*

NHS Support: *"Without this help I would have felt very alone and would not have understood how to cope. ..I have been a carer for many, many years ... as a result of services received, **my aims / attitudes have been reinforced and I have been able to use my knowledge etc. to help and support other (newer) carers.**"*

Implications and considerations for the future

- ❑ Carer numbers are increasing; the majority will be people of working age
- ❑ The main increase over time has been in carers with the heaviest responsibilities
- ❑ Well targeted health and well-being services for carers work and save money: are they being prioritised, or squeezed? Can they be a priority in the integration of health and social care?
- ❑ Workplace flexibility and support for carers are effective, but should carers bear their costs? What should be the cost distribution between employers, employees, the state?
- ❑ The needs of carers of older people, of a spouse or partner, of a child, all differ – should long-term and life-time caring be a priority for support?
- ❑ Co-residence / separate residence both place significant demands on carers – is there enough focus on support for distance caring, weekend caring, the double domestic shift?
- ❑ Caring alongside parental /grandparental roles brings financial and time pressure and risks to health and wellbeing - unless roles are chosen and supported
- ❑ Is re-planning of services amid LA resource constraints placing even greater reliance on carers without offering them adequate financial support, breaks and services?
- ❑ Emphasis is increasingly moving to private, paid for, services – is this fair, how could compensation of carers' costs / lost income be prioritised?
- ❑ How to balance expenditure/emphasis on employment, financial, services support for carers?

All three types of carer support can deliver cost savings

- **Preventing hospital or residential care admissions:** the services had the potential to prevent carer breakdown and reduce hospital admissions among carers / those they care for
- **Supporting carers to sustain their caring role:** avoiding or delaying costs of residential care
- **Earlier identification of physical and / or mental health issues:** health checks diagnosed previously unknown conditions, with high levels of referrals for further medical intervention
- **Improved health and well-being of carers:** early well-being support / regular targeted health checks can delay the onset of health problems and help sustain caring roles
- **Improved partnership working / better care co-ordination –** offers scope for cost savings by: pooling resource inputs; avoiding duplication; higher take-up through carer awareness; new pathways to prevent re-admissions or patient-carer breakdown; signposting carers to other support / services
- **Efficiency savings in GP practices:** achieved by reducing DNAs; helping carers attend appointments; reducing carer GP visits; treating health issues earlier; enabling carers to continue for longer
- **Assisting carers to return to, or remain in, paid work:** potentially huge cost savings; carers miss out on up to £1.5bn earnings; inadequate services for person cared for key barrier to work for carers
- **Informal networks of support among carers:** reduce the need for / costs of alternative services

Costs of service delivery and cost per carer supported*

Breaks: Total spending £283,563-£2,253,026; total cost per carer supported £603-£6,000

Health Checks: Total spending £229,855-£982,839; total cost per carer supported £336-£2,336

NHS Support: Total spending £570,499-£783,857; total cost per carer supported £171-£1,483

Source: QRTs, University of Leeds. *Calculated by dividing total expenditure (DS funding + any local resources) by number of carers supported

Comments, questions and discussion welcome

Contact details:

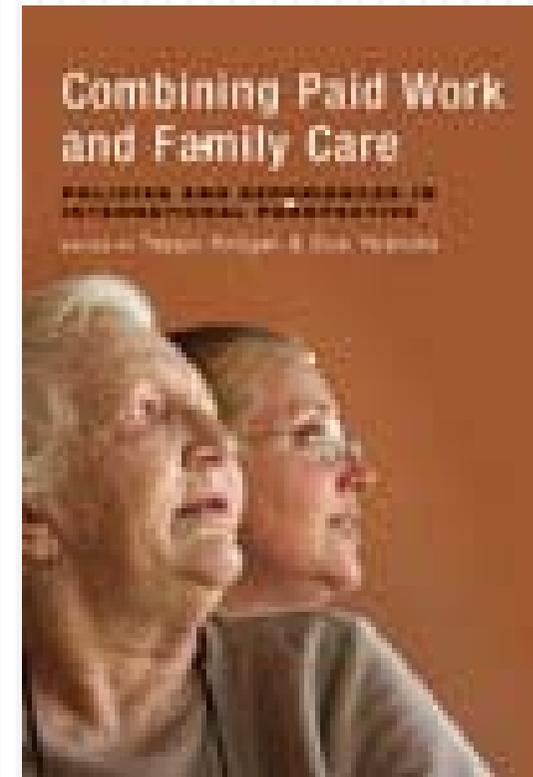
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Combining Paid Work and Family Care: policies and experiences in international perspective

T Kröger and S Yeandle (eds.)

Bristol: Policy Press (2013)



Main legal and policy changes relevant to carers: UK	Development relevant to carers'		
	Income / finances	Work / employment	Services / support
1967: Dependent Relative's Tax Allowance			
1975: Invalid Care Allowance (ICA) (single women caring for parents only)			
1986: ICA made available to married women			
1995: Carers (Recognition & Services) Act introduced LA carer's assessment concept			
1999: National Carers' Strategy			
1999: Employment Relations Act employees gained right to 'reasonable time off' to deal with family emergencies			
2000: Carers and Disabled Children Act (strengthened right to Carer's Assessment; carers eligible to receive services/direct payments)			
2003: ICA re-named Carers' Allowance , carers aged 65+ able to claim, subject to 'overlapping benefits rule			
2002: Employment Act: parents of disabled children, right to request flexible working			
2004: Carers (Equal Opportunities) Act: LAs must inform carers of rights/consider their wish to work in assessments			
2006: Work and Families Act extended R to R flexible working to carers of adults			
2007: Pensions Act: introduced pension credit for carers			
2008: National Carers' Strategy			
2010: National Carers' Strategy ('refreshed' by Coalition Govt)			
2010: Equality Act: prevents carers from discrimination re care of a disabled person			
2011: Short Breaks Duty regulations (Children & Young Persons Act 2008)			
2012: Draft Care and Support Bill: if enacted, will place a duty on LAs to meet a carer's assessed needs for support (subject to a financial means test)			
2013: Children and Families Bill: if enacted, will remove requirement to be a carer from right to request flexible working after 2014			