

**The role of adult
social care in
improving
outcomes for young
people who provide
unpaid care**



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Outline

- Policy context; study objectives
- Study overview and methods
- Secondary analysis of national datasets – Methods and preliminary results
- Next steps

Policy context

- 2011 UK census: 350,000 young people aged 16 to 25 providing unpaid care
- Care Act 2014; Children and Family Act 2014
 - Duty on local authorities to consider needs for support of young carers
 - Needs: participate fully in education and employment
 - Local authority assessment to include impact of caring on young carer's wellbeing, personal development and physical and mental health
 - Support can be met by providing formal care services to the person they care for

• BUT...

Policy context (2)

- Substantial ongoing cuts to adult social care funding in England since 2009/10
 - Number of adults receiving formal care services ↓ (Fernandez et al 2013)
 - Unmet need ↑ (Forder and Fernandez 2010)
 - Reliance on unpaid care ↑ (Forder and Fernandez 2010)

Policy context – Young and young adult carers

- Previous studies of outcomes for young carers:
 - **Education:** missed school (The Children’s Society 2013); lower attainment (Dearden and Becker 2003); higher rate of dropout (Sempik and Becker 2014)
 - **Employment:** lower incomes (Dearden and Becker 2014)
 - **Health:** poorer mental and physical health (Office of National Statistics 2013; McAndrew et al 2012)

Objectives

- Produce evidence on the role of providing formal care service to adults cared for by young adult carers in:
 - Reducing or removing need for unpaid care for some young adult carers
 - Improving outcomes for young adult carers
 - Potential in reducing costs

Outcomes: education, employment, mental and physical health, social participation, personal relationships, quality of life

Overview of study

Timeframe: September 2016 to February 2019

Focus on

- Young adult carers *providing unpaid care to an adult*
- Ages 16 to 25
 - probability and intensity of providing unpaid care to an adult highest for this age range (Pickard 2008)
 - Important period for transition to further education and employment

Two strands:

Strand 1. Secondary data analysis of nationally representative datasets

Strand 2. Survey of young adult carers and the people they care for

Overview of study (2)

- Consultation with local authorities, charities and young carers
- Project Advisory Group: local authorities, service users, charities working with young carers (The Children's Society), Department of Health, academic experts
- Young Adult Carer Advisory Group: Ten young adult carers, support workers
- National Social Care Research Ethics Committee approval: January 2017

Study website: www.youngadultcarers.uk

Strand 1 – Secondary data analysis

Two datasets: *Survey of Carers in Households* and *Health Survey for England*

Survey of Carers in Households (2009/10)

- Demographics; intensity of care provision; self-reported impacts of caring on respondents
 - Impacts: social participation, relationships and quality of life

Health Survey for England (2011-2014)

- Unpaid care provision; intensity of care provision; formal care support received; educational attainment; physical and mental health ; self-reported impact of care on health and employment

Some preliminary results

- Young adult carers in the *Survey of Carers in Households*
 - N=104
 - 65% female
 - 21% caring for two or more people
 - 70% caring for 10 or more hours a week
 - 70% caring for a parent or grandparent
 - 26% providing personal care; 45% physical help; 78% practical activities (e.g. preparing meals, taking to doctor or hospital)
 - 72% sole carer for main person cared for
 - 14% receive support from formal social care services

Preliminary results – Survey of Carers in Households

Impact of caring responsibilities

- bad or fairly bad quality of life: 4%
- Health affected by caring: 37%
- Employment affected by caring: 13%
- Education affected by caring: 8%
- Personal relationships, social life or leisure affected by caring: 35%
- Leisure activities/time affected by caring: 33%
- Feeling depressed: 15%
- General feeling of stress: 21%

Preliminary results – Survey of Carers in Households

Chi-squared tests of associations between:

Formal Social Care Receipt
(yes/no)

and

1. Quality of life (good/neither good nor bad/bad)
2. Personal relationships, social life or leisure affected by caring responsibilities (yes/no)
3. Health affected by caring responsibilities (yes/no)
4. Employment affected by caring responsibilities (yes/no)
5. Leisure activities/time affected by caring responsibilities (yes/no)
6. Feeling depressed (yes/no)
7. General feeling of stress (yes/no)

Preliminary results – Survey of Carers in Households

Chi-squared tests of associations between:

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2. Personal relationships, social life or leisure affected by caring responsibilities (yes/no)
3. Health affected by caring responsibilities (yes/no)
4. Employment affected by caring responsibilities (yes/no)
5. Leisure activities/time affected by caring responsibilities (yes/no)
6. Feeling depressed (yes/no) **p-value=0.091**
7. General feeling of stress (yes/no) **p-value=0.063**

Formal social care receipt →
↑ rate of depression;
↑ feeling of stress

Preliminary results – Health Survey for England, 2011-2014

- N=3,760 young adults (age 16 to 25); n=353 young adult carers

	All young adult (n=3,760)	Young adult carers (n=353)
Age: mean (SD)	20.5 (3.0)	20.7 (2.9)
Sex: % female	55.2	61.8
Education: %		
FT student	42.7	40.8
Higher education degree or equivalent	11.7	9.9
Less than higher education qualification	45.6	49.3
In employment: %	41.4	34.8
Ethnicity	81.7	82.7
Area deprivation: % in lowest two quintiles	47.0	49.9
Warwick-Edinburgh Mental Wellbeing scale (WEMWBS): mean (SD) [NB. Higher scores → greater wellbeing; score range: 14 to 70]	51.4 (8.5)	49.8 (8.9)
Self-assessed general health: % good or very good	87.1	77.9

Preliminary results – Health Survey for England, 2011-2014

Chi-squared tests of associations between:

Formal Social Care Receipt
(yes/no)

and

1. Health affected by caring responsibilities
(yes/no)
2. Employment affected by caring responsibilities
(yes/no)
3. Wellbeing Scale Score (WEMWBS)

Preliminary results – Health Survey for England, 2011-2014

Chi-squared or t-tests of associations between:

Formal Social Care Receipt
(yes/no)

and

1. Health affected by caring responsibilities
(yes/no)
2. Employment affected by caring responsibilities
(yes/no) $p=0.058$
3. Wellbeing Scale Score (WEMWBS)

Formal social care receipt →
↑ probability that employment
affected by caring

Next steps

- Further secondary analyses
- Survey has been launched; link at www.youngadultcarers.uk
- Image competition to coincide with launch of questionnaire
 - Experiences of caring
- Attending the Young Carers Festival in July 2017
- Staging of first stakeholder workshop in September 2017
 - Preliminary findings and their implications
 - Recruitment and methods for the primary data analysis
 - Knowledge exchange activities

Questionnaire for young people supporting adult family and friends

- Demographic information
- Support provided
 - number of people supported, relationship to person(s) supported; number of hours; tasks; if lives with main person supported
- Support received as a carer
 - from other family members or friends
 - from formal social care
- Formal support received by the adult they support
 - Is support suitable and adequate?

Questionnaire for young people supporting adult family and friends

- Impact of caring on their education, employment and wellbeing
- Aspects of wellbeing:
 - Social activities – Survey of Carers in Households (SCH)
 - General health - SCH
 - Anxiety - Generalised Anxiety Disorder Questionnaire (GAD-7)
 - Depression - Short Mood and Feelings Questionnaire (SMFQ-short)
 - Mental wellbeing – Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)
- Positive Aspects of Caregiving (Tarlow et al 2004)

Questionnaire for people helped by family or friends

- Demographic information
- ADL/IADLs
- Unpaid and formal help received
- Living arrangement and housing tenure
- Financial information

*** Links to further support and information are included at the end of both questionnaires.**

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Thank you for your attention!

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