Young Carers

Children as family carers: research, policy & practice

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Whose responsibility is it to care?
1992: Start of research

- No reliable ‘official’ figures
- Little public or professional awareness or recognition
- No young carers policy or law
- No ‘rights’ or entitlements
- Few young carers projects or services
Who are young carers and young adult carers?

“Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.

The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.” Saul Becker in The Blackwell Encyclopedia of Social Work

Young adult carers are as above, but aged 18-24. Commonly, however, YACs in transition include 16 & 17 year olds too.
What do young carers do?

<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Domestic</td>
<td>65%</td>
<td>72%</td>
<td>68%</td>
</tr>
<tr>
<td>General &amp; nursing</td>
<td>61%</td>
<td>57%</td>
<td>48%</td>
</tr>
<tr>
<td>Emotional</td>
<td>25%</td>
<td>43%</td>
<td>82%</td>
</tr>
<tr>
<td>Intimate</td>
<td>23%</td>
<td>21%</td>
<td>18%</td>
</tr>
<tr>
<td>Sibling care</td>
<td>11%</td>
<td>7%</td>
<td>11%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
<td>29%</td>
<td>7%</td>
</tr>
</tbody>
</table>
## Number of children caring
England & Wales (Census 2001, 2011)

<table>
<thead>
<tr>
<th>AGE</th>
<th>2001 England and Wales</th>
<th>2011 England and Wales</th>
<th>Increase</th>
<th>% increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 - 7</td>
<td>5,465</td>
<td>9,985</td>
<td>4,520</td>
<td>83%</td>
</tr>
<tr>
<td>8 - 9</td>
<td>7,834</td>
<td>12,148</td>
<td>4,314</td>
<td>55%</td>
</tr>
<tr>
<td>10 - 14</td>
<td>62,661</td>
<td>72,266</td>
<td>9,605</td>
<td>15%</td>
</tr>
<tr>
<td>15</td>
<td>21,402</td>
<td>23,848</td>
<td>2,446</td>
<td>11%</td>
</tr>
<tr>
<td>16 - 17</td>
<td>52,580</td>
<td>59,671</td>
<td>7,091</td>
<td>13%</td>
</tr>
<tr>
<td>All</td>
<td>149,942</td>
<td>177,918</td>
<td>27,976</td>
<td>19%</td>
</tr>
</tbody>
</table>
Hours per week spent caring, England & Wales (Census 2011)

<table>
<thead>
<tr>
<th>AGE</th>
<th>1 - 19 HOURS</th>
<th>20 - 49 HOURS</th>
<th>50+ HOURS</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 - 7</td>
<td>7,177</td>
<td>1,166</td>
<td>1,642</td>
<td>9,985 (6%)</td>
</tr>
<tr>
<td>8 - 9</td>
<td>9,424</td>
<td>1,204</td>
<td>1,520</td>
<td>12,148 (7%)</td>
</tr>
<tr>
<td>10 - 14</td>
<td>59,262</td>
<td>7,043</td>
<td>5,961</td>
<td>72,266 (41%)</td>
</tr>
<tr>
<td>15</td>
<td>19,596</td>
<td>2,489</td>
<td>1,763</td>
<td>23,848 (13%)</td>
</tr>
<tr>
<td>16 - 17</td>
<td>47,309</td>
<td>7,520</td>
<td>4,842</td>
<td>59,671 (33%)</td>
</tr>
<tr>
<td>All</td>
<td>142,768 (80%)</td>
<td>19,422 (11%)</td>
<td>15,728 (9%)</td>
<td>177,918</td>
</tr>
</tbody>
</table>
**BBC Surveys, 2010, 2018**

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**Manual for Measures of Caring Activities and Outcomes** for children and young people.

By Stephen Joseph, Fiona Becker, Saul Becker

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### The caring jobs I do

Below are some jobs that young carers do to help. Think about the help you have provided over the last month. Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month. Thank you.

<table>
<thead>
<tr>
<th>Number</th>
<th>Task Description</th>
<th>Never</th>
<th>Some of the time</th>
<th>A lot of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Clean your own bedroom</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Clean other rooms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Wash up dishes or put dishes in a dishwasher</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Decorate rooms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Take responsibility for shopping for food</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Help with lifting or carrying heavy things</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Help with financial matters such as dealing with bills, banking money, collecting benefits</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Work part time to bring money in</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Interpret, sign or use another communication system for the person you care for</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Help the person you care for to dress or undress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Help the person you care for to have a wash</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Help the person you care for to have a bath or shower</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Keep the person you care for company e.g. sitting with them, reading to them, talking to them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Keep an eye on the person you care for to make sure they are alright</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Take the person you care for out e.g. for a walk or to see friends or relatives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Take brothers or sisters to school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Look after brothers or sisters whilst another adult is near by</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Look after brothers or sisters on your own</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
BBC Survey 2010

4,029 pupils surveyed

8% are involved in personal and intimate caring activity (dressing, washing, showering)

29% are involved in emotional care (keeping the person they care for company, keeping an eye on them, taking the person out)
BBC Survey 2018

925 secondary age pupils aged 11-15

22% caring

32% involved in high amounts of caring (MACA scores >14)

9% involved in very high amounts of caring (MACA scores >18)

32% caring for more than one person
BBC Survey 2018
925 secondary age pupils aged 11-15

10% are involved in personal and intimate caring activity - dressing, washing, showering (8% in BBC 2010)

48% are involved in emotional care - keeping the person they care for company, keeping an eye on them, taking the person out (29% in BBC 2010)
BBC Survey 2018
Who they care for

46% care for their mother
40% care for a sibling
23% care for their father
23% care for a grandparent

32% caring for more than one person
### BBC Survey 2018

**Difficulties of the people cared for**

<table>
<thead>
<tr>
<th></th>
<th>Physical disability</th>
<th>Mental health</th>
<th>Long term illness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percentage</strong></td>
<td>35%</td>
<td>24%</td>
<td>24%</td>
</tr>
</tbody>
</table>

- Learning Disability 13%
- Drug Use 4%
- Alcohol problems 2%
% young carers in child populations

- **UK**: 2-3%, 8-22%
- **Norway**: 6%
- **Australia**: 4%
- **USA**: 3%+
- **Sweden**: 7%
- **Canada**: 12-27%
- **Italy**: 3%
- **Switzerland**: 8-10%
- **Germany**: 5-6%
- **Austria**: 4%
- **Japan**: 4-6%
- **Netherlands**: 10%
Young carers in Ireland

**Census 2016**

- Adult completion
- 3,800 carers under 15
- Numbers **fell** from 4,228 in 2011 Census (10% drop)
- Half in 2016 are aged 10 or under
- 79% provide up to 2 hours care a day
- Average = 16 hours care per week
- In total, YCs provide 42,227 hours of care per week
- Or 2.2m hours of care per year

**Health Behaviour in School Children 2018**

- **Pupil self-completion**
- 13.3% of young people aged 10-17 report a regular caring role
- Extrapolation = 67,000 YCs
- YCs report poorer outcomes than non-carer peers
- Lower life satisfaction
- Poorer mental health
- One third bullied at school
- One quarter go hungry to school or bed
## Outcomes

<table>
<thead>
<tr>
<th>Negative</th>
<th>Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restricted friendships</td>
<td>Responsibility</td>
</tr>
<tr>
<td>‘Stigma by association’</td>
<td>Maturity</td>
</tr>
<tr>
<td>Fear of interventions</td>
<td>Skills</td>
</tr>
<tr>
<td>Silence and Secrets</td>
<td>Control</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>Inclusion</td>
</tr>
<tr>
<td>Health problems (PH &amp; MH)</td>
<td>Resilience?</td>
</tr>
<tr>
<td>Educational difficulties</td>
<td></td>
</tr>
</tbody>
</table>
Transitions to adulthood and YACs (2000, 2008)

The process whereby young people move away from dependence for primary, emotional and financial support from their childhood family carers, and their needs for income, shelter and social life are met from a wider range of sources

• Educational problems
• Issues finding appropriate work
• Leaving home problematic
• Career & job choices influenced by skills gained
• Transition support is needed for those aged 16+
Young Carers Aged 16-17

- Most had cared throughout childhood
- Families expected them to do more as they got older
- Schools not supportive
- Lack of career advice
- Low income
- Concern about post-18 support
- Many young carers will continue caring into adulthood
- YC Projects not good at ‘transitions’ work
YC/YACs Online Survey (2013)

295 responses
Aged 14-25

25% at school
41% at college or uni
16% in work
16% NEET

YOUNG ADULT CARERS SURVEY

Researching to improve the lives of Young Carers and Young Adult Carers

If you are a Young Adult Carer aged 14-25 and you provide care, assistance or support to another family member on an unpaid basis we are interested in your views and experiences of school, college or university and work.

Please click here to go to our survey.

YACsurvey.com is a website of Professor Saul Becker and Dr Joe Sempik of the School of Sociology and Social Policy at The University of Nottingham. If you would like more information about this survey please contact joe.sempik@nottingham.ac.uk
Level of caring

Young Adult Carers: Age and Care Level

Mean MAAC Score

- 14 - 15
- 16 - 17
- 18 - 20
- 21 +
Age they started caring

10
Who they care for

52% care for their mother
14% care for their father
14% care for a brother
8% care for a sister
4% care for a grandparent

1 in 5 care for more than one person
Difficulties of the people cared for

<table>
<thead>
<tr>
<th>Physical disability</th>
<th>Mental health</th>
<th>Long term illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>55%</td>
<td>49%</td>
<td>47%</td>
</tr>
</tbody>
</table>
Young Carers/YACs: self-reported disabilities and difficulties

- Mental Health Problems: 45%
- Dyslexia: 25%
- Physical Disability: 21%
- Learning Difficulties: 8%
- Sensory Difficulties: 8%
- Autism/Aspergers: 4%
Absence and lateness for all YC/YACs

<table>
<thead>
<tr>
<th></th>
<th>School</th>
<th>College and University</th>
<th>Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>A quarter</td>
<td>A quarter of all school days are affected</td>
<td>Half of days at college or university are affected</td>
<td>79 days per year were affected</td>
</tr>
<tr>
<td>5%</td>
<td>5% of school days missed due to caring</td>
<td>3 days per month were missed due to caring responsibilities</td>
<td>17 days per year were lost because of caring</td>
</tr>
</tbody>
</table>
Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers (aged 15-17) in Europe

- UK, Sweden, Switzerland, The Netherlands, Slovenia, Italy

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 754702
ME-WE Online Survey (2018/19)

9,427 participants
7,146 aged 15-17

Who receives care?
• 69% care for family member [mum, dad, grandparents, siblings]
• 16% care for >1 family member
• 53% care for close friend
• 22% care for family AND friend
• Grandparent care is highest in Italy [72% cf 13% UK]

2,099 AYCs aged 15-17
70% female
27% male

Family’s health conditions
• Physical disabilities 46%
• Mental illness 40%
  [57% UK cf 18% Italy]
• Cognitive impairments 26%
• Addiction 10%

Friends: 69% have mental illness [82% UK cf 30% Italy]
ME-WE Online Survey

General findings

• Amount of caring (MACA) varies between countries
• Female AYCs do significantly more caring in Netherlands and UK
• Both positive and negative adaptation is found
• AYCs have lower state of wellbeing (Kidscreen) than non-carers [females have lowest]
• Higher levels of caring (MACA) are associated with > school difficulties, bullying, mental health

Impacts

• 36% say their own mental health has deteriorated [country range 18-56%]
• 19% say school performance negatively affected [country range 12-41%]
• 17% report being bullied [41% in UK]
• 16% say they have thought about hurting themselves [range 9-31%]
• 7% say they have thought about hurting others [inc. person they care for] [range 4-13%]
Physical and mental health difficulties due to caring

Italy
- 6% of AYC's report physical health problems
- 18% of AYC's report mental health problems

The Netherlands
- 11% of AYC's report physical health problems
- 24% of AYC's report mental health problems

Slovenia
- 6% of AYC's report physical health problems
- 27% of AYC's report mental health problems

Sweden
- 2% of AYC's report physical health problems
- 40% of AYC's report mental health problems

Switzerland
- 14% of AYC's report physical health problems
- 27% of AYC's report mental health problems

United Kingdom
- 10% of AYC's report physical health problems
- 56% of AYC's report mental health problems
Mental Health impacts: Self-harm and harm to others

Italy
- 11% of AYCs reported self-harming thoughts
- 8% of AYCs reported thoughts of harm to others

The Netherlands
- 13% of AYCs reported self-harming thoughts
- 4% of AYCs reported thoughts of harm to others

Slovenia
- 9% of AYCs reported self-harming thoughts
- 6% of AYCs reported thoughts of harm to others

Sweden
- 13% of AYCs reported self-harming thoughts
- 5% of AYCs reported thoughts of harm to others

Switzerland
- 21% of AYCs reported self-harming thoughts
- 6% of AYCs reported thoughts of harm to others

United Kingdom
- 31% of AYCs reported self-harming thoughts
- 13% of AYCs reported thoughts of harm to others
Why children become carers
- cultural, relational, structural -
A continuum of children’s caring

**CARING ABOUT**
Low levels of caring and responsibility

Most children
‘Routine’ levels and types of caregiving, including some help with instrumental tasks of daily life

Little evidence of negative outcomes

**CARING FOR**
High levels of caring and responsibility

Few children
‘Substantial, regular and significant’ caregiving, including considerable help with instrumental tasks of daily life

Evidence of significant negative outcomes

**TAKING CARE OF**
Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration
From **Vulnerability** …

- Inappropriate care
- Excessive care
- Restricted education
- Reduced life chances
- Affected wellbeing
- Isolation
- High impact
... To *Growth*

<table>
<thead>
<tr>
<th>Learn</th>
<th>Thrive</th>
<th>Achieve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protected</td>
<td>Enjoy</td>
<td>Supported</td>
</tr>
<tr>
<td>Identified</td>
<td>Assessed</td>
<td>Flourish</td>
</tr>
</tbody>
</table>
Messages from research

• Need greater awareness of young carers and YACs by governments, policy makers, professionals

• Early interventions can prevent caring roles from becoming institutionalised and normalised within families

• Services and interventions can improve YCs’ health, mental health, educational experiences, wellbeing and future labour market participation (but robust evidence on child outcomes still in infancy)

• Whole family approach can be beneficial to young carers & families

• Caring roles can be reduced when families receive adequate support, (but little evidence that this is part of intervention plans)

• Targeted support at key transition points may help (desirable, but not yet proven)

• Identification & assessments critical for targeted intervention(s)

• More research and evaluation needed – especially big data/cohort studies and evaluation studies
Thank you for listening!

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Young Carers: Research, Policy and Practice

Guest Editor
Prof. Dr. Saul Becker

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