



# UPBEET conference

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Central Baptist Church, Dundee

## Young adult carers

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Young Carers  
International  
Research and Evaluation  
The University of Nottingham

# **Beginnings (@ 20 years ago)**

- **No reliable government or other figures on the number and characteristics of young carers**
- **Virtually no research and only a few publications**
- **Very few young carers projects or services**
- **No law or policy focused specifically on young carers; no 'rights' or entitlements**
- **Very little public or professional awareness or recognition of young carers**



# Today

- Official statistics (Census 2001)
- Hundreds of research studies in the UK and internationally, with many research and other publications
- 350 dedicated young carers projects in the UK in contact with approx 30,000 young carers (and similar models overseas)
- Legal rights, policy and guidance specifically for young carers, National Carers Strategies (1999, 2008) etc
- Extensive public and multi-professional recognition of young carers

## How?

Organisations that now make up the National Young Carers Coalition and other partners, drawing on research evidence, have developed and evolved services, and lobbied for recognition and support of young carers in the UK. Governments, MPs, Ministers and Ministries, policy makers, local authorities, charities and others have been responsive and enabling.

**The time is now right to do the same for young adult carers**

# Context for the research on young adult carers (16-24)

- These carers are at a critical developmental stage with life plans to be solidified and yet not much is known about them
- Few published research studies on this specific age group
- They tend to disengage with young carers services
- Adult carers are perceived as being 'older' people
- What happens when young carers mature?
- Who is responsible for identifying young adult carers?
- Who is responsible for meeting their needs?



# **National Carers Strategy (England, 2008)**

**By 2018 carers will be:**

- **respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;**
- **able to have a life of their own alongside caring;**
- **supported so that they are not forced into financial hardship by their caring role;**
- **supported to stay mentally and physically well and treated with dignity;**

**And**

- **Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.**

# The research study

- Literature review
- Secondary analysis of 2001 Census data
- Survey of 30 young carers project workers
- Survey of 13 adult carers services
- 5 focus groups with 29 young carers aged 16-17
- Discussions with staff in focus group sites
- Interviews with 25 young adult carers aged 18-24
- 2 consultation workshops with 45 project workers
- Analysis, synthesis and writing up



## Number, % and age of young carers aged 0-24 in the UK, by hours caring per week (2001 Census)

Age	1-19 hours	20-49 hours	50+ hours	Total in UK
<b>0-17 young carers</b>	<b>145,854</b> (83%)	<b>16,113</b> (9%)	<b>13,029</b> (8%)	<b>174,996</b> (100%)
<b>18-24 young adult carers</b>	<b>173,249</b>	<b>29,128</b>	<b>26,941</b>	<b>229,318</b>
	(75%)	(13%)	(12%)	(100%)
<b>Total carers aged 0-24</b>	<b>319,103</b>	<b>45,241</b>	<b>39,970</b>	<b>404,314</b>
	(79%)	(11%)	(10%)	(100%)

## Number, % and age of carers aged 16-24 in Scotland, by hours caring per week (2001 Census)

Age	1-19 hours	20-49 hours	50+ hours	Total in Scotland
16-17	4,229	789	464	5,482
18-24	15,417	3,203	2,495	21,115
Total no of carers aged 16-24	19,646	3,992	2,959	26,597

# Positives and negatives of caring as perceived by young adult carers themselves

## Positives

- Gaining life skills
- Confidence
- Preparation for independence
- Maturity
- Close family relationships
- Giving something back
- Development of empathy, sensitivity and caring skills
- Development of skills and interests for care-related employment

## Negatives

- Missing out on education or work opportunities
- Poor emotional well-being: worry, stress, anxiety, depression, anger, resentment and resignation
- Physical ill-health – tiredness, exhaustion, back-ache, colds
- Neglectful of own health and fitness
- Risk-taking behaviours
- Unfulfilled aspirations
- Restricted life opportunities
- Poverty

# Findings

## Young carers aged 16-17

1-19 hours	20-49 hours	50+ hours	Total
49,711	6,935	4,406	61,052
(81%)	(12%)	(7%)	(100%)

- Most participants had cared throughout their childhood
- Evidence of conflict between their needs for independence and increased family expectations for them to do more as they get older
- Variable experiences of school and support received
- Many reported a lack of adequate career advice
- Low income was affecting their quality of life, opportunities and aspirations
- Great concern about who would support them post 18
- Variable evidence that young carers projects systematically prepared young carers for transitions (life events and services)



# Findings

## Young adult carers 18-24

### Intensity of caring roles

- A third were providing practical support in the home and personal and intimate care *a lot of the time*
- Two thirds were performing household tasks and providing emotional care *a lot of the time*
- Many others were providing a combination of tasks 'some' or 'a lot of the time'

### Impacts

Little time for themselves, juggling competing demands, no space for spontaneity, restricted opportunities for leisure, relationships, employment and training

# Friendships and leisure

- A third were able to participate in activities or hobbies either within or outside the home
- Participation in leisure activities & holidays is on a continuum
- 1 in 4 of the participants were supporting other young carers
- Friends are very important and are chosen carefully

## However:

- Two thirds were not participating in any sporting activity
- Half the sample felt they had insufficient time for themselves
- Caring responsibilities constrained their wish for more of a social life
- Limited transport restricts and isolates carers living in rural locations
- 'Burden of their maturity' can inhibit their ability to make friends
- Friendships can be secondary to caring - some struggle to make friends or intimate relationships and/or, won't have friends back home

# Leaving home or not?

*“Because when I was going to start going to college mum freaked out and she started cutting herself and things, so I thought well if I’m going to start mentioning that [leaving home] that’s going to make her feel a lot worse so I’ve kept it all quiet”. Kelly, aged 20*

Decisions to leave home were often complex and difficult, and in many cases choice about when to leave and where to go were restricted

***Pull to stay at home*** : close inter-dependent relationship, low income, burden it will place on others, fear of consequences, guilt, low confidence, gender and cultural expectations

***Push to leave***: family encouragement, condition of the person being supported and their willingness to accept formal support, other informal support, quality of the care package, and money/grants for higher education

# School

*“I got set on fire I did because I was bullied about being different, being overweight, where I was staying in 24/7 looking after my parents, I’d always be eating snacks, chocolates and all that...Lots of people think because you’re a guy why would you be happy cleaning, not going out, not drinking, being happy, their automatic assumption is you’re either bent or just weird, let’s beat him up. The bullying side of it was incredible”.*

*Peter, aged 19*

- **School could be ‘sanctuary’ or ‘misery’**
- **Mixed experience of teachers - supportive and non-supportive**
- **Bullying**
- **Attendance : affected or unaffected**
- **Attainment – some do very well and achieve good GCSEs/A levels, others leave with no or few qualifications due to learning difficulties, poor attendance and lack of appropriate support for themselves and their families**

# Further and higher education

## College/training provider

- More positive experiences of education at FE colleges – more understanding/flexible, adult-orientated, student services, less bullying, important location for socialising
- But instances of drop-out, problems with training/course provider, and basic level qualifications being attained

## University

- Caring often affects the choice of university and ability to leave home
- Financial struggle to get to university or remain there
- Subject choice affected by caring to some extent – replicate, making a difference or non-care related
- Less awareness of students as carers and therefore 'hidden'
- No specific carers support provide by universities but can tap into student support services
- Quality of student life is different from their peers
- Worry and caring at a distance continues for those living away from home

# **Employment and careers advice**

- **1 in 4 were not in employment, education or training (NEET)**
- **3 were in full-time employment but in low income jobs**
- **Remainder were in further or higher education**
- **Variable experience of career support either at school or college**
- **Some careers staff were identifying and referring on young adult carers for carers support services**

# **Income**

- **Strong evidence of poverty and social exclusion**
- **Evidence of some young adult carers subsidising the family income**
- **EMA and ALG could be affected by attendance levels**
- **Many young adult carers were unable to get part-time work**
- **No participants were in receipt of Carer's Allowance**
- **Lacked preparation to understand the 'benefits maze'**

# **The knowledge gap**

- **All were unconfident about their rights and entitlements to services or benefits**
- **Often lacked information about the care receiver's health condition as well as professionals not involving or listening to them**
- **Lacked clarity about services beyond a young carers service**
- **Two thirds were unaware of their right to a Carer's Assessment**

# Emerging models of service provision for young adult carers aged 18-24

Sole young carer focus

‘keep in touch’

Focused young carer provision

‘teenage transition support’

Volunteering for the service

‘helping hand’

16/18 plus service

‘specialist worker’

Partnership approach

‘shared responsibility’

Adult carers services

‘adult service responsibility’

Ad hoc

‘pick n mix’

# **Adult carers centres**

## **Challenges for supporting young adult carers:**

- 1. Funding constraints or service level agreements**
- 2. Staff felt ill-equipped to work with young adults and their issues**
- 3. Perception that young adult carers are 'hard to reach'**
- 4. Few self-referrals but promotional material perceived as inappropriate**
- 5. Lack of relationship, coordination and referral between services for young carers and adult carers centres**

# 1. Addressing needs: advice, information & guidance



High quality information, advice and guidance about:

- money/ benefits/grants
- carers assessments
- services available for carers and for the person being supported
- the medical condition and health needs of person(s) they care for
- the carer's own health and keeping well
- managing caring tasks safely
- parenting advice and support

## 2. Addressing needs: services & support

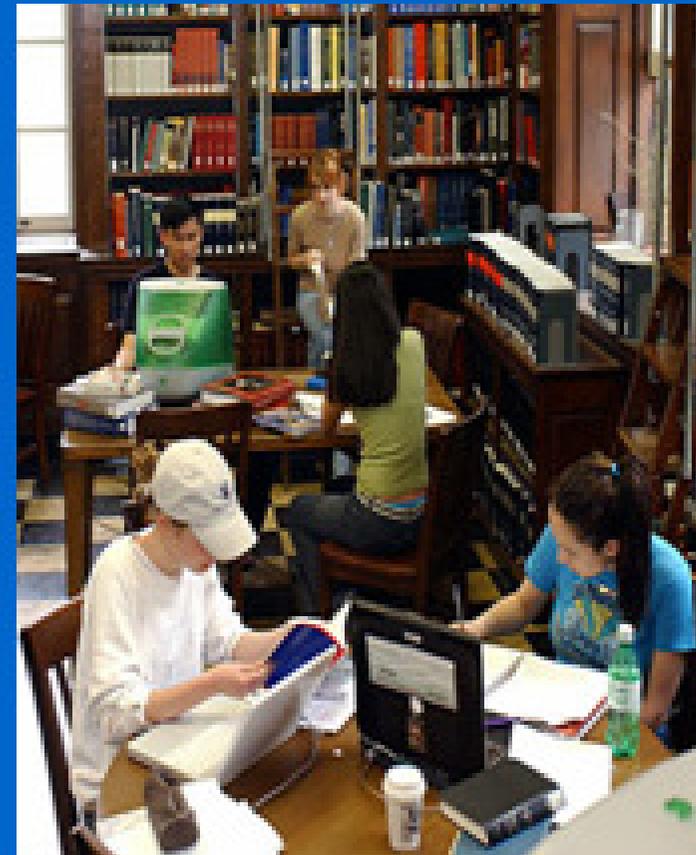
Services that support young adult carers' needs as carers would include:

- counselling and/or relaxation therapies to build resilience and cope with stress
- breaks from caring
- carers' assessments
- emergency planning
- adequate & affordable transport
- suitable housing, aids and adaptations



## 3. Addressing needs: education & training

- Early intervention to avoid inappropriate levels of caring and optimum outcomes including academic achievement
- Robust anti-bullying strategies
- Greater awareness, recognition and support for carers in all schools, colleges and universities
- Advice and assistance about opportunities in further and higher education and how to obtain necessary financial assistance
- Assistance to balance the demands of care-giving and further education and ongoing learning



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## 4. Addressing needs: job seeking & careers advice

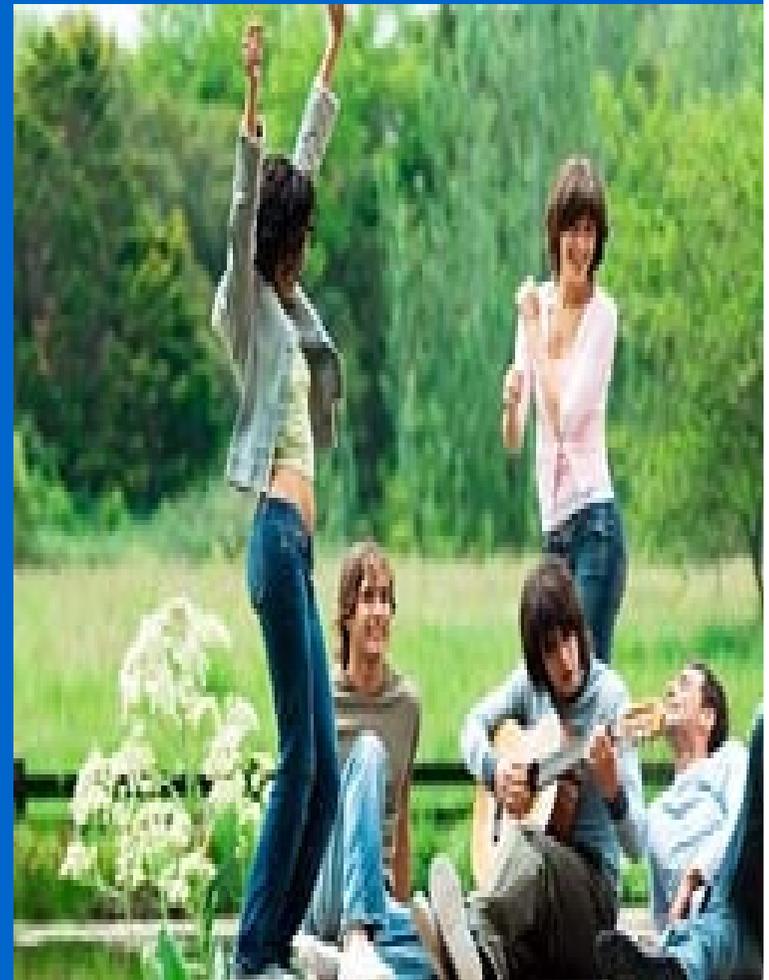
- Careers advice up to 24 years  
- sensitive to the implications  
of caring but not reinforcing  
caring as the only career  
option
- Information and advice about  
flexible training and learning  
opportunities
- Job-seeking support: job  
search, interview skills, CVs,
- Carer-friendly employment  
practices and support in the  
workplace



## **5. Addressing needs: activities & peer support**

**Peer support and affordable leisure opportunities to promote physical and emotional well-being:**

- **activities available locally for leisure and wider participation**
- **affordable/subsidised activities to promote health, well-being and inclusion**
- **opportunities to meet other young adult carers**
- **opportunities for social networking**



# 14 Key messages and ways forward (a)

1. Young adult carers have similar needs to other carers but developmentally they are at a significant period of change and need timely, appropriate and sensitive support
2. Young adult carers' standards of health, well-being and transitions can be improved by the provision of good quality and carer-sensitive health, medical, social care, housing, transport, education, careers and employment services
3. (Adult) carers services need to better identify, engage and support young adult carers – they need to 'reach down' to this age group
4. Young carers services need to be more outcome-focused and plan for and deliver interventions which prepare young carers for key transitions, including 'adulthood' and for adult services
5. There needs to be better integration and joint working between local services for young carers and adult carers
6. Young adult carers should be provided with high quality information, advice and guidance alongside relevant services
7. Commissioners should identify the needs, desired outcomes and services for young adult carers and commission accordingly, including promoting the rights of young adult carers

## **14 Key messages and ways forward (b)**

- 8. Local authority carers' strategies should include specific references to this group of carers and outcomes for them**
- 9. Young adult carers need to be helped to 'self-identify' and recognise their caring contribution and roles**
- 10. Services need to be family-focused, flexible, reliable, good quality, coordinated and non-stigmatising**
- 11. Young adult carers need dedicated services and support at the same time as the person they help to look after needs services and support**
- 12. An assessment of the needs of young adult carers and those they support is a key gateway to information, services and support for all family members**
- 13. A 'whole family approach' is central**
- 14. Robust and reliable measures are needed to compare and evaluate interventions and services for young carers and young adult carers**

**New developments:**  
**Outcome measures**



**Young Carers  
International**  
Research and Evaluation  
The University of Nottingham

# Manual for Measures of Caring Activities and Outcomes for Children and Young People

Published by  
The Princess Royal  
Trust for Carers &  
Young Carers  
International, March 2009

Comic Relief and Princess Royal Trust for Carers **Young Carers Grants Programme 2008-11**

## Using the **Young Carers** Tasks and Outcomes **Questionnaires**

### Introduction

You will already be aware that the Princess Royal Trust for Carers has commissioned the University of Nottingham to conduct an independent evaluation of the funded projects/services under this grants programme. As part of the evaluation process the University of Nottingham evaluation team were commissioned to develop an outcomes measuring questionnaire in order to more effectively identify the impacts of the funded interventions on young carers. These guidance notes explain how to use the questionnaires and what will be done with the results.

Many thanks in anticipation of all your assistance which will help the young carers sector to develop evidence-based approaches to supporting children and young people.

We care  
what YGU think.



Guidance notes for funded projects using the young carers tasks and outcomes questionnaires

# MACA-YC18

## Multi-dimensional Assessment of Caring Activities – Young Carers 18 item Scale

## MACA-YC45 Clinical assessment tool

### 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.**

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

MACA-YC18  
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Developed for The Princess Royal Trust for Carers.

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# PANOC-YC20

## Positive and Negative Outcomes of Caring – Young Carers 20 item Scale

### How caring affects me

Below are some things young carers like you have said about what it feels like to look after someone. Please read each statement and tick the box to show how often this is true for you. There are no right or wrong answers. We are just interested in what life is like for you because of caring. **Thank you.**

	Never	Some of the time	A lot of the time
1 Because of caring I feel I am doing something good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Because of caring I feel that I am helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Because of caring I feel closer to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Because of caring I feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Because of caring I have to do things that make me upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Because of caring I feel stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Because of caring I feel that I am learning useful things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Because of caring my parents are proud of the kind of person I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Because of caring I feel like running away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Because of caring I feel very lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Because of caring I feel like I can't cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Because of caring I can't stop thinking about what I have to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Because of caring I feel so sad I can hardly stand it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Because of caring I don't think I matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Because of caring I like who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Because of caring life doesn't seem worth living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Because of caring I have trouble staying awake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Because of caring I feel I am better able to cope with problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 I feel good about helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 Because of caring I feel I am useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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