Research into Young Adult Carers Aged 16-24 in Surrey

Report

Surrey Young Carers

January 2012

Lindsay Constable

"Nothing in life has any purpose if it is not done, ultimately, for someone else."

Charles Handy: Inside Organizations
Lindsay Constable is the 16-24 Researcher for Surrey Young Carers, Action for Carers (Surrey). The statements and opinions contained within this publication are those of the author, and have been reviewed and accepted by Action for Carers (Surrey).

Copyright
© Lindsay Constable 2012

Acknowledgements
The author acknowledges with gratitude the help of all the young adult carers who so openly and honestly shared their experiences and views through interviews, discussions, forums, focus groups and questionnaires. Thanks and appreciation go to the staff of Surrey Young Carers, Action For Carers (Surrey), the Mid Surrey Project and the staff of carer services locally and nationally who contributed to this research. Thanks also go to Professor Saul Becker, whose guidance and advice has been paramount to the success of this project within such a short timescale.

Funding
The funding for this research was provided by private donations to Surrey Young Carers, Action for Carers (Surrey). The author worked as a Research Officer for Surrey Young Carers, Action for Carers (Surrey).

Competing Interests
The author declares no financial or competing interests.

Ethical Considerations
This research has been conducted under the strict professional and ethical guidelines, principles and practice of the European RESPECT Code of Practice for Socio-Economic Research. (RESPECT: Professional and Ethical Codes for Socio-economic Research in the Information Society. www.respectproject.org)

Citation
This report should be cited as:
Constable, L (2012) Research into Young Adult Carers aged 16-24 in Surrey. Action for Carers (Surrey)
for

Jenny
## Contents

Foreword by Professor Saul Becker 6

Foreword by Jane Thornton and Karen Holdsworth Cannon 7

Executive Summary 8

1.0 Introduction and Organisational Outline 16

2.0 Research Background 17

3.0 Recommendations Outline 20

4.0 Young Carers: An Historical Perspective 21

5.0 Surrey’s Socio-Economic and Geographical Context 26

6.0 The Barriers Facing Surrey’s Young and Young Adult Carers 27

7.0 Ongoing UK Service Responses to the Transition Needs of Carers aged 16-24 35

7.1 North Staffordshire Carers Association 35

7.2 Action for Carers Plus: Lincolnshire 36

7.3 The Carers Centre, Brighton and Hove 37

7.4 York Carers Centre 38

7.5 Youth Action Wiltshire 40

7.6 Islington Young Adult Carers Group 41

7.7 The Hub Young Carers in Bedfordshire 42

7.8 Young Carers Support Project (Croydon) 44

7.9 Worcestershire Young Carers Transition Service 45

7.10 The Dundee Young Carers UPBEET Project 46

7.11 The Edinburgh Young Carers Project 46

7.12 The Oxford Hub: Magdalen College Young Carers Project 47
<table>
<thead>
<tr>
<th>Section</th>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.13</td>
<td>The Suffolk Strategy for Supporting Young Adult Carers</td>
<td>47</td>
</tr>
<tr>
<td>7.14</td>
<td>Ongoing UK Service Responses: Conclusion</td>
<td>49</td>
</tr>
<tr>
<td>8.0</td>
<td>Surrey's Young and Young Adult Carers in Context</td>
<td>52</td>
</tr>
<tr>
<td>8.1</td>
<td>Young Carers in Surrey aged 16-17</td>
<td>52</td>
</tr>
<tr>
<td>8.2</td>
<td>Young Adult Carers in Surrey aged 18-24</td>
<td>53</td>
</tr>
<tr>
<td>9.0</td>
<td>The Positives of Caring</td>
<td>57</td>
</tr>
<tr>
<td>10.0</td>
<td>The Overall Experience for Young Adult Carers aged 18-24 in Surrey</td>
<td>57</td>
</tr>
<tr>
<td>11.0</td>
<td>Res Ipsa Loquitur: The Facts Speak for Themselves</td>
<td>60</td>
</tr>
<tr>
<td>12.0</td>
<td>Research into Young Adult Carers aged 16-24 in Surrey: Conclusion</td>
<td>63</td>
</tr>
<tr>
<td>13.0</td>
<td>Key Recommendations for Action for Carers (Surrey)</td>
<td>66</td>
</tr>
<tr>
<td>14.0</td>
<td>Key recommendations for internal consideration and in consideration of lobbying external organisations, stakeholders and service providers</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>Bibliography</td>
<td>69</td>
</tr>
</tbody>
</table>
Foreword

By Professor Saul Becker, Head of the School of Sociology, Social Policy and Social Work at The University of Nottingham

There is much wisdom in this excellent research report by Lindsay Constable of Surrey Young Carers, Action for Carers.

Young adult carers – children aged 16-17 and young adults aged 18-24 – have been largely ignored by policy makers and service providers across the UK, including health, social care, further/higher education, and career and employment services. The neglect of young adult carers’ needs, and the lack of awareness about their caring circumstances and lives – renders them invisible, hidden from public view and wider concern.

But young adult carers are many in numbers – a hidden army of young people – and they will be found in your neighbourhood, in your community, on your street. Amongst every group of young people of this age will be some who are spending much of their time, and their lives, involved in day-to-day care-giving. Their lives and opportunities, as this report shows clearly, are constrained by their caring roles and responsibilities. Whilst there can be positive outcomes, such as feeling closer to the persons for whom they care, the negative consequences of caring on their own health, well-being, relationships, education, labour market participation, and so on, are legion.

This research report shows clearly the situation of young adults who care in Surrey. It reveals their experiences, needs and what kinds of services and interventions are most likely to deliver the positive outcomes that these carers wish for, so that they can have a life of their own, participate in further or higher education, gain their own independence, access the labour market and paid employment – all on a level playing field with young people of the same age.

The suggestions for ‘what works’ and recommendations have a firm foundation in research evidence. The answers that policy makers and service providers require to deliver better outcomes and services for young adult carers are contained here. This report provides a blueprint for action. Let us hope that in these hard times, young carers and young adult carers will be seen as worthy of an investment. A decent society will recognise that without adequate recognition and support for young carers and young adult carers, we cannot claim to be decent at all.

Professor Saul Becker
Foreword

By Jane Thornton, Chief Executive and Karen Holdsworth Cannon, Chair, Action for Carers (Surrey)

In the course of our work with both young carers and adult carers over the last decade or more it has become evident to us that the needs of young adult carers in particular are not being adequately addressed; indeed young adult carers did not really appear on anyone’s radar. For most young people in this age group, turning 16 is an exciting time when they can begin to spread their wings and think about how they will fulfil their hopes and aspirations for their future as an adult. For young carers however, this can be a time of great anxiety where the services and support they have known may no longer be available to them and what is on offer does not meet their needs as a young adult. For many, their caring responsibilities and the lack of support they receive will be limiting their future life chances.

Over the years, our Young Carers’ Service has striven to ensure that where possible we help young adult carers move to support from adult services and our Carers and Employment service in particular has been working to engage other agencies in this joint work. But it’s difficult to maintain contact with these young adults as their lives are shifting and we do not have the resources for the specific support that they need. Building on the great work already undertaken by Professor Saul Becker and his team in particular in this area nationally, we realised that we needed to have some firsthand evidence of the needs of this group of young people in Surrey, to hear directly from them and to explore with them what support and services would make a difference to them. How could they be supported better into further education, training and work, so that they don’t suffer economically and socially as a result of their caring role? How can they be enabled to have fulfilling social and personal lives, not adversely affected emotionally by caring?

Surrey Young Carers wanted to stimulate the debate by commissioning this research in the hope that it will generate a positive response from all agencies. We ourselves have already begun to act on some of the areas that the research has highlighted and we will be urging our partners in both the statutory and voluntary sectors to look at how they can meet the recommendations outlined here. We are extremely grateful for the generous donations from a number of supporters, which have enabled us to fund this piece of research. We could not otherwise have undertaken it. Supporting young adult carers is not any one agency’s responsibility; it is incumbent on all services to ensure that these young people don’t remain hidden and can access the best support possible to enable them to fulfil their dreams.

Jane Thornton
Chief Executive

Karen Holdsworth Cannon
Chair
Research into Young Adult Carers aged 16-24 in Surrey
Lindsay Constable
Surrey Young Carers, Action for Carers (Surrey), 2012

Executive Summary

This study, funded for one year by Surrey Young Carers, Action for Carers (Surrey) uses a variety of methodologies to gather the views of young adult carers, families and professionals, and investigates the needs, identification and barriers to accessing provision that face young carers aged 16-24 years old living in the County of Surrey.

The research includes a literature review, national and local research, secondary analysis of the 2001 Census and a questionnaire to 133 young carers. It also includes consultations with thirteen adult carer projects around the country, three focus groups and discussions with carers, discussions with staff from all areas of the charity including administrative, back care, employment, education and development, GP’s recognition, together with discussions with service providers and stakeholders, eleven adult carer support groups and in depth structured interviews with 13 young adult carers from across Surrey.

This research provides data on the number of young adult carers; the changing nature of their caring tasks and responsibilities; their experiences of education at school, college and university; their friendships, relationships, leisure and lifestyles; income, jobs, careers and aspirations; issues to do with leaving home and independence; the role of young carer’s projects; emerging service responses; and how their needs can best be met. The experiences and needs of carers aged 16-17 (who are legally children) and 18-24 year olds (who are legally adults) are discussed.

Recommendations in this report are made in two categories: firstly; internal administrative, infrastructural and working practice developments within Action for Carers (Surrey); and secondly, a ‘wish list’ of changes and improvements - included in a series of mirrored ‘Becker’ recommendations - for those working with young and young adult carers in Surrey, that can be made within both Action for Carers (Surrey) and the realm of broader caring communities, service providers and stakeholders.

Findings concerning Carers in Surrey aged 16-24

- In a questionnaire to one hundred and thirty three carers aged 16-24 from across the county, of the 34 respondents, nearly one in six were in the highest risk category of concern.

- Over 70% of carers aged 16-24 in Surrey felt emotionally upset about the tasks they had to complete in the course of their caring role. Two thirds
felt they had been abandoned and 'did not matter anymore.' For just over 40% of them, for some of the time, 'life did not seem worth living.'

- Many Surrey carers aged 16-24 felt they were trying hard to be a 'perfect parent' themselves and had taken on pseudo-parental roles at an early age over younger member(s) of their household, in order that their siblings would avoid having to experience the difficulties that they had endured.

- No Surrey carer aged 16-24 in the survey was 'at ease' with their caring role.

**Findings concerning Young Carers in Surrey aged 16-17**

- Census 2001 data shows that there are 631 young carers aged 16-17 in the County of Surrey, with 68 of these (11%) caring for more than 20 hours each week and another 38 (6%) caring for more than 50 hours per week.

- Most carers in this age group felt constrained in their relationships as they got older.

- Carers reported that schools and colleges had failed to identify their caring responsibilities. Many reported that their teachers did not know, nor understand their circumstances. Carers had received poor career advice and they knew very little about local services for adult carers. Young carers were anxious that their support would cease when they became 18 years old.

- All of the participants in the study were anxious about a lack of careers advice and a lack of support at school in general. More than 50% of participants reported that they had received careers advice at school, or through Connexions, but that this was mostly general advice given to all students. No one reported having any careers advice specifically for them in their caring roles.

- Young carers aged 16-17 often neglect their own health: Over 80% of Surrey carers aged 16-17 stated that they regularly take personal responsibility for heavy lifting due to their caring role.

- Young carers aged 16-17 in Surrey think and plan carefully for their futures, often with the thought in mind that their siblings may be required to take over their roles if they wish to pursue further education.

- Just under half (45%) of Surrey's young carers aged 16-17 reported that as a result of having to complete caring tasks, they had missed between two and six days at school or college in the two working weeks prior to
completing the questionnaire. One reported missing 'a few weeks to a month of study over a two month period.'

- At the ages of 16 and 17, young carers within Surrey are engaging with and feeling supported by children's services. Nearly 20% of all known carers aged 16-17 in Surrey are fully engaged with Surrey Young Carers and the Mid Surrey Project.

- It was felt by all 16 and 17 year old young carers that they would like to be made more aware of what they can expect in their lives as they move towards adulthood.

**Findings concerning Young Adult Carers in Surrey aged 18-24**

- Census 2001 data shows that there are 2403 young adult carers aged 18-24 in the County of Surrey. This is 3.4% of all people in that age group. Nearly 20% (465 people) are providing care for more than 20 hours per week and 221 of these (9.2% of the total) are providing care for more than 50 hours per week.

- Surrey's young adult carers feel more restricted than other young adults in terms of their opportunities to go out, join in with activities and go away on holiday. Just under half of all young adult carers reported feeling isolated and lonely most of the time.

- Young adult carers often neglect their own health. More than four fifths stated that as a result of caring they felt physically exhausted, ill and stressed some or a lot of the time. Some reported they were forced into undertaking intimate caring responsibilities that were both distressing and unappealing.

- Some young adult carers in Surrey reported having difficulties with their education. Some institutions were reported to be treating carers badly despite being informed of the carer's responsibilities. Two young adult carers felt they had been ignored as a punishment and institutionally marginalised for their caring roles.

- In general, this group were more heavily involved in caring than their younger counterparts and this had restricted their participation in other life events and activities. As regards socialising, many young adult carers reporting strained relationships, increasing physical and mental demands and an increase in 'intimate care' requirements as they had grown older.

- Most 18-24 year olds found colleges to be more supportive than their schools, however, some had left without gaining qualifications. None were aware of any specific carers support available for them at university and none were aware of what help may be available to support their relatives,
how to access it and who supplies it whilst they were away at university. There was an overall anxiety and a lack of awareness both from university students and those carers wishing to go to university.

- It was reported in most cases, that there was insufficient time to look for or take on paid work, and most young adult carers aged 18-24 in Surrey said they experienced significant financial hardships as a consequence of caring. Many found it too difficult to combine paid work with the conflicting demands of caring.

- Some young adult carers had low esteem and poor confidence, felt alone and were unsure of how to make progress in accessing the labour market. Others felt they had no transport and could not search for work. Some did not have the confidence to engage with adult groups and others remained as informal 'hangers on' to existing children services.

- The future aspirations of Surrey's carers aged 18-24 are not dominated by money and qualifications, but by their caring responsibilities.

- All of the young adult carers could have been accessing support from adult carer's services provided by the voluntary or statutory sectors, but very few had ever used an adult carers service, and then not to any great degree. Of the 13 young adult carer interviewees in this study, eleven had had no contact with adult services, and two reported having made attempts to make contact with adult services but had received no response.

- More than 90% of the Surrey survey felt they were doing good, enjoyed helping, and were closer to their family member as a result of caring. Over four fifths felt they were gaining new skills through their caring role. Such skills included independence and organizational abilities. Some reported that caring had given them the chance to develop new skills for coping in crisis or complex situations.

- Young adult carers aged 18-24 in Surrey are currently institutionally and administratively 'archived' into oblivion and thereby 'lost in transition' at a stage where they should be receiving signposting and support to assist them to engage with a range of adult services for the next phase of their lives.

- The 18-24 year old young adult carer group represents 2.3% of the total adult carer population in Surrey but just 0.1% of them are fully engaged with adult services, whereas 9.4% of the over 25’s of the total census are reported to be actively engaged.

- If the status quo continues, within two years of this report in the region of 150 young adult carers will have moved into the 'transition' phase of their lives, will no longer be contactable, no longer engaging with any support service and they will remain hidden from view.
Food for thought: Ideas that work around the UK

**Education:** Promoting awareness with universities, schools and colleges. Encouraging educational establishments to take a firm and active part in identifying young adult carers, with training and workshops for staff in schools and colleges, and awareness sessions for students. Giving advice on courses at colleges through the use of drop in sessions. Promoting 'sustainable learning' through a 'C4CK - Credits for Caring Kids' initiative. Helping with gaining qualifications: ASDAN youth awards, NCFE qualifications, first aid, food hygiene. Helping with 'A' levels and degrees to students in the local university, City and Guilds qualification for carers. Assisting with driving lessons, CBT (motorcycle basic training) and the 'Wheels to Learn/Work' programme.

**Planned Activities:** Sports and social sessions to create opportunities for respite and fun. This could include social evenings, pub quizzes competitions, sponsored walks, party and night clubs, film nights, ten pin bowling, bag packing in a local store to raise money, residential weekends, meals out, cinema, go-karting, bowling, ice skating, tobogganing, spa days, watching football, games and craftwork evenings, cooking and X-box.

**Services:** Personalised, individual casework services with 'one to one' and 'personal action plans', together with group work or a self assessed, self referred specially designed 'MOT.' Use made of electronic communications or telephone and text message support or an online chat room. Advice offered on housing, finances, higher education and careers, or requests/help to buy equipment and resources through discount cards negotiated with local shops. Family Link Workers trained to look out for young adult carers, as they already have extensive links with families. One to one support through outreach workers.

**Information:** Producing a regular newsletter (in alternative languages for these speakers in their communities) and signposting for young adult carers and their families to local services. Offering advocacy and support in education, training, family matters and employment to reduce their caring roles and responsibilities. Signposting for young adult carers and their families to local services to facilitate benefits maximisation.

**Empowerment:** Employing young adult carers to run awareness training or involved as ambassadors and council members who are empowered to speak with meet with MP’s and health/other care professionals, and to campaign on issues that affect them. Having a strong presence at health and well-being fairs and fresher's fairs. Helping young carers to engage speakers to talk on issues that they themselves have raised.

**Training and Employment:** Training courses and workshops: emotional and practical support as to how to cope being a carer, advice and information about the transition from child to adult services and adult life. Coping strategies for dealing with difficulties in preparing for and engaging in employment, education and training. Workshops in self-esteem, anger management, panic attacks, stress management, sexual health and conflict resolution. Training in 'general living',
careers advice, c.v. construction, interview and life skills. Classes in personal development and entitlement to benefits. Training in accessing flexible opportunities to combining education, training and employment with their caring role. Courses in healthy living and lifestyle, relaxation techniques, dealing with tiredness, exercise and healthy eating. Training in coping with depression, communicating with family, friends and professionals, and planning for the future.

**Leadership and Development:** Appointing a 'Young Adult Carers Champion' to network, raise the profile, and promote the rights and needs of young adult carers. Developing partnerships, exit strategies, carer friendly employment practices and help fundraise and campaign, and encouraging more young adult carers to come forward to receive support. Championing and raising support to facilitate social inclusion, support and services that are appropriate with their age. Helping with employment to gain flexible training opportunities. Assisting and accompanying young carers to appointments, meetings and interviews and giving support in the workplace. Training for big employers in the local area, who may employ young adult carers or allow work placements in the future with individual approaches on behalf of and in support of the young adult carers to organisations and employer.

**Key Recommendations for Action for Carers (Surrey)**

1. Surrey Young Carers should develop an exit strategy for all young carers turning 18 who are no longer able to access young carers services. As part of the exit strategy a joint or single visit should be completed with Surrey Young Carers and Action for Carers (Employment) to review current needs and signposting to adult provision. This should include making a referral to Carers Support, looking at training and work opportunities, looking at manual handling needs, becoming a Carers Ambassador and joining Action for Carers (Surrey) through the Supporter Affiliation form.

2. Action for Carers (Surrey) should source additional funding for three years specifically for work with 18-24 young adult carers, based on national and local findings. They should employ a part time 'Transition Worker' to provide information, signposting, drop in sessions, develop website information and most importantly to act as a link between Action for Carers (Surrey) and the wider services to ensure that current young and young adult carers do not become 'hidden carers'. Management of this role may need to sit with Action for Carers (Surrey) and Action for Carers (Employment), due to the age of the carers being supported. This would need to be included into the funding application and considered by Senior Staff.

3. Surrey Young Carers should positively develop the outcomes for 16-18 year olds currently accessing the service who may start to lose contact with them. Part of the current Activity Coordinator role could develop the
recommendations suggested by young carers in the interim report such as a resource/signposting pack that all 16 year olds receive. This should provide information on age appropriate support. Action for Carers (Surrey) should also develop drop in sessions for older carers aged 18-24, with a rolling programme throughout the year on matters such as c.v writing, completing applications for jobs and universities, opening bank accounts etc. This could be achieved in partnership with Action for Carers (Employment), utilising their connections and expertise.

4. Consideration should be given to appointing a 'Young Adult Carers Champion' to lobby on behalf of and represent young adult carers, and to raise the profile of young adult carers with care providers, stakeholders and the wider business community. The role could investigate internships, apprenticeships and flexible working or studying arrangements with local employers and educational institutions, and ensure that a personalised service is being provided to young adult carers. The Champion could also seek out additional funding streams to ensure the sustainability of the project to support young adult carers aged 18-24.

5. Efforts should made to improve data processing, handling and storage by utilising a shared data base throughout Action for Carers (Surrey) with meaningful, accurate data obtained and stored that would enable greater efficiencies and accuracy in data input and retrieval, and the ability to use it in subsequent research and to evaluate outcomes.

6. Evaluation of the changes undertaken should subsequently be carried out to determine 'what works', and 'what good looks like'. It is imperative that any change results in positive, robust outcomes for the young adult carers themselves. Statement of ‘provision’ of a service needs to be matched by best practice, best value and best outcomes. Evaluation will also better facilitate the application for and securing of further funding if so desired.

Key recommendations for internal consideration and in consideration of lobbying external organisations, stakeholders and service providers:

1. The development of services and interventions for carers aged 16-17 and 18-24 should be concerned with outcomes rather than types of services and models.

2. Young and young adult carers should be involved fully in planning services.

3. Services for young carers aged 16 to 18 need to prepare young carers for the transition phase in their lives.
4. After consultation with young carers about the issues most pertinent to them, young carer’s projects should develop preparation programmes for young carers in transition. This could include job/course search skills, grant applications for university, c.v construction, first aid, cooking, benefits, relationships, adult social care services etc.

5. Systems need to be created to monitor and evaluate interventions, services and outcomes, using robust measures, instruments and tools that enable comparison over time and place.

6. All agencies, including local authority and carer’s services, should provide young and young adult carers with information about their legal rights, including the right to a carer’s assessment from the local authority; a potential gateway to services and support for carers and their family.

7. Young carer’s projects and other services need to provide a seamless service to young adult carers aged 18 to 24. Young carer’s projects need to build relationships and bridges with local adult carer’s services to help services recognise and become more engaged with the needs of young adult carers.

8. Universal services, such as schools and primary health care have a role to play in supporting young and young adult carers alongside more specialist provision. Universal service providers need to be alert to the specific needs of these carers and find ways to deliver their particular service to them.

9. Agencies that would not traditionally be associated with meeting the needs of carers also need to identify and engage with young adult carers. For example, colleges, universities, Job Centre Plus, employers, leisure services providers and others need to be sensitive to the needs, issues and barriers confronting this group of carers and which affect their opportunities for further education, learning, leisure, careers and paid work.

10. Some young adult carers will be parents themselves and may need parenting support in this role at the same time as they need support because of their ongoing caring responsibilities to others.

11. The needs of young adult carers aged 18-24 and the outcomes that are required through service interventions need to be integrated fully into the local authority’s carer’s strategy.

12. Adult carer’s services need to address the barriers that are inhibiting carers aged 18-24 from using their services and address their own lack of relevance to this group - as perceived by young adult carers themselves.
Research into Young Adult Carers aged 16-24 in Surrey
Lindsay Constable
Surrey Young Carers, Action for Carers (Surrey), 2012

1.0 Introduction and Organisational Outline

This study, funded for one year by Surrey Young Carers, Action for Carers (Surrey) uses a variety of methodologies to gather the views of young adult carers, families and professionals, and investigates the needs, identification and barriers to accessing provision that face young carers aged 16-24 years old living in the County of Surrey.

Action for Carers (Surrey)\(^1\) is a non-profit making independent charity that has been raising awareness of the needs and concerns of carers since the early 1990's. It is led by carers, run by an executive committee of carers and is supported by professionals from health, social services and the voluntary sector. Its main aim is to raise awareness of the needs and concerns of carers throughout the county and to work in partnership with statutory services such as health care and social care teams to promote how best they can serve carers within Surrey. Action for Carers (Surrey) also works with national carers organisations such as Carers UK and the Princess Royal Trust for Carers to ensure that Carers get better access to services and support throughout the UK. Action for Carers (Surrey) manages five voluntary services: GP's Recognition Service, 'Giving Carers a Voice', Surrey Young Carers, Action for Carers and Employment, and Action for Carers Moving and Handling Back Care.

The GP Carer Recognition team work with GP surgeries in Surrey to assist GPs to recognise carers and keep them informed of carers’ rights and issues. They help to ensure that carers are registered so that they can gain access to the services they really need.

'Giving Carers a Voice' raises awareness of carers’ needs and concerns.

Surrey Young Carers\(^2\), Action for Carers (Surrey) has been supporting young carers across Surrey since 1996. It offers free impartial information and support to young carers and aims to promote the needs of young carers in all childcare and adult settings. Surrey Young Carers receives funding from adult and community care services, the Carers Grant and the Children's Fund. Surrey Young Carers supports carers up to the age of 18 in both an individual and group setting, around issues of caring. Surrey Young Carers provides an advocacy service for young carers, and raises awareness and promotes the needs of young carers within a multi-agency setting. It runs regular training and learning workshops and forums to give young carers 'a voice', and organises and runs events, outings and fun days for upwards of 160 young carers. It also publishes a

\(^1\)http://www.carersnet.org.uk/actionforcarers/afc.html
\(^2\)http://www.surrey-youngcarers.org.uk/about/about_us.html
quarterly newsletter\textsuperscript{3} and assists schools by providing free consultations; briefings within INSET days and staff meetings; assembly talks to students; help in setting up school young carer groups; and providing primary and secondary schools with PSHE materials.

Action for Carers and Employment\textsuperscript{4} (ACE) is a service provided by Action for Carers (Surrey). ACE provides specialist support, information and advocacy for carers, and former carers, in relation to employment, training, returning to learning and leisure activities. ACE provides information by telephone or a one to one meeting within ACE offices, the carer’s own home or at a mutually convenient location. All Action for Carers and Employment (Surrey) services are free and confidential. ACE works closely with local statutory and voluntary organisations to raise awareness of carers needs, and actively encourages employers to adopt carer friendly working practices. ACE runs free workshops specifically for carers, in various locations throughout the county, tailored to meet the needs of carers who would like to increase their confidence, or want to improve their IT or administrative skills.

Action for Carers (Surrey) Back Care Support\textsuperscript{5} has trainers and advisors who provide information, support and training to adult carers on all aspects of moving and handling. The service’s aim is to support carers to reduce the risk and likelihood of incurring muscle strain and/or back injury by providing back care information support and training which may help reduce these risks. People are vulnerable at any age to the risk of injury from moving and handling. Action for Carers (Surrey) Back Care Support, offers small handling equipment for trial, and provides training in the use of equipment. In addition, on behalf of the carer, they liaise with additional support organisations such as NHS acute and community teams, social care teams and voluntary agencies.

2.0 Research Background

Aim: "Using a variety of methodologies, gather the views of young adult carers, families and professionals, and investigate the needs, identification and barriers to accessing provision that face young carers aged 16-24 years old living in the County of Surrey."

The research includes a literature review, national and local research, secondary analysis of the 2001 Census, a questionnaire (Joseph manual modified\textsuperscript{6}) given to 133 young carers, consultation with 13 adult carer projects around the country to see 'what works', three focus groups and discussions with carers, discussions with staff from all areas of the charity including administrative, back care, employment, education and development, GP’s recognition, together with

\begin{footnotesize}
\textsuperscript{4} http://www.carersnet.org.uk/ace/ace.html
\textsuperscript{5} http://www.carersnet.org.uk/actionforcarers/backcare.html
\end{footnotesize}
discussions with service providers and stakeholders, eleven adult carer support groups and in depth structured interviews with 13 young adult carers from across Surrey.

In 2008, Professor Saul Becker published his report into 'Young Adult Carers in the UK; Experiences, Needs and Services for Carers aged 16-24'. This research adapts and uses his 'mixed methods' investigation for the County of Surrey. The data presented in Becker’s report provides new insights into the diverse experiences and needs of what is now commonly established as a hidden and neglected group of carers.

As with the Becker survey, this research provides information on the number of young adult carers; the changing nature of their caring tasks and responsibilities; their experiences of education at school, college and university; their friendships, relationships, leisure and lifestyles; income, jobs, careers and aspirations; issues to do with leaving home and independence; the role of young carer’s projects; emerging service responses; and how their needs can best be met (Becker, 2008:p1). As in the Becker study, the experiences and needs of carers aged 16-17 (who are legally 'children') and 18-24 year olds (who are legally 'adults') are discussed differently, however, there are significant similarities in their age group experiences. In the UK, many service providers and stakeholders have integrated Professor Becker’s recommendations into their own work practices, and his recommendations have also been fully introduced into the Carers Strategy for Scotland, 2010-2015.

Joseph et al (2009) reported responses from 410 young carers ranging in age from 7 to 22 who were recruited via The Princess Royal Trust for Carers database of UK projects and asked to complete two questionnaires to assess caring activities and caring outcomes, respectively. Following statistical analysis, researchers reduced the length of the two questionnaires and piloted them with another 124 young carers. The statistical procedure allowed them to select a small set of items that are representative of a particular domain of activity. From this, 42 items were chosen to compose questionnaires called the Multidimensional Assessment of Caring Activities (MACA-YC18) and the MACA-YC42 (18 or 42-item self-reported measure checklists respectively) that can be used to provide both an index of the total amount of caring activity undertaken by the young person and a detailed picture of the caring activities undertaken by an individual. The questionnaires are designed so that carers can indicate how often they carry out different tasks by ticking ‘never’, ‘some of the time’ or ‘a lot of the time’. From these items, six subscales of caring responsibilities are created, which fall under the categories of domestic tasks, household management, personal care, emotional care, sibling care and

---

9 Joseph, S., Becker, S., Becker, F and Regel, S (2009) Assessment of caring and its effects in Young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for Young Carers. Child Care Health and Development, 35(4) 510-20
financial/practical care.

Joseph’s manual also included a 20-item self-report measure called the Positive and Negative Outcomes of Caring (PANOC-YC20) that can be used to provide an index of the positive and negative outcomes of caring. The PANOC-YC20 can be used before, during and after receiving support in order to identify any changes that have occurred. Both measures are useful to young carer organisations interested in evaluating their intervention strategies, and the measures provide the resources with which to evaluate whether interventions are associated with changes in levels of caring activity. The PANOC-YC20 is particularly useful in that it focuses not only on the positive and negative outcomes of caring, but also whether support has resulted in a reduction of negative outcomes and an increase in positives ones.

In this research, use was made of both the MACA-YC42 and PANOC-YC20, with modifications made to the questionnaires to accommodate the audiences of both young carers from Surrey Young Carers (SYC) and young carers from the Mid Surrey Project (MSP). Both SYC and the MSP work with young carers in Surrey, but have different strategies, working practices and interventions. Together they form the main young carer support organisations for the county.

Additionally, in this research, two further tools were employed from the Joseph Manual: A short questionnaire entitled ‘What I Like and Dislike about Caring’ and a Post Intervention Self Assessment (PISA-CR2). The ‘What I Like and Dislike about Caring’ questionnaire was used to gain an understanding of the nature and extent of the caring role undertaken and the young carer's feelings about the caring tasks they do. The ‘Post Intervention’ questionnaire was used to elicit young carers’ views about the interventions they have received and the impact these have had in certain areas of their lives. For example, it asked young carers what type of support they have received, their views about the support and any resultant changes in terms of their experiences of school or college and the amount of caring activity undertaken. Again, in this research, both questionnaires were modified to be specific to the young carers who attend either SYC or the MSP.

In this research, a final 'pack' of MACA-YC42, PANOC-YC20, 'What I like..' and PISA-CR2 was created with a covering letter specific to the individual attending either SYC or the MSP, and posted with a Freepost return option to all young and young adult carers aged between 16 and 24 on the SYC and MSP databases. Questionnaires were also made available at forums, should the young carer wish to have clarification of any point or not wish to complete the questionnaire in their own homes. In total questionnaires were sent to 133 young and young adult carers, and there was just under a 26% response rate.

In addition to the 'Joseph questionnaire', a further research initiative was undertaken. This was in the form of a personal structured interview with young adult carers only between the ages of 18 and 24. Initial contact was made with young adult carers through use of the SYC and MSP archives, together with local knowledge of young adult carers obtained from carer support groups, their
friends, SYC and MSP workers, colleges and from siblings already engaged with young carer services. The identification of young adult carers for this survey interview was problematic - and indeed is the crux of this research. Of the 30 young adult carers identified, thirteen agreed to take part in the interview stage. Following initial contact and introduction, the interviews were subsequently carried out either by telephone at an agreed time in the day or evening(s) of the candidates choice, or at a 'safe' location at which an existing young carer forum or activity was taking place.

Constructed under Moser's (1989)\(^{10}\) guidelines and Dearden's (1998)\(^{11}\) research design, the structured interview was designed to discover a little about the carer's role and responsibilities, their relationship with their families, their knowledge of and participation in support services and their career or career aspirations. The interview comprised of two direct and 27 indirect questions, and covered other aspects of the candidate's education, employment and training, their lives outside of caring, their access to transport and finances and their own perceptions of the barriers they faced. Telephone interviews were carried out because they were inexpensive, convenient, saved time in travel and interviewees were called at a time that was convenient to them. Interviewees were given the choice of a personal or telephone interview.

Where personal interviews were carried out, this was done in a safe and controlled environment at a young carer project venue. This was done for three reasons: firstly there was, on hand, someone to talk to at the YC project; secondly there was a project worker available for support if necessary, and thirdly the carer knew the environment to be safe whilst away from their home. In some cases, initial contact was made by a trusted care worker who was well known to the interviewee. All these measures were taken to engender confidence in the interviewee and to elicit honest responses. In all cases, interviewees displayed a confident manner and opened up to the questions posed. The interviews were later transcribed and analysed into thematic headings, as outlined in Dearden's research methodology.

### 3.0 Recommendations Outline

Recommendations in this report are made in two categories: firstly, internal administrative, infrastructural and working practice developments within Action for Carers (Surrey), and secondly, a 'wish list' of changes and improvements - included in a series of mirrored 'Becker' recommendations - for those working with young and young adult carers in Surrey, that can be made within both Action for Carers (Surrey) and the realm of broader caring communities, service providers and stakeholders.


\(^{11}\) Dearden, C and Becker, S (1998) Young Carers in the UK: A Profile. Young Carers Research Group, Loughborough University: Leicester
4.0 Young Carers: An Historical Perspective

Over the last thirty years or so, the central importance of carers has been highlighted in social welfare policy. In 1982, for example, the Barclay Report\textsuperscript{12} concluded that social services should concentrate resources on developing a partnership with carers. Citing De Chillo \textit{et al} (1987) 'Children of psychiatric patients: rarely seen or heard'\textsuperscript{13} and Lynch and Bakley's (1989) study, 'Serving young children whose parents are mentally retarded'\textsuperscript{14} Jo Aldridge (2003)\textsuperscript{15} showed that research on young caring began in the early 1980s when medical and social scientists began to look at the wider issues influencing the consequences for families.

From this early research, a new environment was created in which researchers considered caring more as a welfare issue. Aldridge stated that these early studies all suggested that children in a caring role were relatively uncommon. She also found that identifying young carers in order to gain some insight into their numbers often proved difficult because families were wary of divulging their circumstances in which they had to rely on their children for care. Aldridge pointed out that identification in practice relies on the perceptiveness and understanding of professionals in recognising the triggers for young caring. She said, 'We cannot be precise about how many children young carers there are, because studies conducted to date have largely been unable to provide reliable estimates of potential national populations of children with caring responsibilities' (Aldridge, 2003:pp8-9).

Over the following two decades, concern mounted about the health and welfare of young carers who provided informal care for family or friends with chronic illnesses (Doran \textit{et al}, 2003\textsuperscript{16}) but up until this time, estimates of the numbers of young carers in the UK had largely been pieced together from \textit{ad hoc} local studies and household sample surveys. In Banks' (2001) study, 'Seeing the Invisible Children and Young People Affected by Disability' he reported that estimates of the numbers of young carers in the UK varied enormously from 10,000 to 50,000 (Banks \textit{et al}, 2001).\textsuperscript{17} Aldridge also suggested that research into young caring was additionally complicated by the absence of definition and of few data in which specific ages are considered; she commented, 'There has been no uniformity in definition used by researchers or in the 'age band' studied' (Aldridge, 2003:p9).

Additionally, specific difficulties have arisen in the identification of young carers in a UK population that comprises nearly one in six (9.1 million) non-white residents and 2.1% black residents. In their research into the strengths, barriers and needs of black families in which young people have caring responsibilities, Jones et al (2004) found that agencies did not routinely gather information on young carers, and that professional awareness of young carers was low. Their study of 40 agencies and 20 families in Manchester highlighted the inappropriate nature of many of the services available to black people and their families, and they reported that black young carers especially were 'largely invisible' to agencies - but were essential to maintaining family life. Additionally, they reported that young black carers did not identify with the term 'carer' as they felt it made no positive difference to them or their families.

Eight years on, there is still no single definition of what a young carer is. Definitions range from the broad to the specific. Macmillan Cancer Support, for example, suggests that a young carer is, "If you are under 18 and you spend any of your time looking after someone who is ill, then you're a young carer." Barnardos, however, says, "Young carers are children who help look after a member of the family who is sick, disabled or has mental health problems, or is misusing drugs or alcohol." The NHS states that a young carer is, "Someone aged 18 or under who helps to look after a relative who has a disability, illness, mental health condition or drug or alcohol problem." Furthermore, in Dundee, a young carer is, "Someone aged 5-21 years who looks after, or helps care for, a family member who has a disability, mental ill health, a blood borne virus or a problematic use of drugs or alcohol." Whereas in Edinburgh, young carers are as old as 25: "Young carers are people aged 5 to 25 years old who care for or are affected by someone else at home - usually a parent or sibling. The person they care for may suffer from mental health problems, disability, chronic illness or drug and alcohol misuse."

In 2000, Becker and Becker created a new, wider and more comprehensive definition after they realised that many young carers were being defined by reference to the amount of care, i.e. 'substantial' - rather than the 'significance' of care. They said, "Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. These children carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would be usually associated with an adult. The person receiving the care is often a parent, but can be a sibling, grandparent or other relative who is disabled, has some

---

18 ONS: 2011 estimates for 2009, UK
21 http://www.barnardos.org.uk/what_we_do/our_projects/young_carers.htm
22 http://www.nhs.uk/CarersDirect/young/young/Pages/what-is-a-young-carer.aspx
23 Dundee Carers project http://www.youngcarers.co.uk/
24 Edinburgh Young Carers Project http://www.youngcarers.org.uk/about
chronic illness, mental health problem or other condition connected with a need for care, support or supervision." This definition is now accepted and widely used by many carer organisations around the country and has been adopted by the Blackwell Encyclopaedia of Social Work.26

Young 'adult' carers however, are less visible in the academic arena and less visible in the world of service provision and outcomes. At the age of 18, children pass into the adult world. As Levine et al (2005)27 pointed out, "This neglected group is important, because young adults are at a critical developmental stage. They have passed the turbulence of early and mid-adolescence, but most have not yet solidified life plans and choices; for many, education extends into their 20s, and marriage and childbearing typically occur at older ages."

Arnett (2000)28 calls the ages 18 to 25 the years of 'emerging adulthood' and a distinct period of frequent changes, distinguished by “relative independence from social roles and normative expectations . . . the most volitional years of life.”

At the age of 18 years, a child passes into what the psychologist Erikson (1968) called the sixth 'Stage of Development'; the 'Young Adult'29 in which, he says, “young adults seek intimacy and satisfying relationships, but if unsuccessful, isolation may occur.” The NHS calls this graduation into adulthood a 'transition'30 - a term now used widely in young adult carer transition projects, around the UK, relating to, in most cases, carers over the age of 18 but under 25. The Social Care Institute for Excellence (2005)31 points out that, "It is a fact that children grow into adults: Provision for children has to take into account their long term needs and interests as well as their more immediate ones" (Waine, 2005:p5). Interestingly, Levine (2005)32 studied the prevalence, characteristics and responsibilities of young adults aged 18-25 who are caregivers for ill, elderly or disabled family members or friends. She discovered a high proportion of young adult male carers and this raised questions about the appropriateness of support services, which were typically used by older women carers.

In 1999, Frank et al had shown that social exclusion and isolation could also be 'self created' as a form of defence mechanism by young carers. In his study, 'On Small Shoulders'33 Frank reported that for some young carers, "the act of self exclusion becomes easily justifiable." For without self exclusion, some former young carers would have been unable to cope with the pressures and dilemmas of caring. Young carers, he said, "can quickly become cut off from the shared experiences of their friends and peers [and] the avoidance of certain kinds of social contacts is often considered necessary as a defence against being viewed

30 http://www.nhsdirect.uk/CareersDirect/
as 'unusual' or 'abnormal'" (Frank et al, 1999:p9). Frank also showed that the self exclusion of young carers can lead to a longer term 'deficit legacy' in which, as they reach young adulthood, young adult carers display anxiety over mixing with other adult company and older social groups. Young adult carers also showed the development of negative perceptions concerning matters of self-worth and self-esteem, and a lack of confidence in communicating feeling and emotion with older adults.

In her study of young carers in Merseyside, Bilsborrow (1992:p18) reflected on carers as a free 'resource' and feared that service provision would not be adequate for this group. "Most people" she said, "are cared for by informal carers. Care in the family is taken for granted and services are structured on this assumption." Later, Waine's (2005) report, 'Developing Social Care Values and Principles' introduced a new concept; that of the child or adult carer as a 'consumer' - a term imported from economic theory - whereby the consumer does not consider themselves to be a 'resource' but is often considered such by organisations and services. Waine pointed out that, "particularly with respect to carers, there are arguably tensions with a concept of empowerment. If carers are seen as resources this may induce the concept of the carer as an alternative to public service provision, and that some providers may be encouraged to disempower carers by resisting their requests for support" (Twigg and Atkin, 1994; op cit Waine et al, 2005). Therefore carers may be identified as a "new reserve army of unpaid labour" (Twigg, 1999).

It seems then, that for young adult carers moving from childhood and into this 'transition' phase of their lives, the past two or three decades of research have revealed that at this fragile age of 18 to 25, young carers may be marginalised, excluded and socially disadvantaged. This situation is possibly made worse because their emotional and behavioural needs for companionship and social interaction are heightened. Evidence suggests that this increased marginalisation may result in magnified social isolation and invisibility, which in turn can lead to young adult carers having their own health issues. For example, one of Frank's (1993) interviewees reported "psychological asthma" and her "hair falling out because of stress over caring." As Traupmann and Hatfield (1981) reflected, "People who have someone to share their ideas, feelings, and problems with are happier, healthier than those who do not." It is interesting to note that over half of Frank's research interviewees required counselling for stress related illnesses.

Aldridge (2003:p72) showed that the nature and extent of caring tasks may also be determined by the age of the carer, with greater responsibility and workload being undertaken as the carer grows up through childhood and into

---

34 Bilsborrow, S (1992) You grow up fast... Young Carers on Merseyside. Barnardos
adulthood, with young adult carers taking on extensive roles usually associated with a parent. Recently in Surrey some young adult carers have reported that as they have grown into adulthood, their child-parent roles have reversed, and they now see themselves as the parents of their parents.

One of Frank's (1999) revelations was that, "Of all the consequences of caring, the hardest one to reveal and examine is concerned with the concealment of caring itself." It has been well documented elsewhere; Walker (1996) and Aldridge and Becker (1993) that young carers are unwilling to identify themselves for a whole host of reasons. Citing one of his research interviewees, Frank (1999) reported, "I kept everything hidden. Everything was terribly shameful. Our house was weird. Both my sister and myself intended to keep people out of the house" \(\text{(anon young carer; op cit Frank et al 1999:p12)}\). Walker (1996:pp8-18) found that young carers often lived in households in which there also existed an older sibling carer. As a result, the younger carer was considered not to be the 'main carer' and therefore remained largely invisible to children's services. However, she pointed out that, "Where there is an adult carer [in the household] this did not mean that the burden on the young carer was necessarily less than in households where the only adult was the person in need of care."

Similarly, in Aldridge's (1993:p45) research, 'The Silent Carers', she showed that, "One of the effects of caring on young carers was their inability or reluctance to talk about their conditions or experience. In effect, caring had served to silence them." Many young carers in Aldridge's study found it difficult to talk, did not want people to know about their circumstances, or were afraid of telling "for fear of the consequences." Frank later went on to investigate the presence of 'significant barriers' to young and young adult carers. Thus the concealment of caring roles among young and young adult carers has given rise to the concept of the 'hidden army' of invisible young carers\(^{42}\) as in Becker's and others' studies.

In her report, 'Prevention and Intervention: Young Carers and their Families' Aldridge (1997:p16)\(^{43}\) reflected that it is both the disabled and their young carers who face disabling barriers: "We recognise that in an ideal world, where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognise unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, family carers are going to be expected to continue their support. We do not want children who are having to fulfil this role to continue to do so unsupported." To remind you, that was 1997.

5.0 Surrey’s Socio-Economic and Geographical Context

Sharing its border with Greater London, East Sussex, Kent, West Sussex, Hampshire and Berkshire, Surrey is the second smallest shire county in the South East. It has a population of 1,127,300 (June 2010)\(^{44}\), and is the most densely populated county in the South East.\(^{45}\) 73% of Surrey is designated as Green Belt and 25% is an area of extreme natural beauty (AONB) known as The Surrey Hills. Surrey is also the most wooded county in Great Britain, with 22% woodland coverage. In terms of ethnic breakdown, Surrey has 83.2% White British, 9.36% non-white or mixed race and 2.11% Black or Black British population.\(^{46-47}\)

At £26.5 billion\(^{48}\) (2007) Gross Value Added (GVA), Surrey is the largest sub regional economy in the South East with 79.3% of the working population economically active and 75.3% of its working age population in employment. The average weekly earnings of Surrey residents are £623.40 (ONS, 2009) and one in five of all working residents are managers or senior officials. At £20,169 per head (2007), Surrey has the highest Gross Disposable Household Income (GDHI) of all counties in the South East.\(^{49}\) The Local Competitiveness Index 2010 shows that Surrey’s eleven boroughs and districts are in the top 25 most competitive nationally, with Guildford ranking as the most competitive ‘city’ in the UK.\(^{50}\) Surrey’s population is well qualified, with 40% of the working population qualified to NVQ Level 4 or better. The population is relatively wealthy and the health of people in Surrey is generally better than the UK average with, on a typical day around £300,000 being spent on community health care and meeting the needs of a diverse population.\(^{51}\)

Paradoxically, in March 2010 there were 27,800 unemployed people in Surrey, that being 4.8% of the working age population\(^{52}\) with some 12,263 people claiming jobseeker’s allowance in August 2010. There are four census Super Output Areas (SOA’s) in Surrey that are among the most deprived 25% in the country\(^{53}\) and there are some 23,330 children and young people that live in poverty in Surrey; that being nearly 10% of the entire 0-19 yrs old population.\(^{54}\) It is of interest to note at this stage that of all the young and young adult carers interviewed and questioned in this research, four young carers who were discovered to be in the ‘most vulnerable by any criteria’ (Becker, 2008) category, also reside in four of the twenty most deprived SOA’s in the country. One of whom lives in the third highest ‘income deprivation’ domain SOA and another who resides in the highest ‘income deprivation affecting children’ domain SOA. The third of these most vulnerable young carers lives in the top ‘overall income

\(^{44}\) Population Estimates Unit, ONS: Crown Copyright 2011
\(^{45}\) http://www.Surrey.gov.uk. 2010
\(^{47}\) http://www.guardian.co.uk/news/datablog/2011/may/18/ethnic-population-england-wales#data
\(^{48}\) ONS: GVA for the South East, Regional Briefing, 2010
\(^{49}\) http://www.Surrey.gov.uk. 2010
\(^{50}\) http://www.cforic.org/pages/ukc2010.php
\(^{51}\) NHS: Surrey Health, Annual Report. 2009-10
\(^{52}\) http://www.Surrey.gov.uk. 2010
\(^{53}\) http://www.communities.gov.uk/2010 Index of Deprivation
\(^{54}\) Surrey LEA, 2010
deprived' and 'income deprived affecting health, disability and employment' domain SOA. Given further research opportunities and by using a Geographic Information System it would be interesting to map and ascertain evidence to support an hypothesis of clustered, causal links between caring, multiple deprivation and outcomes for young adult carers; or vice versa.

6.0 The Barriers Facing Surrey's Young and Young Adult Carers

In 2010 the Centre for Analysis of Social Exclusion, London School of Economics published a report into 'An Anatomy of Economic Inequality in the UK' in which they highlighted significant evidence on the position of carers:

- Carers are less likely to be in paid work than the general population: only 3 million of the 4.5 million carers of working age are in paid work, with one in five carers giving up work in order to care.
- Carers are more likely to be in low paid and low status professions: almost 45% of men and 55% of women who are in paid work, but caring for more than 20 hours per week are in routine occupations.
- Carers are more likely to suffer from ill health that further reduces their chances of returning to or finding work. Note: Carers UK reports that in the 2001 census, carers providing high levels of care were twice as likely to be ‘permanently sick’ as those not caring.
- Young adult carers are less likely to be in further or higher education: Among young adult carers age 16-24, fewer than 16% of women and 21% of men who were caring for more than 20 hours per week were in education. Whereas over 25% of non-carer 16-24 year olds are in education nationally.
- Bangladeshi and Pakistani men and women are three times more likely to provide care than their White British counterparts and these carers are three times more likely to have a long standing limiting illness than their counterparts. Note: This may have significant implications for the provision of personalised services in Surrey to targeted, geographical areas of need.
- Many carers who are currently in work are at risk of falling out of work because of a lack of services and a lack of support at work: only 25% of working carers reported that they felt they receive adequate support to enable them to combine work with care.
- Carers are more likely to be on low incomes: Those who care for more than 20 hours per week are more likely to be in poverty than others.
- With demographic change, the prevalence of caring responsibilities is likely to increase in the future.

---

56 http://carersuk.org/Policyandpractice/Research
In Becker's 2008 report into 'Young Adult Carers in the UK'\textsuperscript{57} he illustrated some of the positive aspects of young carers projects for 16-17 year old carers. He cited several projects as being young person focused without being patronising; projects as 'safe places' and places to meet and develop friendships; projects as confidential spaces; and projects as providers of a break from caring. However, of most concern to him was that young carers projects usually have to stop working with carers once they reach 18. Research with 16 and 17 year old young carers in Surrey also echo these sentiments. After spending almost their entire life with Surrey Young Carers or the Mid Surrey Project, participants of focus groups of 16 and 17 year old carers have all displayed anxiety on where they go for help once they reached the age of 18. Even at the age of 18 and above, some have sought advice, but little has been forthcoming:

"I have tried and tried to contact social services - I rang and they said they would get back to me, but they never have. I feel like I have been pushed aside."  
(Surrey young adult carer, aged 19)

"I was supposed to have a carer’s assessment - it was arranged, but they didn’t do it! I am 18 and they said I was too young - I rang and rang, and kept saying I was 18, but I have just been phased into the background."  
(Surrey young adult carer, aged 18)

Becker noted that many young carers develop strong bonds and attachments with other young carers and project staff and when their projects come to an end at the age of 18, the carers subsequently feel a real loss. There was little evidence from around the country that existing projects prepare young carers for the ending of their service, and for this loss (Becker, 2008:p64).

Therefore in Surrey, it is a recommendation that young carers have an exit strategy for all young carers turning 18 who are no longer able to access young carers services. As part of the exit strategy a joint or single visit should be completed to review current needs and signposting to adult provision such as, making a referral to Carers Support, looking at training and work opportunities, looking at manual handling needs, becoming a Carer Ambassador and joining a supporter affiliation scheme. In the Mid Surrey Project, a successful, very informal 'network' already exists, and run by older ex-carers. The most logical route for young carers aged 18+ to take is to migrate straight to adult services, although, as Becker noted, in reality many services for adult carers are working with much older carers, as some of the young carers themselves recognise:

"You'll be in a group with like 30, 40 year olds... and you'd be treated as... a child basically, yes... and it's demoralising and daunting going into a room with a lot of older people. The rest of them are ancient compared to us! And it's focused more to the older generation."  (anon, op cit Becker, 2008:p65)

In Becker's (2008) study, it was rare for young carers aged 16 or 17 to know anything about local services for adults. In Surrey, sample testimonies show that none of the sample had any more than a passing knowledge of adult services, and the lack of knowledge even extended to those who had passed beyond this age. As Stanley et al (2003) reported, "Although all young carers aged 16 or over are entitled to a separate carers assessment, they are less likely than others to be offered one."58 59

"Adult services available to me? Not a clue... not a clue... not a clue."  
(Surrey young carer, aged 17)

"Adult services? I know there is an adult services fund? Or group?  
Or... I think, not sure - never been told... not sure? Is there?"  
(Surrey young adult carer, aged 19)

In Surrey, most young carers said that they would like to continue to receive some form of support beyond the age of 18, but with different 'rules' directed towards the 16-24 year old carer social group. In forums, Surrey's young carers were also able to offer a whole range of possibilities from using new media to social networks, to gatherings and signposting. One suggestion was the formation of a transition group for support. As the 2004 DFES Research report RR602 pointed out, "Young carers and their families should be actively involved in the design and delivery of services and an ongoing dialogue with them should be established."

The consequences of not engaging young adult carers in the design and delivery of services are clear; as the report explains, "If they [young carers] are not involved, then they often vote with their feet, leaving the service unable to meet the demands of its targets."60 The report continues, "What is required is an organisational culture of participation." Kirby et al (2003)61 emphasised the need for organisations to bring about change in order to ensure sustainable outcomes. He identified four stages in the process of changing cultures and institutionalising participation in organisations:

- 'Unfreeze' existing attitudes, procedures and styles of working
- 'Catalyse' change through the use of 'Champions' of participation
- 'Internalise' change through communication and partnerships working
- 'Institutionalise' by mainstream practice

58 Supporting Young Carers and Young Adult Carers in Suffolk: A Multi-Agency Strategy for Suffolk 2010-2013. The Children's Society: Essex
The concept of the creation of a 'Champion' is also discussed in a number of case studies in the DFES report, described as, "a key individual who promotes participatory practices both within and beyond partnerships and develops the agenda within the mainstream." Furthermore, the report points out that "while champions of participation are important in encouraging service users’ participation on a personal level, there is also a need to develop mechanisms to ensure the sustainability of participation work. This would ensure that momentum is not lost when key workers leave their posts" (DFES, RR602: p30). It is a recommendation within this report that consideration is given to appointing such a Young Adult Carers Champion.

During the course of this research, structured interviews, questionnaires and forums have been held with in excess of 150 young and young adult carers from across Surrey and barriers that face young and young adult carers in the county have been identified. Examples of such barriers have included financial, social, emotional, physical and institutional.

**Financial Barriers:** Dearden and Becker, (2000)\(^{62}\) highlighted the fact that, "A lack of education and ongoing caring responsibilities serves to exclude some young adult carers from the labour market" (Dearden and Becker, 2000; op cit Becker 2008: p21). Aldridge (1993: p17) also showed that many young carers are denied any prospect of choice because of limited personal or family finances that "prevent the activation of any caring alternative." One interviewee reported:

"Because I am caring, I'm not earning, I'm not saving and therefore I am unable to access education."

*(Surrey young adult carer, aged 18)*

Another reported,

"I'm looking after mum and have to be near, on the phone to go, but that means I am just cleaning for minimum wage - yet I am qualified to do other work, I just can't afford to go that far away from her... and when I get a call, I then lose money."

*(Surrey young adult carer, aged 22)*

In Dearden and Becker’s (2000) study they reported that one of the most important decisions which young adult carers face was that relating to their own choice of career or job, and that this decision had been substantially influenced by their parent’s illness. It is of interest to note that the House of Commons report (2008:46)\(^{63}\) ‘Valuing and Supporting Carers’ stated, "Carers currently face a stark choice between engaging in education and training without any financial support, or living on benefits."

---


http://www.publications.parliament.uk/pa/cm200708/cmselect/cmworpen/485/485i.pdf
Social Barriers: Research in Surrey has revealed that just under half of all young adult carers reported feeling isolated and lonely most of the time:

"I am not able to socialise - I want to go out... but I always have to cancel."
(Surrey young carer, aged 16)

"I miss out on all my friends because mum is so depressed, and I don't feel appreciated."
(Surrey young adult carer, aged 19)

Research shows that young adult carers feel more restricted than other young adults in terms of their opportunities to go out, join in with activities and go away on holiday (Action for Young Carers, 2005; Dearden and Becker, 2000). Frank et al (1999) described this as a form of 'self-exclusion' – a way of carers coping with and adapting to the demands placed upon them (op cit Becker, 2008:p20).

Emotional Barriers: Research in Surrey shows that over 70% of young adult carers felt emotionally upset about the tasks they had to complete in the course of their caring role.

"I wash my teenage brother, cook the food, feed him, dress him, clean up after him - he needs his dignity... but the smells make me want to be sick."
(Surrey young adult carer, aged 18)

Two thirds of Surrey's young and young adult carer respondents also felt they had been abandoned and 'did not matter anymore'. Just over 40% of the study also reported that for some of the time, 'life did not seem worth living'.

"If I look after my dad it makes him happy and his life is easier, but when he gets depressed I just want to end it."
(Surrey young carer, aged 16)

Dearden and Becker (2000) made several important points about the effects of caring on young adults aged between 16 and 25. Firstly, “Caring can be stressful, particularly for young people living with parents who experience pain, mental distress, or who have a terminal or life threatening illness. In a few cases stress and depression were severe enough to lead to physical and psychological ill health” (Dearden, 2000:p43). Interestingly, during early research in Surrey, statistical analysis of data compiled using one of Becker's methodologies has allowed identification of those young and young adult carers who were “of most concern on every scale.”

---

The identification of the most 'at risk' carers was facilitated by interpreting the scores on the PANOC-YC20: Low scores on the positive scale and high scores on the negative scale may indicate that an individual is suffering from emotional distress. The manual points out that those carers of most concern will be those who score very low on the positive and very high on the negative scales. In finding these cases, the report recommends that carers identified to be in this category should be flagged and a further, fuller assessment undertaken on them by qualified health and social care professionals (Joseph, et al 2009:p11).

In a questionnaire to one hundred and thirty three young and young adult carers from across the county, of the 34 respondents, nearly one in six were in this highest category of concern. Action has since been taken to refer these 'at risk' carers to appropriate professional support. Without this research, it is doubtful that the situation of these vulnerable young people would have been identified and it is therefore recommended that better and more accurate data should be collected by Action for Carers (Surrey), allowing analysis to be conducted more regularly within the county.

"I do everything because I don't want my brother going through what I have had to go through. It was a bad time."
(Surrey young carer, aged 17)

Frank et al (1999) found that former young carers spoke of wanting to provide a better experience for their own children or that they were trying hard to be a perfect parent themselves, in order to avoid their children having to experience some of the difficulties that they had had to endure during their own childhood (op cit Becker and Becker 2008:p21). Research in Surrey suggests that this sense of responsibility may also therefore extend further into sibling care, in which the young carer takes on a pseudo-parental role at an early age over a younger member(s) of their household. As one Surrey young adult carer put it,

"As I have got older I have taken on ever more responsibility; I have to do everything for them [siblings]; I take them on outings; it now feels like I am their mum."
(Surrey young adult carer, aged 18)

Another reported,

"They [siblings] know just how to upset me. Sometimes they make me want to just leave them and walk out but I know I can't. I have to look after them so much that one of them now calls me 'mum', and shouldn't because I'm not."
(Surrey young carer, aged 17)

Physical Barriers: Action for Carers (Surrey) Back Care Support 67 has trainers and advisors who give information, support and training to adult carers on all aspects of moving and handling. The service's aim is to support carers to reduce

---

67 http://www.carersnet.org.uk/actionforcarers/backcare.html
the risk and likelihood of incurring muscle strain and/or back injury by providing back care information support and training which may help reduce these risks. They stress that advice may only be given to adult carers, but not to young carers, who should not participate in any caring activity in which they risk injury due to heavy lifting. Research in Surrey has revealed that over 80% of all young carers stated that they regularly take personal responsibility for heavy lifting in their households due to their caring role. People are vulnerable at any age to the risk of injury from moving and handling.

"I’m finding it difficult doing the heavy lifting when I look after dad, but I can’t stand seeing him helpless."
(Surrey young carer, aged 17)

Another reported,

"If I don’t help pick him up, my dad would rot to death."
(Surrey young carer, aged 16)

Becker (2008) reported, “Tiredness, exhaustion, back-ache, and being prone to colds and ulcers were all identified as physical impacts of caring [and that] project workers said that young adult carers often neglect their own health” (Becker and Becker 2008:p37). As one seventeen year old Surrey young carer at a forum stated,

"Rules and regulations? We’re told not to lift heavy things, yes? It’s impossible!
You have to do what you have to do."
(Surrey young carer aged 17)

In this research in Surrey, more than four fifths of respondents stated that as a result of caring they felt physically exhausted, ill and stressed some or a lot of the time, and sometimes this was set against a backcloth of domestic violence or distressing tasks.

"My disabled sister doesn’t know just how much what she is doing is hurting me."
(Surrey young adult carer, aged 18)

Another reported,

"Sometimes my dad refuses to take the tablets and it becomes very unpleasant. I can’t get any support and my dad becomes violent.
It makes me so angry - and my mum is emotionally affected. I know this has caused stress to my [sibling] and caused me to do badly in my exams."
(Surrey young carer, aged 17)

Aldridge (1993:pp17-29) reported that young carers were often forced into undertaking intimate caring responsibilities that are both distressing and unappealing to both them and to the care receiver. She also found that in several
instances, social services professionals assumed that if the young carer seemed to be "happy doing such tasks, then such a situation was acceptable." Aldridge found no evidence of any young carer being "at ease" with their caring roles.

**Institutional Barriers:** At an early stage in this research, a structured interview was carried out with a 19 year old young adult carer who came across as positive, capable, diligent and independent. When questioned about his role he reported,

"I'm alright! I get support from my college and I'm clear that I want to become a youth worker - with the qualifications that I am working towards."

(Surrey young adult carer, aged 19)

Less than six weeks later, this student stated that he had had recent difficulties with his college, who were reported to be treating him badly. He reported that he had been made to wait for hours to see his tutor, despite informing the college of him having caring responsibilities to attend to. This young adult carer felt he was being ignored as a punishment and institutionally marginalised. He said in a later communication,

"I'm now told that if I don't turn up 100% of the time, 100% on time, they'll throw me out of college next year, and I've already missed a year."

(Surrey young adult carer, aged 19)

The carer reported having received no help from adult services. Although outside their remit, a great deal of work was undertaken by Surrey Young Carer staff with this 19 year old to support, investigate and alleviate his plight at his educational institution; which has seemingly placed barrier after barrier in his path. A further report from a young adult carer at the same college said,

"The tutor at my college called me and the two other carers in my class a 'complete waste of space.' Just us. Just the carers because we can be late sometimes... they have no idea what my life is like - I feel like I am doing this all for nothing."

(Surrey young adult carer, aged 19)

In Surrey, just under half (45%) of participants in the questionnaires and interviews reported having missed between two and six days of school or college in the two working weeks prior to completing the questionnaire, as a result of having to complete caring tasks. One respondent reported missing "a few weeks to a month [of study at college] over the past couple of months."

The impact of poor school attendance and attainment was highlighted in Dearden and Becker’s (2000) study of ‘Growing up Caring’68, in which one sixth

---

of their sample had no GCSEs. Frank et al (1999) found that former young carers often said that their teachers did not know of their experiences and circumstances, nor did they understand how caring affected their pupils (op cit Becker, 2008:p20). It is a recommendation in this report that a greater effort is made to lobby universal services, such as educational institutions to have a role to play in both identifying and supporting young and young adult carers alongside more specialist provision. As Becker stated, "Universal service providers need to be alert to the specific needs of these carers and find ways to deliver their particular service to them." (Becker, 2008:p4)

7.0 **Ongoing UK Service Responses to the Transition Needs of Carers aged 16-24**

In Becker’s research, he observed a number of young carer transition projects around the UK that catered for young adult carers aged up to 25 yrs old. "The challenge we faced" he pointed out, "is that the age range cuts right across children's services (to 18) and adult services (18+). This arbitrary distinction is problematic because there is an issue of who funds such services and it has little bearing on what the needs and issues are" (Becker, 2008:p58). One solution muted was that of a composite group that spans the 16-25 age group which "may in fact be more effective because it would provide some continuity at a pivotal time of transition."

Becker outlined a number of emerging service responses to the transition needs of carers aged 16-24 in the UK. In this Surrey research, together with a number of other UK based newly emerging projects, contact was made with each of the projects originally studied by Becker. Project representatives have been interviewed to identify their successes to see 'what good looks like', 'what works' and what ideas may be transferrable and achievable in order to meet the needs of our own young adult carers in the County of Surrey.

Some of these UK projects, due to new funding challenges, have ceased to provide a young carer service beyond the age of 18. Instead, some of these now offer young adults in transition the option to 'keep in touch' should they need to do so. Indeed, this may be a cost effective option for Action for Carers (Surrey) by utilising existing resources and making some minor policy changes.

7.1 **'Supporting Teenage Transitions' - North Staffordshire Carers Association**

This project originally provided a range of services for young carers up to the age of 18, including individual support, evening and holiday activity groups and trips. It also sought to raise the awareness of young carers in schools, with foster

---

70 http://www.carersfirst.com/up2u_project
carers and with voluntary and statutory bodies. As a consequence of obtaining youth opportunity funding the project developed a young carers forum open to carers up to the age of 19, deployed consultations and created an emergency fund. This successful underpinning later resulted in the project obtaining funding from the Big Lottery, and now covers the whole of North Staffordshire supporting young and young adult carers through to the age of 25. The emphasis of support is mainly for those in the 'Not in Education, Employment or Training' (NEET) category, however, they run life skills and self esteem classes, and encourage participation in mainstream activities to develop social and individual needs. Project workers offer individual support, schools liaison services, sport sessions and drop in sessions. Referrals can be made by colleagues, professionals and parents or by self-referral. 'Supporting Teenage Transitions' now has a caseload of 30 young adult carers and the project is now called UP2U. They gained Big Lottery funding - secured to 2014 - and they now run drop in days at local colleges. Much networking is done to promote their work and raise the profile of young adult carers in the community. They also now offer extensive training in life skills and healthy living.

7.2 Action for Carers Plus: Lincolnshire

In this case, a study of the needs of young adult carers was conducted in 2005 by Action for Young Carers in Lincolnshire; an established young carers service within Carers Federation Ltd. Three years worth of funding from The Big Lottery, which commenced in 2007, has enabled the development of a new service, known as 'AYC+' for carers aged 18-25 years. The key aims of the service are to reduce the isolation of young adult carers, to improve their confidence and self-esteem, and to enable them to have greater independence. The service seeks to do this by the provision of social groups, planned activities, individual casework, circulation of a newsletter to young adult carers and local organisations, and signposting young adult carers and their families to relevant sources of support and information, including carers’ assessments. Young adult carers were involved in many aspects of the identification and development of the service.

During the first three years of activity, AYC+ identified several young adult carers in this age bracket, but it was not easy to find them. They knew from their census research that there were many young adult carers, but adult carer groups knew of just a few young adult carers. In the summer of 2011 the young adult project joined with other young adult groups from surrounding counties for a residential trip. In 2012 they are looking to employ three young adult carers to run awareness training and give presentations to groups, parties and educational institutions to raise awareness. Action for Carers Plus in Lincolnshire now has a strong carers league with both adult and child partnerships.

The original project was not successful in the first three years and they found it very difficult to engage with young adult carers. They later discovered that had they encouraged the young carers to remain 'in touch' when they reached 18,

71http://wwwcarersfederation.co.uk/ayc/index.php/young-carers-age-18-25
they would have remained with them. Initially the project had no new young adult carers other than those who had 'migrated' from the young carer project. In 2007 there were 20-30 young adult carers 'on the books' but by 2011, and as part of the local authority remit, they had "115, well engaged and supported young adult carers." The Project Director reminded me that "Young adult carers are very difficult to engage once they have left the services of young carers projects." The project found that the young adult carers did not want activities per se - although they do run them - so the project gives support and encourages independence for carers to carry on safe in the knowledge that further support is available. They also publish a regular newsletter aimed at this age group and run a social evening that is regularly attended by about 20 carers.

Action for Carers Plus: Lincolnshire now receives a stream of information and people who have been signposted from other agencies - social service, job centres, colleges (some of which are considered 'too big to care') and this network has taken three years to develop. In 2011 they funded three young adult carers to act as ambassadors to make presentations to colleges to raise the profile of carers in their communities. At the age of 25, young adult carers in this project are signposted to adult services - with whom they have good relationships - and carers are "noticeably more confident." "For the first time" the Director reported enthusiastically, "we are organising and running a festival (expanding the young carer's festival to this age group) for Lincolnshire young adult carers - three days and two nights in Skegness!" "Why not load up a car full of Surrey's young adult carers and bring them up? It should be fun!" AYC+ has all the hallmarks of becoming a most successful transition project.

7.3 The Carers Centre, Brighton and Hove

In 2007, staff at the Brighton and Hove Young Carers project identified that the needs of young carers aged 18 plus were not being met. They then appointed a part-time member of staff to pilot provision and to provide specialist support. Their project aim is to reduce social isolation through activities and to enable young adult carers to self assess their needs through a specially designed 'MOT' which signposts them to local services, gives advice and support in issues in education, training or family matters, and to empower them to speak with health care professionals about both their needs, and that of their carees. In the early days, much time was spent in promoting the service with local further and higher education establishments. One of the local colleges now takes a firm and active part in identifying young adult carers in their establishment.

In 2007 the project was seeking further funding to continue its work. Most of the young adult carers they work with care for 20 hours per week or more and that the early research - when they were setting up the project - showed that there were 851 young adult carers in Brighton and Hove. The project has been most successful, with at the start in 2007, just 10 carers 'on their books', but there has been a steady increase to a current caseload of 32 young adult carers (2011);

72http://www.thecarerscentre.org/16-25-carers/
nine males and twenty-three females. Of those young adult carers, three are in
the NEET category, one is in employment; four are in higher education; nineteen
in further education and one is undertaking an apprenticeship. Work tends to
revolve around a focus on the individual rather than broad-brush stroke
initiatives. Over the past four years there has been a great deal of work done to
engage with local colleges and sixth forms, and it is felt that these educational
institutions were now very positive about their relationship with and support for
young adult carers. They reported that, 'Those [colleges] that have students who
come from out of the area definitely feel they are less effective at engaging with
the young carers.'

The project now supports carers aged 16-25 and they run training for staff in
colleges, awareness sessions for students and they have a strong presence at
health and well-being fairs and fresher's fairs. The staff are also trying to run out
a similar service to the big employers in the local area, who may employ young
adult carers or allow work placements in the future. Individual approaches are
made on behalf of and in support of the young adult carers, to organisations and
employers, resulting in recently securing funding for college fees for one carer,
and for another, aged 19, to remain in education and to buy equipment and
resources. They have, at the young carers requests, recently created a 'Young
Adult Carers Council' to give carers the chance to meet with MPs and
professionals and to run campaigns on issues that affect them.

The main concerns were that they found that once lost from 'the system', the
young adult carers are very difficult to reengage. It was reported that the project
has had no new young adult carer approach them through any route other than
their own project. Funding is becoming tight and due to financial constraints, a
number of roles had now been rolled into one - back care, ICT, research and
employment for example. Relationships with GP surgeries was improving, but
the most difficult task currently, is in finding apprenticeships for young adult
carers; and the big employers seem to be reluctant to commit. However, as there
are so few young adult carers 'on the books' the aim is to give each of them the
highest quality service they can.

7.4 York Carers Centre

The York Carers Centre has provided a service for young adult carers aged
between 16 and 25 years old, since 2003, when a local study identified a need for
this service. The local authority provided funding for 6 hours per week and most
young adult carers had previously used the young carers support group before
the transition to 16+. The original aims of the project were to engage with and
offer support, information and advice to young adult carers; to ensure a smooth
transition from the young carers service into adult services; and to raise
awareness of the specific needs of young adult carers with other services
including GP practices and education providers including the local university.

73http://www.yorkcarerscentre.co.uk/content/young-adult-carers-18-25
Since 2003, the York Carers Centre has continued to receive local authority funding.

In 2011, the project is running events for young adult carers; their latest, and truly comprehensive bi-monthly newsletter shows that they are running: a pub quiz; a ‘hole in the wall’ competition; a sponsored walk in association with the York Wellness Coach - in which young adult carers raise money for a local cancer charity. They are running Christmas events such as parties and visits to night clubs, offering discount cards negotiated with local shops and are running a ‘launch night’ at a local brewery to advertise the discount cards! They are also running a film night and ten-pin bowling evenings, an evening at a local ice cream parlour, and they are organising bag packing in the local supermarket, to raise money. This impressive list of activities all takes place within a two-month period.

York Carers Centre also offers one to one support via electronic communications or by telephone, but largely they offer the opportunity for young carers to socialise with other young carers. In 2003 they only had 8 young adult carers on their books, with all bar two ‘graduating’ from the young carers group. By 2011 they had 36 fully engaged young adult carers. Originally, for many of the events they organised, the young adult carers did not want to turn up. They looked into this and found that as the young carers became older and had some spare time they tended to want to spend it in a life outside of caring, and at that stage, not to be associated with a caring role.

As a result of this research, in 2011 York Carers Centre is now also running one to one interviews following self-referral. Interestingly, again as a result of this research, in 2009, instead of providing a bespoke 18-25 young adult carers service, they have integrated as much as they can into their own employment and training service. This has had several benefits; they felt they could provide the best support for training and employment, and there was no longer an age barrier. They now work in education and training at any age from 16 upwards, and they reported that there was already in place a mechanism for natural progression past 18 and beyond, and indeed, right up to older ages. They have had considerable success with NEET’s in this way; who do not wish to engage with young adult carer services, but simply want help to find employment.

York Carers Centre now feels that they can provide a more personalised service, targeting an individual and matching that person to the employer at 16, 17 and beyond. Also, they say, funding is simplified: having already had funding for NEET service employment, they believe that as a result they are now providing a much better service. Relationships with adult services is said to be good, and they report having "fantastic young carer services" but their care workers have found that in young carers’ transition to adult services, there was "nothing to offer this group other than flower arranging and a bit of cake making - which served older groups better." York Carers Centre’s relationship with its local university is said to be "not too bad..." The university allows them to do presentations but to date there has not been one referral of a university student. Greater success has been reported with local colleges, especially the College of
Ripon and St John - a teacher training college - that now runs workshops for teachers on the subject of young adult carers. "One thing is for certain - many young adult carers simply do not wish to engage with us. They want a life outside of caring and do not wish to be involved in any of our services."

7.5 **Youth Action Wiltshire**

The young adult carers service within Youth Action Wiltshire began as a pilot in 2005. By 2007 they worked with 50 carers aged 16-25 years, with two part-time staff equivalent to a full-time member of staff. The key aims of this project are: to help young NEET carers to re-engage in the workplace; to raise their aspirations, and to ensure they are receiving the support to which they are entitled. The service will advocate with, or on behalf of the young adult carer, to reduce their caring roles and responsibilities if they request this. The support provided is tailored according to individual need, and starts with the identification of an individual support plan in order to agree the level and type of support and to identify individual personal goals. The service also provides a variety of courses and qualifications (e.g. ASDAN youth awards, NCFE qualifications, first aid, basic food hygiene) and the option of a residential weekend.

In 2011, the original aims of the project still stood, with a reported 'good cohort' of young adult carers on their books. The project helps young adult carers to gain qualifications, help them with benefits applications, and offers help with 'A' levels and degrees to students in the local university "as they cannot move far away." A care worker commented, "We give them help with signposting, and even driving lessons - with driving instructors on board to help!" There is also a new project that was trialled elsewhere in the county then rolled out recently across Wiltshire - called C4CK - Credits for Caring Kids - which runs for carers from 13 upwards, but includes older groups too. It is a volunteering project doing anything from environmental work, or first aid at work - basically 'sustainable learning' and Youth Action Wiltshire are finding that older carers now return to them with C4CK. For every hour they volunteer, they get a £2 credit that can quickly amass into £180 or so that goes towards driving lessons, or a computer or a nest egg for their education.

Carers find that they are both helping themselves and others, *and* effectively earning - but it is a 'credit' towards something else. For example, they can do a CBT (motorcycle basic training) to go with the 'Wheels to Work/Learn' moped leasing programme so that they can ride to work, or attend respite leisure activities such as paintballing. The project director reports, "This is VERY successful. We started with just one 17+ and then in 2009 had seven - after just a few months." In 2011 there were 23 participants on this scheme, with a range of qualifications being obtained including first aid and community sports leadership. Although much of Youth Action Wiltshire's funding comes from the county, most comes from donations. They report trying to get better respite care, but have found this very difficult to fund.

---

74 [http://www.youthactionwiltshire.org/services/young-carers/](http://www.youthactionwiltshire.org/services/young-carers/)
Recent initiatives to find carers in schools and colleges in Wiltshire has been "amazingly successful" starting with just 600 on the books in 2010, but now that they take young adult carers right through to 24, they have 1199 five to twenty-five year olds fully engaged. After realising that adult carer groups were not really engaging with the young adult carers, they reported that they "now offer any young adult carer aged 18+ a form of 'personalised support' with individual help when we can do it... but there is still not enough being done."

In 2010, the project mentored 49 young adult carers and provided personalised, one to one support in this way, with four sessions for each client. They also created a 'Personal Action Plan' for each of them. The relationship with colleges is now said to be "excellent" - although it has taken a great deal of hard work to accomplish. Swindon College now has a young adult carer 'line worker', and throughout Wiltshire, if students remain in the 6th form, there is now in place a great deal of help available for them. For example, Youth Action Wiltshire have negotiated with Clarendon College Trowbridge for a young carer to stay on and do a three year A level course - so that they get three A levels, but spread over three years instead of two years, as their caring takes up so much of their time.

Inevitably, there is uncertainty over the availability of funding in the future, so Youth Action Wiltshire have briefed and trained Family Link Workers (called 'PSAs') to look out for young adult carers, as they already have extensive links with families.

### 7.6 Islington Young Adult Carers Group75

Sitting within the Family Welfare Association Young Carers Service, the Islington project for young adult carers (aged 16-25) was established in 2006 with funding from the London Borough of Islington until 2010. The project had a part-time member of staff and no volunteers. It aimed to facilitate the transition of young adult carers into adulthood, to assist them in achieving independence and fulfill their expectations; to equip them with advocacy and leadership skills in order to enable them to have greater control of their lives; and to provide them with advice and information about all relevant services available in Islington. The group meets on a monthly basis for social activities and is user-led, using a number of 'empowerment methodologies.' The group is being widely promoted within the Borough and it has developed eligibility criteria and its own assessment tools.

Starting in 2006 with just two young adult carers, Islington Young Adult Carers Group now has 24 young adult carers on its books but the group is unaware of how many carers there are in the Borough. They provide 1-2-1 support with meetings held once a month held in the carer's centre and they have good relationships with adult carer groups; but they say this took over a year to build. The reason they use the carers centre is because they want to have a foot in each

---

75 [http://www.islington.gov.uk/Health/carers/young_carers.asp](http://www.islington.gov.uk/Health/carers/young_carers.asp)
camp - with young adult carers still helped by children's services, but also providing them with a natural transition route into adult services, whom they say have expertise on things like benefits applications etc. They reported, "It seems to work and there are several positives - adult services for example then get to know them at an early stage, whereas in the past they were not." They also hold a group meeting every month, and either stay in and order take away and discuss and plan issues, or some months they go out for a meal, go to the cinema or generally socialise. They also get speakers in to talk on issues that they themselves have raised - as they want. Islington’s young adult carers have stated that they would like to have residential visits with respite care paid for, although it was pointed out that these trips are expensive and they never have the money. In 2011 young adult carers made a DVD with 'Headliners' about being a carer - and many have been involved in other small projects.

Islington Young Adult Carers Group uses a variety of 'assessment tools.' These are not formal assessments, but the group has developed a set of tools that enable them to find out more about the general life of their carers. "It was imperative to get on side the adult carer services, as they are the only ones who have the expertise to deal with adult issues such as the benefits system." Young carers can also take part in all of the events for carers that are organised in the Borough: There are training courses on how to cope with being a carer, as well as events that celebrate caring. There is also a City and Guilds qualification for carers being promoted on their website, which Islington's young adult carers may be interesting in obtaining.

Originally they were funded through to 2010 by the Borough, but in April 2011 lost their funding for young adult carers, and with this uncertainty, they now only utilise the young carers budget and do this "very carefully." Their activities are, in any case, reported to be "not that expensive - some food etc., and the hire of a hall." Their work originates from a list of referrals: adult services publish a newsletter that includes the Islington Young Adult Carers’ activities and it is generally by this route that young adult carers become known to them. They "do not go out looking for them." Current services run right through from ages 16-25 and care workers say they are now able to identify young adult carers as they finish secondary school. They reported however, that their 18-25 funding is now stopping completely and any future provision must come from adult services alone.

7.7 The Hub Young Carers in Bedfordshire76

The Becker Report cites that, set up in 2007 with funding from Bedfordshire County Council and the Local Network Fund, Carers in Bedfordshire is a voluntary sector carer’s centre and a member of The Princess Royal Trust for Carers network. One element of its service, The Hub, is specifically for young adult carers aged 16-21. The key aims of The Hub are to provide support for young carers aged 16-21 throughout Bedfordshire with an emphasis on

76 http://www.carersinbeds.co.uk/page_2356275.html
addressing their emotional needs, supporting them with matters relating to employment and education, and providing them with advice and information about the transition from child to adult services. These aims are achieved through a number of interventions: individual sessions, telephone calls and text message support, a popular social night held every four weeks, outings and other events. The Hub promotes its work and receives referrals from other professionals throughout Bedfordshire including social services, Macmillan nurses, general practitioners and schools. Also, young carers, who already use a project provided by Spurgeons are introduced to ‘The Hub’ three months before their sixteenth birthday in order to prepare them for the transition. Additional funding has recently been secured from Luton Borough Council and East of England Development Agency in order to deliver this service in Luton and Dunstable.

The original project began in 2007 with just four young adult carers who 'graduated' from the young carers project. It is now an extremely successful project with over 80 fully engaged young adult carers from Bedfordshire and Bedford Central (two separate authorities). In 2007 the project was established just for 18-21 year olds but as a result of the findings of the Becker study, the age range had been extended to 24 yrs old, as recommended.

The Hub Young Carers Bedfordshire has had funding uncertainties of late, but continue to be funded by the local council and more recently, NHS Beds, and they have sought and obtained Big Lottery funding for their newer developments. Initially the original researcher was funded for one day per week, then after the obvious early successes, this was increased to three days per week after just three months.

The original research was done ‘from the ground up’; with the researcher meeting with Saul Becker and by following his methodology, identifying the problems and barriers that young adult carers face in Bedfordshire, and the transition through from young to young adult status at 18 plus.

The Hub Young Carers Bedfordshire continually strive to provide emotional and practical support; help with employment, education and training; information, advice and informal one to one sessions; and they help young adult carers develop coping strategies for dealing with difficulties. The Hub organises and runs social events, activities and fun group nights that are very well attended, and they communicate through a quarterly newsletter. Moreover they try to provide a more personalised service to young adult carers, by offering help in any areas that the carer thinks is important to them at that time; particularly in attempting to motivate to engage young adult carers to have a healthy lifestyle, be prepared for and engage in employment, education and training, and in making a successful transition to adult life.

A major success of the project has been the 'Hub Night' - a central point where members have fun, be active or just relax in a safe and friendly environment and

---

77 http://www.spurgeons.org
take some time out for themselves for a few hours. The Hub runs once a month in Kempton and Leighton Buzzard from 19:30 to 21:15. At the Hub they have a coffee bar and kitchen area, TV’s and music, Wii, PS3 and an IT suite. They also have pool, darts and air hockey; a sports hall for dodge ball, indoor cricket, football, badminton and volleyball; and beauty and relaxation therapy for their female members, with the services on hand of a qualified therapist. Unsurprisingly, the Hub Night is well attended.

In conjunction with the Hub Night, there are organised social events and activities; including go-karting, bowling, ice skating, tobogganing, spa days, watching England at Wembley, meals out and the occasional weekend away. The project organiser also now co-ordinates a number of CRB checked and well trained volunteers to assist with this amazing programme of activities.

Starting in 2011, for the first time they are piloting a social return on investment and have engaged a volunteer from the local university to do this for them. The aim of this is to evaluate the project thus far in order to give them more ammunition to apply for further funding.

7.8 Young Carers Support Project (Croydon)\textsuperscript{78}

In 2008, Becker reported that this project supports young carers from the early age of 7 right up to the age of 25. The young carers support project sits within ‘Off the Record’ (a youth counselling organisation with a drugs and alcohol project). The project has a number of funders (PCT, Connexions, and the local authority). The project has four members of staff (three full-time and one part-time) supporting young carers in the Borough of Croydon. The project provides: respite for young carers including activities and trips; study support and motivation for those who encounter difficulties at school; home school liaison and a learning support club; and support for young carers and their families.

In 2011, Young Carers Support Project (Croydon) remains predominantly a counselling service, with counselling provided for drugs abusers, Compass (asylum seekers and refugees aged 11-18), but also young and young adult carers from the age of 14 to 25 yrs old. They offer a range of personal development life coaching workshops to all ‘Off the Record’ clients - including young and young adult carers. Such workshops include self-esteem, anger management, panic attacks, stress management, sexual health and conflict resolution. However, these workshops are available through self-referral only.

The project also runs awareness raising workshops for professionals, including ‘Young Carers Awareness’. In their work, project workers offer to converse in French and Spanish languages for these speakers in their communities.

Once young carers are in the young carers project at an age younger than 18 they are permitted to remain in the project until they are 25 yrs old, but they do not

\textsuperscript{78}http://www.offtherecordcroydon.org
admit young adult carers over the age of 18 who have not been in the young carers project. “This may be for historical reasons, or funding perhaps?” The project recently lost in the region of £80,000 funding in one area and another £15,000 funding in their Carer Support grant. As a result, they are no longer able to provide life coaching and they are looking to move from the 14-25 age range down to a 13-19 service only.

In 2011 Young Carers Support Project (Croydon) had on their books over 100 young adult carers in the 18-25 yrs old age range. There is some anxiety over what other impacts this loss of funding will have on this group. Current funding is through Croydon Council, and there is a Connexions Worker funded through IYSS - Integrated Youth Support Services.

7.9 **Worcestershire Young Carers Transition Service**

The Worcestershire Young Carers Transition Service came about through recognition by independent youth charity YSS and Worcestershire County Council that young adults were often not making the transition to adult services after they had outgrown the young carers service, which works with young carers up until their 19th birthday. A strategic review conducted in 2008 into carers’ services in the local area identified that the county had 2,000 carers aged 16-24 years-old, 400 of whom were providing 20 hours or more of caring every week. It was therefore considered essential to focus specific attention on this particularly vulnerable group.

A group of young adult carers met with YSS to discuss their experiences since leaving the young carers service and through doing so, highlighted why there was need for an additional service for their age group. The young adults explained that they did not relate to the groups provided by adult services. They did not see any common ground with the other adult carers and felt their lives, responsibilities and issues were totally different. Adult carer support services were felt to be "only appropriate for older carers, usually of retirement age, who were dealing with partners with dementia or severe arthritis." The young adult carers were mostly looking after disabled parents, and by contrast were trying to find ways to begin their adult lives. The outcomes of this research underlined the importance of implementing a service that would recognise young adult carers as a distinct group, and one in need of a service that met their individual needs.

NHS Worcestershire funds the service in partnership with Worcestershire’s Adult Social Care and Children’s Services. Funding is for 18 months in the first term and is being assessed again in October 2011 to see if it is meeting the goals of creating positive outcomes for young adult carers. There are currently 19 young adult carers aged between 16 and 19 who are eligible to access the existing transitions service. Services provided include: signposting; assisting and accompanying for appointments; meetings and interviews; support in education

---

79 http://youngpeopleinfocus.fastnet.co.uk/madetomeasure/casestudies/young-carers-transition-service
80 http://www.yss.org.uk
and training; supporting 'general living'; and in providing a personal support
network. They have recently researched and set up a service that now fully
accommodates young adult carers right through to 25 yrs old.

7.10 The Dundee Young Carers UPBEET Project81

The Dundee Young Carers Project is based in Scotland and has been successfully
working with young people since 1999. Their remit is to find hidden young
carers and raise awareness of young carers issues. The main funding bodies of
the project are The Dundee Partnership and the Henry Smith Charity. They say
that they have found that many young carers do not want to be identified as
young carers, due to particular family situations; many young carers do not want
to be singled out as 'different'.

The project considers a young carer to be up to the age of 21, and says that they
have found that many of these young (adult) carers are often excluded from
normal childhood support networks. In September 2011, with an award of over
£640,000 funding, the Dundee Carers Centre UPBEET project is one of three
Tayside projects sharing £2.3million from the Big Lottery Fund. One young adult
carer said UPBEET, "Has helped me with applying to college, and finding a place
of my own."

The Dundee UPBEET project can help carers aged 16-21 years access
confidential information and support in areas including person development,
entitlement to benefits, c.v and interview skills, as well as accessing flexible
opportunities to combine education, training, or employment with their caring
role.

7.11 The Edinburgh Young Carers Project82

Edinburgh Young Carers Project works with young people aged 5 to 25 years old
who care for or are affected by someone else at home - usually a parent or
sibling. It was established in 1994 as a community development project in North
East Edinburgh and with support from the local authority and National Lottery
Charities Board expanded in 1996 to provide support to young carers from
across Edinburgh. It became incorporated as a not for profit company limited by
guarantee in 2000. It is managed by a voluntary Board of Directors and employs
a Head of Service, eight members of staff and sessional workers. Edinburgh
Young Carers Project is one of the best established and largest organisations in
Scotland dedicated to working with and supporting young carers.

Their mission is, "To improve the lives of young carers through support,
information, training, working in partnership with other agencies and promoting
social inclusion." They provide services such as: Person-centred emotional and

81 http://www.youngcarers.co.uk/
82 http://www.youngcarers.org.uk/
practical support for young carers in groups and one-to-one; Information and links to services for the families of young carers and/or to the person being cared for. They provide opportunities for young carers to get away from their caring situation and have fun; support to facilitate social inclusion; they raise awareness of young carers and their needs; provide training to agencies and professionals; develop partnerships to address the needs of young carers aged 5-25, and support research and provide data. They also promote the rights and needs of young carers and support young carers and young adult carers to participate and express their own views.

7.12 The Oxford Hub: Magdalen College Young Carers Project

This project aims to help young carers both within and outside of their university community. From its base in the 'Hub' around 500 students give back to organisations within Oxford. One such project is the young carers project 'MCYCP'. Young and Young adult carers from within and outside the college are invited to events that are held in the unique atmosphere of the Magdalen college, where they engage with weekly sessions that include fundraising, games craftwork, cooking and X-box etc.

7.13 The Suffolk Strategy for Supporting Young Adult Carers

The 2010-2013 multi agency strategy for Suffolk is the first such strategy in the county specifically aimed at Young and Young Adult Carers aged 5 to 24. It sets out to improve the outcomes of young and young adult carers aged 5 to 24 years old, and their families. In keeping with Becker's recommendations, Suffolk specify in the scope of their strategy that reference to 'Young Carers' and 'Young Adult Carers' should be the same - and encompasses all young carers from ages 5 to 24. The strategy builds on the innovative approach taken in 1994 to support young carers by the young carers team at Suffolk Family Carers. The desired outcomes of the strategy have been informed by the government's 'Every Child Matters' strategy together with 'Our Health, Our Care, Our Say', national research and local consultation.

Suffolk's vision is that by 2013 they will have identified all young and young adult carers in Suffolk, or those who may become young carers, and that they are empowered to make real choices about their lives and how much care they provide; young and young adult carers will feel that 'the system is on their side' and feel confident about themselves; that young and young adult carers feel they have a life of their own; that the needs of young adult carers aged 16 - 24 will be better understood, and support and services will be in place to ensure they have

---

83 http://www.oxfordhub.org/node/5738
84 http://www.suffolk-carers.org.uk/
87 Department of Health, 2006
real choices. The main principle is that no young or young adult carer in Suffolk should be disadvantaged because of taking on caring responsibilities for another member of the family. The report notes that significant progress has already been made at the time of publication (2010), notably; the appointment of a 'Young Adult Carers Champion' and the appointment, by Suffolk Family Carers of a new post of 'Transitions Project Manager'.

The report notes that since it was commissioned, Becker's (2008) research and the initial findings of the Suffolk Young Adult Carers Transitions Support Service highlighted the needs of young adult carers aged 16-24 and underlined the importance of supporting young carers aged 16-18 right through into adulthood. The report further notes that they found that young adult carers tend to perceive 'normal' adult services as being only relevant to 'older people'. There are 1603 young carers aged 5-17 and 1820 young adult carers aged 18-24 in Suffolk. However, this is believed to be a 'significant underestimate' of the true numbers. Work with 126 pupils at an average sized Suffolk secondary school revealed 26 additional young carers, and a recent study in Central Ipswich alone has already revealed 112 'hidden' young adult carers aged between 16 and 24. Very few data are currently collected on young and young adult carers in Suffolk.

The report further points out that the negative effects of caring are magnified and compounded by wider social disadvantage or exclusion such as unemployment, poverty, poor housing, rural isolation, or ill health amongst other family members. Evidence from the 2001 census (and indeed my own research) shows that the prevalence of young carers may be higher in areas of deprivation, and this has been confirmed in the recent study by OFSTED.

In 2009, Suffolk Young Carers undertook local consultation with 24 young carers to find out their priorities. Among others, there included 'specialist support to help make decisions about continuing to care, and exit strategies' and 'support and services... that are appropriate with their age.' Most wanted careers advice right up to the age of 24 years - and services 'sensitive to the implications of caring but not reinforcing caring as the only career option.' Other requests were for flexible training opportunities, c.v. construction advice, interview skills courses and more importantly, carer friendly employment practices and support in the workplace when they find it.

Suffolk's bold multi agency delivery plan focuses on key sections with overarching outcomes. Firstly workforce development; that all staff working with families across all organisations in Suffolk have a knowledge and understanding of young carers 5-24, and that young carers are 'everyone's business' - that they are recognised, acknowledged and supported throughout Suffolk. There have been a number of recent changes at senior level since the original report was published, which has resulted in a state of young adult carer provision uncertainty, however, their website (October 2011) shows that Suffolk

---

88 Part of Suffolk Family Carers
89 OPCS: 2001
90 Suffolk Family Carers database, 2009
91 Supporting Young Carers. OFSTED, June 2009
Family Carers are now trialing a 'Transitions Pilot Project' for young adult carers, with fortnightly activities and support groups, in Ipswich.

7.14 UK Service Responses to the Transition Needs of Carers aged 16-24: Conclusion

Around the UK, service providers, organisations and institutions are beginning to wake up to the fact that young adult carers are not receiving the support they need and are entitled to. As a result of the Becker report, more research is being conducted into local needs and more services are being provided for young adult carers. Notable new projects include:

Powys Carers Service92 is a new initiative to carers aged 16-25 who are 'recognised as a different social group'. They provide one to one support through an outreach worker, advocacy and weekly meetings in both north and south Powys.

Solihull Carers Centre93 say, "In the transition from children to adult services many carers can be lost at this confusing time, when there are changes all around." Solihull now provides a service to young adult carers between the ages of 18 to 30, providing one to one, peer support, education training and employment, advocacy, social activities, signposting and support. They also run a weekly 'Drop In' session at the local You+ Shop.

Lewisham Carers Centre94 has in 2009 conducted award-winning research into young adult carers in Lewisham. They found that like young adult carers across the country, "none of this group of 16-24 year old carers is aware of any of the services available to them besides Carers Lewisham." Half of their young adult carer sample were not receiving any support and felt isolated. Lewisham are now using the research to bid for funding.

Young Adult Carers, Merton95 has conducted its own research in this field, young adult carers aged 16-24 in the London Borough of Merton now run their own project in which they provide education, training and employment advice, benefits maximisation, emotional support, advocacy and counselling.

Hereford Young Adult Carers96 run a 'Hereford YAC' project for carers aged 16-25, and offers signposting, college support, training and employment assistance. It also organises social group meetings.

North Durham97 is running a new pilot scheme has begun in 2011 in North Durham by the Barnardos charity. They say, "Young carers are being looked after

---

92 http://powyscarers.org.uk/
93 http://www.solihullcarers.org/
94 http://www.merton.gov.uk/local-centre/lewisham
95 http://www.merton_young_carers_june_06.pdf
96 http://www.herefordshirecarerssupport.org/hyac/index.htm
97 http://www.barnardos.org.uk/what_we_do/our_projects/young_carers.htm
relatively well by children’s services, schools and other organisations. But by the
time these young people reach adulthood, they start to slip under the radar. The
children's services stop and the young people don't get picked up and transfer
into adult services.” In 2011, North Durham's immediate aim is to alert support
services to the fact that their young people exist.

Scarborough and Rydale Carers Resource\(^98\) consider a young adult carer to be in
the age group 18 to 35 yrs old. They have been running a new project for this
group for the past six months and say that they are raising the profile of young
adult carers in the community. They now run events and hold drop in sessions at
Yorkshire Coast College and Hull University and attended the People's Carnival
to raise awareness. They have secured Big Lottery funding for this project.

Renfrewshire Young Adult Carers\(^99\) has a new (2011) online service has begun
for young adult carers aged between 18 and 25 yrs old. This is a weekly service
with an online chat room. They also run an information shop and give advice on
housing, finances, higher education and careers.

Torbay Young Adult Carers\(^100\) is currently supporting more than 60 young adult
carers through the NHS. Their own research suggests that there are “hundreds of
young adult carers aged 16-25 yrs old in Torbay.” They are running a campaign
to encourage more young adult carers to come forward to receive support.
Having good relations with local education institutions, they now give advice on
a variety of supportive courses at South Devon College and offer as much
additional learning support as the young carer needs.

Telford's 16+ Young and Young Adult Carers\(^101\) supports carers 'in transition'
between the ages of 16 and 25 receive support in encouraging independence and
self determination, education and social recreation activities, and they are
provided with an 'age appropriate forum for self help, respite and emotional
support. They are also given information about all the key services that are
available to them in Telford.

Cardiff and The Vale's\(^102\) Lottery funded Crossroads "Give us a Break" project
works with young and young adult carers from 7 to 25 yrs old, with an emphasis
on the needs of young adult carers aged 18-25 yrs old. They say that from their
own research they have found that, "When young adult carers reach 18 and
adulthood, they may face additional difficulties in trying to juggle education,
training or employment with their home life and their caring role while
becoming more independent. Young adult carers face a disadvantage that they
aim to address."

The Cardiff project now provides help in education, employment and training.
They also run workshops and activities, provide respite care, one to one support,
courses and signposting. A comprehensive range of courses delivered includes relaxation techniques; dealing with tiredness; exercise and healthy eating; coping with depression; communicating with family, friends and professionals; and planning for the future.

The above list indicates what works and what is being accomplished around the country. Significant, personalised and targeted support is being provided to young adult carers from Darlington\(^1\) to Devon,\(^2\) from Truro\(^3\) to Dundee\(^4\)-in whatever part of the country you look; in Northampton, Bath, Essex, and Birmingham\(^5\) young adult carers are supported. A young adult carer project even forms part of the Coventry Chief Executive’s 2011 job description, "As part of a consortium Carers Support Service will be leading the Caring to Succeed Project; a 3-year National Lottery funded project commencing early in 2012. This project will enable us to offer further support to young carers and young adult carers (aged 18-25) across Warwickshire." More poignantly, in the South West, the South West Carers October 2011 website\(^6\) and facebook\(^7\) page says, "We are the lost ones - 'too old' to be a young carer, but 'too young' to fit in with adult carer groups."

According to the 2011 Joint Strategic Needs Assessment\(^8\) "Surrey has a national reputation as having some of the best and most innovative carer led services in the country" (JSNA 2011). Yet Surrey has no personalised, targeted support in place specifically for young adult carers aged 18-24 yrs old. In this research, not one interviewee reported satisfactorily engaging with any adult services. Interviewees expressed concerns and anxiety over their lack of knowledge as to what was available to them, how to go about getting help and where to go for it.

Without personalised support for them, within the next two years nearly 150 young adult carers will also have fallen off the radar and swell the ranks of Twigg’s and Becker’s 'Hidden Armies'. The evidence as to 'what works' and 'what good looks like' from national research is plain to see - and overwhelming. Around the UK organisations and support services are beginning to galvanise into action and the profile of young adult carers is being raised nationwide to prevent this vulnerable social group continuing to be disadvantaged.

\(^{1}\) http://www.darlington.gov.uk/Health/Childrens+Services/Disabled+Children/Pathways+to+Support.htm
\(^{4}\) http://www.youngcarers.co.uk/
\(^{5}\) http://northamptonshireyoungcarers.org/carers_1825.htm
\(^{6}\) http://www.bathnes.gov.uk/healthandsocial/carers/pages/AdultCarers.aspx
\(^{7}\) http://www.affc.org.uk/young
carers/10001609108662
\(^{8}\) http://www.youngcarers.co.uk/carers/young-adult-carers.html
\(^{9}\) http://ciscaf.ceredigion.gov.uk/page.aspx?pid=201&lang=eng
\(^{10}\) http://www.thecarersnetwork.org.uk/young-carers/support-groups-for-young-carers/axis-young-adult-carers-project
\(^{11}\) http://uk.linkedin.com/jobs/jobs-Chief-Executive-2019026
\(^{12}\) http://www.swyoungadultcarers.co.uk/
\(^{13}\) http://en-gb.facebook.com/people/Southwest-Young-Adult-Carers/100001609108662
\(^{14}\) JSNA Joint Strategic Needs Assessment Carers, 2011-2012: Surrey
8.0  **Surrey's Young and Young Adult Carers in Context**

Until now, little has been known about young adult carers aged 16-24 in the county of Surrey. At present, a range of children services provides for young carers to the age of 18, and at the age of 18, young adult carers move to adult services for support.

8.1  **Young Carers in Surrey aged 16-17**

Census 2001\(^\text{116}\) data shows that there are 631 young carers aged 16-17 in the County of Surrey, with 68 of these (11%) caring for more than 20 hours each week and another 38 (6%) caring for more than 50 hours per week. The latter is slightly lower than the UK average of 7% (Becker, 2008:p1).

Becker found that carers in this age group were constrained in their relationships as they got older. Schools had failed to identify their caring responsibilities and had even 'punished them' for caring. Carers had received poor career advice and they knew very little about local services for adult carers. Young carers were also anxious that their support would cease when they became 18 years old (Becker, 2008:p1). This research shows that young carers in Surrey face similar issues, fears and concerns, barriers to accessing provision of services and a lack of signposting at 16-18 for the transition years. One Surrey young carer said,

"*My school has given me no careers advice whatsoever, and none as a carer - yet I told my school that I am a carer but they thought that this was not important.*"
(Surrey young carer, aged 16)

All of the participants in the study reported feeling anxious about this lack of careers advice, and a lack of support at school in general.

"*I would like to get more help for an apprenticeship - for example the Olympics are coming up - surely they are a big employer - there's no help at school - nothing.*"
(Surrey young carer, aged 17)

Another reported,

"*At school, there's no advice for carers, there's no group - and there has to be more than me. Sometimes I wish I did not feel alone in my school.*"
(Surrey young carer, aged 17)

Carers who are institutionally 'allowed' to become hidden, face a greater uphill task to return to education, employment and training. The 2010 OFSTED report\textsuperscript{117} into reducing the numbers of young people not in education, employment or training noted, "The most successful providers recognised that young people who had dropped out of education and training often needed help to resolve personal and social problems before they could return."

In Surrey, more than 50\% of participants on the study reported that they had received careers advice at school, or through Connexions, but that this was said to be mostly general advice "given to all students in class tutorials and the like" and no-one reported having any careers advice specifically for them in their caring roles. This research has found that there is little doubt that young carers aged 16-17 think and plan carefully for their futures, often with the thought in mind that their siblings may be required to take over their roles if they wish to pursue further education. As one young adult carer said,

"I need someone to help find out about funding when I leave school and [sibling] is beginning to take over - and I want to go to university. Is there any [funding]? I have been doing all I can and I need reassurance that I can back up what I can't do myself."

(Surrey young adult carer, aged 18)

In November 2011, there are 1.16 million NEETs aged 16-24 in the UK,\textsuperscript{118} representing over 15.6\% of all people in that age group.\textsuperscript{119}

8.2 Young Adult Carers in Surrey aged 18-24

Census 2001 data\textsuperscript{120} shows that there are 2403 young adult carers aged 18-24 in the County of Surrey and this is 3.4\% of all people in that age group. Nearly 20\% (465 people) are providing care for more than 20 hours per week and 221 of these (9.2\% of the total) are providing care for more than 50 hours per week. Again this is slightly lower than the UK average of 12\% (Becker, 2008:p2).

For this age range, Becker found that this group were more heavily involved in caring than their younger counterparts and that this restricted their participation in other life events, activities and socialising. He revealed that many young adult carers reported strained relationships, increasing physical and mental demands and an increase in 'intimate care' requirements. Most 18-24 year olds found colleges to be more supportive than schools, however, many had left prematurely without gaining qualifications. Becker said, "It was rare for any young adults to identify that their careers adviser had asked them about whether

\begin{itemize}
  \item 117 OFSTED (2010) Reducing the numbers of young people not in education, employment or training: what works and why. Ref 090236, OFSTED, 17 Mar 2010
  \item 118 http://www.bbc.co.uk/news/mobile/education-15870240
  \item 119 http://www.guardian.co.uk/education/2011/feb/24/young-people-neets-record-high
  \item 120 OPCS 2001 Census, updated for population growth. OPCS 2008.
\end{itemize}
they had caring responsibilities and if so, the impact and implications for studying or careers" (Becker, 2008:p2).

Of the young adult carers participant in Becker’s study and at university, none were aware of any specific carers support available for them at university. In tandem with Becker’s study, none of the Surrey survey young adult carers were aware of what help may be available to support their relatives, how to access it and who supplies it. This is despite momentum at the highest level to get institutions to 'wake up' to the challenges.

In research in Surrey, questions raised by young adult carers at forums designed to 'give carers a voice', has found anxiety and a lack of awareness both from university students and those carers wishing to go to university. This research has found that neither Surrey University, nor its Student Union currently identifies young adult carers in its educational institution. Their representative reported, "We have seen very few issues associated with student carers in the past and as there are other groups whose needs are more visibly pressing within the University community, we have not previously directed our resources towards having a single person who specifically looks after young carers."

The Learning and Skills Council 2009 report entitled, "Including Carers: Towards a Framework for Meeting the Needs of Carers in Further Education and Adult Learning" set out to investigate and make recommendations on how mainstream educational provision could be made more accessible to carers. They said, "A carer’s capacity to attend regularly, complete assignments and sit exams is not dependent on their own commitment and self-discipline but on the health of someone else, and the needs of the person they care for which can change suddenly and dramatically." The report continues, "To enable carers to access and succeed in education, educational providers need to understand the impact of unpredictability and to adapt their policies and practices to offer carer-students tailored flexibility and supportive learning arrangements, at the key points where these are needed."

The report noted that there was potential for joint working with educational providers at a strategic level to improve liaison with educational providers to develop appropriate models of support for carers as learners. There are clearly barriers in further education as, the report notes, "There is no systemic approach to capturing data on the number of carers in the student population." It continues, "At the moment, the onus is on the student to make the college aware of his or her caring role and to ask for flexible arrangements. This is an unrealistic expectation of learners who may lack confidence or fear of being stigmatised. The lack of any specific policy to support carers works against disclosure and prevents the collection of accurate knowledge about who they are" (NIACE, LSC, 2009:p25).

121 Correspondence: Surrey University Representative, 12th April 2011
At an interview with the Prime Minister, David Cameron, a Shropshire young adult carer, Sarah Thomas spoke of how she feared she could not go to university because she did not know how her parents would cope at home. Mr Cameron urged Sarah to "involve the local council and get support in place, to allow her to go to university." This view was echoed by shadow education secretary Andy Burnham, who said, "It is absolutely crucial that young carers are identified and supported."

The 2009 Ofsted report, 'Supporting Young Carers' stated that there existed, "a lack of joint and inter-agency training across partnerships, including social care, health, education and the voluntary sector." In Marsden's (1995) study on the impacts of caring on education for young carers in the London Borough of Enfield, he found that of 38 young carers, 15 were thought to be definitely restricted in their educational progress as a result of caring and 20 were considered to possibly be restricted. In only three cases did respondents say that their educational progress was unaffected. The 2010 Princess Royal Trust resource for schools and universities, 'Supporting Young Carers' cites one anonymous young adult carer,

"My dream is to go to university and it has always been in my head that I wouldn't go to university too close [to home] because it was my way of gaining independence. However, I am not sure I can go because it means leaving home and there isn't the support there for everyone else if I go."

The report continued, "Young carers may need more intense support when moving on from school into further education or the workplace or with living on their own and establishing relationships. A young carer moving away from home, perhaps to college or university, should trigger a review of the care needed for the person who needs care." "Further Education colleges should be aware of young carers' issues and have policies and practices in place to support them so that young carers are not disadvantaged and are enabled to have equal opportunities to attend courses if they wish. Flexibility and/or support with coursework demands may be needed at times for some young carers."

The report further noted that at the time of writing (2010) The Princess Royal Trust for Carers and The Children's Society were unaware of any UK university with support in place for young adult carers. The 2009 Learning and Skills Council (LSC) report concluded, "In the experience of carers centres and the

123 http://news.bbc.co.uk/go/pr/fr/-/local/shropshire/hi/people_and_places/newsid_9192000/9192515.stm
125 Marsden, R (1995) Young Carers and Education. London Borough of Enfield, Education Department
National Extension College (NEC, 2009)\textsuperscript{128} carers who lack confidence or learning skills can and do access educational opportunities if these are tailored to their needs, and a proportion then progress to mainstream accredited courses. Colleges have the capacity for targeted publicity, outreach, advice and guidance, taster courses and mentoring, and these activities could be directed at carers, but are not at the moment."

It is therefore a recommendation of this report that agencies that would not traditionally be associated with meeting the needs of carers be encouraged to identify and engage with young adult carers. For example, colleges, universities, Job Centre Plus, employers, leisure services providers and others need to be sensitive to the needs, issues and barriers confronting this group of carers and which affect their opportunities for further education, learning, leisure, careers and paid work. As Levine et al (2005)\textsuperscript{129} noted, "Concerted efforts are essential to ensure that young adults who become caregivers are not deterred from pursuing educational and career goals."

Becker reported that half his survey sample had insufficient time to look for or take on paid work, and that most young adult carers aged 18-24 experienced significant financial hardships as a consequence of caring (Becker, 2008:p3). Many found it too difficult to combine paid work with the conflicting demands of caring. One quarter of his sample was not in education, employment or training (Becker, 2008:p3). Many young adult carers had low esteem and poor confidence, felt alone and were unsure of how to make progress in accessing the labour market. Many felt they had no transport and could not search for work, and simply felt that combining work with caring was not feasible. Becker found that unlike other young people, the future aspirations of carers aged 18-24 were not dominated by money and qualifications, but by their caring responsibilities.

As with young adult carers in this Surrey research, all of the young adult carers could have been accessing support from adult carer services provided by the voluntary or statutory sectors, but as Becker found, "very few had ever used an adult carers service, and not to any great degree." He continued, "Many young adult carer services are now aware of 'gaps' in service provision and are questioning to what extent they have a responsibility for filling that gap. Carers centres working with (older) adult carers identified a range of factors (or barriers) that made it either unfeasible or more challenging to engage with young adult carers aged 18-24" (Becker, 2008:p3).

Of the 13 young adult carer interviewees in this study in Surrey, eleven had had no contact with adult services, and two reported having made attempts to make contact with adult services but in one case, despite making several attempts to contact them, they received no response. Thus in parallel with the Becker study, young adult carers in Surrey can be seen to be not engaging with adult carer services to any great degree; and Surrey’s young adult carers face comparable


issues, fears, concerns and barriers to accessing provision. However, the high figure of ‘hidden carers’ should, as Becker puts it, "be a 'wake-up call' to governments and carers organisations" (BBC, 16 Nov 2010).

9.0 The Positives of Caring

Throughout this research there has been much evidence gathered on the positives of caring. Such positives include independence and organizational abilities, a feeling of self worth, closeness to family members and the acquisition of new, marketable skills. More than 90% of the Surrey survey felt they were doing good, enjoyed helping and were closer to their family member as a result of caring, and over four fifths of Surrey’s young carer respondents felt they were gaining new skills through their caring role. Indeed, as one Surrey young adult carer put it,

"I really do enjoy caring; I feel good about what I do - I love it because my sister then knows she is loved and that we are with her all the way through her disabilities. Caring has allowed me to learn about how other people with the same illnesses cope."
(Surrey young adult carer, aged 19)

A sixteen year old carer who had been caring for their grand parent for over eight years, stated,

"I wash the clothes, Hoover the rooms and tidy up, I weed the garden and sometimes even decorate the rooms. Then I am happy when my Nan realises what I am doing and appreciates it. Caring for her has made me an independent person as I'm used to having to deal with all these things."
(Surrey young carer, aged 16)

Becker reflected that more than a quarter of young carers in his study stated that caring had accelerated their maturity and had given them the chance to develop new skills for coping in crisis or complex situations (Becker, 2008:p36).

10.0 The Overall Experience for Young Adult Carers aged 18-24 in Surrey

Evidence in this research shows that adult carer services are not satisfactorily engaging with, nor providing for the needs for young adult carers aged 18-24 in Surrey. Although provisions are made in essence, the outcomes for this 18-24 year old cohort are currently, poor.

---

Professor Becker’s main recommendations in terms of service developments were that:

1. The key factor to be considered by adult carer services in the development of services and interventions for young adult carers should be concerned with outcomes rather than types of services and models. The development of outcome-focused services and models of intervention will require adult carer’s services to consult young carer’s services and other specialist and universal providers, and critically, to involve young adult carers themselves, about the desired outcomes and how best to proceed to develop services and interventions for this group.

2. Adult carer’s services need to address the barriers that are inhibiting young adult carers from using their service and their own lack of relevance to this group as perceived by young adult carers themselves.

3. Different models of service delivery should be tried and tested more widely to see which work best in delivering stated outcomes.

4. Systems will need to be developed and put in place to monitor and evaluate performance and outcomes, using robust measures, instruments and tools that enable comparison between interventions/services over time and place.

5. All agencies, but especially local authority services and adult carer’s services, should provide young adult carers with information about their legal rights, including the right to a carer’s assessment from the local authority, which is a potential gateway to other services and support for the young adult carer and could trigger an assessment and support for the person they care for.

It is a recommendation of this report that consideration be given to lobbying organisations, stakeholders and service providers to provide better support for young adult carers in Surrey aged between 18 and 24. It is recommended that initiatives should be undertaken to build bridges with and to encourage the engagement of all interested parties and service providers in seeking to improve the outcomes of young adult carers in Surrey.

At the ages of 16, 17 and up to the age of 18 yrs of age, there is ample evidence to suggest that young carers within Surrey - from right across the county - are engaging with and feeling supported by children's services. Of the 631 sixteen and seventeen year old carers that are believed to exist in the county, nearly 20% are currently fully engaged with Action for Carers (Surrey)\textsuperscript{131} and Surrey Young Carers and Mid Surrey Project for Young Carers. Together with other groups and organisations these organisations have been instrumental in successfully engaging with and supporting young carers aged 16-18 (and younger, but not within the remit of this research) through a range of

\textsuperscript{131} AC(S) SYC / MS Project Data March 27th 2011, to coincide with the UK Census date
interventions, assessments, signposting, activities, forums and workshops. As one Surrey young carer said,

"To be honest, I don’t know where to start! I have help and support for me to go to college; to go to football, I’ve had advice on all sorts of things; I’ve always had someone to talk to, and someone’s always been there who understands… and LOTS, LOTS more!"

(Surrey young carer, aged 17)

Another young carer, from the Mid Surrey Project reported,

"I’ve had emotional support - there’s always somebody there if I call and need to talk because things are bad at home; they’ve [the project] taken me out on day trips, taken me out for meals and made sure that there’s someone at home to mind things for me. They’ve helped me make new friends, understand about my caring role and have given me support in every way possible."

(Surrey young carer, aged 16)

These two anecdotes are by no means isolated examples. However, at forums carried out during this research, it was felt by all 16 and 17 year old young carers participating, that they would like to be made more aware of what they can expect in their lives as they move towards adulthood and it is a recommendation of this report that more is done through the introduction of an exit strategy to accommodate the needs of young carers as they reach the transition stage of their project and to signpost their move into adult life.

At the age of 18 or 19yrs old, however, in Surrey, circumstances change dramatically. Young adult carers are currently institutionally and administratively 'archived' into oblivion and thereby 'lost in transition' at a stage where they should be receiving signposting and support to assist them to engage with a range of adult services for what Becker calls the next 'phase of their lives.' Several such individuals currently 'lost in transition' and who are not in any way engaging with adult services have been contacted. Some of these do not have the confidence to engage with adult groups and others remain as informal 'hangers on' to existing children services in the hope that, as one 22 year old carer put it, "something might come from it."

National research indicates that we should not be delivering our young adult carers straight into the hands of adult services unless they are going to be thoroughly supported and engaged. The Lincolnshire Action for Carers Plus Project - which was initially mentioned as a success story in the Becker report (Becker, 2008:p72) - revealed that like Surrey, they initially knew of just 20-30 young adult carers, but reported that they now have 115 well engaged, well supported carers in the 18-24 yrs old age group. The Project Director said, "If you let them go at 18, you will never find them again; young adult carers are very difficult to engage once they have left the services of Young Carers."
11.0 Res Ipsa Loquitur: The Facts Speak for Themselves

Surrey’s figures speak for themselves. If the current situation is allowed to continue, then within two years of this report in the region of 150 young adult carers will have moved into the ‘transition’ phase of their lives, be no longer contactable, no longer engaging with any support service and they will remain hidden from view. This is clearly one of Surrey’s challenges to face.

It is therefore paramount that all support services - including Action for Carers (Surrey) - do not lose touch with young carers as they move into the adult world. This can be achieved through institutional, administrative and infrastructural changes, including better data collection interfaces, data storage and information retrieval. Better use must also be made of improved signposting to adult services and there must be an exit strategy for all young carers.

Institutions, including Action for Carers (Surrey) should also regularly evaluate their actions, developments and interventions to see ‘what works’ and regularly ask the question "it would be even better if?" Support services should also be encouraged to concentrate on, as Becker suggests, "outcomes, rather than provision" for this 18-24 yr old group of carers. For example, a representative of an adult support group reported, "We provide a trip to a flower show to which 18-24’s are invited", but none come. Or, as another reported, "I run a men’s group in a local pub, but no 18-24’s turn up." This may be, as Becker puts it, "concentrating on the provision" of some service possibly irrelevant to this age group, and "with a resultant poor outcome" for young adult carers in Surrey.

The Government’s 2010 report, "Recognised, Valued and Supported: Next steps for the Carers Strategy"\(^{132}\) points out that, "Carers embody the spirit of the Big Society. Supporting carers’ well-being is therefore in all our interests." It continues, "Our Big Society reforms will see public services opened to challenge, and local commissioners and care providers held to account.”

Point 1.3 (p.8) of the report stresses that, "Many young carers remain hidden from health, social care and education services - partly as a result of those services needing to do more to identify them. The consequences are that many young carers are not offered or do not seek early access to information and advice.. to help them care effectively and safely. They may also find it hard to know how to access information and advice.. decisions about education and employment, support from the welfare and benefits system, and their own health and well being may well be overlooked."

In point 1.5 (p.9) this report notes, "Access to relevant and timely information and advice is vital, particularly at times of significant change, for example, to help carers negotiate the transition from children’s services to adult health and social care services."

The Government report concludes with the 'next step'; that Revised guidance on undertaking Joint Strategic Needs Assessments will be published during 2011/12, recognising the importance of identifying the needs of carers in the local population. The Joint Strategic Needs Assessment (JSNA) Carers for Surrey reports that carer led services now support over 10,000 people a year through a range of services including:

1. Information, advice, and advocacy for carers provided to 9300 adult carers.
2. Flexible home based breaks for carers provided to 5500 carers a year.
3. Young carers services supporting about 1200 young carers a year.
4. Back Care services for carers supporting 770 carers a year.
5. GP Carers Recognition service (with support from Surrey NHS).
7. A Carer's training programme promoting health and well being.
8. Core funding for Action for Carers (Surrey) to help give carers a voice.

However, within Surrey there is a need to address not just carers per se, but to examine the identification of, needs, provision and outcomes for specific ages of carers within the overall carer community, and most particularly those young adult carers within the 18-24 yr old age group. This report recommends that action be taken to encourage the JSNA to delve one data layer deeper than it currently does. It currently examines the numbers of carers by district, the number of hours of care provided and those is receipt of carer's allowance. However, it currently fails in that it does not examine the role, provision and level of need of a more detailed specific strata of the population; the 18-24 young adult carer cohort.

The JSNA reports that at present there are about 10,000 adult carers in Surrey; "Surrey County Council funds services to over 10,000 carers a year via the Joint Carers Commissioning Group at a cost of just over £5million a year." That equates to roughly £500 per adult carer. Older groups are unmistakably catered for in the report: there are 7772 carers aged 65 yrs+ that being 3.9% of the 65+ population.133 Thus, gerontological issues, needs and services are clearly addressed, however, the provision and outcomes of older carers in the community is not covered within the remit of this research. Although the JSNA considers "Current Services in Relation to Need," it does not identify the key element of the age/need demographic of the county of Surrey and therefore young adult carers aged 18-24 are not being identified, they are becoming hidden from view and are being lost in this transition phase within Surrey.

Research conducted with all carer support groups in the county has been helpful in compiling an analysis of the outcomes for Surrey's young adult carers aged 18-24 and although generic provision is made for all age groups, the outcomes for the 18-24 cohort have been found to be poor. Becker stated, "Young carer's projects and carer's centres providing support to young adult carers aged 16-24

133 POPPI - Predicted number of Carers, Estimated population for 2012, op cit JSNA, 2011-2012: Surrey
years should be encouraged to network with each other in order to share learning, materials and ideas. This would encourage and support best practice with this age group of carers and could reduce the development time involved in launching a new service for these carers” (Becker, 2008:p81).

There is ample evidence to show that many carer support groups right across the UK, who no doubt make extremely worthwhile and valuable contributions to carers per se, have largely evolved into hegemonic structures that tend to favour particular social groups, such as the older carers, whilst tending to marginalise and exclude their younger counterparts. This could be perhaps for historical reasons, or to reinforce a sense of institutional cohesion. Becker’s and other studies (Arnett, 2000; Frank et al, 1999) have revealed that it is possible to identify young adult carers as a ‘different social group’ to older (or indeed, younger) carers.

In his study, ’The Changing Social Structure in Britain,’ Thrift (1989)\textsuperscript{134} pointed out that, ”It is important to recognise that not all social groups have equal access to the institutions. Some social groups have the power to dominate these institutions, and so have a correspondingly better chance of imposing their interpretation of the world on other social groups.” He continued, ”Through the institutions they dominate, they can produce and accumulate meanings which are favorable to their interests and which other groups accept as the ‘natural’ order of things.”

Thus, there may exist across the UK an institutionalised hegemonic dominance and emphasis on the meaning of ‘older carer’ as the norm and hence the automatic marginalisation of the young adult carer as being ’not of that social group’. It is therefore imperative that organisations begin to identify young adult carers in their own right and as a different social group in order that institutions can begin, as Kirby et al (2003) suggest, to unfreeze existing attitudes and catalyze change. This is a role that could be encompassed by a ‘Young Adult Carer’s Champion.’

In 2008 Becker stressed that, “Universal and other specialist service providers need to be more alert to the specific needs of young adult carers and find ways to deliver their particular services to them. Ways to reach out to and engage with young adult carers will need to be addressed particularly for those not previously identified by young carers services and for those who belong to ‘hard to reach’ communities.” (Becker, 2008:p81)

Therefore, without clear identification of young adult carers in our communities, they will remain hidden, as Kobena Mercer (1990)\textsuperscript{135} the cultural critic, argued, ”Identity only becomes an issue when it is in crisis.” Is it in crisis? For young adult carers in Surrey, there is evidence that this is the case.

12.0 Research into Young Adult Carers aged 16-24 in Surrey: Conclusion

There are 106700 adult carers in the UK\textsuperscript{136}. There are 2403 young adult carers aged 18-24 in Surrey.\textsuperscript{137} This represents approximately 2.3% of the adult carers in the country. Surrey currently engages with or supports around 10,000 adult carers.\textsuperscript{138} Of those 10,000 adult carers, just twelve 18-24 young adult carers are reported to be fully engaged with adult services. Young adult carers are often not recorded on databases, nor engaged, and some are said to be "not to be the main carer." These carers form Surrey's 'hidden or invisible army.'\textsuperscript{139}

Hidden and forgotten, unsupported, ignored, displaced and marginalised they might be, but these hidden carers make a considerable financial contribution to the local and national economy. Research by the Department of Sociology, Leeds University has placed the economic value of the contribution of young adult carers to the economy to be £15,260 per year\textsuperscript{140} (Bruckner, 2007). This is an effective contribution made by every young adult carer in the country. Despite the fact that the 18-24 year old young adult carer group represents 2.3% of the total adult carer population, across Surrey just 0.1% of them are fully engaged with adult services, whereas 9.4% of the over 25's of the total census are reported to be actively engaged.

The Equality Act 2010, in recognising the vital role that carers play and the disadvantage this role can bring with it, has strengthened carers' protection against discrimination both in the workplace and when accessing services.\textsuperscript{141} Currently in Surrey, young adult carers aged 18-24 are not being identified, and personalised services with positive outcomes, are not being satisfactorily provided for them.

"We have no extra resources to deal with 18-24's."

"All our carers are in the 70+ bracket."

"There's a flower show and boat trip they can attend."

"Age is not an issue; they just don't come."

"I run a group, but no one comes."

Just as the York Carers Centre\textsuperscript{142} pointed out at the start of their own research, "There was nothing to offer this 18-24 yr old group other than flower arranging and a bit of cake making - which served older groups better." The 2004 DFES Research report RR602 reflected that the consequences of not engaging young adult carers meant that, "The young adult carers would simply vote with their

\textsuperscript{136} OPCS 2001 Census, updated for population growth. OPCS 2008.
\textsuperscript{137} OPCS 2001 Census
\textsuperscript{138} JSNA Joint Strategic Needs Assessment Carers, 2011-2012: Surrey
\textsuperscript{139} Research highlights Britain’s Young Carers
http://news.bbc.co.uk/local/shropshire/hi/people_and_places/newsid_9192000/9192515.stm
\textsuperscript{142} http://www.yorkcarerscentre.co.uk/content/young-adult-carers-18-25
feet."^{143} Organisations can provide a thousand flower show visits, but if the young adult carers do not engage with this provision, then the outcomes for this vulnerable group will be poor and they will remain vulnerable, unidentified, unsupported and hidden.

The government report, "A Life Outside of Caring"^{144} pointed out that a personalised approach is required. The government's advice on this is plain and simple, "Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible, for example, that advice and information should be inclusive of all, including young and older carers.. and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can best be supported. Personalisation also offers the opportunity to think more creatively about the use of a wider range of community services."^{145} This should be the case in Surrey.

Becker's report concluded that, "The needs of young adult carers and the outcomes that are required through service interventions need to be integrated fully into every local authority's carer's strategy. We have shown clearly that unless specific recognition and consideration is given to carers aged 18-24, then they are very likely to be ignored by, or remain invisible to, adult service providers in health, social care and carer services." (Becker, 2008:p81).

So what needs to change? Firstly, there has to be openness and better cooperation between adult services and those multi-agency organisations that are seeking to move forward our collective understanding and provision of services to support young adult carers. As Becker reported, "Adult carer's services need to address the barriers that are inhibiting young adult carers from using their service and their own lack of relevance to this group as perceived by young adult carers themselves" (Becker, 2008:p82). He continued, "Commissioners of services/interventions for young adult carers should identify clearly the outcomes that they want to achieve and deliver for young adult carers (and which young adult carers want for themselves and their families), and commission the services/models which best deliver these outcomes within given resources." (Becker, 2008:p81).

Secondly, Becker noted, "A key principle for the development of all services should be that young adult carers are involved, where they wish to be, in the discussions and planning of such services" (Becker, 2008:p81). Research in Surrey, with one to one discussions, questionnaires, forums and structured interviews has shown that there is no shortage of positive and worthwhile contributions from the young adult carers themselves. Young adult carers have a wealth of knowledge and a full contribution to make in determining their needs.

---

and positive outcomes, and of shaping provision of services. After all, for some, they have a lifetime’s experience of the issues and barriers they face. The Government reinforces this message in its 'Next Steps for the Carers Strategy 2010'\textsuperscript{146} that states, “Our Big Society reforms will see public services opened to challenge, and local commissioners and care providers held to account. The knowledge, expertise and experience of carers will be vital.”

It is a recommendation that much more use be made of the experiences and successes that have been identified in this research from around the country. Forums, festivals, signposting, use of new communication media, advice, help lines, drop in sessions, social gatherings, meetings, legal advice, cv composition, e-learning packages, a dedicated magazine, self esteem classes, and entitlement awareness sessions are all worthy options to develop the engagement of this group.

In this way, Surrey could provide what Becker calls a 'seamless service from age 5 to 25' for all carers. But of course, this is subject to funding, perhaps better use of existing resources and a shared vision. Surrey’s Interagency Strategy 2011-2014\textsuperscript{147} has gone some way to seeking to introduce this vision and children and adult services, stakeholders and agencies alike, should fully embrace it.

Thirdly, it is recommended that streamlining and better, more effective use of existing young carer services both within Action for Carers (Surrey) and the wider care community should be investigated. For example a range of infrastructural and procedural adaptations should be considered such as better data collection, information storage and data manipulation. There is also scope for economies of scale and to dovetail these improvements with existing services such as Action for Carers (Employment) and the development of innovative, young adult carer led services such as online forums. Emphasis should always be made on targeting the positive outcomes for the 18-24yr old young adult carer group.

Lastly, it is recommended that all adult services should be encouraged to engage with and provide appropriate 'personalised' services for all carers, be they eighteen or eighty. Advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups. As the government points out, “Universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can best be supported” (A Life Outside of Caring\textsuperscript{148}:p19).

From research evidence and the identification of projects from around the UK, it has been found that young adult carers generally do not make use of the

\textsuperscript{147} Interagency Strategy for Young Carers in Surrey, 2011-2014
provisions that adult carer services provide. As a result of this, both national and local research demonstrates that the outcomes for this age group are poor. Young adult carers in Surrey are being let down. Research in Surrey shows that the majority are not satisfactorily engaging with Surrey's adult services, nor are they receiving the transitional signposting and support they need; and for all the political rhetoric, Surrey's young adult carers are effectively being institutionally archived into a socio-economic wasteland.

13.0 **Key Recommendations for Action for Carers (Surrey)**

13.1 Surrey Young Carers should develop an exit strategy for all young carers turning 18 who are no longer able to access young carers services. As part of the exit strategy a joint or single visit should be completed with Surrey Young Carers and Action for Carers (Employment) to review current needs and signposting to adult provision. This should include making a referral to Carers Support, looking at training and work opportunities, looking at manual handling needs, becoming a 'Carers Ambassador' and joining Action for Carers (Surrey) through the supporter affiliation form.

13.2 Action for Carers (Surrey) should source additional funding for three years specifically for work with 18-24 young adult carers, based on national and local findings. They should employ a part time 'transition worker' to provide information, signposting, drop in sessions, develop website information and most importantly to act as a link between Action for Carers (Surrey) and the wider services to ensure that current young and young adult carers do not become 'hidden carers'. Management of this role may need to sit with Action for Carers (Surrey) and Action for Carers (Employment), due to the age of the carers being supported. This would need to be included into the funding application and considered by senior staff.

13.3 Surrey Young Carers should positively develop the outcomes for 16-18 year olds currently accessing the service who may start to lose contact with them. Part of the current Activity Coordinator role could develop the recommendations suggested by young carers in the interim report such as a resource/signposting pack that all 16 year olds receive. This should provide information on age appropriate support. Action for Carers (Surrey) should also develop drop in sessions for older carers aged 18-24, with a rolling programme throughout the year on matters such as c.v construction, completing applications for jobs and universities, opening bank accounts etc. This could be achieved in partnership with Action for Carers (Employment), utilising their connections and expertise.

13.4 Consideration should be given to appointing a 'Young Adult Carer's Champion' to lobby on behalf of and represent young adult carers, and to raise the profile of young adult carers with care providers, stakeholders and the wider business community. The role could investigate
internships, apprenticeships and flexible working or studying arrangements with local employers and educational institutions, and ensure that a personalised service is being provided to young adult carers. The Champion could also seek out additional funding streams to ensure the sustainability of the project to support young adult carers aged 18-24.

13.5 Efforts should be made to improve data processing, handling and storage by utilising a shared database throughout Action for Carers (Surrey) with meaningful, accurate data obtained and stored that would enable greater efficiencies and accuracy in data input and retrieval, and the ability to use it in subsequent research and to evaluate outcomes.

13.6 Evaluation of the changes undertaken should subsequently be carried out to determine 'what works', and 'what good looks like'. It is imperative that any change results in positive, robust outcomes for the young adult carers themselves. Statement of 'provision' of a service needs to be matched by best practice, best value and best outcomes. Evaluation will also better facilitate the application for and securing of further funding if so desired.

14.0 **Key recommendations for internal consideration and in consideration of lobbying external organisations, stakeholders and service providers**

14.1 The development of services and interventions for carers aged 16-17 and 18-24 should be concerned with outcomes rather than types of services and models.

14.2 Young and young adult carers should be involved fully in planning services.

14.3 Services for young carers aged 16 to 18 need to prepare young carers for the transition phase in their lives.

14.4 After consultation with young carers about the issues most pertinent to them, Young carer's projects should develop preparation programmes for young carers in transition. This could include job/course search skills, grant applications for university, c.v's, first aid, cooking, benefits, relationships, adult social care services etc.

14.5 Systems need to be created to monitor and evaluate interventions, services and outcomes, using robust measures, instruments and tools that enable comparison over time and place.

14.6 All agencies, including local authority and carer's services, should provide young and young adult carers with information about their legal rights,
including the right to a carer’s assessment from the local authority; a potential gateway to services and support for carers and their family.

14.7 Young carer’s projects and other services need to provide a seamless service to young adult carers aged 18 to 24. Young carer’s projects need to build relationships and bridges with local adult carer’s services to help services recognise and become more engaged with the needs of young adult carers.

14.8 Universal services, such as schools and primary health care have a role to play in supporting young and young adult carers alongside more specialist provision. Universal service providers need to be alert to the specific needs of these carers and find ways to deliver their particular service to them.

14.9 Agencies that would not traditionally be associated with meeting the needs of carers also need to identify and engage with young adult carers. For example, colleges, universities, Job Centre Plus, employers, leisure services providers and others need to be sensitive to the needs, issues and barriers confronting this group of carers and which affect their opportunities for further education, learning, leisure, careers and paid work.

14.10 Some young adult carers will be parents themselves and may need parenting support in this role at the same time as they need support because of their ongoing caring responsibilities to others.

14.11 The needs of young adult carers aged 18-24 and the outcomes that are required through service interventions need to be integrated fully into the local authority’s carer’s strategy.

14.12 Adult carer’s services need to address the barriers that are inhibiting carers aged 18-24 from using their service and address their own lack of relevance to this group - as perceived by young adult carers themselves.
Bibliography


AC(S) SYC / MS Project Data March 27th 2011, to coincide with the UK Census date

Action for Young Carers (2005) Young Carers: The Next Step Forward. The Carers Federation Ltd


Becker, F and Becker, S (2000) Young Carers in their own words. Calouste: London Gulbenkian Foundation


Bilsborrow, S (1992) You grow up fast as well... Young Carers on Merseyside. Barnardos


Department of Health, 2006


Dundee carers project. http://www.youngcarers.co.uk/

Edinburgh Young Carers Project. http://www.youngcarers.org.uk/about


http://en-gb.facebook.com/people/Southwest-Young-Adult-Carers/100001609108662

http://www.affc.org.uk/young-carers/young-adult-carers.htm
http://www.barnardos.org.uk/what_we_do/our_projects/young_carers.htm
http://www.bathnes.gov.uk/healthandsocial/carers/pages/AdultCarers.aspx
http://www.bbc.co.uk/news/mobile/education-15870240
http://www.carers.org/local-centre/lewisham
http://www.carersfederation.co.uk/ayc/index.php/young-carers-age-18-25
http://www.carersfirst.com/up2u_project
http://www.carersinbeds.co.uk/page_2356275.html
http://www.carersnet.org.uk/ace/ace.html
http://www.carersnet.org.uk/actionforcarers/afc.html
http://www.carersnet.org.uk/actionforcarers/backcare.html
http://www.carersresource.net/
http://carersuk.org/Policyandpractice/Research
http://www.communities.gov.uk/2010 Index of Deprivation
http://www.cvmhdp.org.uk/content/public/online_directory/default.asp?id=383
http://www.darlington.gov.uk/Health/Childrens+Services/Disabled+Children/Pathways+to+Support.htm
http://www.devon.gov.uk/young_carers.pdf
http://www.guardian.co.uk/education/2011/feb/24/young-people-neets-record-high
http://www.guardian.co.uk/news/datablog/2011/may/18/ethnic-population-england-wales#data
http://www.herefordshirecarerssupport.org/hyac/index.htm
http://www.islington.gov.uk/Health/carers/young_carers.asp


http://www.merton.gov.uk/merton_young_carers_june_06.pdf

http://news.bbc.co.uk/go/pr/fr/-/local/shropshire/hi/people_and_places/newsid_9192000/9192515.stm


http://www.nhsdirect.uk/CarersDirect/

http://www.nhs.uk/CarersDirect/young/young/Pages/what-is-a-young-carer.aspx

http://www.northamptonshireyoungcarers.org/carers_1825.htm

http://www.offtherecordcroydon.org

http://www.oxfordhub.org/node/5738

http://powyscarers.org.uk/


http://www.spurgeons.org

http://www.solihullcarers.org/

http://www.suffolk-carers.org.uk/

http://www.Surrey.gov.uk. 2010

http://www.surrey-youngcarers.org.uk/about/about_us.html


http://www.swyoungadultcarers.co.uk/

http://www.telfordyoungcarers.org.uk/#/about-16-young-carers/4542420444

http://www.thecarerscentre.org/16-25-carers/
http://www.thecarersnetwork.org.uk/young-carers/support-groups-for-young-carers/axis-young-adult-carers-project

http://www.torbaycaretrust.nhs.uk/latest_news_and_events/Pages/TorbayYoungAdultCarers.aspx

http://uk.linkedin.com/jobs/jobs-Chief-Executive-2019026

http://www.yorkcarerscentre.co.uk/content/young-adult-carers-18-25

http://www.youngcarers.co.uk/

http://www.youngcarers.org.uk/

http://www.youngpeopleinfocus.fastnet.co.uk/madetomeasure/casestudies/young-carers-transition-service

http://www.youthactionwiltshire.org/services/young-carers/

http://www.yss.org.uk

Interagency Strategy for Young Carers in Surrey, 2011-2014


JSNA Joint Strategic Needs Assessment Carers, 2011-2012: Surrey


Marsden, R (1995) Young Carers and Education. London Borough of Enfield, Education Department


NHS: Surrey Health, Annual Report. 2009-10


ONS: 2011 Estimates for 2009, UK: Crown Copyright

ONS: Gross Value Added for the South East, Regional Briefing. 2010

OPCS 2001 Census, updated for population growth. OPCS 2008

POPPI - Predicted number of Carers, Estimated population for 2012, op cit JSNA, pp2011-2012: Surrey


Suffolk Family Carers database, 2009


Supporting Young Carers and Young Adult Carers in Suffolk: A Multi-Agency Strategy for Suffolk 2010-2013. The Children’s Society: Essex
Supporting Young Carers. OFSTED, June 2009

Surrey LEA, 2010


Research into Young Adult Carers aged 16-24 in Surrey

“This research paper is superbly well-written and organised, and judiciously referenced. A model executive summary too! It makes a very strong case for showing the importance of this neglected group - especially the 18-24 year old young adult carers, which is very timely given swingeing cuts in public expenditure.”

Professor Sylvia Chant FRSA. Professor of Development Geography, The London School of Economics and Political Science, University of London

If you are, or know a young adult carer aged 16-24 in Surrey and would like more information on the services available, please contact: Action for Carers (Surrey), Astolat, Coniers Way, Guildford, Surrey GU4 7HL Tel: 01483 302748 ACS@actionforcarers.org.uk

Services of Action for Carers (Surrey):

Research into Young Adult Carers aged 16-24 in Surrey.
Lindsay Constable
Surrey Young Carers, Action for Carers (Surrey), 2012

Constable, L (2012) Research into Young Adult Carers aged 16-24 in Surrey. Action for Carers (Surrey)