

Young Adult Carers in the UK

Experiences, Needs and Services for Carers aged 16-24

Fiona Becker and Saul Becker

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"We're real people, with real issues, listen to what we say."





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Foreward

By Dr. Philippa Russell, Chair, Standing Commission on Carers

When Gordon Brown launched the New Deal for Carers in 2007, he stressed the importance of supporting families as 'the bedrock of our society'. But he also emphasised the importance of understanding the nature of the modern family and the urgent need to renegotiate the often complex rights, roles and responsibilities of the different family members in a way which was fit for the 21st Century.

The National Strategy, launched in July 2008, and a Cabinet Office strategy paper, 'Think Families', reiterate the same theme – namely the importance of investing in families, in effect both valuing and supporting the role of family carers, whilst protecting and promoting their own life chances. Family carers do not form a homogeneous group – like those they support, they are drawn from every age group and every section of the community. And increasingly, as this new study reminds us, they include a growing number of young carers, children and young people who cherish their vital caring role but who are also ambitious to achieve the 'Every Child Matters' outcomes or their equivalents in other UK countries.

A key objective within the National Strategy is to ensure that young carers do not undertake inappropriate caring roles and that they can achieve and enjoy life alongside their peer group. But the rhetoric and the reality may be very different. Caring can start very young – but young carers grow up, often with anxieties and low expectations about the transition to adult life. This new study from Young Carers International Research and Evaluation, The University of Nottingham, funded by The Princess Royal Trust for Carers in association with The True Colours Trust is so important because it investigates the experiences, needs and service responses to the 290,000 young adult carers aged 16-24 in the UK today. The data within this study provide new and important insights into the diverse experiences of what is often a 'hidden' group of carers. It reminds us of the importance of thinking strategically about the 'care' careers of young adult carers; of the risk of loss of ambition and opportunity; and the hugely complex business of leaving home with the confidence that high quality replacement care is available in their absence.

Care and support are high on local and national agendas at the present time – but younger carers can be easily marginalised, their specific needs neither necessarily well understood nor well reflected in local authority, PCT and education strategies. This study is essential reading for commissioners and providers of both children's and adult services. The challenge is real. There are an estimated 229,318 adult carers aged 18-24 in the UK, 5.3% of this age group in the population. Their health and well-being matter. But we need to better understand the complexity of their lives, the challenges in balancing critical family roles with the demands of education, employment opportunities and developing adult relationships if we are to achieve positive outcomes. This study contains a wealth of information about the lives, experiences, aspirations and expectations of an important group of young citizens. I warmly welcome the evidence and recommendations provided as an important contribution to the delivery of the National Carers' Strategy, the work of the Standing Commission on Carers which I chair and to the wider debate about how we can best provide support for carers at the start of a very challenging 21st Century! Young carers are our future citizens – but they need proactive commissioning and we need better awareness of their specific experiences and aspirations. We have much to learn about creating good transitions to fulfilled adult lives for young carers and this study provides an evidence base for the development and delivery of more personalised support and better outcomes for a vital but often 'silent minority' of young people.

Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24

Fiona Becker and Saul Becker

Published by The Princess Royal Trust for Carers in association with Young Carers International Research and Evaluation, The University of Nottingham, November 2008.

Executive Summary

This study, funded by The True Colours Trust in association with The Princess Royal Trust for Carers, investigates the experiences, needs and service responses to the 290,000 young adult carers aged 16-24 in the UK today. The research is a 'mixed-methods' investigation and includes a literature review, secondary analysis of 2001 Census data, a survey of 25 young carers projects, a survey of 13 adult carers services, five focus groups with 29 young carers aged 16 and 17, discussions with staff at focus group sites, and in-depth interviews with 25 young adult carers aged 18-24 across Britain.

The data presented in this report provides new insights into the diverse experiences and needs of what is a 'hidden' and neglected group of carers. The report 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 carers projects; emerging service responses; and how their needs can best be met. The report also includes a series of recommendations for service development for those working with carers aged 16-17, carers aged 18-24 and adult carers.

Throughout, the experiences and needs of 16-17 year old and 18-24 year old carers are discussed separately. While there are many similarities in their experiences there are important differences in their needs that correspond to the particular developmental stage in their lives and their 'career' as carers. One group (carers aged 16-17) are still legally 'children' whilst the other group (carers aged 18-24) have the legal status of 'adults'. These categories have major implications for services in the UK and for who is responsible for meeting the needs of children who are carers and adults who are carers.

Findings concerning young carers aged 16-17 include:

- Census 2001 data show that there are 61,051 young carers aged 16-17 in the UK, with 11,341 of these (one fifth) caring for more than 20 hours each week and 4,406 caring for more than 50 hours per week – that is 7% of all carers in this age group.
- Most young carers in our sample wanted to go out more but they were constrained in this by the growing expectations from their family that they should take on more caring responsibilities as they got older.
- Young carers' views about school life fall into one of two main camps: those who had found recognition and support (as carers) from school staff or those who had found the opposite – that school staff had failed to identify their caring responsibilities, and, in some cases, had even 'punished' them for caring.
- Parental encouragement and positive attitudes towards education were important factors that also influenced young carers' school attendance and achievement.
- Many young carers reported that they had had poor career and job search advice, either through school, Connexions or their local equivalents.
- Leaving home was complex, involving discussions and negotiations within the family, as well as being confident of alternative caring sources.
- Young carers aged 16 and 17 knew very little about local services for adult carers, including services (if any) for carers aged 18+.
- Most young carers were anxious that the support they were receiving from a young carers project would cease when they became 18.

Findings concerning young adult carers aged 18-24 include:

- There are 229,318 young adult carers aged 18-24 in the UK, and this is 5.3% of all people in that age group. One quarter of all young adult carers in the UK (56,069 people) are providing care for more than 20 hours per week and almost 27,000 of these (12% of the total) are providing care for more than 50 hours each week.
- Young adult carers in our sample are involved in a wide range of caring tasks and responsibilities and some are very heavily involved in caring. Just under two thirds of our sample are providing emotional care 'a lot of the time' and this was a task that many young adult carers found particularly arduous and which restricted their participation in other life events, activities and socialising. Just under a third are providing personal and intimate care 'a lot of the time' which included helping the person(s) they support to wash or take a bath.
- Where a parent's condition deteriorated, then the amount of caring increased unless adjustments were made to care packages or support materialised from other family members.
- Just over a third of our sample reported having 'strained relationships' with the person(s) that they were caring for.
- For those looking after siblings, the amount of caring could decrease as their brother or sister matured and they were able to do more for themselves.
- Many young adult carers were unaware of what help may be available to support their relatives, how to access this and who supplies it.
- All young adult carers described having an increasing number of other demands on their time alongside their caring responsibilities, be it to do with education, jobs or personal relationships.
- Young adult carers valued good and informed careers advice although their experience of getting this was variable. It was rare for any young adults to identify that their careers adviser (or equivalent) had asked them about either whether they had caring responsibilities and if so, the impact and implications for studying or careers.
- Understanding and appropriate support from school staff had made a significant difference in terms of engagement and achievement for those with caring responsibilities when they were at school.
- Generally, young adult carers reported that their experience of college was more positive than school because of its flexibility, its adult-orientated focus and staff who were more understanding and supportive of young adults with caring roles. However, some young adult carers had left college prematurely without completing their intended qualifications.
- Young adult carers at university are required to balance caregiving with their academic studies and learning. Some do this by 'caring at a distance' and returning home at weekends or holidays to provide care. Others balance care and study by continuing to live at home and travelling to their local university, enabling them to maintain their regular caring roles.
- Young adult carers who are studying at university but return home each day to care have substantial and significant caring roles which appear to be no less time consuming than for those caring and living at home who are not in higher education.
- Of the young adult carers at university none were aware of any specific carers support available for them at their university. Similarly, they were often unaware of local services for carers that might be able to support them because traditionally those carers services have not reached out to university populations.



- Young adult carers often chose friends and/or partners who were sympathetic and understanding of their situation. Several respondents spoke of the 'burden of their maturity' and how this affected their ability to make friends because it had made them different from their peers and restricted their ability to be spontaneous and carefree.
- Half of our sample said that they felt they had insufficient time for themselves. Life was constantly busy with little free time, time to be alone or opportunities for rest and relaxation and this was particularly the case for those carers who were providing high levels of emotional care or where they were caring for more than one person. This also affected their ability to look for or take on paid work.
- Most young adult carers aged 18-24 experience significant financial hardships as a consequence of caring and living in a low income family where there is physical or mental ill health, disability, and alcohol or drug misuse. Family income is very tight and there is strong evidence of poverty and social exclusion for all family members and of young adult carers using their own money to subsidise the needs of parents.
- Just under a third of our sample had recently or were currently engaged in part-time employment as a means to getting additional money for themselves or their family. Others found it too difficult to combine paid work with the conflicting demands of caring.
- Almost one quarter of our sample were not in employment, education or training (NEET).
- Some unemployed young adult carers felt very much alone and unsure of how to make progress in accessing the labour market. Low self-confidence and not having the necessary qualifications impeded their success or they simply felt that combining caring and work was not feasible. Lack of transport was also mentioned as a factor, particularly in rural locations, so that they could not search further away for work.
- Unlike other young people whose future aspirations are often mediated by money and qualifications, young adult carers' futures are also mediated by their caring responsibilities, particularly where they are caring for a parent, rather than sibling, and where there is no other extended family support available.
- Emotional pressures and demands for care make it especially hard for young adult carers to leave home. Others choose not to leave in order to protect siblings from assuming a caring role.
- Not all young adult carers in our sample had received a young carers service - despite some of them caring for many years on a regular and substantial basis during their childhood, and having significant, inappropriate, caring roles which had affected their schooling and emotional well-being.
- Many young carers services are now aware of the 'gaps' in service provision for young adult carers and questioning to what extent they have a responsibility for filling that gap. A few of our sample were accessing '18 plus' or other transitions-related services that were new developments arising from the work of young carers projects. A number of models of provision are emerging which will require evaluation in order to test their effectiveness.
- All of the young adult carers in our sample could, in theory, have been accessing support from adult carers services provided by the voluntary or statutory sectors. In fact, very few had ever used an adult carers service and not to any great degree. 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.

Recommendations include:

1. The key factor to be considered in the development of services and interventions for carers aged 16-17 and 18-24 years should be concerned with outcomes rather than types of services and models. Commissioners and service providers should identify clearly the outcomes to be achieved and delivered for these groups of carers.
2. A key principle for the development of services should be that young carers and young adult carers, who wish to do so, are involved fully in planning services.
3. Services for young carers under the age of 18 need to prepare young carers, especially around the ages of 16+, for the next 'phase' in their life. This might include signposting or referral to other service providers.
4. Young carers projects need to develop preparation programmes for young carers in transition – this should include the issues most pertinent to them such as job/course search skills, grant applications for university, CVs, first aid, cooking, benefits, relationships, adult social care services etc.
5. Systems will need to be developed and put in place to monitor and evaluate interventions and outcomes, using robust measures, instruments and tools that enable comparison between interventions/services over time and place.
6. All agencies, but especially local authority services and carers services, should provide young carers and 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 services and support for carers and their family.
7. Young carers projects in conjunction with adult carers and other services need to consider the best ways to provide 'seamless services' to young carers after they reach 18. Young carers projects need to build relationships and bridges with local adult carers services to help adult services recognise and become more engaged with the needs of young adult carers.
8. Universal services, such as schools and health care (especially primary health care) have a role to play in supporting young carers and young adult carers alongside more specialist provision. Universal service providers need to be more 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. So, for example, colleges, universities, Job Centre Plus, employers, leisure services providers and others all need to be alert and sensitive to the needs and issues confronting this group of hidden carers and which affect their opportunities for further education and 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, and the outcomes that are required through service interventions, need to be integrated fully into every local authority's carer's strategy.
12. Adult carers 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.



Chapter 1 - The research in context

Background

Little is known about young adult carers aged 16-24 in the UK. Information is sparse about the issues and challenges that they face due to being carers, what would be appropriate support and the best methods and routes to reach them. As recently acknowledged in a report by the Social Exclusion Unit (2006): “The transition from childhood to adulthood is becoming increasingly complex, difficult and risky...The transition to adulthood is more difficult if you also have to deal with one or more of the following issues: poor housing; homelessness; substance misuse; mental health issues; poor education or long-term employment” (p 7). The decisions made at this age, including education and employment, are some of the most important and far-reaching decisions taken at any time of life. Yet disadvantaged young adults, including young adult carers, are often least equipped with the skills required. For young adult carers in transition, especially those caring for a parent with severe mental health or substance misuse problems, some may not have the advice or guidance from within the family to help them navigate through this period of change in their lives at the same time as they continue with their caring responsibilities.

The Social Exclusion Unit’s report highlights the fact that services are often age-related and are for adults or children and that: “...there are relatively few examples of public services that address the specific needs of 16-25 year olds in the round or that ensure effective transition from youth services to adult services” (p 8). Indeed, The Princess Royal Trust for Carers’ own Young Carers Services report that young carers start to drift away from their services around the age of 16 and upwards. However, few carers of this age group take advantage of the other services and groups offered by adult carers’ services, suggesting that many young adult carers, at present, are unsupported and do not relate to the ‘adult’ services that are available from voluntary sector carers centres (such as those offered by The Princess Royal Trust for Carers) or adult social care services provided, administered or commissioned through local authorities.

The research

Our study, funded by The True Colours Trust in association with The Princess Royal Trust for Carers, investigates the experiences, needs and service responses to carers aged 16-24 in the UK today. While there are a few existing studies of young adult carers (reported in Chapter 2), most are small-scale and based on a local population, and some are rather dated.

We make a distinction in this report between 16-17 year old carers (‘young carers’ – see Box 1.1) and 18-24 year old carers (‘young adult carers’) because both groups of carers are at a different developmental stage in their lives and ‘career’ as carers; one group are legally ‘children’ and the other are legally ‘adults’; and while they have experiences and needs that are similar there are also important differences that need separate identification and discussion. Moreover, young carers are generally the ‘responsibility’ of children’s services while adult carers fall into the remit of adult services. Box 1.1 gives our definition of young carers and young adult carers.

Box 1.1: Definitions

We define **young carers** as “children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision” (Becker, 2000: 378).

We define **young adult carers** as people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision.

Research questions and design

While we know a great deal about the millions of adult carers, and an increasing amount about young carers, there is little available research on, or dedicated services for, young adult carers aged 18-24 in the UK.

Chapter 2 shows that the existing research evidence base has not considered the following questions about the needs and experiences of young adult carers:

- What factors affect the extent and nature of caring for young adult carers?
- How do experiences of education affect educational outcomes and job prospects of young adult carers?
- What are the experiences of young adult carers at college or university?
- How are the aspirations of young adult carers affected by their caring responsibilities?
- Do young adult carers receive a carer’s assessment?
- What are the information needs of young adult carers?
- Are there gender differences in the experiences of male and female young adult carers?
- How do young carers projects prepare young carers for their service ending and link them into adult carers services?
- What supports and services do young adult carers receive?
- What service provision do young adult carers need and want?

Our investigation builds on what is already known and seeks to address these questions. It includes an analysis of the particular experiences and difficulties faced by 16-17 year old carers and young adult carers aged 18-24; the barriers that they face to education (including further and higher education) and training; issues around their economic well-being and independence; their vulnerabilities and resilience and protective factors; and the models of service delivery that could best meet their needs and deliver positive outcomes.



Our research study includes the following:

- **Literature review**, to determine what is already known about this group of carers;
- **Secondary analysis of 2001 Census data**, to identify the hours spent caring by age of the 290,000 young adult carers aged 16-24 in the UK;
- **Survey of 25 young carers projects** in contact with at least 359 carers aged 16-17, of which eight projects were also in contact with 95 young adult carers aged 18-24, to determine the key issues around transitions as identified and experienced by project staff themselves;
- **Survey of 13 adult carers services** to identify the extent to which adult carers services engage with young adult carers;
- **Five focus groups** with **29** young carers aged 16 and 17, to understand the needs and experiences of this group at this transitional stage in their lives, from their own perspective;
- **Discussions with staff** at the 5 focus group sites;
- **In-depth interviews** with **25** young adult carers aged 18-24 across Britain, to identify their experiences, needs and the support they access and receive;
- **Analysis, synthesis and writing**, to bring together all sources of data in a comprehensive whole and to identify the key findings and implications for future policy and practice with young adult carers.

Ethical approval for this study was granted under the Research Ethics Procedures of the School of Sociology and Social Policy at The University of Nottingham. Informed consent was obtained from all the participants in the study. All names in this report have been changed to protect the anonymity of participants

Samples and methods

Young carers aged 16-17

As part of our study we conducted five focus groups with a total of 29 young carers aged 16 and 17 of whom 18 were girls and 11 were boys. The purpose was to understand, from their perspectives, their needs and experiences and their views about the services and support that they believe could help them best at this transitional stage in their lives. Focus groups were conducted across Britain in North Staffordshire, Brighton, Lincolnshire, Glasgow and Bridgend. The participants in these focus groups were primarily from 'stand alone' young carers projects, from young carers projects within carers centres, and in addition some were from specialist services in contact with adults with mental health problems or substance misuse.

In addition, we conducted a survey of 25 projects working with at least 359 young carers aged 16-17 (one internet-based project did not keep details of ages so the real figure will exceed this). We asked project workers about the needs of young carers aged 16-17, the key transition issues they face, how young carers are helped, and how they could be supported in the future. The survey gave us valuable information about the experiences and needs of young carers aged 16-17 from the perspective of those who work most closely with them.

The five focus groups and projects survey confirmed the pattern of findings about young carers generated through dozens of other research studies on young carers conducted during the last decade. They also gave us new data on the key transition issues facing 16-17 year old carers.

Young adult carers aged 18-24

We conducted in-depth interviews with 25 young adult carers - 18 females and 7 males. The age range varied between 18 and 24 years although the average age was 19 due to the way the sample was identified. The participants lived in seven fieldwork sites across England, Scotland and Wales. These sites are: Brighton, North Staffordshire, Lincolnshire, Nottingham, Bridgend, Rhonda and Taff Ely, and Glasgow. All of the participants described themselves as white British, Welsh or Scottish except three people who belonged to BME groups - Pakistani or Indian.

The participants were identified through an invitation sent to all young carers projects to identify those willing to be a fieldwork site. Sites were then selected on the basis that they had contact with a number of young carers aged 18 and above. A total of ten projects were involved as some sites had more than one service provider in their locality.

The individual interviews with young adult carers were semi-structured, intended to cover a range of themes and issues considered important in the transition from adolescence to adulthood for young adult carers. Six broad themes were explored: family background and structure, the needs and services received by the person they care for, the experience of caring, the impacts of caring and protective factors, carers support, and their aspirations for the future. On average interviews lasted an hour and a quarter each. All interviews were recorded and transcribed for thematic analysis.

In addition, we conducted a survey of 8 young carers and transitions projects in contact with 95 young adult carers aged 18-24 and a survey of 13 adult carers services. Adult carers services were asked whether they provided any support to carers aged 18-24, about the needs of this group, the transition issues they face and how they could be supported in the future. These surveys provided us with valuable information about the extent to which young and adult carers services recognise and engage with young adult carers aged 18-24 and the models of support that are currently available for this group.

Data analysis

All our interviews with young adult carers used a semi-structured interview schedule which had been devised on the basis of our knowledge of the research literature, the focus of our inquiry and our experience of working in this area of research for over 15 years. We were mindful that the interview process could prompt personal and painful feelings and therefore it was important for the researchers to be understanding of this, to pace the interview appropriately and ensure that participants had someone else to talk to afterwards if needs be. Using a semi-structured interview schedule enabled us to explore in more depth those issues already known to affect young adult carers and it enabled participants to identify new issues and themes particular to their own circumstances and experiences of caring. The resulting data are both rich and detailed, including information and accounts important to the participants as well as to the researchers.

All of the interviews were recorded and transcribed fully. The transcripts were carefully reviewed, using a coding frame containing 49 items, utilising a Framework Approach to qualitative data analysis and data management. The Framework Approach enables us to classify and organise data from interviews with young people and text from our surveys (see below) according to key themes, concepts and emerging categories. The themes derive from an interrogation of the data and the coding (or 'indexing') of the data into distinct topics. The approach allows us to relate different themes from different people to be related to each other, abstract categories can be identified, and explanations developed. For example, the fact that certain topics surface in more than one thematic column for several research participants can be taken to signal that there are interconnections among the themes concerned. This approach helped us to develop complex understandings of young carers', young adult carers' and professional perspectives by facilitating a comparison of themes across interviews and subjects (see Becker and Bryman, 2004, p 308 for more details of the Framework Approach to qualitative data analysis).



In addition to interviewing young carers and young adult carers, questionnaires were devised for staff working in the field. This methodology was particularly important because it allowed us to compare the direct experiences of young carers and young adult carers with those who were working closely with them. The questionnaires used semi-structured open-ended questions in order to enable staff to reflect on their experiences of working with these carers, their needs and concerns. These questionnaires were reviewed and examined for common themes and issues, as above. We were able to compare these with those themes and issues that had emerged from the focus groups and individual interviews with young carers and young adult carers in order to identify areas of commonality and difference in the perspectives of workers, young carers and young adult carers.

Getting information and data from a diverse range of stakeholders, staff and carers, allowed us to piece together a fuller picture of the experiences and needs of young adult carers in the UK today. What became very clear from this process was how similar and common the themes were from all of these different stakeholders. Despite our sample of young carers and young adult carers being relatively small ($n=53$) we have some confidence in generalising from it to a larger degree than would have been possible because we had confirmatory evidence from a wider range of stakeholders working with a much larger number of young carers, young adult carers and adult carers. The findings from our own study are reported in the subsequent chapters of this report.

Chapter 2 - 'What we already know': the literature reviewed

Introduction

Levine et al (2005) have argued rightly that young adult caregivers have almost been totally ignored in research. However, as a group they are an important subpopulation of carers to consider because, as young adults, they are at a critical developmental stage with many having not yet solidified their life plans and choices about education, work, marriage and parenthood. While there is a growing body of research evidence on young carers aged under 18, there is far less research evidence on young adult carers aged 18-24. The research (and issues) presented in this report cut across both the young carers and adult carers literatures: young carers aged 16-17 years are included within the extensive young carers literature and those aged 18 plus are subsumed within the adult carers literature. However, both sets of literatures rarely draw out the specific needs and experiences of either age group - in other words, young carers aged 16-17 and young adult carers aged 18-24 are generally 'invisible' in existing studies of carers. This lack of attention is mirrored in the 'service world' by a paucity of specific services and interventions for carers aged 18-24.

In this Chapter we outline the key themes and issues that have been identified in the small number of research studies on young adult carers in the UK, as a background to our own research findings which we report in Chapters 3-12. The aim here, therefore, is to summarise 'what we already know' about this group of carers.

Caring responsibilities and the effects of caring

Existing studies have had little to say about the type of caring responsibilities that young adults do and how their caring tasks change over time. Because of this gap in the literature these are issues that we examine in our own research, reported in Chapter 4. Rather, what has been identified in previous studies on young adult carers are the positive and negative aspects of caring for young carers, as summarised in Box 2.1.



Box 2.1: Positive and negative aspects of caring during childhood and early adulthood as identified in existing research studies

Positive aspects

Confidence and inner strength.

A close and loving relationship with parents.

A mature and responsible outlook.

Life skills being useful preparation for independence eg homecare, effective communication, being able to multi-task.

Developing a sense of social responsibility and empathy, an understanding about illness and disability.

Having a caring attitude towards others in society.

Able to transfer their caring skills into career and job choices

Negative aspects

Worry/anxiety about the person they care for regardless of whether the young adult carer lives with the person they support or not.

Seeing loved ones in pain or in hospital.

Health problems as a consequence of caring: stress, depression, tiredness.

Insufficient time and money for leisure, holidays and social activities.

Missing school and poor educational performance.

Restricted educational and career opportunities.

Experiencing negative emotions (fed up, lonely, lost, frustrated, guilty).

Lack of recognition and feeling they are not being listened to.

Lower than average family income which restricts opportunities.

Unable to pursue a career or job choices outside of caring roles.

Dearden and Becker's (2004) large-scale study based on data collection from 87 young carers projects concerning a total of 6,178 young carers (aged 5-18 years) found that children become more heavily involved in caring as they get older. This was true of all the different types of caring tasks, but less so of childcare, since younger siblings will also be growing older and require less support. They also found that as carers grew older the difference in gender became more pronounced amongst the 16-18 age group in relation to domestic tasks and intimate care: 85% of girls are doing domestic task as compared to 69% of boys, while a third of girls in this age range are providing intimate care compared to 17% of boys. In relation to the other caring tasks (general, emotional and childcare) gender differences were far less marked.

In a separate study of 60 carers aged 16-25, Dearden and Becker (2000) make several important points about the effects of caring on young adults. First, "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" (p 43). Second, even where young adult carers had left home they often continue to worry about the person they care for. Some resumed their caring responsibilities when they returned home or made arrangements to visit the family home on a daily basis in order to provide care. Finally, young adult carers may gain skills and competencies through young caring but these were often gained at a cost of them missing school and not getting qualifications – such that caring cannot be regarded as an acceptable way for young people to acquire these skills.

Educational experiences

According to the small number of available studies, between a half to three quarters of young adult carers interviewed or surveyed reported that their education had been affected by their caring responsibilities. This finding is congruent with a large-scale study of young carers which shows that around one fifth of young carers have educational difficulties (Dearden and Becker, 2004). The impact of poor school attendance and attainment was highlighted in Dearden and Becker's (2000) study of *Growing up Caring*, 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 pupils. For some young adult carers school was an unhappy place due to their experiences of being bullied or due to name-calling (Action for Young Carers, 2005). Other impacts on schooling which young adult carers described included: reduced opportunities for participating in social activities, tiredness and fatigue, falling behind with work, and getting into trouble (Frank et al, 1999).

The proportion of young adult carers who were in further or higher education in Dearden and Becker's (2000) sample was higher than they had anticipated. They attributed this to a lack of job opportunities for young adults. However, more recent analysis of the 2001 Census data by Yeandle and Buckner (2007) showed a different picture: "Among young adults aged 16-24 caring reduces the likelihood of being a student and thus participating in further or higher education for young men, and, especially for young women" (p 21). Our research (Chapters 5 and 7) outlines in more detail what we found about young carers and young adult carers' experiences of education and how this affects their aspirations, their access to further and higher education (including university), and their access to paid employment.

Leisure and socialising

There is limited information about young adult carers and their use of leisure time or their ability to take a break. The main themes from previous studies are 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. Another local study (Barnardos, 2007) indicated that young adult carers were able to get some leisure time away from the home but they weren't using this time to keep fit and healthy because the cost of this was prohibitive to them. The authors suggested that there should be a leisure card allowing subsidised access to such facilities for carers.

Whilst the emphasis is often about whether or not the carer can take a break, Frank et al (1999) also raise the point that disability and illness usually restrict the whole family's ability to go out and take part in everyday activities together, which in turn affects family dynamics. Restricted income can compound this problem. We examine in more detail the specific experiences of carers aged 16-17 and 18-24 (Chapter 6) with regard to leisure and socialising, and how money issues are central to so much else.

Relationships

Dearden and Becker's (2000) study highlights some of the complexities confronting young adult carers in terms of making and maintaining relationships. The authors surmised that young women were more likely to defer relationships or try to fit them alongside family responsibilities. They also found that only a minority of their sample reported having close relationships with their parents.

Frank et al (1999) suggest that when a relationship develops that places a child in a caring role the whole nature of the child-parent relationship changes and this has consequences for the balance of power between them. The authors discovered that some former young carers (now adults) struggled to understand the reconstructed roles and relationships that they were forced to adapt to. Some still regretted the loss of their childhood.



Frank et al (1999) also 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. We explore in much more detail young carers' and young adult carers' experiences and thoughts about relationships and friendships in Chapter 6.

Work and paid employment

Dearden and Becker (2000) reported that one of the most important decisions which young adult carers thought had been influenced by their parent's illness was that relating to their own choice of career or job: "There may be a danger of young adult carers moving into caring jobs or professions because they feel these are the only skills they have to offer. Many of these jobs will be low paid with few prospects" (p 39). Frank et al's study (1999), involving 66 former young carers aged 19-65 years found a similar picture with almost half of them attributing their chosen career in a caring profession to their experiences of providing care and the acquisition of skills that they felt confident to use. More recent reports on local need by two projects (Action for Young Carers, 2005; Barnardos, 2007) revealed that many young adult carers think that their caring responsibilities will be a barrier to them achieving their preferred career or job. To some extent this is because they realise that they do not have the qualifications they need – which is often as a result of educational difficulties and missed schooling (Dearden and Becker, 2000). Several authors have identified that young adult carers usually have skills and qualities that go unrecognised (time management, organisational skills, budgeting, maturity etc) and that they would not consider including these in CVs despite their relevance to a paid work environment.

A lack of education and ongoing caring responsibilities serves to exclude some young adult carers from the labour market (Dearden and Becker, 2000). Yeandle and Buckner (2007) drawing on 2001 Census data found that caring reduces the chances of young adult carers being in either full-time or part-time paid work as compared to other young people of the same age, and that their chances of being unemployed increase as the number of care hours provided increases. Additionally, the chance of not being in any employment was greater for women than men, highlighting that caring affects women more adversely than men even within the young adult population. Yeandle and Buckner (2007) suggest that: "Supporting working carers has been peripheral to most authorities' work on carers, with few carers being asked about their need for help in maintaining their jobs and careers, and most engagement with carers focusing on those outside the labour market" (p v). Issues concerning the choices and realities of entering the paid labour market are examined in our study in Chapter 7.

Leaving home or not

For all young people the decision to leave home is a significant step to independence. For some, the move away from home will be temporary or transitional with periods living back at home, for example, those that choose to live away at university. For others, the move is a permanent one, for example to live with a partner, to set up home with their own children or to live elsewhere in order to obtain work. Dearden and Becker (2000) found that leaving home was especially problematic for many young adult carers particularly if they had left a parent with high needs for support and help: "Decisions to leave home, either permanently or temporarily, were sometimes influenced by concerns over parental ill health. Many of the respondents made the transition to independent living at an earlier or later stage than they would have chosen" (p 39). In five out of the seven cases where young adult carers had left home in their sample the move was not the result of a planned and positive choice. Rather, it was due to problems within the family and being at a crisis point. The authors concluded that: "A combination of parental illness, lack of support services and a lack of available and affordable alternative accommodation can influence transitions to spatial independence" (p 367).

For those who had made a temporary move away from home it was often the case that they continued to worry about the person they care for, they would resume their caring responsibilities when they returned home during holiday periods and they were worried about their future housing needs (Harrison and O'Rooke, 2003). There was some evidence that even if young adult carers did not delay their departure from home, caring did restrict their choice of educational course or job in order to remain relatively near to home in case they needed to return at short notice to resume their caring responsibilities (Dearden and Becker, 2000). The themes of moving away from the parental home, and the pursuit of independence, are explored in depth in our study, and findings are reported in Chapter 8.

Income

Dearden and Becker (2000) reflect on 'normal' patterns of money flow within families. At 17, for example, money often still flows from parents to children but by 19 it can be from child to parent as children enter the labour market. Dearden and Becker show, however, that this is not generally the case for many young adult carers and many were struggling with living on low incomes in poor families. A second parent's income protected some families but most in this study were lone parents. The authors argue that the increased emphasis on education and training, rather than employment, combined with the erosion of student grants and the introduction of loans and tuition fees, have all resulted in an increased dependence on families and make independence and the transition to adulthood more difficult to achieve.

The relationship between disability, illness, caring and low income was a recurring theme in the report by Dearden and Becker: "Virtually all the families were in receipt of welfare benefits and were outside the paid labour market. Experience of poverty and social exclusion were common" (p 32). The authors argue that increasing the school leaving age and reducing eligibility to social security benefits has extended the period of transition whereby young adults are financially dependent on their parents. In their research study none of the parents with illness or disability was in employment and when they had partners few of these were working. In relation to ill or disabled people, an adequate income enables them to pay for appropriate care and support, reducing the need to rely on family members: "However, illness, disability and poverty tend to go hand in hand and conversely those families most likely to require social care and support are those least able to afford it" (p 28). "Young people who have ill or disabled parents who require their support may be less available for work and more likely to have fewer and lower educational qualifications" (Becker and Dearden, 2000, p 25). The study in York (Harrison and O'Rooke, 2003) found that caring commitments often prevented young adult carers from working and this exacerbated their financial position. Money is a central theme that we examine in our study and we report key findings in Chapter 7.

Services and support

There is an inter-connected relationship between the type and level of services and support that the person being cared for is in receipt of and the type and level of services and support that the carer needs. This relationship holds true as much for young adult carers as it does for all other groups of carers.

Dearden and Becker (2000) found that about a third of the people being cared for had received helpful and valued services, a third received nothing at all, a fifth had their homes adapted, and some had cancelled services that they viewed as intrusive, unnecessary, poor quality or too expensive. The authors found no evidence of any services being provided that were to support disabled parents in their parenting roles. They concluded that once young caring had become firmly established families were more likely to cancel services. However, and this is the key point, where families received good quality and reliable support and services this reduced young people's caring roles:



"Services that are affordable, adaptable and acceptable can greatly improve the lives of all family members and reduce the caring responsibilities adopted by children and young people. These services should support disabled adults as parents as well as supporting their personal care needs. Perhaps the way forward is early assessment of the needs of whole families.... Family-focused assessment should acknowledge and recognise the needs and rights of all family members and should lead to the provision of services which meet these needs and promote these rights." (Dearden and Becker, 2000, p 32)

Existing research, including some unpublished local studies conducted by carers projects (Harrison and O'Rooke, 2003; Action for Young Carers, 2005; Barnardos, 2007), identify that young adult carers want to receive support and specific help linked to their caring role alongside information and advice about the key transition issues affecting their lives. They perceived that their needs were not being met by young carers services or adult carers services as they are currently fashioned. Many young adult carers in these studies have plenty of ideas about what an ideal service should look like for their age group and they were keen to influence such developments.

The York study (Harrison and O'Rooke, 2003) interviewed ten young adult carers, the majority of whom had previously received support from the young carers service there, and the comment from one, "I grew out of the group, but not the support", reflected the views of the majority who wanted some form of continuity of service and peer support: "You don't just get to 18 and feel I can cope with all this and that's it!" (p 20). Similarly, "We don't stop caring for someone when we turn 18, so why do organisations treat us like we do?" (Action for Young Carers, 2005). Many young adult carers in these local studies perceived that services for adult carers were geared to much older carers. They thought that their need for support was of a different nature than older adult carers because of their life stage. They felt they had outgrown young carers social events but that they were too young for the adult carers meetings, leading the authors to conclude that: "It appeared there was a need for a distinct social calendar for this age group" (Action for Young Carers, 2005, p 19).

During times of stress former young carers would contact their (former) young carers project because of the established and trusted relationships they had previously formed with staff, in other words they preferred to use the 'known' support unofficially rather than an unknown adult carers service (Harrison and O'Rooke, 2003). This was identified as a potential problem for young carers services in the future. Parents interviewed in this study wanted the young carers service to continue to support their children particularly because of the life-changing decisions facing them at this point of time. Professionals interviewed in this study thought that the responsibility for service provision for young adult carers was unclear but all of them said there should be a specific service available to assist this age group given the psychological importance of this developmental phase.

In the study in Flintshire (Barnardos, 2007), young adult carers participated in focus groups where they spoke about their needs and experiences, leading the authors to conclude that: "information for young adult carers needs to be more age specific and address such needs as employment, education, leisure and training for roles. Support for young adult carers needs to consist of emotional, social and practical support and an opportunity to access peer support, and with clear pathways into employment, training and education with providers who are empathetic about their caring responsibilities... young adult carers above all want a sympathetic ear for their problems, which are often unique to them" (p 14).

In a local study in Lincolnshire (Action for Young Carers, 2005) young adult carers said that when they reached 18 years of age they found themselves unsupported and yet this was a time when they needed support because of all the decisions and choices they were faced with. In terms of identified needs they most frequently acknowledged that they wanted a break and time out from caring; closely followed by the need for someone to talk to outside of their family; then practical help; and then aids/adaptations and having some company for the person they care for.

Providing a service for young adult carers may not be sufficient in itself unless the barriers that prevent the uptake of support services by young adult carers are addressed. Such barriers were highlighted in the study in Flintshire (Barnardos, 2007): "The young adult carers interviewed seemed to lack the confidence to act on signposting, do not receive information on adult services or feel that they ought to be able to cope because they are adults" (p 38). This study found that young adult carers don't necessarily recognise themselves as carers and therefore information needs to be directed at them about this. Young adult carers and professionals may also assume that because they are adults they can cope with their responsibilities and indeed that society expects them to cope. It was suggested that young adult carers may be more hidden than other carers who may be identified by universal services because of concerns about their school performance (young carers) or concerns about their deteriorating health (older carers). The issues around services and support for young adult carers are explored in depth in our research and findings and implications are reported in Chapters 10, 11 and 12.

In the next Chapter we report the findings from our analysis of Census 2001 data on the number of young adult carers in the UK.

Chapter 3 - Number of carers aged 16-24 in the UK

New analysis of Census 2001 data

The 2001 Census shows that there are 5.8 million unpaid family carers in the United Kingdom, of which at least 175,000 are young carers aged under 18 (Becker, 2008).

Our secondary analysis of Census 2001 data show that just over 61,000 of these young carers are aged 16-17, with 11,341 of these (one fifth) caring for more than 20 hours each week and 4,406 of these caring for more than 50 hours per week – that is 7% of all carers in this age group (Table 3.1).

Table 3.1: Number and proportion of young carers aged 16-17 in the UK, by country and hours caring per week

	Number caring for 1-19 hours	Number caring for 20-49 hours	Number caring for 50+ hours	Total number caring
England	40,138	5,258	3,372	48,768
Wales	3,041	459	312	3,812
Scotland	4,229	789	464	5,482
N Ireland	2,302	429	258	2,989
Total number of carers aged 16-17 in UK	49,710	6,935	4,406	61,051
Total as % of all young carers aged 16-17 in UK	81%	12%	7%	100%

Source: Calculated by the authors from Office for National Statistics Census 2001 data.

Our analysis of Census 2001 data show the number of young adult carers aged 18-24 in the four nations of the UK (Table 3.2). In total, there are 229,318 young adult carers in the UK, and this is 5.3% of all people in that age group. However, this varies between the four UK nations, with the highest levels of young adult caring being in Wales (where someone aged 18-24 has a 5.7% probability of being a carer), compared to England (4.8%). This regional variation may reflect different levels of illness, disability, geography and need across countries, and also differences in the availability of health and social care services and support for ill and disabled people, and for carers.

Table 3.2: Number and proportion of young adult carers aged 18-24 in the UK, by country and hours caring per week

	Number caring for 1-19 hours	Number caring for 20-49 hours	Number caring for 50+ hours	Total number caring	Proportion of this age group who provide informal care
England	140,903	22,547	21,571	185,021	4.8%
Wales	9,675	1,697	1,690	13,062	5.7%
Scotland	15,417	3,203	2,495	21,115	5.0%
N Ireland	7,254	1,681	1,185	10,120	5.5%
Total number of young adult carers in UK	173,249	29,128	26,941	229,318	5.3% (UK average)
Total as % of all young adult carers in UK	75%	13%	12%	100%	

Source: Calculated by the authors from Office for National Statistics Census 2001 data.

Table 3.2 also shows that one quarter of all young adult carers in the UK (56,069 people) are providing care for more than 20 hours per week and almost 27,000 of these (12% of the total) are providing care for more than 50 hours each week.

Table 3.3 provides a breakdown of the young adult carers population by two age bands available in the 2001 Census (18-19 and 20-24). These figures will be important to policy makers who need to know how many young adult carers of different ages there are in the four UK nations, by hours spent caring each week.

Table 3.3: Number and proportion of young adult carers aged 18-24 in the UK, by age, country and hours caring per week

		1-19 hours	20-49 hours	50+ hours	Total number	Total %
Aged 18-19	England	38,341	6,053	4,661	49,055	21%
	Wales	2,784	479	338	3,601	2%
	Scotland	3,910	947	527	5,384	3%
	N.Ireland	2,112	466	275	2,853	1%
Aged 20-24	England	102,562	16,494	16,910	135,966	59%
	Wales	6,891	1,218	1,352	9,461	4%
	Scotland	11,507	2,256	1,968	15,731	7%
	N.Ireland	5,142	1,215	910	7,267	3%
All young adult carers aged 18-24		173,249	29,128	26,941	229,318	100%
All young adult carers as %		75%	13%	12%	100%	

Source: Calculated by the authors from Office for National Statistics Census 2001 data.



Twenty-seven percent of all young adult carers are aged 18-19, and 73% are aged 20-24. Focusing down a little, the data show, for example, that there are 4,661 carers aged 18-19 in England who provide more than 50 hours of care per week, and another 16,910 carers aged 20-24 in England who provide more than 50 hours of care per week.

In total, there are 290,369 carers in the UK who are aged 16-24. Identifying the number and characteristics of young carers aged 16-17 and young adult carers aged 18-24 who are most heavily involved in caring (caring over 20 hours per week, and particularly those who are caring for more than 50 hours each week) is important for policy and service planning purposes. This is a reliable indicator of 'need' in that research on young carers (aged under 18), and Office for National Statistics and other research on adult carers, shows that carers who provide the longest hours of caring each week are those most likely to experience impaired physical and mental health, stress, relationship difficulties and experience restrictions in their ability to participate socially and fully in society, take advantage of education, recreational and leisure opportunities, and are those most likely to need services and support in their caring roles and to meet their own needs (Becker, 2008; Becker and Becker, 2008).

In future, demographic and other changes (for example, the ageing population, the growing number of people with physical and mental impairments able to live in the community or in their own homes; the growing number of babies surviving pre-term births who go on to have care needs; and the growth in the number of children with emotional and behavioral difficulties) will exert a strong *demand* for informal family care, some of which will fall on the shoulders of young adult carers. Thus, it is likely that, over time, more (not less) young adults will be drawn into a caring role. At the moment, five out of every 100 young adults aged 18-24 are carers. The 2011 Census will show how this has changed since the 2001 Census.

Chapter 4 - Managing caring tasks and responsibilities

Young carers aged 16-17 years

The changing nature of caring

Many young carers in our sample have cared throughout their childhood, often starting to care at an early age: *"Caring is the only thing I know and that's what I've been brought up with"*. Our focus group participants reported that they often found their care work both physically demanding (leading in some cases to injuries), and emotionally draining:

"It sometimes gets difficult for me because like when I'm out with me mum doing heavy lifting and stuff like that, there's been a lot of times when I've gone in college and I've just been, I'm in so much pain like I've hurt me back".

"Emotionally I find it really hard, because like when like mum's in and out of hospital and it's like really hard to see her like in that situation while she's feeling down and sometimes when she's got tubes and things on her it's really hard, and then you have to go home and look after your sister and that and then you've got to try and push that aside, because my sister has learning difficulties you've got to try and not take it out on her, and she also gets upset when my mum's in and out of hospital, so it's really hard emotionally".

In cases where caring has become 'institutionalised' within the family, young carers often place their own needs second to those of the person they provide care for: *"Your family comes first and then school or college, well with my life anyway, and then you're right at the bottom, you're kind of the last thing you have to think about"*. Large scale research (Dearden and Becker, 2004) found that as young carers get older they often take on more caring roles and responsibilities which are more personal/intimate care-related as well as responsibilities for household management. Many of the project workers we surveyed confirmed that there was *"Explicit or implicit pressure [on 16-17 year old carers] to devote as much time and energy as possible to helping at home"*. It is not surprising, therefore, that some young carers in our focus groups also acknowledged that their caring roles had increased around the age of 16, partly because their parent(s) had greater expectations of them and what they could and should do in the home:

"she relies on me to do more things to help her with everything... Since I turned 16, my mum's relied on me so much since I was like seven... she just expects me to be able to do things because I'm in college and I have like, I finish like 20 to 1, and, or I have like free periods in the middle and she expects me to come home and do stuff".

"now I've got a lot more stuff for me, with college and everything, so I actually have less time, and my mum's expecting me to do more because I'm older, but I don't have as much time as I did when I was younger".

As young carers get older, and as the person they support gets older, some young carers have to undertake more 'gendered caring roles' which in the past might have been conducted by parents, other adults or older siblings:

"I have an older brother but things like my mum has to do with my little sister because she's 11 now, it's kind of like there's things basically that boys cannot do, because she's got to that kind of age it's things like nappy changing or getting dressed, or getting showers and things, things he can't kind of do. And my step-dad has got a kind of fear about doing that too because of her age. So there's only me and my mum to do everything like that for her. We can't really leave it for any of the boys to do".



Where a parent's condition was variable and changed on a daily or weekly basis, this often lead to some young carers finding it difficult to plan their own timetable at school or college:

"my mum's ok some of the time and then she's not other times, so it's not a constant this hour to this hour type thing. It's a very kind of hit and miss, which is one of the reasons I find my essays so hard, because I think oh I've got ages and then it's like suddenly I didn't have that time any more because I was caring".

There is also an issue of 'safety' in some cases, particularly where there is parental substance misuse. Whilst there is no evidence from the focus group interviews to suggest that young carers aged 16-17 are any more or less likely to use/misuse alcohol or other substances than other people of the same age, many project workers, however, commented on alcohol/drug taking amongst young carers of this age and raised concerns (Box 4.1):

Box 4.1: Substance misuse amongst young carers aged 16-17: perspectives of project workers

"More seriously however is the safety of children whose parents misuse substances with regards to dangers of needle stick injury, unsupervised at times and the increased incidences of domestic violence within families of parental alcohol use".

"Increased risk of injury due to tiredness/young carers at statistically higher risk of accidents in home; Potentially less supervision of young carer, hence greater vulnerability; Vulnerability due to harm from sources other than domestic accidents eg internet, substance misuse as result of reduced supervision".

"There is a risk of self medication for stress etc by using drugs or alcohol, especially if the cared for is dependant on drugs or alcohol themselves".

"Young carers that we have encountered seem just as likely to have used alcohol, tobacco or other drugs as their peers might; indeed, they often specifically talk about these things as an escape from their stresses. However, it does seem to be the case that they tend not to engage in these things so often, probably due to lack of time and opportunity as much as anything else".

"Medication that is used by the person they care for can be easily available and so more accessible to the young person than normal. The young carer may not be challenged over their use of alcohol or other drugs by the parent/s if they are not in a position to do so".

"The use of drugs or alcohol is apparent in some young carers particularly those who care for parent(s) suffering from addictions. However on the other hand a number of young carers have diverted away from this lifestyle under the same circumstances as they have witnessed the damage that can be done. In general at our project there has been very few incidences of late".

The 'positives' of caring

Our sample of 16 and 17 year old carers reported a range of positive outcomes that they associated with caring for a family member. This is significant because much of the existing research evidence on young carers has highlighted the negative outcomes of caring on children. In this study many of the young people wanted to talk about and emphasise the positives. They told us:

"Caring is a good responsibility because in a positive way you're grown up, so you kind of realise some of the difficulties that you might end up in later life. So it kind of prepares you in a sense".

"You feel like you're paying your mum or your carer, for what they did when you were younger, they looked after you when you were younger, now you're sort of doing the same for them".

"Being as close as I am to my family, that's another thing that's really a positive, being really close to my family, because not many teenagers are I don't think".

"Well it's kind of a positive sometimes and a negative in other ways. Since I've been a carer I've like become more level headed and stuff, and I take things more serious and more like, more responsible. And I find that good in some situations and I think that's quite positive. I don't always follow the crowd and stuff".

"Like the skills you gain from it, like being really patient and just being quite sensible, they're quite useful in a lot of other situations, not just your caring role".

It is important that services and support for young carers acknowledge that caring can bring 'positives' to young carers. Interventions will need to accentuate the 'positives' whilst reducing the 'negatives'. These 'positives' can also help young carers to build their resilience.

Young adult carers aged 18-24 years

The onset of caring

Some young adult carers in our sample also started caring from a very early age, whilst at primary school (aged 5 or below) and continued caring throughout their childhood, whilst others started caring much later on, at age 17. The majority of our sample started caring whilst they were at primary school with nine of them being aged 6 or under. In contrast six of the sample started to care when they were aged 15 or above, during which time they would have been experiencing many of the challenges of transition between adolescence to adulthood. Of course, there will be some young adult carers who start caring between the ages of 18-24, however none were in this particular sample. Despite this limitation our sample includes 2 young adult carers who began caring aged 17, and 6 young adult carers who started caring much earlier, *all of whom had never been in contact with any young carers service beforehand.*

None of those interviewed had regarded themselves as a carer until this was defined for them by someone else, most often a health or social care professional, teacher or young carers service. For example, one participant said it was only when she received counselling at college that she became aware that she was a carer despite having lived with and supported her mother, who had mental ill health, for many years: *"...I've never been identified as a carer by anyone you know official, I've never really thought of myself a carer, I mean you know I've been very aware you know my mum was manic depressive and I sort of parent her but I never thought of it in carer terms really".* Similarly, Kyle began to do caring tasks for his mother from an early age and did not regard himself as a carer, rather he saw this as *"helping at home and looking after the family"*, that was until he was referred to a young carers project at the age of 13.



Kyle – caring for his whole family

Kyle is 18 and lives with his mother and three siblings aged 10, 13 and 16. Kyle recalls that he was about 4 years old when he first began to help his mother with domestic and household tasks and this has built up over the years due to his mother's health conditions and his brother's special needs. His mother became physically disabled as a consequence of domestic violence, such that she now has limited mobility, a hearing impairment, balance problems and fluid on the brain. Kyle's brother has dyspraxia, asperger syndrome and curvature of the spine. Kyle is highly protective of his family and has assumed the role as 'head of the household'. He has very heavy caring responsibilities, feeling that he is never 'off duty'.

Kyle missed a lot of schooling which he now regrets as he thinks he was capable of achieving more. He is due to start a new job shortly as a chef in a nursing home and is pleased that his work base is so near home so that he can be on hand if needed by his mother.

Kyle has received support from young carers services and has valued this highly, particularly because of the emotional support he receives. He is now a volunteer at the project as the service stops when young carers reach 18. Through the project he is studying for an NVQ in health and social care. Kyle was unaware of adult carers support services and has never received a carer's assessment. As for the future, Kyle would like to go to university and to travel but he thinks these ambitions will not be achievable because of his lack of qualifications, financial pressures and his family responsibilities.

Who is being cared for?

The majority of young adult carers in our sample were caring for a mother (18). The rest were caring for a sibling (5), a father (2), a grandparent (recently deceased) (1), an uncle (1), a partner (1) or siblings (1). Our sample did not include any parents caring for their own child who had an illness or disability.

Five participants (20%) in our sample were caring for at least two people (both parents; a parent plus a sibling, a parent and her two siblings) with one of these caring for three people.

Why are young adults caring?

There were a number of factors as to why the young adults in our sample were performing caring tasks for a relative(s) and these included: the family structure, their position in the family, the quality of the relationship with the person being supported, and the extent to which that person was receiving or accepting services or support from others, either formally or informally. In over half of the cases ($n=15$) the head of the household was a lone parent and so there was either no one else to care or the majority of the care had fallen onto the young adult carer as the eldest daughter or son. In about a third of cases ($n=7$) there were two parents in the household and in these cases the amount of caring being undertaken by the young adult carers was generally lower in terms of hours spent caring, with one exception. The remainder of our sample were living independently or with another relative.

The people that were being supported by young adult carers in our study had a broad range of care needs due to physical ill health, disability, mental ill-health and alcohol and substance misuse. Some were receiving a range of specialist health and/or social care services whilst others appeared not to be, bar contact with their GP. In many cases our young adult carers identified unmet needs of the person they supported, help for which would have reduced the amount of caring they were required to do. For example, Carla, mum of one, has to accompany her mother every time she goes out anywhere in her adapted vehicle because her mother cannot get her wheelchair in and out of the car. An additional piece of equipment would

overcome this difficulty. In some instances the person receiving support was reluctant to accept help from an external agency, preferring their own son or daughter to do this. For example Jodie, aged 24, said of her mother who has severe epilepsy:

"I'm trying to get someone like a more professional carer that can be with her even more than I can, because obviously soon I'm not going to be able, I'm expecting another baby so I'm not going to be with her as much, and it is harder getting down there [every day] as much as I do because I'm living the other side of town from her, but she's funny about having someone else do it, having a professional carer, she wouldn't want that, a stranger in the house".

What was clear from many participants in this study was that they were unaware of what help may be available to support their relatives, how to access it and who supplies it. It was often difficult for our participants to advocate on behalf of the person they care for or suggest to them that they seek extra support which in turn might reduce their caring responsibilities.

The type and frequency of caring tasks

Each participant was presented with a list of 35 potential caring tasks that had been derived from previous research literature on young carers and adult carers. They were asked to identify whether they performed any of these tasks 'sometimes', 'a lot of the time' or 'never'.

Two thirds of our participants said they performed household tasks 'a lot of the time' (cooking, cleaning and shopping). Whilst undertaking such tasks is probably not unusual for young adults as it is more expected that they will contribute to the running of a home what was more unusual was that just under two thirds were providing emotional care 'a lot of the time'. This consisted of keeping the person being supported company and supervising them ('keeping an eye on them') – this was the task that many participants found particularly arduous and which restricted their participation in other life events and activities. About a third of our participants were providing practical support, for example paying bills, filling in forms and writing letters or emails. Just under a third of our sample were providing personal and intimate care 'a lot of the time' which included helping the person they supported to wash or take a bath.

In addition to the roles and responsibilities that they frequently undertook, many of our sample also had to perform a range of these and other caring tasks 'some of the time', for example administering or reminding the person they supported to take medication, preparing family meals, collecting library books or special foods, caring for siblings including taking them to and from school, taking the person they supported out, giving medication etc. For example, Kyle, aged 18, who cares for both his mother and disabled brother summarised what he did for his mother:

"The biggest thing would be keeping my mother company, somebody there for her, making sure she's safe, make sure she's happy, she's got what she wants basically and around that it would be washing her, dressing her, make sure she's got a meal if she wants a meal or a snack, she's happy to feed herself, she's got no problems with that, moving her from one room to another, if she wants to sit up or lay down, from the living room to the dining room for food...I do all the cooking, I do the cleaning for her, for the simple fact the others can't cook anyway".

There was evidence that some young adult carers have substantial demands placed upon them, in that they perform a number of caring tasks 'a lot of the time' and many other tasks 'some of the time'; whilst other young adult carers are having to perform a lot of caring tasks 'some of the time' and others 'a lot of the time'. This means that many young adult carers in our sample are finding themselves performing a range of caring responsibilities that take up a considerable amount of their waking (and sometimes, sleeping) hours and, therefore, it is unsurprising that they often identify that one of the worst aspects of caring is having so little time for themselves and the necessity of juggling competing demands, or having to plan their lives carefully which inevitably inhibits spontaneity. Crisis points can also prove



to be very stressful for young adult carers, for example Kelly, caring for two parents, said how hard it was to cope at these times:

"...because it's like if my father's drunk and my mum's cut herself at the same time we've got to try and cope with the two of them, and it's kind of hard because I don't want to leave my sister, even though she's 18, I don't want to leave her with my father and go down the hospital with my mum, and my father can't even go down the hospital with my mum because he shouts and swears".

Those that have gone away to live at university (n=4) clearly have temporary relief from most of their caring responsibilities except many still provide emotional support, often conducted over the telephone, at a distance and many say they still worry a lot about the person they support. Project workers have encountered young adult carers at university who combine part-time work (in order to help fund their university course) and studying during the week and then they go home at weekends to care, which puts them under considerable strain. For those young adult carers who are studying at university but return home each day to care (n=3), the evidence shows that they have substantial and significant caring roles which appear to be no less time consuming than for those carers living at home who are not in higher education. This implies that those who choose to go to their local university and remain as carers have either no one else to undertake their caring roles or feel they don't wish to disrupt close family ties, and so they return to these responsibilities after their day at university.

The amount of caring

The extent of caring amongst our sample is variable, from a few hours per week in some cases, during holiday times only, or substantial and regular full-time caring in other cases. Participants were asked to quantify the actual amount of care they did but most said this was very difficult to measure because it varied depending on the condition or emotional state of the person being supported:

"I always struggle with this question, even when I was a young carer, because it's a case of quantifying because a lot of... especially in relation to my mum, a lot of it is just mental side of things, emotional side of things, and so it's not always the regular things, it's really hard to contemplate, to put any figure on it, it depends, because a lot of the things like I help care with is like odd jobs like bringing the shopping in, helping with shopping, just like putting things away, like for my dad, like on oxygen, I have to get him things at night and things like that. But really I can't quantify". (Alex, 19 years)

Jodie is pregnant and lives independently with her son. She provides a range of caring tasks on a daily basis, up to 13 hours some days, for her mother who has epilepsy. In contrast Nicky and her sister share the care of their brother (who has autism, learning difficulties and no formal speech) when their parents are out at work, however they are able to attend college, hold part-time jobs and have some time for socialising.



Jodie – being a carer and a new parent

Jodie, aged 24, lives with her one-year-old son and is expecting her second child. She looks after her mother who suffers with epilepsy and anxiety. Jodie began to look after her mother after spending 5 years in local authority care. She provides around 35 hours care per week - mainly doing domestic tasks, general caring tasks and providing a high degree of emotional support and supervision. She wants her mother to agree to receive support from a professional carer but her mother is very resistant to this.

Jodie left school at 16 with GCSEs. She went on to attend a training centre but left after a while due to the demands of caring for her mother. No one was particularly supportive towards her at college although they knew she was a carer. Jodie then had a number of jobs in caring type roles but has been out of employment for the past three years. Ideally she would like to spend more time at home, socialising and being with her own family.

Jodie received support from a young carers service from when she was 17, moving on to a new 18 plus service. She has enjoyed social activities and benefited from advice and support around debt issues. She uses the service as a reference point and likes having someone to turn to when she is in need of support. Her regret is that this service does not provide activities or trips because she feels she needs more opportunities for a break, to socialise and have fun.

Nicky – choosing to live at home

Nicky, aged 18, lives with her parents, younger sister and brother. Nicky's 13-year-old brother has autism, learning difficulties and no formal speech. He attends a special school but is not in receipt of other services or supports.

Nicky's parents both work full-time shifts and as a consequence Nicky and her sister have to assist with caring for their brother after school and at weekends. Nicky has a very close relationship with her brother as a consequence of caring for him. On the downside she finds that caring restricts her opportunities to socialise, it can make her tired as her brother often wakes early, and she finds that dealing with the reactions of other people when she is out with her brother can be difficult.

Nicky is at college studying for A levels. She plans to go to university afterwards to study sociology and the media. She is adamant that she will stay at home and attend a local university because of her close relationship with her brother, despite her parents supporting her to move away.

For the past 5 years or so Nicky and her sister have been attending a young carers project. She has found the ongoing support from the project extremely helpful and values the trusting relationships she has built up with staff. She was recently involved in helping to secure additional funding for the project. However, official support from the project will cease when she becomes 19. She has no knowledge about what support would be available for her through adult carers services.



Whether the amount of caring actually increased once the young carer became 18 was variable. All of them described having an increasing number of *other* demands on their time be it to do with education, jobs or personal relationships so that they felt more squeezed by the necessity of having to care for someone. For those looking after siblings, the amount of caring often decreased as their sibling matured and was able to do more for themselves and, of course, those who lived away at university were doing less physical caring than before. In other instances, where the condition of the person receiving support deteriorated, then the amount of caring increased unless adjustments were made to care packages or support materialised from other family members.

Daniel – less caring responsibilities as his sister gets older

Daniel, aged 18, lived up until recently with his parents, older brother and younger sister. He is enjoying studying at university although he likes to return home on a fortnightly basis. He has helped to care for his sister since he was aged 12 years. She has autism, Asperger Syndrome and learning difficulties. Due to the presence of other family members, responsibility for supporting his sister has been shared and this has made it much easier for Daniel to move away to university and hold down a part-time job. Daniel does not think his school life or health have been negatively affected by caring although he has found his sister's mood swings and behaviour quite difficult to cope with at times. Of all the caring tasks Daniel does for his sister he would prefer not to give her medication as he worries about the responsibility.





There was some evidence that young adult carers were expected to take on greater responsibility for caring because they were seen as more mature and able to cope with it. For example, one participant said about her mother, who has a personality disorder and suffers with anorexia and bulimia:

"I think she's [mum] become more dependent because she's seen me more as an adult now and so she's treating me less as a child and now relying on me more...she's always questioning me and asking me for choices because she sees me as a wiser person if that makes sense, so actually she feels like I should be helping her more". (Georgia, aged 18)

Georgia - studying to be a doctor



Georgia is 18 years old and has helped to care for her mother for the past 10 years. Her mother has a personality disorder, bulimia, anorexia and a physical disability. Georgia's parents divorced a few years ago and although Georgia lives with her father, who is now retired, she would normally visit her mother on a daily basis and be in regular contact by phone. Georgia thinks that her caring responsibilities have increased with age as her mother has become more dependent on her, particularly about decision-making, which she finds very stressful.

Georgia recently left home to start a medical degree at a nearby university where she is thriving on new challenges and making new friends. Her degree choice was greatly influenced by her experiences as a carer because she had had frequent contact with doctors, not all of it good, but she is determined to make a difference to the lives of others. A local young carers project has been a very important source of support for both Georgia and her mother for the past 10 years. Recently the service got additional funding to develop a young carers forum for those up to 19 years and Georgia has had some involvement with this.

Variables that seem to influence the level of caring by any young adult carer include: the health and needs of the person being supported; the care package in place and any 'gaps' in provision; the degree to which the person receiving support will accept services; and who it is that receives care. Project workers thought gender played a role here in that female young adult carers are more likely to be expected to care than their male counterparts and that females undertake more of the caring even if there are other young adult males in the household.

Young adult carers helping to care for siblings, as opposed to looking after parents or other adult relatives, generally had lighter caring loads because it was shared with other family members and it was associated with less negative outcomes. However, in a few cases where young adult carers are looking after siblings because either the parent(s) or the actual sibling had elected them as the main carer, there was evidence of significant impact and some negative outcomes, for example Rosie (aged 18) cares for her two siblings due to parental alcohol misuse and finds this *"... puts massive strain on mine and my partner's relationship. And we're on the verge of breaking up because of everything"*.

The positive outcomes of caring

All too often the positive outcomes of caring can be overlooked or minimised. Many of our sample identified aspects of caring that they valued and which had positive outcomes for them. Often these sat alongside the more negative aspects as well and in some cases and at some times the negatives outweighed the positives or vice versa.

For at least half of the sample the fact that they could help to make a loved one feel better or cope with daily living was positive: *"It's sort of nice to know your help is kind of contributing you know, making someone else happy you know, and you know I like sort of spending time with her, and just helping out and that sort of thing"* (Jade, aged 19).

Similarly, about a third cited the close attachment that they had with their relative as a positive, although this may often be born of necessity: *“Well it helps my uncle out most of all, it makes his life a little bit easier and I think we’ve actually grown closer because of the illness”* (Daljit, aged 21).

Just under a quarter of the sample mentioned that caring had accelerated their maturity, and it had given them the chance to develop skills for coping in a crisis or complex situations:

“I think really it’s helped me to mature a lot, and also if anything it makes you more appreciative of what you’ve got. Things like your independence. Those two things. Because you do have to be a lot more independent”. (Alex, aged 19)

“I would say it’s kind of helped me deal with more things outside. So I’m equipped to deal with sort of, I don’t know situations where people get stressed out or annoyed, I just see the bigger picture and get over it sort of thing and just move on”. (Sam, aged 19)

Young adult carers developed useful life skills through caring, for example home care, cooking and dealing with officialdom:

“I guess it’s made me learn how to keep house as such, you know, because I don’t know how much, I mean I was like 15 or 16, you know, when I moved back to live with my mum, so I was old enough to do, but I don’t know how many 15 year olds or 16 year olds there are that know how to do, you know, cook proper food, I don’t mean whack a pizza in the oven, it would be like proper meals, and care for the house, look after the house, know how a house runs and everything”. (Carla, aged 19)

The majority identified the development of empathy, caring, sensitivity and other positive attributes: *“It’s given me a lot of insight, emotional you know receptiveness, yes very emotionally receptive to people and I feel that that’s very important, so that’s a positive”* (Charlotte, aged 19). In addition a few said they had a better understanding of disability and discrimination than their peers and this meant they were more accepting of difference and less judgemental:

“It’s given me like, I suppose it’s given me a good head on my shoulders because it’s made me like understand what it’s like to be a carer and to look after disabled people, it’s made me not discriminatory against like disabled people or anything like that and it’s kind of opened my eyes to a new kind of... new experience and new like types of people”. (Ellie, aged 20)

Finally, for some of our sample, caring had directly affected their qualifications or career choice, be it consciously or unconsciously, and for some this was viewed as extremely positive rather than restrictive. For example, Katie is completing a degree in social welfare and her future career is likely to be in this field. She thinks that this would not have been the case had she not got the experience of caring for her brother, who has cerebral palsy, and the voluntary work she does at a her brother’s special school and for an adult carers sitting service.

Caring and health impacts

The majority of our sample of 18-24 year old carers identified that caring had an effect on their own health and that they experienced negative health outcomes directly related to caring. These included:

Negative emotional well-being: worry, stress, anxiety, depression, anger, upset, resentment, and resignation were the range of emotions experienced by many of the young adult carers in our sample. For some, the combination of these emotions was overwhelming; take, for example, Rosie, who is caring for her two siblings:

“I’m always angry and I take it out on my partner a lot, I’m always just stressed out because of the kids. I get upset a lot of the time, just, I hardly ever laugh...Some days I can be alright, and then the rest of the time I’m just stressed out, upset, just an emotional rollercoaster. And I think to myself I wouldn’t be like this if the strain would go, meaning the kids...”



Many young adult carers often worry about the person they care for and this worry does not dissipate when they manage to take a break from caring: *"... there's also like the fear in the back of your mind that when you go out, you leave, and you know that they're not very well, that something might happen to them"*. (Lauren, aged 19)

Physical ill-health: tiredness, exhaustion, back-ache, and being prone to colds and ulcers were all identified as physical impacts of caring, however they were far less frequently mentioned by our sample than were the negative emotional impacts from caring. Project workers said that young adult carers often neglect their own health and that some are overweight due to a poor diet and a lack of time to exercise. They also identified that some young adult carers engage in risk-taking behaviour such as unsafe sex, drinking alcohol to excess and taking drugs. However, it was also acknowledged that many young adults without caring responsibilities equally take risks and experiment. The pressures of caring combined with strained family relationships and isolation and/or bullying were thought to make young adult carers more prone to misuse alcohol or drugs as a form of 'escapism'. This warrants further investigation in future research.

Some young adult carers had their own health needs that were *unrelated* to their caring roles but which brought additional pressures to bear. These included those conditions that were congenital (blood disorders, joint problems etc) as well as learning difficulties or sports injuries. For example, Katie (aged 20) has Chron's disease (a chronic bowel condition) that requires hospitalisation from time to time but nevertheless she provides regular and substantial care for her 17-year-old brother who has cerebral palsy: *"...I know when I get stressed the Chron's flares up. When I was younger I used to suffer from migraines when I was quite stressed out, but luckily I've outgrown them"*. Another participant, caring for her mother, has lupus, an autoimmune condition that affects her skin, hair, eyes, muscles and heart. The presence of ill health can make caring more difficult, tiring and stressful for the carer and their own health needs should not be overlooked.

When caring ends

Bereavement and the death of the person being supported, whilst leading to the end of current caring responsibilities, can leave young adults with needs that require resolution such as emotional support or counselling, making practical arrangements following a death, change of house tenancy, securing appropriate benefits, and continuing with or making new plans for their future education, training or employment. These young adult carers experience a different type of transition whereby their role and in some cases their identity, which has been tied up with caring, have changed requiring them to adjust to a different lifestyle and family circumstances as well as adapt to their loss. Only one participant in our sample had ceased caring due to bereavement. Sarah (aged 18) had lived with her grandmother since birth and took on caring tasks for her grandmother as her health deteriorated three years earlier. During that period Sarah missed a good deal of school, which impacted on her examination results. She is now learning to cope on her own with some limited support from extended family but is no longer eligible to attend a young carers project for formal support as this stops for those aged 18 years and above.

Chapter 5 - Education: school, further and higher education

Young carers aged 16-17 years

School as 'sanctuary' or 'misery'

Almost all of the young carers aged 16-17 in our focus groups were at school or college. For some, going to school was an important 'escape' from caring: *"I used my education as a way of blanking out the fact that my mother was ill...what I do is put my head in a book, and just reading and stuff like that"*. Some young carers talked about their resolve to do well at school: *"Caring makes me fight harder to get where I want, because I know that even with all this responsibility you know I still want to achieve what I want"*. Others reported that going to school allowed them to see friends as they had little other time to socialise: *"I actually like school for the reason that I get to see my friends at school, because I don't really see them at all anywhere else"*. Clearly, in these cases, school provides an important respite from caring which could also compensate for some of the 'deficiencies' in the young carer's peer and other networks. However, there was also evidence that while school can be a form of sanctuary for some young carers, it can be a source of misery for others. For example, some young carers reported being severely bullied at school specifically for being a carer: *"That's why I left school...because of the bullying... being different"*. Many of the project workers we surveyed were concerned about the lack of recognition and support schools give to young carers: *"I feel that the schools could be more sympathetic towards young carers...Schools... should be more aware of the issues young carers face"*.

Supportive and non-supportive teachers

It was clear from the focus groups that young carers' views about school life fell into one of two main camps: those who had found recognition and support (as carers) from school staff or those who had found the opposite – that school staff had failed to recognise their caring responsibilities, and, in some cases, had even 'punished' them for caring.

Those young carers who fell into the first group talked about "supportive" teachers who could be approached and who would listen: *"I could confide in her a lot better, she understood what I was on about"*. In almost every case this was a matter of 'personality' rather than 'policy'. By this we mean that there is no evidence from our focus group discussions that young carers were systematically identified by schools or teachers as carers requiring specific support (policy). Rather, the good relationships that were made between young carers and some supportive teachers were more to do with them 'getting on' (personality). This was confirmed by some of the project workers who responded to our survey:

"We find the schools have difficulty in identifying any young carers... and when they are identified, little or no support is usually offered. Seems to depend on who identifies a young carer and if they have an understanding on what to do with the information... I have no experience or knowledge of any of our comprehensives supporting an individual because they are a young carer during the transition".

In other cases, unfortunately, there was strong evidence that young carers had their needs as carers ignored by teachers and schools, and in the worst cases, had actually been punished for caring, intentionally or unintentionally, by being given after-school detentions for arriving late or failing to do homework on time (when these had been related to caring responsibilities). Most schools didn't know when a pupil was a carer, as two carers told us: *"They didn't know at all. They never asked me why I was behind with my homework or anything like that"*; *"They kind of assumed that you were lazy or stuff like that, they never really asked"*. Project workers also confirmed that most of the schools that they were in contact with failed to recognise young carers:

"...the majority of schools are not taking responsibility for recognising the roles young carers play at home and are therefore not making reasonable adjustments to assist young carers fulfil their potential".



"The main challenge so far has been establishing good links with secondary schools and colleges to raise awareness about the needs of this group".

Sometimes schools 'found out' in the last year of secondary education, by which time it was often "too late" for young carers to be able to experience the benefits of a positive and supportive school environment. Many projects identified how schools could improve their response to (known) young carers, for example one project suggested: *"Be flexible i.e. can phone home. Do coursework at lunchtimes. Supportive and understanding. Raise awareness of young carers issues to all pupils. Have a young carer lead in school and a school young carers policy"*.

Young Adult Carers aged 18-24 years

Positive school experiences

School had been a positive experience for some young adult carers in our sample, particularly where there were other family members who were available to share caring roles and responsibilities. For example, Daniel's schooling was unaffected by caring because he, his brother and parents, all shared the care of his sister who has autism and aspergers syndrome. Similarly, Jade's school attendance and achievements were good, unaffected by her mother's ME, because her grandmother provided lot of support to the whole family.

There were others who found school staff particularly understanding of their circumstances and this made a positive difference to their experiences of and achievements at school:

"... if I had to write up an article on the best school it would be that school, because most schools only get you through the school day to do with the curriculum and all that. They helped me extra-curriculum, and personal life, it's like my PE teacher before he had a stroke, I used to have, I've still got his mobile number and I still keep in contact and all that, so they go beyond the actual teaching side of it". (Peter, aged 19)

"One teacher was really, really good, she was my registration teacher, she was awesome, she knew the situation, she was my health and social care tutor as well, so she was amazing with helping me, she was always there with a cup of tea for me and talking things through". (Katie, aged 18)

One participant received good support in school only when his attendance had become problematic. Based on his experience and that of other young carers, he told us that:

"I don't think there is enough contingency plans in place in schools, my personal experience is ok, your attendance is dropping, they then go how do we sort this?... at some schools they do amazing work with young carers, I know of one where they have young carers groups and they like designated someone to be responsible for young carers, and it does have a big effect, because I know they released a song about young carers, and things like that, and that was all done through school and I could never of imagined anything like that at my school". (Alex, aged 19)

Parental encouragement and positive attitudes towards education were important factors that also influenced young carers' school attendance and achievement. For example Carla, who cares for her mother, recalls: *"I don't remember I ever missed it [school] because of caring, because my parents always brought me up to believe that education was very important. I don't think they would have let me [miss school] to be honest even if they needed it I don't think they would have let me, because they were like you go to school"*.

Poor school experiences and achievement

Although all the young adult carers in our sample had left school it was important to understand their experiences of school and the consequent impacts it had on them since experiences and attainments at school often lay the foundation of what can be achieved later, whether this be further or higher education, training or employment:

“There’s a big difference between how different schools treat and support young carers, because in some schools they’re excellent, but then there’s some schools that are absolutely atrocious, so many young carers, and I’ve been on the verge myself, of just because of the pressures at home thinking what’s the point of school, that comes second, I care more about things at home, and then because they don’t get the grades at school they can’t go on and get A levels and then go on to university, and it means that a lot of young carers who have definitely got the ability and potential to go onto university have been denied it because of the problems in school, because of people not understanding the problems and their situation”. (Alex, aged 19)

About a third of our participants had negative experiences at school that took various forms:

A lack of understanding from school staff about young carers’ roles and responsibilities at home and why they were sometimes late or absent from school or failed to complete homework on time. One participant told us:

“They didn’t understand, they really didn’t take into consideration at all that at home I didn’t have time to do homework or anything, and so like most lunchtimes I’d be in like detention or something, doing my homework, because when I got home it would be like, oh well need to make tea, need to do all the washing up and do all the cleaning... So generally they didn’t give a monkeys that I was caring at home”. (Natalie, aged 19)

Despite government guidance (DfEE, 1999; DfES, 2006) that recommended schools should consider designating a member of staff to have responsibility for young carers, there was no evidence of this within any of the schools that our participants had attended or, if there was, our carers were completely unaware of their existence, and any designated staff were therefore of no help to them.

Bullying: Being bullied at school was an experience suffered by nearly a third (n=8) of all those interviewed, however, not all of this was directly related to caring. Some were bullied due to their appearance, ethnicity, being quiet, or working hard whilst others were bullied because their family was seen as ‘different’ or ‘odd’ or because they were too mature, and in some cases it was a combination of these reasons:

“I got set on fire I did because I was bullied about being different, being overweight, where I was staying in 24/7 looking after my parents, I’d always be eating snacks, chocolates and all that...Lots of people think because you’re a guy why would you be happy cleaning, not going out, not drinking, being happy, their automatic assumption is you’re either bent or just weird, let’s beat him up. The bullying side of it was incredible”. (Peter, aged 19)

“[they’d say] oh sick stuff probably, well...my mum was a bit of a retard and stuff like that, whatever. And then they said something about me and her and I thought...it got to me at the start, when I was about 12 and I didn’t really know how to handle it all, didn’t really know what to do, it really got me into trouble sometimes, really felt like I could put my fist through something”. (Sam, aged 19)



Peter – bullied for being a carer

Peter, aged 19, began to undertake caring tasks when he was about 6 years old due to both his parents being physically disabled. For many years Peter accepted caring as being a normal part of his life and was something he enjoyed doing for his family. He experienced severe bullying at school which he attributes to the fact he was different from other pupils because of him being over weight and because he was a carer. Subsequently Peter moved to another school where he was much happier, well supported and able to attain GCSEs and A levels. After a short spell at college, which did not suit him, he left to work in a security job in a supermarket. Long hours, depression and a recurrent shoulder injury resulted in Peter leaving his job and he has not been able to work since then.

Peter now lives with his fiancée Laura in a first floor flat quite near his family home. He visits his parents weekly but is no longer their carer. Laura is awaiting knee surgery, experiences a lot of pain and has very limited mobility. Peter regards himself as Laura's carer because of her needs for support – he thinks this will be the case long term. In the main Peter is doing a range of caring tasks including domestic tasks, general care, emotional support and aspects of personal and intimate care for his fiancé.

Until he was 18, Peter attended a young carers project, which he enjoyed socially and which helped to build his self-confidence. For a while he enjoyed being a volunteer with the project but due to other demands he has not sustained this. Peter is not in receipt of any adult carers services and is unsure what might be available. Ideally he would like to do a university course in music but thinks this is impossible given the cost, travel distance and caring responsibilities for his fiancé. He hopes that by next year they will have married and completed the renovations to their flat.

Low attainment and attendance: The educational experience of some young adult carers had left them without the qualifications they would have wished for and that some were capable of achieving, and this has impacted on them now as young adults, restricting their opportunities for further education or training as well as affecting their economic potential. This was the case for about a third of our participants and most often low attainment was linked to missing school because of caring, and in some cases bullying was also a factor. For example, David (aged 18) is dyslexic, and currently works in a warehouse. He said that the worst aspect of being a carer was the fact he had missed so much school: *"I think, well I know, I could have done a lot better in school, now thinking, going back from where I am now, if I could do it all over again, I'd do it all over again, I'd go back to school and go to university but it's just one of those things, it's life"*.

Poor school attendance had also made it difficult to sustain school friendships and have a social life, thus creating further negative outcomes. A small number of young adult carers interviewed had learning difficulties, in particular dyslexia, and being absent from school meant they could not get the additional support that they required and this affected their eventual exam results.



David – achievement compromised by caring

David is an 18 year old young man currently employed in a warehouse job on a temporary basis. He lives with his parents, younger brother and sister. Aged 13 years, David took on caring responsibilities for his mother after she suffered a stroke and seizures. She was left unable to walk and relied heavily on David for domestic help, personal care and to look after his siblings as David's father was working long hours. David thinks that because of caring he has learnt to cope with difficult situations and he has consequently matured. The downside of caring was that his schooling suffered due to a high level of absences and this factor coupled with his dyslexia, meant he did not achieve academically, which he regrets.

The perception of project workers was similar to our participants in that they identified that some young adult carers had experienced difficulties at school. They were concerned about the number of young carers leaving school aged 16 with no qualifications. To address these concerns they suggested there should be better training for school staff so that they can identify and support pupils more appropriately; schools should make more flexible arrangements about homework; they should refer on to other services as appropriate; and schools and the careers service should provide high quality advice, which encourages young carers to consider career choices and opportunities beyond caring. Understanding and appropriate support from school staff can make a significant difference, in terms of engagement and achievement, for those with caring responsibilities.

Further (college) and higher (university) education

“Young adult carers have reported to the project a sense of frustration at services, because they feel things are not made easier for them in order to move into or continue with further education. However, we have encountered that most young people are quite driven and do have aspirations”. (Project worker)

Of our 25 young adult carers, just over two thirds were in further (n=9) or higher education (n=7). Of those in further education four were attending college in order to study for A levels and the others were taking a vocational qualification (childcare, access to nursing, animal care or electronics) (n=4) or completing a ‘preparation for employment’ programme. The number in further or higher education was perhaps higher than we had anticipated and this may be attributable to the way the sample was sought. In contrast project staff said they find that often young adult carers are not in education due to barriers that impede them, for example, low family income, no or few qualifications, low self-esteem, teenage pregnancy, inability to leave the cared for person, lack of motivation or time, insufficient support and guidance at school, and a lack of appropriate courses close to home.

A small minority (n=4) of our participants were currently working on a part-time basis in addition to completing further or higher education. Three participants, all aged 18-20 years, were in full-time work and six participants (almost one quarter) were not in employment, education or training (NEET).

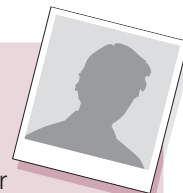
Positive experiences within further education

On reflecting on their experiences of college, current or past, young adult carers currently attending college found it to be a more positive experience than school because of its flexibility, its adult-orientated focus and staff who were more understanding and supportive of young adults with caring roles:

“...they treat you like an adult, you’re not some little kid that’s dashing around.. they’re far more understanding, they are. I mean I had a coupe of days off last week, with dad being in hospital, and mum having to go and visit him made her a bit worse, so I had a couple of days off last week and you know they don’t ask questions about it, I just say, look my mum isn’t well, and they’d be like, that’s fine you don’t have to explain anything”. (Natalie, aged 19)

Natalie – a positive experience at college

Natalie, aged 18, lives with her mother and older sister. Natalie first started to do caring tasks when she was 9 years. Her mother suffers from a number of physical illnesses including fibromyalgia and cataplexy which together cause muscular pain, fatigue, collapse and restricted mobility. Natalie consequently has heavy caring responsibilities both in terms of undertaking domestic tasks and providing personal care and emotional support for her mother. Natalie describes having a close relationship with her mother and feels that due to caring she has matured and become a good listener. However, she finds that the lack of time for herself and for doing her course work are the most negative consequences of caring.





School was a poor experience for Natalie because she was bullied about her weight and she felt her teachers lacked any understanding about her caring responsibilities and the implications this had for her attendance and achievement. Natalie is keen to become an art therapist. She is attending a local college where staff are supportive and understanding of her situation. Natalie has appreciated being part of a young carers project for the past 3 years. Meeting other young carers who live in similar situations and having time for relaxation and fun have been very important to Natalie. She has recently 'moved up' to a young adult carers group, which is under development, and she is enthusiastic about the help the service can provide and the social contacts she will have as a consequence.

The support and understanding from college staff was highly significant for some of our young adults, for example Becky described how she was sustained and supported during a crisis period when her mother had to be in hospital for ten weeks due to mental health difficulties:

"...we had lots of different tutors and my main, well the course like coordinator, she was fantastic with me, she changed into like my second mum kind of thing ... I don't know what I would have done without her really...I didn't have any money and they would give me money each week so that I could get my food and they made sure I ate when I was in college, just things like that and [they helped] if I had any sort of problems whatsoever".

Many who had been bullied at school found this not to be the case at college and indeed thrived on making new friends there. One participant, now studying at university, described how she had left school at the age of 12 because of being bullied, but, after two years of home tutoring, she attended a local college where she completed her GCSEs and A levels. The support of college staff and a helpful student counsellor had enabled a positive outcome for this young woman.

Another participant who had left school with no GCSEs and who cares for both parents has found college to be an extremely positive experience because it has given her the chance to socialise and see her friends, which she would not otherwise be able to do, and because she perceives she is getting the necessary support to achieve:

"And like the teachers are really supportive as well, because obviously now because as I'm getting higher the work is getting harder, and being dyslexic as well it's not easy. So we do have like separate tutorials and they're like how are you going? how is things? because of the house and that". (Kelly, aged 20)

Negative experiences of further education

There were a few young adult carers who had left college prematurely without completing their intended qualifications. Factors that had influenced this decision included: the competing demands of caring and studying, problems with the actual course or training/course provider, or pregnancy. For example, Jodie, mum of one, was doing key skills at college but left when it became too difficult for her to care for her mother and attend college. She said staff at college had been aware of her caring responsibilities but seemed uninterested and unsupportive. She went on to do a number of caring jobs with children and adults that she enjoyed before becoming pregnant.

Higher education and caring responsibilities

Young adult carers at university have to balance caregiving with their academic studies and learning. Some do this by 'caring at a distance' and returning home at weekends or holidays to provide care to a parent or other family member. Other young adult carers balance care and study by continuing to live at home and travelling to their local university, enabling them to maintain their regular caring roles.

Some young adult carers in our sample had been successful in getting a place at university. In these cases it would seem that a combination of parental encouragement and support

and interest from either a school or college, or from a young carers project or significant other, had facilitated this academic achievement and progression. In addition where parents are themselves more willing to accept services and support from others, this enables and encourages young carers to progress to higher education.

Daljit – combining caring and undergraduate studies

Daljit, aged 21, is in her final year at university. When Daljit was 17 she and her older sister assumed the caring role for her uncle who has diabetes and ME. The need for this followed an incident in the family home that forced Daljit, her sister and uncle to leave. Daljit now balances her university studies with her caring responsibilities; she stays at university for three days per week and has to return home each week to care for her uncle and allow her sister to undertake her studies. Daljit describes having a close relationship with her uncle, enjoying the support and encouragement he gives, and she wants to continue caring for him for the foreseeable future. For her, the more negative aspects of caring are the ways they restrict her social life and her inability to be spontaneous. Daljit has had severe financial problems due to the way her student grant assessment has been calculated. Fitting in part-time work is not an option for Daljit although it would have eased the financial pressure. Daljit wants to go on to complete post-graduate studies however she will have to delay this due to cost.



Caring and degree choice

Seven people in our sample were studying for undergraduate degrees in a range of subjects (sociology (2), law, medicine, consumer studies and marketing, psychology, social welfare) at universities in Nottingham, Brighton, Newport, Edinburgh and Cambridge. Some young adult carers choose subjects at university that were care-related, for example medicine or social welfare. This may be a conscious or unconscious choice. However, others did the opposite and *consciously* choose subjects *unrelated* to caring to open up other career pathways and opportunities. Some said they had chosen their subject because it was something they enjoyed or were good at rather than any obvious link to their caring experiences, whilst for at least three people there was a clear connection between choice of subject and experiences of caring, be they wanting to replicate good professional practice or seek to enhance it:

“...you know I want to help people and I’ve seen the medical side like, all the doctors and things and how badly they’ve treated my mum some of them, some are really good, don’t get me wrong but I’ve seen a couple who, and it makes you want to think, you know I wish I could correct that and I know I’m only one person, I can’t really do that much, but it’s nice to get into the profession and try to do something for someone.” (Georgia, aged 18)

“I think sociology in particular is like the subject of people who have injustices inflicted upon them, a lot of the time, it’s about looking beyond the surface of things and of course with my mum I’ve become very aware of like the failings of the system you know because I’ve been sort of left to pick up the pieces of those things, so I would say that definitely influenced me.” (Charlotte, aged 19)

Katie – choosing a carer-related career

Katie, aged 20, has been fully involved in the care of her brother for many years. She sees this as a consequence of their close relationship, his preference for her help and because both their parents have ill health. Katie’s brother, aged 17, has cerebral palsy. He has high care needs due to the severity of his condition such that Katie provides domestic, general, intimate and emotional care for him on a daily basis.





Although Katie would like more time for herself and less stress, she enjoys caring for her brother, describing it as very rewarding. Indeed her enthusiasm for caring influenced her degree choice in social welfare, which she is currently completing, and her intended future career in carers services. Katie is building up some good experience through her two part-time jobs in an after school club at her brother's special school and as a sitter for an adult carers service.

Katie attended a young carers project for 6 years. Aside from the social aspects she thinks the project helped to build her confidence through activities, particularly drama. She is now a volunteer for the project. She is a strong advocate of the need for an 18 plus carers service and has been involved with attempts to set this up in partnership with the local carers centre. Katie is now planning for her own independence as she recently became engaged and intends to set up home next year. She plans to be close by to her family so that she can continue to be supportive.

Support for young adult carers in higher education

Of the seven young adult carers at university none were aware of any specific carers support available for *them* at their university. Similarly, they were often unaware of local services for carers that might be able to support them because traditionally those carers services have not reached out to university populations. In all but one case none of the students had been made aware, through leaflets or the student handbook/guides, that there was a local carers service that might be able to assist them. One person had remained in touch with a young carers project back in her hometown, whilst another had contact with the 18 plus service based in a local carers centre at her university town, which she found to be extremely helpful and resulted in her mother getting an assessment of her needs too. A couple of participants had used student services at their university for assistance with issues related to caring, namely student finance and counselling.

There was evidence that support for carers *who are staff* was being taken seriously at one of the universities, but this was not extended to students that were carers, although there is a student support service and counselling service that *all* students can access which provides a broad range of support and/or signposts people onto other services as necessary.

Project workers thought that some young adult carers capable of going to university were unable to do so because of their caring responsibilities, their uncertainty about the application process, obtaining grants/loans and the fact that their families could not assist them financially. Although some workers identified good examples of partnership working with Connexions others thought that schools and Connexions/careers services should provide greater encouragement to young carers/young adult carers in order to enable them to consider further and higher education, thereby increasing their choices, opportunities and economic potential.

Ella – pursuing a career as an early years practitioner

Ella, aged 20, lives with her mother who has suffered with ME for the past 12 years. Although Ella is one of several siblings, it is she who has assisted with the care of her mother and her sister since she was 8 years old. Ella thinks caring resulted in her maturing early and has helped her understand the impacts of disability and discrimination. Because Ella's mother employs her own carers, Ella's main caring responsibilities are to assist with shopping, as well as provide companionship and support for her mother with other daily living activities. Ella was a high achiever at school. She is now employed as a nursery nurse and intends to qualify as an early years practitioner. Her strong desire to work with children, a lack of self-confidence coupled with anxiety about leaving her mother, all influenced her decision to turn down a scholarship at a university outside her hometown.



Chapter 6 - Friendships, relationships, leisure and lifestyle

Young Carers aged 16-17 years

A need for a social life

Like most young people, as young carers get older they want increasingly to be able to go out and socialise, make new friends and enjoy themselves. Some recognise that this is different to when they were younger: *"when you're like 13, 14, you don't want to be out as much, like I was perfectly happy staying in, looking after my family, being with my family, whereas now I want to, you know, I want to go on somewhere after college and go out with my friends, or you know, go and do stuff for me"*. This sense of regret was common in our sample. Another young carer told us: *"It's just like not being able to see friends and always having to be there, and you do feel like you are missing out, you are missing out like part of growing up and going out and seeing life, exploring new things"*.

While most of the young carers aged 16 and 17 in our sample wanted to go out more, they were constrained in this by the growing expectations from their family that they should take on *more* caring responsibilities as they got older. For some young carers, this meant that they had few or no opportunities to socialise: *"I basically have a non-existent social life, because there's so much time spent caring that there's not really time for yourself"*; *"Well I haven't really had a relationship for ages because I don't go out anywhere a lot. Like some of me friends they'll go out like most nights and not do anything, whereas I just stay in just in case me mum needs me"*.

Some young carers want desperately to get out and meet people, and to form *close* relationships: *"I'm sort of after a girlfriend at the moment, because I feel like I sort of need the companionship"*. Half a dozen young carers projects told us that there was evidence from their projects of some young carers, especially women, getting into close and intimate relationships prematurely, or getting pregnant, related to their caring roles:

"Their [female young carers'] need for affection and attention can be overwhelming and can lead them into potentially abusive relationships".

"There is also the possibility of them entering into inappropriate relationships, as they may be looking for someone to look after them for a change".

"We have number of young women who became pregnant, not sure if figures are in line with local/national figures or if we have relatively more teenage pregnancies within young carers service".

However, the UK has the highest teenage pregnancy rate in Europe and there is no reliable evidence as yet that young female carers are any more or less likely to get pregnant than other girls of this age or whether this pattern is related to other factors such as class, attitudes and intergenerational patterns of teenage parenthood rather than caring.

Choosing friends carefully

A number of young carers told us that they choose their friends carefully (not necessarily spontaneously), and they will only consider making friends and attachments with people who they think will understand and be sensitive to their caring situation and be respectful of their family:

"I wouldn't go out with someone who wasn't able to kind of understand and take, it's not just me it's kind of like my home situation and my family on board as well as just me, and that's kind of hard sometimes".



Being open with existing friends about caring responsibilities was not always possible for some young carers. Some have tried to keep their caring roles hidden or secret from friends because they are embarrassed or are not sure how people will react:

"I can't invite my friends to my house because I'm afraid they might take the mick out of him [disabled brother], or take the piss out of him. That's how I feel. That's why I don't tell no one, I'd rather keep it to myself".

Others rarely if ever invite friends back to their house:

"it's quite a big thing letting someone come back to your house and seeing your family and your home life, especially if there's different situations there and you don't really know how they're going to react and it's sometimes slightly daunting".

"you don't really want to tell friends about that, you just want to keep it like a happy friendship, and like normal as possible because you haven't got that at home".

Some young carers, especially those living in more remote or rural areas, face an additional barrier to making and maintaining friendships, namely infrequent public transport (See also Becker and Becker, 2008).

Young Adult Carers aged 18-24 years

Loss of personal free time

Half of our sample said that they felt they had insufficient time for themselves. Life for them was constantly busy with little free time, time to be alone or opportunities for rest and relaxation and this was particularly the case for those carers who were providing high levels of emotional care or where they were caring for more than one person. In turn this affected their ability to choose to do activities, to have a social life or to be economically active outside the home. This was illustrated in the case of Becky (aged 20) who said:

"I just find it really hard to do all the time because I mean I'm trying to juggle my own life, like trying to juggle with mum, the house, we've got animals as well, I've got to look after them, then I've got my social life, my work side of life, it's just hard to juggle everything".

In another example a young adult carer revealed that of all the caring tasks she did for her mother, who has chronic asthma, she would like to spend less time keeping her company because of the restrictions this has: *"it's like I'm always with my mum and my sisters, I'm not on my own, it does my head in".*

Restricted opportunities for leisure and a social life

Project workers identified that many young adult carers have limited opportunities for social and leisure activities due to a lack of money and time, and in some cases poor transport links. There was ample evidence from our sample that many young adult carers could not pursue interests or leisure activities that they would have liked to participate in. Their view was that this was due to a combination of insufficient time, money and, for those living in rural locations, a lack of public transport. Two thirds of the sample came from families reliant on state benefits and education grants. Young carers projects, for those that had previously attended one, not surprisingly had been highly valued because of the opportunities they provided for socialising, outings and trips, something that young carers would not otherwise have experienced. For some young adult carers the worry of what might happen to their loved one if they were absent from home (self-harm, suicide or falls) served to curtail their participation in leisure and social activities or it meant that when they were out they were constantly worrying or feeling guilty. The use of mobile phones made going out more feasible for some, knowing that they could be contacted and return at short notice.

Restricted participation in leisure and community-based activities

Participants were asked to identify whether they were able to participate in any types of leisure, recreation or community activities in order to see if they were able to develop interests, keep fit and/or pursue hobbies in addition to their caring responsibilities. Going to the cinema and night clubbing were the activities that our participants most often said they could do. They were least likely to participate in community activities, local politics or faith-based activities. Two thirds of our sample was not participating in any sport, which is of concern given its importance for individual health.

About a third of our sample were able to participate in activities or hobbies of some kind and a quarter of the sample were involved in supporting other younger carers or helping with the development of a new carers service. An inability to take a holiday was cited most often as a regret. Often this was due to a combination of being unable to afford one and the difficulties of going away and leaving the person they supported. Very few of our participants were involved in any community-based or faith-based activities and none were involved in local politics.

The ability to participate in activities was unevenly spread across our sample. Those that participated in a broader range of leisure and community activities were most likely to be university students whereas those participants who were completely excluded had their own children and/or significant caring responsibilities and/or lived in a rural location or were unemployed. This suggests that there are a number of processes at play here. Those young adult carers who had the highest educational attainment (those at university) were able to access leisure and other recreation and activities as part of their 'new life' as undergraduate students – activities readily available, often on campus or locally as part of the student experience. Those least likely to be able to engage in leisure, recreation and other activities seemed to be constrained by two overriding factors: firstly, a lack of disposable income and secondly, heavy caring responsibilities and/or parenthood. Where these combined they created a powerful barrier to participation. Even singularly they were able to restrict participation but this became more marked when they operated together.

Strained and difficult relationships

Strained and difficult relationships were evident for some of our sample in respect of their relationships with the person(s) being supported; with friends; or with starting or sustaining close or intimate relationships with others of a similar age.

Regular and sustained caring for a parent or sibling is not the usual course of events for most young adults; rather, they are seeking gradual independence from their birth families. In many ways caring inhibits this 'normal' pattern of Western developmental progression and therefore it is not surprising that maintaining a close, positive relationship with the person being supported was problematic for a minority of our sample. Over a third (9) of them reported having *strained relationships* with the person(s) that they were caring for. In some instances this was because a parent was abusive towards them or failed to protect them, in other cases it was because the behaviour of the person being supported was challenging and difficult to manage (often siblings), whilst in other instances it was because the act of caring caused resentment due to its consequent restrictions on aspects of the young adult carers' lives. Project workers identified that relationships at home can become very strained at the point where the young adult is trying to assert greater independence and where caring responsibilities are negatively affecting their studies or employment. In a small number of cases, where the onset of caring began in late teens, young adult carers were challenged by the need to accommodate changes that caring brought to the relationship:

"...when she became ill, before that we were, we were really quite close because obviously dad's death brought us very close together and I've kind of always been a mummy's girl but now it's just, now it's just kind of like changed like we, I, don't know the roles have just reversed and I find that really hard to cope with because I'm not used to that, I'm not used to being the carer, well I am a carer inside, but I'm not the one that wants to be caring for their mum". (Becky, aged 18)



The challenge of making and keeping friends

The value and importance of friendships and intimate relationships was expressed by many of those interviewed. Project workers observed that some young adult carers, who have more control over their free time, have got a small group of close friends, whereas others with less time and less self-confidence remain socially isolated. Nearly all of the young adult carers in our sample gave examples of how they had needed to put their friendships second to caring and that sometimes friends did not react well to this or excluded them because of this. For some, bullying had been a feature of their lives at school and this had affected their ability to make friends and trust others now. Young adult carers often chose friends and/or partners who were sympathetic and understanding of their situation. Several participants spoke of the burden of their maturity and how this affected their ability to make friends because it had made them different from their peers and restricted their ability to be spontaneous and carefree: *“Well it is to do with my maturity and my kind of responsible outlook on things, you know I find it very hard to be sort of carefree or inconsiderate, you know, as teenagers tend to be”*. (Charlotte, aged 19)



Charlotte – wanting to meet other carers

Charlotte is 19 and currently studying for a degree in sociology after which she hopes to qualify as a counsellor. She decided to live at home, rather than live away at university, because of her caring responsibilities and her close interdependent relationship with her mother. Her experience of providing care for her mother, who suffers with manic depression, in addition to her own experience of counselling has influenced her choice of degree and career plan. Aged 12, Charlotte left school due to bullying and her own emotional difficulties following an acrimonious parental separation. However, attending a college which was supportive of her needs and getting individual counselling helped her to settle down and achieve the qualifications needed for university entrance.

Despite Charlotte having contact with a range of professionals in health and education over the years she was never referred to a young carers service. She has no knowledge of what adult carers services may be available to her although she would like to meet other carers as she feels they would understand her better than many of her fellow students whose life experiences are so radically different from hers.

Chapter 7 - Income, jobs, careers advice and aspirations

Young carers aged 16-17 years

The financial circumstances of families

One of the key transition issues facing young carers aged 16-17 is money. Most of the young carers who participated in the focus groups lived in families who were living on low incomes and this was also a recurrent theme identified by the 25 projects we surveyed:

"Many of the families we work with are from a low socio economic status and are often lone parents".

"Every service user we worked with had a low income. We needed to source in-kind donations, sponsorship and grants to provide free activities for the group".

While some parents were in paid employment (especially if it was a child that was ill or disabled whereby the parent could get to work if another person contributed to their care), most families relied on social security benefits and many of the young carers at college received Educational Maintenance Allowance (EMA). Some young carers told us that money was so tight that sometimes there was not enough to buy food, and that they and their family could go hungry:

"And I worry about me mum then because she's not eating what she should be eating. It's not like we can eat three meals a day, like you should do, because we haven't got the money to do that... So sometimes I go without food to give it me mum. Do you know what I mean?".

Money (or lack of it) is a real problem in families where there is illness or disability. There is an abundance of research evidence from official and other sources that show a strong association between illness, disability, mental ill health, informal caring and poverty, and social exclusion (Becker, 2008). Young carers' families often have additional costs (because of illness and caring) that also put a strain on finances. For example, every young carer that we interviewed had a mobile phone and this was seen as a critical 'lifeline' for them and their family – enabling them to be on constant call if required. While most teenagers will have a mobile phone, for young carers this was of particular significance and an additional cost. A further additional expenditure for many of these families was on public transport to take the person being supported to medical and other appointments and to do/carry shopping etc. Many of the experiences and needs of young carers aged 16 and 17, and their parent's experiences, are thus linked closely with their material and financial circumstances, which are closely associated with the presence and additional costs of illness/informal caring.

Barriers to paid work

Most of the young carers in our sample did not have paid jobs. Only a couple reported that they had part-time (unskilled) employment. Some project workers also confirmed that most of the 16-17 year old carers they worked with did not have paid employment:

"I have only come across a couple of young carers who have gone into paid work at that age who are sole carers".

"No free time to get a job because of caring role...".

"Jobs are often fitted around their caring schedule so choices are limited".

"Young carers were identified as being NEET in 16 to 19 age range".

To a large extent the reason why most young carers didn't have paid work is explained by the fact that there was very little 'spare' time over and above caring responsibilities, school, college and other teenage interests, to actually go out and find or get a job, or keep it. Some young carers told us that they would like to have a part-time job but it was simply impossible given their caring circumstances.



Drawn to local jobs

Half a dozen projects in our survey observed that many of the 16-17 year old carers they worked with were drawn to local jobs rather than necessarily the best jobs for them:

"Young carers often choose local jobs in preference over a better job, or they choose jobs (especially part time) to work around their caring responsibilities".

"Young carers can have difficulty finding work/further education close enough to home to be able to be accessed easily. They may also need flexi/part-time hours if they have to work around the needs of another person. This can be reflected in the wages that they are likely to attain and the type of work which they enter".

A few wanted to apply for local apprenticeship schemes but felt at a disadvantage compared to other young people of the same age without caring responsibilities:

"If an apprenticeship is like too far away and it's too hard to get to, you could just leave home, but since you have to care for like your parent and that it would be a lot harder to leave home, so have to think more about a local job, so that might make it harder, because someone else would have an advantage because they could just go away straightaway, so they'd go for them and not you".

Drawn to 'caring' jobs

Other young carers aged 16-17 were drawn towards caring-related careers, for example in child care, nursing or health and social care:

"And it involves me mum as well, so it's sort of like I'm doing something that, I wanted to do this anyway, all my life I've wanted to do health and social care anyway, it's just sort of a big part of having me mum there because I've got the experience... I've got the experience because I'm always working at home, I do everything in the house, gardening, cooking, cleaning, painting, making the beds, getting my mum dressed, bathing me mum, everything".

Ten of the projects we surveyed also noted that many of their young carers were attracted to jobs in caring-related fields, and their comments included the following observations:

"They often appear to be drawn to jobs in the 'care' sector as this has been their experience to date. Whilst this may be right for some it is not the case for all young carers, and ends up in some young carers not achieving their full potential".

"Many of the young carers I have worked with aspire to work within the care sector either as a health care assistant, nurse or as a social worker or support worker as for many this has been their lives for a number of years. Sadly others have had no real aspirations for the future and can not see themselves ever being free from their real caring roles".

"Some not at all, but some (especially females) tend to drift into caring type jobs - care homes, child care etc, usually because they know how to do the job, have lots of experience and don't always need qualifications".

Help needed

Many of the young carers told us that they would value information and advice about paid work (particularly part-time work) and help in developing a CV, personal statement and other job-search skills (including interviewing skills). Clearly, at an earlier age, interest in the world of paid work was less important and relevant, but as young carers get to 16+, paid work (and the income it provides) becomes more significant, particularly in low-income families. It also offers an opportunity for young carers to have a break from caring: *"I suppose when you do actually have a job it gives you a chance to go and socialise and it can put your mind off being a carer".*

Many young carers reported that they had had poor career and job-search advice, either through school, Connexions or their local equivalents. Some had been disappointed at the advice they had been given: *"I used to go and see my careers adviser and she'd try and convince me to go and become a piece of cannon fodder and join the army. I want to see the world yes, but I don't want to see it in a box, you know"*.

Key organisations that should help

Many project workers identified the key organisations that they thought should be working with and supporting young carers aged 16-17. They identified education, careers/Connexions, employment services and social care (social services) as being the most important sources of support for this age group:

"The key organisations who could make the most difference to young carers are universal services who have access to all young people... schools, colleges, careers/connexions advisers, youth workers, GPs etc".

"Education, many schools are still unwilling to acknowledge the presence of young carers within their school; Connexions – every young carer should have a personal adviser to help with transition; The Youth Service – so many young people attend a youth club or centre and have good positive relationships with youth workers, this needs to be expanded so the youth workers are aware of services available to young carers they may know".

"Social services – better working between adults and children and families from top to bottom!; Connexions; GPs; Schools/colleges; All social and health care staff".

Young Adult Carers aged 18-24 years

Financial hardship

In common with other research, our study confirms that many young adult carers aged 18-24 experience significant financial hardship as a consequence of caring and living in low income families with illness and disability (Yeandle et al, 2007, Carers UK, 2007). Project workers reported that most young adult carers with whom they are in contact with have complained of financial difficulties. The majority of our sample (n=21) were living in families reliant on state benefits for their income which was causing them hardship, and restricted their opportunities for full participation in everyday life: *"I mean we find it hard because we can't afford a lot, we can only afford the bare essentials. I find it hard because I've got no money to myself, mum finds it so stressful too..."* (Becky, aged 18). There were just two families in which both parents were employed (a sibling was the care receiver in both) and two where the father was the sole earner (the mother was the care receiver in both).

Rosie – a new parent and a carer, living in poverty

Rosie, aged 19, has sole care of her new baby and her brother and sister aged 7 and 12 years respectively. When she was 15, Rosie left home due to parental alcoholism and violence. This interrupted her schooling such that she left without any qualifications and a poor attendance record. She spent time living with friends or in a hostel, managing to pick up casual work in catering or retail. Aged 18, Rosie felt she had no choice but to assume the care of her siblings due to her mother's alcoholism and treatment of the children. Rosie, despite wanting her own independence, was determined that her siblings should not go into local authority care.





Rosie is finding life extremely difficult as she seeks to balance new motherhood with parenting her siblings and maintaining a relationship with her baby's father. Poverty and a lack of family support have left Rosie feeling excluded and unable to pursue work, leisure or social activities for herself or her family. In addition, Rosie's siblings present challenging behaviour, attributable to their own loss and trauma, and this is undermining the stability of this family unit.

Rosie regrets not having the opportunity to build an independent life with her partner and baby. She knows little about her entitlements to services and feels particularly let down by children's services, which she says have not followed through their offers of support. Rosie and one of her siblings are receiving some support from a local project for children whose parents have problems with substance misuse. She is very concerned that her sister has been out of school for some months with nothing else in place for her. Ideally, Rosie would like to train as a plumber if she could get the opportunity to return to college but for now she sees this as a remote possibility.

Young adult carers, dependent on state benefits, spoke of the implications of their financial circumstances and the 'felt exclusion' from their peers. For many it restricted their ability to go out socially, take a holiday or buy personal items like clothing:

"...like when summer comes, like my friends, they all want to do something, but I always have to watch my pennies, I can go maybe next week, but not this week, sort of thing. And it just puts a downer on the rest of them, well if you don't go then we're going to have to change it all around and stuff, and I just feel really bad". (Daljit, aged 21)

"The toughest thing is having no money to go out and buy clothes, I mean I have to wash my clothes every day just so I've got clean clothes to wear again and some are getting too small for me to wear". (Sarah, aged 18)

Educational Maintenance Allowance

Box 7.1: Educational Maintenance Allowance

EMA is a means-tested benefit designed to support young people from low income families to remain in education or specified training programmes. Young people aged 16-18 can claim it and based on parental income they can receive up to £30 per week (England). The benefit is available in other UK countries too.

Virtually all the young adult carers in our sample who had been to college had received an Educational Maintenance Allowance (EMA) and this had been an important source of income for them. What frustrated and dismayed some was when this allowance was under threat because of their attendance dropping due to caring. There was a view that colleges had to be more flexible about this for young adult carers as sometimes their lack of attendance was beyond their control. Some participants described how they had to supplement the family income from their own education allowance because benefit amounts were insufficient for their family's needs or because parents were unable to manage their money well enough. For example, Kelly explained how she has to be very careful about spending her adult learning grant because she needs to 'loan' it to her parents to help pay for household bills as her mother has a tendency to waste money and her father spends his money on alcohol.

There was evidence that many young adult carers did not understand the benefits or income coming into their household as this was seen more as the domain of their parent(s) or relative(s). As long as this attitude prevails young adult carers are in no position to be able to question or seek advice about whether their family is receiving all to which it is entitled.

There was no suggestion either that young carers services had systematically helped young carers to understand the 'benefits maze' or sources of assistance in relation to benefit queries as part of preparing them for the future. This was in contrast to those young adult carers now receiving support from a specific young adult carers service where this advice and information had been very forthcoming and welcomed.

Carer's Allowance

None of our participants were in receipt of Carer's Allowance and less than a handful were aware of its existence. However, the eligibility criteria for this benefit can work against young adult carers who are seeking to combine caring with studying for further qualifications or training. Additional income from Carer's Allowance would help to alleviate the financial difficulties that many of our young adult carers and their families were experiencing and the consequent felt exclusion.

Box 7.2: Carer's Allowance

Carer's Allowance is payable to those aged 16 or over who spend at least 35 hours a week caring for a person getting Attendance Allowance, or Disability Living Allowance (at the middle or highest rate for personal care), or Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension). Carer's Allowance is not payable to anyone in full-time education with 21 hours or more a week of supervised study or who earns more than £95 a week after certain deductions have been made (such as income tax).

Careers advice

One of the key decisions that all young people are faced with between 16-18 years in particular is what future career or work do they wish to do and what necessary training and/or qualifications will they need? At least half of our young adult carers, now aged between 18-24, said they always had a clear idea of what they wanted to do, for example teaching, medicine, law, childcare, art therapy. In these cases they did not particularly value or need careers support. There were others for whom that advice and support was very necessary because they were uncertain what to do and often they were the ones who had no or few qualifications and fewer options open to them. Of these participants some found there was good support from their school or connexions/careers service whilst others found the opposite to be the case:

"Well we had a careers adviser and she was really horrible. And she was like, because I'm dyslexic and I done a slow learning class and I'd done no GCSEs, she was like you're not going to be able to get a job, so you might as well get pregnant, and that really hurt me". (Kelly, aged 20)

"We had a careers advice woman, but I saw her once and that was it, at the start of year 10 like, even 2 years before I left". (Emily, aged 18)

It was clear from our interviews that young adult carers valued good and informed careers advice although their experience of getting this was variable. Some had received useful careers advice and literature whilst at school or college:

"I know we had a careers interview like once, and they usually had little booklets that you could read, to see if university was for you, and you know they were quite helpful. Mainly sort of discussing with each other, you now, like giving advice and seeing where I should go". (Jade, aged 19)

"Just after I got out of college and I was stuck for things to do. I went to Connexions just to see what was open to me and they kind of helped me out for a bit. I needed a bit of counselling as well and I got a bit of that there". (Sam, aged 19)



There were a few in our sample that had been referred on to a young carers project or young adult carers service by Connexions advisers. This suggests that there is some awareness of carers' issues within this professional grouping and that they can make appropriate referrals where they know of a local carers service.

It was rare for any young adults to identify that their careers adviser (or equivalent) had asked them about either whether they had caring responsibilities and if so, the impact and implications of them for studying or careers: *"No they didn't really ask me any questions about it. No they were just like, well what do you want to do?"* (Natalie, aged 19). Project staff also made the valid point that where young carers are missing school they also miss out on careers events and advice provided in schools which reinforces their disadvantage.

Some of our participants spoke positively about the support they had received from a specialist worker at either a young carers project, or a young adult carers worker. The latter was particularly important because young adults, once out of school or college, find it harder to access careers advice and so having this support either to find a suitable course or local job was especially helpful to them.

Full-time employment

Only four participants (one sixth) in our sample were living in families where there was at least one person in employment, with this number rising to six when non-resident fathers are included. The condition of the person being supported and the high number of lone parent households seemed to account for this low rate of employment.

Looking at our young adult carers, three out of the sample, all aged 18-20 years, were in full-time low income work, one of whom was trying to save money in order to fund a future place at university. The low number in employment was partly attributable to the age of the sample – in that the majority were aged 20 years or less and therefore many were still in some form of education or training. However, just under a quarter ($n=6$) of the sample was unemployed, three of whom were not actively seeking work due to their own parenting responsibilities, their own disability and/or their caring responsibilities:

"I want to get a job I do, I won't say I don't because I do, but it's the fact that I'm always worrying about my mum and it's the fact... I just don't like leaving her, because obviously I've been here at times when she's had real bad asthma attacks and I've had to call the ambulance, I know it's silly but I'm used to ringing them, at one point we were calling them nearly every other week, it got that bad and then I just don't like leaving her in case she has an asthma attack". (Emily, aged 18)

Part-time employment

Despite most participants' families struggling on low incomes, just under a third of our sample ($n=8$) had recently or were currently engaged in part-time employment as a means to getting additional money for themselves or their family. The reason that a minority of the participants were in part-time work was attributed to the scarcity of such work and/or the conflicting demands of combining caring with education and part-time employment. Of those that had worked part-time, four had done this in order to specifically save money prior to going away to university as they knew they could not rely on parents for back-up. There was evidence that many of our young adult carers wanted to work part-time either now or in the recent past but this choice was simply not open to them. Besides the financial consequences of this it also meant they were denied valuable work experience which would have benefited them in gaining future employment.



Alex – had to save for university

Alex, aged 19, is in his first year of a law degree and lives away from home. He is an only child. He has been helping to care for both his parents since he was about six years old; his mother has arthritis, diabetes and depression and his father has a heart condition and is diabetic. For Alex the most negative aspects of caring have been the emotional strain and the financial difficulties for the family as a consequence of reliance on state benefits. Indeed prior to university Alex worked long hours in order to raise money to supplement his studies at university knowing that his parents would be unable to assist him with this. On the positive side, Alex considers that his maturity and his ability to be independent were gained because of his caring responsibilities.

Alex was bullied at school, something that he attributes to his caring role and being seen as 'different'. However, he received good support from a form tutor, school counsellor, college tutors and parents. Alex's experiences made him determined to succeed academically. For three years, up until he was 18, Alex received support from young carers services and feels he benefited from the support and, in particular, from the opportunities it brought to him in terms of youth participation in service development at a local and national level. Alex no longer receives any carers' support and feels uninformed about the options available should he need help. He perceives adult carers services are for older carers and that there is a gap in services for young adults like him.

Unemployment

We did not find that any of our participants had given up work to care, which can be the case for older carers (Yeandle et al, 2007), rather there was evidence to suggest that some young adult carers find it difficult to get into employment in the first place. Some of the sample that was unemployed felt very much alone and unsure of how to make progress. Low self-confidence and not having the necessary qualifications impeded their success or they simply felt that combining caring and work was not feasible. Lack of transport was also mentioned as a factor, particularly in rural locations, so that they could not search further afield for work (Becker and Becker, 2008).



Ahmed – aspiring to seek work

Ahmed, aged 23, lives with his mother and 6 siblings. His father passed away a year ago following a stroke. Ahmed, along with his siblings, has helped to care for his mother for the past nine years. His mother suffers with depression and has fits. Ahmed and several of his siblings have a genetic condition that affects their skin and joints; additionally Ahmed is dyslexic and has some learning difficulties. Ahmed feels these difficulties have held him back and that he has experienced a lack of appropriate help or support from school, college and the careers service. He completed a HND in business at college but has been unable to secure employment.

Ahmed enjoys living at home with his family and has no plans to leave. In part this is due to a lack of self-confidence and his previous experiences of being bullied as a consequence of his ethnicity and learning difficulties. He feels safe and secure living at home and likes to contribute to the care of his mother, giving practical assistance with domestic chores, keeping his mother company and helping with the child care of his younger siblings.

Ahmed attended a young carers project from the age of 16 for 3 years. When he was 18 he received individual help from the project where he was supported into a place at college and referred on for social work support. However he remains unemployed and feels uncertain of the next steps to take. He would welcome further support from a carers service in order to mix with others and find out more about his entitlement and other supports available.



There was evidence that those who were unemployed needed support to help them into the workplace and in two cases they were receiving this help from a specific transitions worker for 18-24 year olds. Both young adult carers reflected on the helpfulness of this worker in terms of providing support, advice and information about potential jobs and course opportunities.

Project workers identified barriers that prevented some young adult carers entering the workforce which included: a lack of qualifications, little or no experience of work, their caring responsibilities and no respite arrangements, poor social skills and low self-confidence. They perceived that employers and others often overlook the positive skills and attributes that many young adults develop as a consequence of caring, for example, time management skills, coping in crisis, level headedness, budgeting, and being empathetic. They thought that employers generally needed to have a better understanding of what carers do, be more understanding of their situation and have carer-friendly employment policies in place, including carers' leave and flexible working. They identified that any carers service targeted at this age group had to include the provision of help and advice for those seeking work, giving them confidence in job-searching and interview skills.

Aspirations

Aspirations held by young adults vary widely as a consequence of a number of determinants that include: the aspirations of parents for their children, family income, socio-economic status, ethnicity and self-belief (Gutman and Akerman, 2008). For young adult carers there are additional factors that affect their aspirations – the nature and extent of their caring responsibilities and how long these may continue. Indeed some participants in our study were unable to think long-term about their future because of their existing caring responsibilities. Project workers reported that many young adult carers are very 'present-orientated' and unable to plan ahead. Some sibling carers worry about what will happen when their parent(s) die and the additional responsibilities that may fall to them. However, many of the young adult carers in our sample were able to identify their short-term aspirations. Some hoped to be in work (they expressed specific types of job); others intended to complete their further or higher education; and a few talked of settling down or raising their own children.

Most of the young adult carers, when speaking of their aspirations, qualified these by saying it would depend on the needs of the person they care for; indeed all these young adult carers recognised that what they could do in the future could be mediated by what would be expected of them at that time in relation to the needs of the people they support. Unlike other young people whose future aspirations are often mediated by money and qualifications, young adult carers' futures are also influenced by their caring responsibilities, particularly where they are caring for a parent, rather than sibling, and where there is no other extended family support available.



Becky – delaying her career aspirations

Becky, aged 18, has assumed caring responsibilities for her mother for the past two years after her mother began to suffer from severe depression and anxiety. The responsibility of caring for her mother has fallen onto Becky as her father died 7 years ago; whilst her older sister has left home and helps on a sporadic basis only. Although Becky's mother has been formally assessed and receives medical and some psychiatric support, Becky is providing domestic care, help with household management, and keeping an eye on her mother, for example prompting her to wash and take her medication, as well as providing emotional support and reassurance. Becky finds caring stressful and difficult, leaving her little time for herself. Caring has delayed her plan to go to university to qualify as a teacher. She has compromised her plans by gaining a childcare qualification so that she can work for a few years to save up for university. However, she has been unable to find a job in childcare and has taken a job in a fast food outlet because of the necessity to earn money for herself and her mother.

Becky has now been receiving individual support from an 18 plus carers support worker. She describes this support as her 'lifeline'. She has received two carer's assessments and has recently applied for funding for driving lessons as she lives in a rural location with limited transport links. Being able to drive would reduce Becky's feelings of isolation and enable her to seek employment more widely, safe in the knowledge she could get home to her mother if needs be.

The career aspirations of those in our sample with no or few qualifications to a large extent were relatively modest in contrast to those young adult carers who had done well at school and who were either at further education doing A levels or higher education doing a degree, the latter having the highest aspirations for their future careers and earnings potential. Those at university often expressed themselves in terms of wanting to work in a profession including social work, teaching, medicine, law, environmental health and counselling. The pattern of career aspirations to some extent reflects the pattern of aspirations amongst many teenagers and is associated closely with educational attainment, which in our sample is also related to their caring responsibilities. A key implication of our findings is that if we want young adult carers to have high aspirations about their futures then we may need to intervene early to ensure they get the best out of their education – because of the close relationship between educational attainment and career aspirations.

Chapter 8 - Leaving home and independence

Young carers aged 16-17 years

Thinking about independence

As young people get older they start to think about when they might eventually leave home and get their own accommodation and independence ("freedom"). Some young people leave home at 17 and 18 to go to university, or to set up their own home alone or with a partner. The focus group discussions with 16 and 17 year old carers show that thinking about, and actually leaving home, is difficult if not impossible for some young carers. Some young carers told us categorically that they could not leave home because they had ongoing caring responsibilities: *"I couldn't do that, couldn't leave my mum, no way, no matter what age I am, I'm not leaving my mum, until she passes like"*.

Others told us that they want to leave home when they can, and have their own independence and freedom: *"Oh yes, I'm looking forward to it I am. I know it sounds like I don't care, and I really do care, but I'm going to be able then to have my own freedom, my own rules"; "I'd like to run my own life rather than someone else's"*. However, even where young carers were clear that they want to leave home in the near future, whether they could leave or not was often more difficult, involving discussions and negotiations within the family, as well as being confident of alternative caring sources:

"I would like to move out sometime, but I don't want to do it until I know there's going to be no problems, like for me family or anything, I know that there'd be someone there all the time sort of thing, but I mean if I was to move on like soon, before like that, then I wouldn't want to go anywhere far, like if I couldn't get anywhere like in the street or in the estate then I wouldn't do it basically... I mean I don't like the area I live, but I prefer like if I was going to move out to be somewhere close to home sort of thing".

Many young carers in our sample said that if and when they moved out of their parental home, they would move nearby rather than a long way away: *"if I did actually move I would come back at the weekends to see him"*. A number of young carers in our sample aspired to going to university. Some had decided that this was not possible given their caring roles, and others found the decisions and choices difficult and painful:

"My mum's really quite supportive of me going to university and stuff like that... if I go, but I mean my mum like I said she's really, really supportive of me going and she doesn't want to, you know, but I'm quite hesitant about, you know, it's not just for her, because I've been so close to my family for so long it's really weird thinking not being part of that any more".

Young Adult Carers aged 18-24 years

A challenge for young adult carers

"One of the main issues of concern for young adult carers is the future. Not all young adult carers desire to leave home, however most of them do want more independence and time to explore own relationships and own employment opportunities. This is difficult to mediate with the caring responsibilities. However, it is even more difficult where there are mental health issues and/or substance misuse. In cases like this we have observed the family is reliant on the young carer not only for practical but emotional support. This support is hard to let go of when it has been normalized and the young people feel very guilty to want to disengage from this role at least partially". (Project worker)

Project workers identified that one of the most challenging issues for all young adult carers concerns their ability to leave home as and when they wish. Emotional pressures and demands that some families expect of young adult carers make it especially hard to leave. Project workers find that young women are often expected to continue to care whereas young men, particularly when they have assumed the 'head of household' role as part of caring can find it difficult to relinquish this position. In addition, project workers observed that often professionals tend to assume that the young people want to continue caring indefinitely. Consequently, project workers find that young adult carers either stay at home or live very close by to be on hand, aside from some who live away at university. Feelings of guilt are strongly felt by those who do decide to leave. Those who remain at home can feel trapped in some cases, and unable to take advantage of opportunities open to many other young adults.

The majority (n=17) of young adult carers in our sample were living at home ('co-resident') with the person(s) they care for. However, a minority had gained either temporary or full spatial independence, in other words they were either living away at university (n=4) or in their own homes with either a partner or their own children (n=4). Whilst only two of the sample had ever been in the care of the local authority many had, however, experienced periods of separation from a parent or parents due to hospitalisation, divorce or parental separations that had affected them adversely:

"I used to have counselling for the effects it [caring] was having on me because of the emotional strain it was having, of seeing your mum going into like a mental hospital, staying in there for a month at a time, coming out for a few weeks, then going back in".
(Alex, aged 19)

Choices about leaving home

The young adult carers in our sample who lived with the person they supported were asked if they had a choice about leaving home or not. In some cases they had chosen to stay because of close family ties where interdependence between the carer and person being supported had developed, often over and above a usual parent-child or sibling relationship. For example Charlotte (aged 19) attends a local university, she briefly tried to live in a hall of residence but returned home because of her close bond with her mother, who has mental health difficulties, and her discomfort about being amongst other students whom she perceives to be immature: *"I find home quite safe, I feel like I'd be very stressed out living anywhere else particularly living with students, I couldn't live in a house full of students, it would remind me too much of living with you know mum's abusive boyfriend because of all the drinking and staying up all night and irresponsibility".* Similarly Katie attends a local university so that she can continue to help to care for her brother to whom she is very close. Worry about the person they cared for was a real barrier to some young adult carers leaving home:

"... I was always thinking oh my god like yes it's only London but I think it's two hours away, what if she fell, what if something happened? That's going to take me two hours and the thought of being that far away from her just really scared me, partly because it was like leaving home for the first time and secondly because I just thought god what if anything happened". (Ellie, aged 20)

"Yes I've always thought of leaving but in the back of my head I'm thinking but if I leave and my dad will basically will struggle because he works and when he comes home looks after my mum, it's not going to be easy. But yes I've thought about it...I've spoke to mum about it and she's always saying yes - just leave, leave. You know like, she can't wait or something, we'll be alright, she only says that because she wants my life you know getting back into gear, but when she has problems with her legs and she has a bad day then she calls me, so if I did leave, like half an hour away, and she has a problem and it's bad, it's going to take me half an hour to get to her". (David, aged 18)



Others choose not to leave home in order to protect siblings from assuming a caring role – this was the case for Emily who would not consider leaving home because of the impact that this would have for her younger siblings, particularly now her mother, who has severe asthma, is pregnant and will need more support in future:

“Because she’s getting worse and it just isn’t the time I don’t think to move out and leave my little sisters to look after her because I mean they’ve got their own...like they’ve got things to do, one’s got school and the other has to work at home because she’s left school because obviously she was getting picked on, so she’s left school so she’s got that to worry about and it just isn’t fair to lumber it on my sisters I don’t think”. (Emily, aged 18)

In a number of cases young adult carers simply had no choice about leaving home either because of their financial circumstances (for example, if they were still at college, unemployed or earning a low wage) and/or because of their caring responsibilities alongside pressure that the person being supported brought to bear. Becky currently has a low paid job and money is extremely tight in the family. She reflected how these circumstances, her mother’s mental health, combined with her own feelings of guilt, prevented her leaving home for the foreseeable future. For some, raising the possibility of leaving is just too difficult, for example, Kelly (aged 20) when asked if she had broached the subject of leaving home said: *“No. Because when I was going to start going to college mum freaked out and she started cutting herself and things, so I thought well if I’m going to start mentioning that [leaving home] that’s going to make her feel a lot worse, so I’ve kept it all quiet”*. Another participant observed the difference between her concerns and those of her friends in relation to their accommodation needs: *“I do always think, like when I think of the future, when I talk to my friends about the future, they always think of living alone or with a partner, and whereas I’m always thinking we’ve got to have a room downstairs and a toilet downstairs!”*. (Daljit, aged 21)

Kelly – unable to leave home

Kelly is 20 and lives with her parents, both of whom are unable to work, and her younger sister aged 18. Kelly has heavy caring responsibilities in respect of both parents: her mother has mental health difficulties, she has attempted suicide and self-harms, whilst Kelly describes her father as ‘an alcoholic’ who uses drink to cope with the pressures of home life. Although Kelly does some domestic and health care tasks, including cleaning her mother’s wounds after self-harming incidents, her key caring role is that of providing continuous emotional support for both parents, ensuring their safety, keeping them company and trying to ensure all is calm in the home in order to avoid tension and conflict which would adversely affect her parents. Kelly thinks that as a consequence of caring responsibilities she is a good listener and supportive of her friends. But she is exhausted by her caring responsibilities; she feels torn between meeting the different needs within her family and she worries about them when she is out of the house.

Although Kelly has been a carer for over 10 years, it was only when she was aged 19 that she was referred to a young carers project, where she is now a volunteer because there is no specific service provision for young adult carers. Leaving home is something to which Kelly aspires. However, this possibility provokes such a negative reaction in her mother that Kelly is currently unable to broach the subject. On the whole Kelly feels more positive about her life now and considers that the support and attitude of college staff, her friends and her social worker are helping her overcome her feelings of depression and isolation.



What we did not find amongst our sample, unlike findings from a previous study (Dearden and Becker, 2000), was that young adult carers had left home in an unplanned way as a consequence of the stress of caring and a breakdown in family relationships.

Living away from home

For those living away at university the worry and concern about their relative did not cease and indeed managing this was stressful for some. Georgia, a first year medical student, described how her mother, who has mental health difficulties, is frequently ringing or texting her with her worries or asking for advice. For others living away from home has enabled them to gain physical and emotional distance from their family for the first time and has been welcomed although it was not without feelings of guilt and continuing concern about their relative.

What made it possible for those that chose to live away from home was a combination of circumstances including: finances, the extent and severity of the needs of the person(s) being supported, the existence of other support for the care receiver either formal or informal, whether the carer had a partner or their own child, and the attitude and encouragement of the person being cared for where this was an adult. For example, Alex is an only child, is in his first year of a law degree, and described the encouragement he had from both his parents who have care needs: *"...ever since I went to college they were like we don't want you to worry about us, we will be fine, if we need to get support in we can, we want you to go to university if you want to."* Similarly Jade, whose mother has ME, received encouragement from her family and was able to go away to university partly because of the high degree of support her grandmother provides for all the family.

Jade – living away at university

Jade, aged 19, is currently in her second year at university and living away from home. She hopes in due course to complete her studies and pursue a career in musical theatre which is one of her key leisure activities. Her mother has ME which results in her experiencing periods of dizziness, extreme fatigue, breathing difficulties and fainting. She consequently has to rest a great deal and often needs to use a wheelchair. Jade contributes to caring for her mother alongside her father, two brothers and grandmother. Because of the support from other family members Jade has been able to leave home to study, however she worries about her mother when she is away and can't afford to travel home as often as she would like. When she is at home Jade helps with shopping, cooking, providing emotional support and looking after her youngest brother. Jade is positive about her caring role and enjoys being able to spend time with her mother and helping to make her feel better.

When she was younger Jade had sought out the support of a young carers project but there were none local to her. She has since sought support from a carers centre in her university town and is getting involved with the development of a new service for young adult carers. She particularly wants this service to help her have contact with other young adult carers and wants more information about her mother's condition and ways to alleviate it.



Chapter 9 - Young carers projects

Young Carers aged 16-17 years

The importance of young carers projects

Young carers projects were highly valued by the young carers in our focus groups. This is perhaps not surprising given that the participants of the focus groups were getting support from young carers projects and had been recruited for the focus groups through those projects. Five key positive characteristics of young carers projects were identified by the young carers (Box 9.1):

Box 9.1: Positive characteristics of young carers projects identified by young carers aged 16-17 years

1. Projects are child/young person-focused, without being patronising.

2. Projects are places to meet people in the same situation and develop meaningful friendships:

"They're all in the same boat as me, they understand, so you can kind of like relax a lot more, and it's just, it's really nice after a while of having so much stress, and stuff like that, just being able to say, you know I'm not the only one, type of thing".

"It's like we all come from a big family, because we all know like what we're all going through".

3. Projects are safe spaces:

"It was just away from everything else, it was just, you know, a lot of space where we could all kind of come and you know, know that everyone else knows what you're going through type of thing, and it was so completely away from, it was separate from your friends at school, and it was separate from your home life, it was just this whole like individual little thing that was just kind of, you know, there".

"There's just like such an empathy between each other, so we can understand each other's problems a lot more".

"It's not the same if you go to a youth group, because we all have like the same thing here, but if you go somewhere else you're not going to have that same feeling and it's a secure kind of feeling, and that warm feeling".

4. Projects are confidential places:

"You can tell them anything, it's confidential".

"You feel more willing to talk to leaders here than you would do at school".

5. Projects provide a break from caring:

"You get like a break from stress and stuff as well. Like when they take you out places, like you get a break and you get to meet new people and stuff".

"It's just like three hours a week just to yourself, so you don't have to think at all about your family and that".

In these contexts, young carers are able to develop meaningful friendships and relationships with each other and with project staff and volunteers. What projects *did* with young carers varied between projects but most often it included open-ended group work activities such as discussions, drama, sports, creative arts and trips out, and one-to-one support, advice or casework. Some young carers described how projects had helped them in other aspects of their lives, including school: *“the young carers project actually helped me go back to school because when I first joined the young carers project I wasn’t in school, and I don’t think I would have gone back to school if it wasn’t for the young carers project”*. Others talked about how the project had helped them find new interests.

Lack of preparation for transitions and support

There was little evidence from what we were told by young carers that projects focused explicitly on some of the key transition issues to do with, for example, further education, jobs, money and independence. Some project workers confirmed this, saying they did nothing explicitly about transition issues whilst others told us that they did do work around transitions, including, for example: *“We have carried out sessions on sexual health, drugs and alcohol awareness and also some young carers have undertaken personal development courses and team building work”*.

However, of concern to most of our participants was the fact that young carers projects usually have to stop working with carers once they reach the age of 18. This was a strong theme across all the focus groups; many of the young carers were apprehensive about what would happen when they reached 18 knowing they would be ineligible to use their project:

“It’s like young carers have put something there for us, and it’s just like taking it away and like knowing we won’t see them again, it’s like picking up and dropping you. Yes, it is gutting. I’m not being sarcastic but it is really gutting, it is going to be sad in a way”.

“It’s like being a big family and then all of a sudden being told, being like kicked out, it doesn’t seem fair, it’s like your parents are everything and like they pack your bags at 18, get out! It’s like that. It’s just not fair”.

To a large extent, young carers – especially those who have been using an ‘open-ended’ project for many years – have developed very strong bonds and attachments with other young carers and project staff, for the five key reasons identified at the start of this section (child focus, confidential, safe, etc). When projects do come to an end for those aged 18+, these benefits and ‘positives’ are lost. Many projects are only funded to work with people up to this age, and some young carers in our sample recognised the precariousness of existing funding arrangements and found this undermining:

“don’t let us rely on charities and Children in Need and stuff like that, because it’s one thing that carers don’t normally have in their life is stability and to have a group that we all feel as comfortable as we do in, you know, you’re not going to get that without the financial stability that isn’t around now, that we really need”.

There is little evidence from what we have been told that projects prepare young carers for the ending of their service and for this ‘loss’. One project told us that there is a need for *“clear exit strategies to enable the young person to take control of their own life and not continue to rely on services and other people”*.

Some young carers can maintain contact with a project as a ‘volunteer’, but this is a different role which others do not want. Instead, most if not all want to continue to receive a service and support as young people aged 18+ who are carers.



One route for these young carers is to access adult carers services that, theoretically at least, provide support for adult carers of *any* age. In reality, however, many services for adult carers, including many of the PRTC Carers' Centres, are working with much older carers, as some young carers themselves recognise:

"you'll be in a group with like 30, 40 year olds, or could be up to that age, and you'd be treated as... as a child basically, yes, because you've got the least amount of like life experience and qualifications and that, you'd be treated like that basically, it's demoralisation yes... and the daunting thought of going in a room with a lot of older people instead of these guys of our age, it seems a bit daunting just sat there and saying your problems to people that could be your parents and stuff, it's like daunting as well".

"the rest of them are ancient compared to us! It's not very appealing. Even though the trips are very good and stuff, some of the trips, it's focused more to the older generation".

It was rare for young carers aged 16 and 17 in our sample to know anything about local services for adult carers, including services (if any) for carers aged 18+. Less than a handful had some knowledge of adult carers centres. Moreover, there was mixed evidence that young carers projects informed young carers of the services available for adult carers, or of the help available to 18+ carers when their own young carers project intervention came to an end.

Most young carers told us they would like to be able to continue to use a young carers project or similar after they were 18 – sometimes referred to in our focus groups as 'Young Carers Plus'. They saw these projects as being continuations of existing projects with an older upper age limit, or as separate projects for young adult carers aged 18+. Whatever the mechanism for the establishment of this type of Young Carers Plus project, young carers in our sample thought that such projects would need to provide them with advice and information about further and higher education, careers, jobs, job-search skills, CVs, money advice etc. In addition, young carers also identified a number of other interventions that they said would help them now and in the future. These included more help in the home so they didn't have to do certain tasks; more help for the person being supported; some company for their ill/disabled parent; aids and adaptations to the home to make it more accessible and safe; and ongoing awareness-raising to inform the public and others about young carers.

Support by telephone or the Internet

Very few (three) young carers said that they would like to use 'virtual' systems of support. Most of our sample reacted strongly against telephone helplines (and Internet) as possible sources of support in the future, with a strong preference for face-to-face support:

"I wouldn't like that... Just phoning a random person and talking to them, I wouldn't know who I was talking to, I'd rather talk one-on-one, than just on a phone line, it's not the same".

"I wouldn't trust them or anything, I'd just be too nervous to talk with somebody over the phone, I wouldn't like it, I'd stutter and things".

"I preferred seeing people in person, not just talking to them online, because I was sat on my own with a computer, whereas what's nice is going into a big room full of people, other young carers, and all their smiley faces, and you can just relax and it's such a nice atmosphere".

Whilst these views are important to hear from these particular young carers, it should be acknowledged that many young carers do use the Internet for information, social networking and support. Had we interviewed young carers using the youngcarers.net site (provided by The Princess Royal Trust for Carers) we would no doubt have found a wider set of responses. However, what is clear is that for some young carers the personal face-to-face relationships are still very important and give them an opportunity to be outside of the home for a while too.

Transition groups

A number of young carers projects in our survey said that they were thinking about or developing specific projects/groups for carers aged up to 25 but that this presents a fundamental challenge:

"The challenge that we faced is that the age range we are working with cuts across children services (up 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 – i.e. there isn't any real difference between the needs of an 18 yr old and a 19 year old. Composite groups such as the one that I was working in that span the 16-25 age range – may in fact be more effective because they provide some continuity at a pivotal time of transition".

One project worker who set up a transitions project told us:

"The group was principally concerned with the transition to adulthood. Initially, we developed the project with the aim of transitioning the young people into adult services. It became apparent quite quickly that this was very limiting and counterproductive. What is the merit of moving people from one service to another in and of itself? We shifted the focus to empowerment and facilitating the transition into adulthood. We provided an 'employment and training forum', Q&A session with local MP about caring issues, provided intensive first aid training and a 'housing forum'. Group discussion were also had about various challenges relating to caring. All these activities were undertaken because they were identified as priorities by the group membership and they all are concerned with transition issues into adulthood".

"I can assert with some authority that the service we provided to younger people 16/17 and older people 23-25 was vastly more age appropriate than what was provided by either the young carers service (for the -18s) and by the local carers centre (for the 18+). The local carers centre was particularly age-inappropriate with the average client there being approximately age 50/55...Isn't it better to retain the already established contact and rapport with such service users particularly during this period of transition and the associated challenges relating to housing, employment, relationships, shift in identity etc".

Young adult carers aged 18-24 years

The nature and significance of young carers projects

The 19 young adult carers in our sample who had received a young carers service during their own childhood were highly positive about their experiences of those services. Those who had used a young carers service did so for periods lasting from a few months up to 10 years, with two thirds of these (n=13) receiving a service for between 3 to 6 years.

Many participants gained a great deal from the support and social activities provided by the young carers service. They valued group work activities, trips and short holidays – these were particularly important for young carers whose own families could not afford to do this or who would not be physically fit enough to take part in such activities or travel:

"Well it was just a big activity group really, I mean doing different things and like meeting new friends and it was great and even my Nan didn't have a problem with it because my aunty or my next door neighbour would offer to come down and watch her while I was out, so it was really good and I wasn't gone long it was just six until ten so I wasn't gone long".
(Sarah, aged 18)



Most welcomed the opportunity to have a break from caring provided through group activities. For some it was regarded as 'a legitimate activity' by their families, in other words parents sanctioned and supported it. Young carers projects engaged with young carers in a child-centred way, often giving space for activities alongside the opportunity for individual support when they specifically requested it, hence allowing young carers some control:

"I'll go and I'll chill out for two hours, and you know that's what I find really great about it. I mean I don't have to talk about caring because that's not what they're there for. But if I do have a problem with it then I can just say, well look at the moment I'm having a bit of a rough time, is there anything you can help me with, and I won't be scared of saying that to them, because that's what they're there for". (Natalie, aged 19)

"The being able to talk if you need to talk to somebody. I enjoy the going out as well, but the most important thing is being able to talk with staff". (Kyle, aged 18)

For many, the value of young carers projects was about friendships that they developed with other carers who were able to understand, empathise and provide support for each other in a way that others, without caring responsibilities, could not. Acceptance of each other and a non-judgemental attitude was fostered within these projects:

"When I was in school and into my second year I was being bullied, so I didn't like getting out. That's why I liked it when I got into this group; I liked it because I was doing something. And the people weren't like picking me out because you're different". (Ahmed, aged 23)

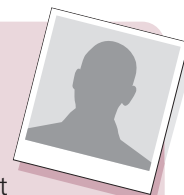
"I found the group was really, really helpful it was just the fact of going to the little group once a week for a couple of hours, not having to talk about what it is that you do, just knowing that everyone else around you is in the same boat, that was just the support there really that helped me, just going in there knowing that this person next to me cares for someone". (Lauren, aged 19)

Many of these services promoted the resilience of our participants through building their friendships, enhancing their self-confidence, developing new skills, interests or achievements, and some were supporting parents as part of a family approach which was appreciated by carers. However, there is an issue here about 'dependency' given the length of time that many young carers spent attending a project and, in some cases, a lack of specific 'outcomes' focus. Some interventions continued from year to year while others were more focused by time or task/outcome. The variation across projects indicates that there is no evidence-informed consensus on what approach projects should adopt with regards to total length of time or focus. There is no coherent evidence on 'what works', for whom, and why.

Not all young adult carers in our sample had received a young carers service – despite some of them caring for many years on a regular and substantial basis, and having significant, inappropriate, caring roles during their childhood which affected their schooling or emotional well-being. These six young adult carers – a quarter of our sample – seem to have 'slipped through the radar' of schools, young carers services and social work assessments of children in need or carers or, as in one case, there was no locally available service. It was promising to discover that an 18 plus young adult carers service was now supporting two of these six carers and another one of them is accessing support through an adult carers centre.

Sam – never received support from a young carers project

Sam has helped to look after his mother, who has epilepsy, osteoporosis and a physical impairment for the past 15 years. Now 19, Sam is currently looking for work after his last job in a garage came to an end. He always felt he lacked support in school and that his teachers lacked any understanding of his situation. Although Sam had friends at school he always felt different from them due to his caring responsibilities, the need for him to have consideration of his mother's needs and his consequent maturity. He enjoyed college more than school but decided to leave after a year. He found the Connexions service at college was helpful and it is they who



referred him to an 18 plus young adult carers service run locally by a young carers project. Prior to this, Sam had never been referred to a young carers service and had been unaware that such support was available.

At the time of being interviewed Sam's mother had a recent fall and consequently she had carers coming in to see her four times a day. Having other carers in the house causes Sam some disquiet although the extent of his caring responsibilities has lessened significantly. Sam feels that his mother's health will not hold him back from getting work, indeed she is encouraging him to do so. Sam would eventually like to live independently but says he would have to be close by to his mother so that he could continue to support her.

When young carers services end

Concern was expressed at all the fieldwork sites as to what should follow on for young carers once they become ineligible for a young carers service. Projects at the fieldwork sites were at one of three stages in terms of service development for young adult carers: awareness/exploration; or planning for provision; or delivering support.

Concern about *who* is responsible for providing such support and exactly *what* should be provided for young adult carers was also evident in the responses to our survey completed by young carers projects, adult carers services and through our networking with other projects. It was evident that many young carers services are now recognising gaps in service provision for young adult carers and questioning to what extent they are responsible for filling that gap.

Of the 19 in our sample who had received young carers support, there were a number of scenarios as to what support was on offer for them once they reached 18 years. It was evident that the options for support for former users of young carers services who turn 18 varies due to local differences with regards to: project or service specifications, prioritisation of young adult carers and their recognition within local authority carer strategies, service level agreements with local authorities, funding arrangements and provision by adult carers services. Some young adult carers in our sample were struggling with a reduced level of support from their young carers project since reaching 18: *"...to go from quite a bit of support to none is quite dramatic, how do you adjust to that while you are adjusting to so many other things going on in your life?"* (Georgia, aged 18), whilst others were benefiting from ongoing or new support provision for their age group.

Lauren – positive experience of support from a young carers project

Lauren, aged 19, is currently studying for A levels and she hopes to pursue music at her local university in due course. She is the youngest of four siblings and the only one now living at home. Lauren became a young carer for her mother after her parents divorced when she was 10 years old. Her mother is physically disabled due to osteoarthritis, spondilitis and vertigo. Although her mother's condition has recently improved following surgery, Lauren often does domestic tasks at home and provides emotional support and companionship for her mother. She thinks that caring has made her relationship with her mother a close one and she is more mature and independent than her peers, however she is distressed by the constant worry about her mother. Lauren has health needs of her own as she has lupus, a disease of the autoimmune system, which causes her tiredness and discomfort.

Lauren was referred to a young carers project after her teacher became concerned about her school absences. For Lauren, the young carers support was highly valuable, and she regretted it coming to an end when she was 18. She has made lasting friendships with other young carers, joined a carers' rock band that she enjoys and sought assistance from project workers when she and her mum faced difficulties about their housing and benefits. Lauren has recently been assisting with the development of promotional materials for a new 18 plus service being piloted by the local carers centre.





Chapter 10 - Emerging service responses to the transition needs of carers aged 16-24

Our surveys of young carers projects and adult carers centres show that while there are difficulties for young and adult carers services to engage with the specific transition needs of carers aged 16-24, there are, however, a number of service responses which are relatively new or still in development. Here we present these 'models' and illustrate some of them with information about specific projects/services that are in place or are emerging across Britain.

'Models' of emerging service responses

'Keep in touch'

Some young carers projects, due to funding mechanisms, cease to provide a young carers service beyond the age of 18, although they always offered the young adults the opportunity to 'keep in touch' should they need to do so. However, this approach is of no help to young adult carers who start caring after the age of 18 years or those who have had no prior contact with a young carers project.

Some of our participants felt let down or very upset when they became ineligible for support from a young carers project and said how much they missed the continuity of contact with staff and friends. There was a recognition by a few that it was 'time to move on' and that they no longer needed such support as their caring role had either lessened or that they would be living away at university or needed more time for other things such as studying, relationships and parenting. Although young carers projects may have informed young adults of alternative support mechanisms there was a general lack of awareness about these amongst our participants and a lack of confidence in knowing who and how to approach other services. This would suggest more preparation needs to be done to help young carers make the transition to other services and supports that will help them through their transitions unless, of course, the young carers service provides a continuous service to those aged 18 plus.

'Teenage transition support'

Young carers projects normally deliver activities and group support by age, up to age 18. A project in one fieldwork site was running a group for 16-18 year olds, giving them an opportunity for outings, relaxation and workshops to address pertinent issues or concerns. Another project (North Staffordshire – see Box 10.1) employs a worker specifically to assist with issues of transition for those aged 14-18 years, signposting and supporting young carers to re-engage with education or move onto further education or training and also to raise awareness amongst those professionals working with teenagers, for example, Connexions advisers and college staff. Another project (YCNNet – see Box 10.1) provides web-based support for young carers including those in transition.

Box. 10.1: 'Supporting teenage transitions' – North Staffordshire and YCNNet

North Staffordshire Carers Association, Young Carers Project

The project provides a range of services for young carers up to the age of 18 years including individual support, evening and holiday activity groups, and trips. It also seeks to raise awareness of young carers' needs in schools, with foster carers, and with voluntary and statutory agencies; it provides a specific service for young carers who care for a sibling with an illness or disability; and it provides a whole family approach for parents with mental health or substance misuse difficulties. There is a specific transitions worker focusing on young carers aged 14-18 years funded by the local PCT and NSCA funding on an annual basis. The specific aims of this post are to raise awareness of young carer issues with students undertaking health and social care courses in colleges

as well as college staff; develop partnership working and awareness of young carers' needs with other service providers such as Connexions; assist young carers who have disengaged from school in order to reintegrate them back into education; and to engage and support young carers in moving on to further education, training or employment. As a consequence of obtaining youth opportunity funding the project has a young carers forum open to young carers up to the age of 19 years which has been involved in consultations, managing a young carers emergency fund and which organises trips in the summer holidays. For further information contact: gill.porter@yahoo.co.uk

YCNet Interactive

The Princess Royal Trust for Carers provides an online, interactive advice, support and information service for young carers up to age 19 in the UK. This web-based service offers the following facilities: discussion boards for young carers to ask questions, share experiences and find answers; blogs written by young carers and the YCNet team members; a safe chat room; 'agony aunts' who reply to specific questions either online or privately; an e-newsletter; and games with prizes. Two youth workers staff the service. The service aims to provide support, information and advice for young carers in addition to facilitating mutual support between young carers and reducing their isolation. YCNet has a user group to give ideas on improving the service. It also has a buddying system whereby new members can be matched to existing members when they first join. For further information contact: www.youngcarers.net

'Volunteer'

Three projects in our fieldwork sites, which provided a service for young carers up to 18, offered former young carers the opportunity to volunteer with them, hence enabling a link to be maintained (Rhondda and Taff Ely – see Box 10.2). In some cases young people were also offered the opportunity to use the experience of volunteering towards achieving an NVQ. Young adult carers who volunteered often said they enjoyed being able to 'give something back' and that it enabled them to keep a link with the project and the trusting relationships they had forged with staff and other carers. In some projects this meant that young adult carers could still gain support for themselves and their families.

Box 10.2: 'Volunteer' - Rhondda and Taff Ely Young Carers Project, NCH Wales

This project has been in operation for six years and offers a service to young carers up to the age of 19. The project provides five different activity groups, banded by age, meeting once a fortnight. Due to its rural location and infrequent bus service the project has to provide all the transport to enable young carers to attend. For those aged 16-19 the group activity is a mix of social and therapeutic support. Individual support is also provided for those with high needs and this can include family support and signposting to other services such as careers, drug services, health and counselling. The project delivers awareness raising sessions with secondary schools in order to improve the identification and support of young carers. Once young carers reach 19 years they can opt to become a volunteer with the project to assist with running the groups for the younger carers and in so doing access accredited training and gain some useful work experience. Offering the opportunity for volunteering was a pragmatic response to the needs of the young adult carers who did not want to lose touch with the young carers project and who were still in need of some support. The project recognises the gap in service provision for young adult carers and is in the early stages of forging joint working with a local adult carers service with the intention of setting up specific support for them. For further information contact: Tel: 01443 437709



The volunteering 'solution' has limitations since not all young adult carers can or wish to volunteer and some will be unsuited to the role. In some instances the volunteers were using transport places to and from meetings that might otherwise be used for other young carers, and in some projects volunteers are not necessarily entitled to receive formal individualised support to assist them with their own issues of transition or caring. The opportunity to volunteer was not available for those who began caring after the age of 18 years since they would have had no prior contact with a young carers project. Nevertheless, for some young adult carers volunteering gave them a good deal of satisfaction, some support and could be used as evidence of work experience.

Sophie – volunteering for the young carers project



Sophie lives with her mother and three siblings. Her parents divorced five years ago but she remains close to her father who lives nearby and who works as a professional carer. Aged 19, Sophie is currently completing an access to nursing course at college. She became interested in nursing after spending time in hospitals with her mother and brother, both of whom have care needs. Sophie's brother has cerebral palsy whilst her mother has chronic arthritis and other physical health problems which are undiagnosed as far as Sophie knows. The family receive a variety of services to assist them, including a weekly personal assistant for Sophie's mother, special schooling and a befriender for her brother. Nevertheless Sophie provides a high level of care both in terms of helping her mother with household and general tasks, and daily personal and health care for her brother. Sophie has a close, warm relationship with her brother, however her relationship with her mother is more strained. Ideally Sophie would like to leave home to go to university but she thinks that the cost of this and her caring responsibilities may make this unachievable.

Sophie has enjoyed the support of a young carers project for 5 years. She has enjoyed making friends and participating in activities there with the opportunity to get one-to-one support when necessary. She is currently acting as volunteer at the project as there is no separate provision available for young people once they reach 18.

Young adult carers aged 18-24 years

Three projects attended by our participants had specific funding for a transitions worker whose role was to develop support for those aged 18-24 years (see Box 10.3 for two examples). Funding for such posts was varied, from 6 hours per week to full-time, and this impacted directly on what they were able to deliver. The specialist young adult carers workers were aiming to help young adult carers do several or all of the following:

- Improve their mental and physical well-being;
- Enhance their confidence and self-esteem;
- Promote age-appropriate respite activities;
- Assist young adults to access employment, training or education;
- Ensure income/benefit maximisation;
- Understand and promote choices;
- Access training, and sometimes certification, on aspects of caring and life skills;
- Access a carer's assessment and additional support services where appropriate.

A key advantage of an 18 plus service is that young adult carers who start caring from this age and upwards can access a specialist service that is not 'tied' to previous service receipt from a young carers project.

Box 10.3: 'Young carers plus' – Lincolnshire and Brighton & Hove

Action for Young Carers Plus (Lincolnshire)

A local 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 the Carers Federation Ltd. Three year funding from The Big Lottery, which commenced in 2007, has enabled the development of a new service, known as 'AYC Plus' for carers aged 18-25 years. The service has a full-time member of staff and part-time administrator. The key aims of the service are to reduce the isolation of young adult carers, improve their confidence and self-esteem, and 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 and continue to be involved in the planning of activities. For further information contact: emily.jarvis@carersfederation.co.uk or s.lindley@carersfederation.co.uk

The Carers Centre for Brighton and Hove

Staff within the young carers project at the Carers Centre identified that young carers aged 17 were very concerned that their needs would not be addressed once they turned 18. Consequently, they decided to pilot the provision of specialist support for young adult carers and in 2007 appointed a part-time staff member to do this. The project aims to reduce the social isolation of young adult carers through regular social activities; to enable young adult carers to self-assess their needs through a specially designed MOT which signposts them to local services; to provide specific advice and support for young adult carers with issues affecting them including education and training or family matters; and to empower young adult carers to speak to health and social care professionals about their needs and the needs of the carer receiver. The underlying philosophy of the project is that it is user-led and participative given the age of its target audience. Much time has been devoted to promoting the new service and raising awareness of young adult carers' needs with local services including further and higher education providers. As a consequence of this work one of the colleges now asks all prospective students at interview if they are involved in caring. The project is now seeking further funding to enable it to continue due to the needs it has identified and the difference it has made to the lives of young adult carers locally. For further information contact: richardlambert@thecarerscentre.org



Emily – using an 18 plus specialist support service

Emily, aged 18, lives with her two younger sisters and mother in a rural setting. Emily's father, whom she describes as an alcoholic, lives locally but she has little contact with him. Emily has been undertaking caring tasks for her mother, who has chronic asthma and agoraphobia, since she was aged 14. The health of Emily's mother has been deteriorating over the past few years and this coupled with the fact that Emily's mother is now pregnant, has meant her care needs have increased. Emily's caring tasks include general care, child care and emotional support. She worries a great deal about her mother and what might happen if she is left unattended. In the past this has meant she has missed school and college such that she has not gained the qualifications she wanted to achieve. The infrequent public transport and distance to college also worked against her regular attendance at college.



Emily received individual support from a young carers project when she was 17 preferring this to group support. Since turning 18 she has been supported on an individual basis by an 18 plus project worker attached to a young carers service. She has found it particularly helpful to have someone to talk with outside of her family and valued the assistance she has received in order to find a suitable online training course and to identify a counselling service. Emily would like to have a job in child care next year, however she worries that her mother's health and the new baby could impede her aspiration.

'16 Plus' (16-25)

Other projects offered their 'plus' service to young carers aged 16 upwards, in an attempt to keep them engaged and so as to provide a more age-appropriate service for mature 16 and 17 year olds who were outgrowing young carers provision, to take them through to age 25 (see Box 10.4).

Young adult carers spoke positively about the approaches that transitions workers adopted in that they treated them like adults, provided them with information as needed, and offered choice about the extent and level of support thereafter. For some of our participants their transition worker was the first person they would turn to for help outside of their own immediate family. There was, however, variable evidence of whether these workers could offer a more holistic family approach.

Having a specialist worker or service for young adult carers may have the potential to bring positive outcomes for this group. However, what is less clear is whether such workers should be based within an existing young carers service, which is what we encountered in this study, or should they be part of an adult carers service or centre? Perhaps their location is less important than their approach, links and networks to secure the best outcomes for this user group.

Box 10.4: '16 Plus' - York, Wiltshire, Islington and Bedfordshire

York Carers Centre

A local study into the needs of young adult carers was conducted in 2003, following which a young adult carers service has been provided since 2003 for young people aged 16-25 years. The local authority provides funding for 6 hours per week on a fixed-term basis. Most of the young people using the young adult carers support are those who previously used the young carers project and who want similar support (individual casework and social activities) but tailored to their specific age group. The key aims of the service are to engage with and offer support, information and advice to young adult carers; to ensure a smooth transition from the young carers service to adult carers 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. The service also links in with a generic support service for young adults already in operation in York and uses their base for meetings as young people more readily identify with it. Young adult carers will also access other support provided by the carers centre, in particular advice on benefits and financial matters. For further information contact: sharron.smith@yorkcarerscentre.co.uk

Youth Action Wiltshire

The young adult carers service within Youth Action Wiltshire began as a pilot in 2005 and has built up since then. During the last financial year they worked with 50 carers aged 16-25 years. They have two part-time staff equivalent to a full-time member of staff. The key aims of the project are: to help young carers not in education, employment or training to re-engage in the workplace; to raise their aspirations, and to ensure they are receiving the supports 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 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. For further information contact: victoria@youthactionwiltshire.org

Islington Young Adult Carers Group

The Islington project for young adult carers (aged 16-25) was established in 2006 and has funding from the London Borough of Islington until 2010. The project sits within the Family Welfare Association Young Carers Service. The project has a part-time member of staff and no volunteers. It aims to facilitate the transition of young adult carers into adulthood, assisting them in achieving independence and fulfilling their expectations; equipping them with advocacy and leadership skills in order to enable them to have greater control of their lives; and providing them with advice and information about all relevant services available in Islington. The group meets on a monthly basis for social activities. The group is user-led, using a number of empowerment methodologies. The group is being promoted within the borough and it has developed eligibility criteria and assessment tools. For further information contact: gaby.santacruz@fwa.org.uk

The Hub Young Carers (Carers in Bedfordshire)

Carers in Bedfordshire is a voluntary sector carers 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. It was set up in 2007 with funding from Bedfordshire County Council and the Local Network Fund. The key aims of The Hub are to provide support for young carers aged 16-21 throughout Bedfordshire with an emphasis on 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 The Hub service in Luton and Dunstable. For further information contact: robert.cunningham@carersinbeds.co.uk

'Partnership'

The question of who should provide a service for carers aged 18 and over was a recurrent theme during the study – should young carers services be 'stretching upwards' or should adult carers services be 'reaching downwards' or would a partnership approach be more appropriate? A young carers project, at one of our fieldwork sites, was in the process of developing a partnership with an adult carers centre so that they might jointly deliver support for young adult carers, recognising that they both had different skills and knowledge to bring to the partnership. In setting up a new initiative there are inevitably challenges, not least of which is funding and staff time. This partnership has yet to come to fruition fully in terms of establishing a service but nevertheless it is an important development and one that we could learn from in due course.



'Pick and mix'

Some of our sample was accessing support or advice from more than one source depending on what they knew about, where they were living and the nature of their needs or difficulties. For example, other sources of support mentioned besides those that were specific carer services included: social work support, Citizens Advice, youth projects, student services at college or university, counselling services, or a local councillor. What might have helped all young adult carers would have been a directory of local services, universal and specialist, that they could contact if needed. If such a directory did exist in their locality, our participants were unaware of it.

'Adult services responsibility'

All of the young adult carers in our sample could, in theory, have been accessing support from adult carers services provided by the voluntary or statutory sectors. In fact, only two out of the 25 in our sample had ever used an adult carers service and not to any great degree; both found staff welcoming and had used the support or activities on offer. However, both felt self-conscious about the wide age gap between themselves and other carers present. One of the young adult carers was also surprised to be the only Asian person using the service and would have preferred a more culturally appropriate service.

The rest of the sample were not using adult carers services for one or more of the following reasons: they were already receiving a specific 18 plus service; they had gone away to university and no longer felt the need for carers support; or they had no knowledge of either how to contact them or what help might be on offer; they had built up familiar and trusting relationships with their young carers project and this put them off accessing adult carers services where no relationships had been developed. Where young adult carers were aware of adult carers services, usually because their young carers services had been provided by a carers centre, they perceived that adult carers services served much older carers and therefore were not really relevant to their own needs: *"...they only cater for like if you're 50, so like the theme nights they had were like the 1940s war night, so that was the theme, why would any 18 year old want to go to that?"* (Georgia). Our evidence suggests that there is a gap, with some exceptions, in service provision since our young adult carers did not identify with or generally use adult carers services and yet they had outgrown young carers services, if they had used them at all.

The lack of engagement by adult care services

Although the principle focus of our study was to investigate the needs and experiences of young adult carers, we were interested to find out whether services for adult carers had knowledge of or contact with this particular group of carers. Anecdotal evidence from young carers projects suggested that very few young adult carers had contact with adult carers services and so we wanted to explore this further. Thirteen adult carers services/centres within The Princess Royal Trust for Carers network were surveyed about their engagement with young adult carers aged 18-24 years. Five of the centres said they had no contact with any young adult carers in this age range whilst the remainder (n=8) had some contact, although numbers were small ranging from 3 to 45 young adult carers per centre. Of those services/centres that had contact with young adult carers most often this contact was a one-off or infrequent and rarely sustained contact. Young adult carers had sought advice or support from carers services/centres on one or some of the following issues: information, advice and in some cases advocacy on benefits or employment issues; information about health conditions of the person being supported or themselves; education and training opportunities or funding; moving/leaving home; and advice on short break funding. Some had sought emotional support, for example, following bereavement. Finally, some had joined activity groups open to all carers (yoga, sewing, swimming, and outings). Only one centre surveyed had a group specifically for 18-24 year olds but only two people were attending it.

Carers centres identified a range of factors (or barriers) that made it either unfeasible or more challenging to engage with young adult carers:

- funding constraints were cited most often as a barrier;
- service level agreements which are focused on the provision of services for *older carers*;
- a lack of self-referrals from young adult carers, however, carers centres recognised that their publicity and outreach work was not targeted at this age group;
- centre staff felt less equipped to work with young adults;
- centre staff were not geared up to provide the advice, information or the type of support that young adults need;
- young adult carers are 'hard to engage' because they have many other demands on their time including studying, relationships, employment or training or they have become disengaged due to troubled childhoods, particularly in instances of parental substance misuse;
- a lack of 'relationship', coordination and referral between services for young carers and for adult carers.

Clearly, our survey of 13 adult carers services/centres is only a small snapshot and further inquiry is needed. Many centres were very interested in our research and very conscious that there is a gap in service provision for this age range. Our findings suggest that adult carers services/centres need to be fully engaged in the debate about service development for 18-24 year old carers alongside young carers service providers. This will be particularly the case for adult carers services that share the same buildings, space, management or are co-terminus with young carers projects and where relationships between the two are not well established or are not established at all. There is a real challenge here for how these separate services can become more integrated or joined up for the benefit of young adult carers.



Chapter 11 - Looking forward: meeting needs and service development for carers aged 16-24 in transition

The support that young adult carers require aged 16-24 years

In this Chapter we summarise our findings on the needs of young carers aged 16-17, and young adult carers aged 18-24, and identify the implications for future service provision. Box 11.1 identifies what carers aged 16-24 told us that they and their families needed. These needs are consistent across both age groups.

Box 11.1: 'The support we need': perspectives of carers aged 16-24

- More support for the person they care for, including aids and adaptations, a directory of care services, transport etc, which would help the people they support directly and reduce the amount of care work carers have to do in the family;
- Opportunities for meeting and socialising with other carers either through informal groups, activities and/or short holidays and outings;
- Advice, information and guidance about issues such as housing, education (including grants, loans, funding for education/training), training opportunities, debt, social security benefits, and the health of the person they care for;
- Job-seeker skills training, CV preparation and identifying suitable jobs;
- Signposting to other agencies who can assist them and their families;
- Respite care and short breaks from caring;
- Transport, including funding for driving lessons and a frequent, low cost bus service;
- Individualised support (one-to-one casework) from someone interested in listening to them about care and other issues affecting their lives;
- Assessments of their needs;
- Counselling;
- Support or advice by phone or online (including social networking).

Throughout this report we have discussed 16-17 year old and 18-24 year old carers separately. While there are many similarities in their experiences there are important and subtle differences in their needs that correspond to the particular developmental stage in their lives and their 'career' as carers. As we said in Chapter 1, we also think that it is helpful to distinguish between the two age groups because one group (carers aged 16-17) are still legally 'children' whilst the other group (carers aged 18-24) have the legal status of 'adults'. Irrespective of how we conceptualise 'childhood' and 'adulthood' or the 'transition' between the two, these categories have major implications for services in the UK and who is responsible for meeting the needs of *children* who are carers and *adults* who are carers. Thus, we first review our findings about the needs of 16-17 year old carers and then 18-24 year old carers, outlining for both the implications for service development and delivery.

Young carers aged 16-17 years

Key transition issues

Twenty five project workers, who were currently working with at least 359 carers aged 16-17, identified what they thought were the key issues facing this particular group of young carers and the main themes are reflected in their comments presented in Box 11.2.

Box 11.2: Key transition issues facing 16-17 year old carers: perspectives of project staff

"Feeling as though they are unable to plan for the future and achieve independence due to caring responsibilities; having to move on from their existing social structures – including support services, family and people they care for; juggling increasing academic workloads with their caring responsibilities".

"Dealing with relationships – despite often functioning in the adult world they are often ill equipped to deal with the demands of work or full-time education; looking beyond the caring role – developing a plan that allows them to achieve their aspirations whilst having an ongoing caring responsibility; educational achievement and being a carer, finding time for study, not worrying whilst at uni/college etc".

"...a lack of aspirations to achieve academically, sometimes due to peer pressure and the need to be accepted by other young people; the above combine to hinder their access to employment, alongside their caring roles particularly within the mental health area of caring".

"Gap between services offered by young carers projects and adult carers services. No appropriate service for this age range; As many are going out into the wider world, there remains a lack of understanding and awareness of the issues these young carers face. They are expected to become more independent but still have many more responsibilities than their peers; Not feeling like they can leave the cared for".

"Lack of transitional support from child to adult services; concerns regarding leaving home for further education – who will fill the gap at home and will they meet need?; loss of school 'respite' for some when they leave school".

"Lack of, or perceived lack of options due to caring role; lack of qualifications due to time missed from school; emotional issues/pressure of being a teenager and juggling caring responsibilities".

"Becoming independent and sustaining this; parents finding it difficult to 'let go'; parents not able always to support young people through the emotional and practical issues to independence and adulthood".

"Juggling work/study aspirations with caring role; moving to independent living; financing further education".

"Not having the same amount of freedom as their peers at an age when exploring and experimenting are important; limited aspirations due to caring role; missing out on school at a crucial age".



The key transition issues as identified by project workers centre on an inter-related cluster of concerns and challenges for young carers aged 16-17. **Essentially, the transition needs of young carers aged 16-17 are concerned with balancing caring responsibilities and:**

- Continuing education and learning, at school or college
- Dealing with the consequence of poor educational outcomes or attainments (for some young carers)
- Getting good careers advice, job-search preparation etc
- Finding and keeping paid work
- Developing friendships, relationships and attachments outside the family, including intimate relationships
- Building identity, confidence, skills and self-esteem
- Managing on a low income in a poor household
- Wanting (for some) their own independence and 'freedom'
- Wanting (for some) 'their own place'/housing/home
- Wanting the best support and services for the person(s) they care for
- Wanting to maintain support for themselves as a young carer (including anxiety about the ending of the young carers service at 18)
- Finding future support for themselves as a young adult carer, between children's services and adult carers services.

Managing caring and other responsibilities

As many young carers approach or reach the age of 16, more is likely to be expected of them by their families in terms of caring tasks and other household responsibilities. These expectations, and demands, coincide with young carers wanting more time for themselves and the competing demands of college or further education, or in some rare cases, paid employment. There is a real issue here about how young carers aged 16-17 can manage these conflicting expectations and demands, particularly as some of these caring roles are becoming *less inappropriate* as they get older. Services and support for young carers will need to also reduce the inappropriate caring responsibilities of 16-17 year olds, against the grain of family expectations and growing maturity, to enable these young carers to combine caring with completing the final stages of their compulsory education and beginning the next 'stage' of their life be it in training, further education, work, parenthood, travel etc.

Income and money

Most of the families in our sample are on low income. There is a need for young carers and their families to receive all the benefits and services to which they are entitled. Even then, many will still only be able to afford a minimum, barely adequate, standard of living. Many of the young carers in our sample (and nationally) will be children being brought up in poor families, the reduction of which is a key Government priority. Tackling the financial poverty of families where there is parental illness/disability will have beneficial outcomes for young carers in those families – including giving more money for alternative caring arrangements and choices, more money for everyday commodities and food, for transport, and more for other activities outside the home. Many of the young carers in our sample relied on EMA as their only independent source of income, and some gave this to parents because of their financial or other difficulties. It is important that families in which children care receive adequate financial support, including young carers themselves.

Schools and FE colleges

Alongside being a place of teaching and learning, schools and FE colleges can also be an important source of respite and sanctuary for young carers, giving them valued opportunities for developing peer networks and relationships, social skills and other interests. Where young carers are recognised and treated respectfully by supportive teachers, this is valued highly by young carers. Where they are ignored, or, at worst 'punished' for caring within schools, then this can have significant negative outcomes both in the short and longer-term, including for some carers challenging behaviour and/or disengagement with school and learning. Developing a supportive environment for young carers within schools is often left to individual teachers, personality and chance rather than being a matter of policy or procedure. Schools need to think about how they can identify and help young carers in a supportive way, including strategies for preventing bullying of young carers, to maximise positive educational outcomes and provide the respite and space that many young carers want from their school. There is some evidence that young carers are more comfortable in an FE environment than at school because of the ethos and approach, and sensitivity of FE staff.

Friends, relationships and leisure

Forming meaningful attachments and friendships are a necessary component of healthy psychosocial development and are resilience promoting. Almost every young carer aged 16 and 17 in our sample wanted to go out more and make friends but this was often constrained by their caring roles and the growing expectations on them to provide more care or take on more responsibility as they got older. The issue of transport is also relevant here as many young carers and their families are reliant on public transport for getting out. Some young carers keep their caring roles secret from existing friends; others choose their friends carefully – making bonds only with people they think will be understanding, sensitive and respectful. Some young carers are looking to make intimate relationships at this age and some project workers expressed concern that certain young carers were sexually vulnerable while others were vulnerable to misuse of alcohol or drugs. The extent to which these vulnerabilities differ from other young people of this age is unknown.

Young carers projects had become a key source of friendships for every young carer in our focus groups. Project activities have given them an opportunity to make meaningful friendships and attachments with people who 'understand' because of a shared, common experience. Consequently, when young carers become ineligible to attend these projects due to their age, the loss of companionship is experienced in painful ways. If projects have become sources for developing meaningful friendships, then service providers and project workers need to consider how (a) membership of a project can end without causing 'loss' for young carers; (b) how friendships can be sustained; (c) how projects can operate without causing 'dependency'. These issues are explored in more detail later in this chapter.

Leaving home and independence

Young carers aged 16 and 17 need information about their options for leaving home. Like many young people of this age, they will not want to leave home at this stage in their lives, and for young carers this is made more complex because of their caring responsibilities and the 'positives' they attach to caring. However, for some, especially those who want to get jobs or apprenticeships or go to university, there is a real issue about whether they can leave home to fulfil these aspirations and ambitions. Their caring responsibilities place them at a disadvantage compared with other young people of the same age and aspirations. The Carers (Equal Opportunities) Act 2004 (England and Wales), is intended to give carers, through an assessment, an equal opportunity to access paid work, education and leisure (see Box 11.5). Some young carers in our sample were clearly disadvantaged by their caring roles in terms of them having unequal opportunities to access paid work and further/higher education.



Paid work and career support

Unfortunately, there is evidence to show that 16 and 17 year old carers face considerable barriers to inclusion in the paid labour market, either for part-time or full-time jobs. Some are drawn to local jobs or 'care-related' jobs because of their on-going caring commitments at home or because it is here that they feel most skilled. Young carers, like other teenagers, need sound advice and information about the world of paid work, particularly part-time paid employment opportunities. They also need good careers advice to enable them to make informed choices about further and higher education opportunities, and the kinds of work that they might be most interested in and suited to. Sometimes this help is not available through their family, particularly where parental illness, substance misuse or mental ill health has impaired a parent's capacity. Those agencies and professionals giving this advice need to be sensitive and respectful to the young carers' situation and circumstances and how this can affect, or restrict, choices and opportunities in the short and longer-term.

Young carers projects and 'Young Carers Plus'

Preparing young carers aged 16 and 17 adequately for the ending of their service/young carers project at the age of 18 is important to help reduce young carers' apprehension, anxiety and sense of loss.

Young carers projects need to inform carers aged 16 and 17 about the kinds of specialist services and support available to carers aged 18 plus (including carers centres and adult social care/carers services as well as universal services such as health). Projects also need to work with young carers on a specific programme of work concerning transition issues, including information, advice and networking around careers, paid work and job search skills, further and higher education, intimacy and friendships, sexual and physical health, money and budgeting advice, income maximisation, etc. In some cases projects may need to refer young carers on to their local social services/social care authority for a carer's assessment. When they reach 18, young carers projects may need to refer carers on to an adult carers service, including carers centres. Young carers projects will also need to consider whether and how they could continue to offer a continuous service and support to carers who are 18 plus (see Box 11.4).

Box 11.4: Young Carers Support Project (Croydon)

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. For further information contact: helencarter@carerscontactline.co.uk

Listen to young carers

Finally, many of the young carers in our sample talked about how they were invisible to politicians and to policy makers. They wanted their words and messages to be heard by those in power:

"We're real people, with real issues, listen to what we say".

"They have to sit up, they have to pay attention, young carers we don't get the attention we deserve, we're put on as the second, we're second place in a caring role... we're just kind of shunted out into the darkness".

"We have no power ... Whereas if we were old enough, if everyone like down there were old enough to vote they would pay more attention to us because we would be the ones who'd be deciding if they stay as politicians, if Gordon Brown stayed as the Prime Minister or not".

"They don't take us seriously, we've got the most responsible role out of, you know, our whole family and professionals or whatever their kind of line of work generally just kind of still see you as some kid".

Young adult carers aged 18-24 years

Young adult carers in our sample explained that their use of any dedicated carers service would probably be more intermittent than it was when (some of them) made use of young carers projects. Some young adult carers are parents and have childcare needs; some have partners and want to include them in social activities. Others said that they had other commitments that required their attention at this age so that they would not be able to commit to a young adult carers service to the same degree that they had done to a young carers project. Some said they would use online information or phone help lines, although there was still a preference for a face-to-face service that could be used as and when necessary.

The interviews and questionnaire responses from projects showed that young adult carers have needs similar to any other young person of this age, for example a need for advice and information about education, careers, work, relationships, sex and intimacy, their health, money advice, budgeting etc. **However, they also have needs that are related specifically to their caring roles and responsibilities and their experiences and identity as carers.**

Carers' assessments and services

Project workers reported that many young adult carers needed to have more and better information about their rights, including their right to a carer's assessment. This point was borne out by our sample whose responses indicated a low level of awareness about carers' rights generally and specifically in respect of carers' assessments. Two thirds (n=17) of young adult carers in our sample did not know about their right to a carer's assessment under the law, eight were aware of this right and of those, two were waiting for an assessment and only two had received such an assessment. It is of interest to note that of the eight who knew about their right to a carer's assessment all except one were receiving or had received support from a specialist carer service for those aged 18-24 years. In contrast, many of those who had previously received support from a young carers project, or no carers service at all, did not know of their right to an assessment. A very small number were *vaguely aware* of carers' assessments but had never been referred for one by their young carers project or any other source of professional contact (GP, healthcare or social workers, etc) or did not know who to ask for one.

Box 11.5: Legal entitlement to a carer's assessment

The Carers (Equal Opportunities) Act 2004 came into force in April 2005 with the intention of providing a firm foundation for better practice by councils and the health service. It built on existing legislation and support for carers by:

- placing a duty on local authorities to ensure that all carers know that they are entitled to an assessment of their needs
- placing a duty on councils to consider a carer's outside interests (work, study or leisure) when carrying out an assessment
- promoting better joint working between councils and the health service to ensure support for carers is delivered in a coherent manner



The Act amended the Carers and Disabled Children Act 2002 which gave family carers over the age of 16 (and caring for someone over the age of 18) specific rights:

- Carers may request an assessment of their own needs, even if the person receiving care does not wish to have an assessment
- LAs may provide services for carers in their own right, including vouchers for short-term breaks or direct payments in lieu of services for which they have been assessed.

Whether young adult carers had ever been referred on for an assessment depended to some degree on staff perception at carers projects and their sense of the value (and possible outcomes) of carers' assessments in their locality:

"I don't encourage people to have a carer's assessment. I explain about what the young carer's assessments should be, but I know that it's not going to deliver. So I'm quite wary about it, but I will, you know, if I feel people need it, I will battle on their behalf to get it done properly, but it's a battle". (Project worker)

"I think it's hard because you can refer them maybe to adult services and say like look I'd like a carer's assessment done for this 17 year old, they may say well I think children services should be doing that and it kind of gets passed between them and no one has responsibility for knowing who should be doing a carer's assessment, they kind of say oh that's children's services because they're under 18 or then if they're 18 they say oh well it's to do with mum's problems so the adult disability team should be doing it. Actually finding who should be doing a carer's assessment is really hard". (Project worker)

Overall there seemed to be a 'postcode lottery' as to the level and quality of local authority carers' assessments judging by the responses of project staff and responses from young adult carers. However, a number of projects at our fieldwork sites were trying to address this through local inter-agency working.

Given that a minority of participants had received a carer's assessment it was not a surprise to find that approximately a quarter (n=8) of our sample were receiving no support or services as young adult carers whatsoever. Just over a third (n=9) of our sample had contact with a young adult carers service where they could be receiving emotional support, social activities, job/course-searching help, and benefits advice etc. A quarter of the sample had sought advice and information from other providers including Citizens Advice Bureau, housing department or student services. A few (n=4) had participated in support activities or sought advice from a carers centre. Four remained in contact with their young carers project either as a volunteer or as part of a young carers forum with the upper age limit of 19. None of our sample of young adult carers had received any of the following services: a sitting service, respite care, or training on skills for caring, and very few had received counselling, befriending or preparation for job-seeking; indeed they were mostly unaware of the existence of these services or how to access them. This suggests that young adult carers are often uninformed about services which could, if they are eligible, help to ease the burden of caring and potentially enable them to participate more fully in either work, leisure or educational opportunities. The need to fill this 'knowledge gap' will not be the preserve of carers services alone but rather requires the additional engagement of other service providers who have contact with young adult carers (health, careers, benefits agency, adult social care services, specialist service providers etc).



Carla – now awaiting a carer's assessment

Carla, aged 19, lives with her own two year old daughter and her mother in a rural setting. Carla's mother has dementia-type symptoms as well being physically disabled. She is a wheelchair user and experiences pain as a consequence of Raynaud's disease that affects her hands and arms. As a consequence of her health, Carla's mother has high care needs – she receives assistance from professional carers three times a day and, in addition to this, Carla does domestic tasks, shopping and lifting, accompanying her mother to health appointments and provides emotional support on a daily basis. Carla resents the restrictions that caring places upon her particularly in respect of her social life. Poor public transport services and dependence on state benefits have served to intensify her feelings of exclusion and isolation.

Carla enjoyed school where she achieved well academically, leaving when she became pregnant. She has continued to study on a part-time basis at college although she was very disappointed that she could not complete a full-time catering course due to the difficulties of combining the course with her caring responsibilities and a lack of public transport. Carla hopes to move into independent living with her daughter in due course and complete her A levels, however she can foresee that her mother will be unsupportive of this move.

Carla has valued the support of young carers project since she was 12 years old. She cites the activities, residential breaks and opportunity to mix with other young carers as being particularly helpful. She has been closely involved with the development of an 18 plus service at the young carers project and has enjoyed being involved in the development of the service as well as receiving support from the service now that it is established. Carla is awaiting a carer's assessment having been encouraged to apply for one by the 18 plus service.

Our findings show that young adult carers have a need for:

Information, advice and guidance

- information and advice about money/benefits/grants/services available for carers and this should include information about services available for the person that they care for;
- information and advice about the medical conditions and health needs of the person they are supporting;
- information and advice about their own health, including the maintenance of a healthy diet and lifestyle;
- information, advice and training about moving and handling ill or disabled relatives and administering medication or healthcare so that young adult carers do not have to take risks with their own health or safety which would not be asked of an employed care worker;
- information, advice and assistance in undertaking personal and intimate care which respects the dignity of all parties;
- parenting advice and support where a young adult carer has a child of their own and must combine parenting with caring for a parent or other ill or disabled relative, or where they have a significant parental role for a sibling as a consequence of a disabled, ill or substance-misusing parent being unable to provide this.

Services and support

- services and support that young adult carers can receive as carers, including culturally sensitive services where young adult carers require this as part of their religious, cultural or community identity;
- counselling and other therapeutic interventions or relaxation techniques to help overcome the negative effects of caring, to build emotional resilience, relieve stress and for positive personal growth;



- breaks from caring when required and opportunities to take short breaks with the person they care for;
- a formal assessment(s) of their own needs and of their ability to continue to provide care, under adult carers' legislation;
- contingency planning if they were unable to care for their relative for any reason at short notice or in an emergency;
- access to reliable and affordable public or community transport or driving lessons and their own car, so that they can fulfil the range of their caring responsibilities (including shopping, escorting the person they support to appointments, taking them out etc) as well as for their own needs;
- housing of an adequate standard and layout which allows for the person with care needs to maintain their health and as much independence as possible, whilst enabling young adult carers to fulfil safely their caring tasks.

Education and training

- information, advice and guidance about opportunities in further or higher education and how to obtain relevant financial assistance;
- information and advice about flexible training opportunities such as part-time, distance learning or online courses;
- further or higher education institutions (universities) and training organisations to be aware of the needs and potential demands on young adult carers and consider how best to support them;
- help in balancing the demands of caregiving and further education and ongoing (or lifelong) learning.

Activities and peer support

- activities available locally which give young adult carers opportunities for social interaction, leisure and wider participation;
- affordable or subsidised leisure activities which promote the health, well-being and inclusion of young adult carers;
- opportunities to meet other young adult carers in similar situations, to develop peer support systems or networks based on positive self regard, mutual understanding and common acceptance;
- online opportunities for accessing information, advice and guidance and opportunities for social networking with other young adult carers.

Job-seeking support and flexible employment

- employment-related assistance, including help with developing CVs, job-search and interviewing skills, especially where there is a 'deficit' in these skills because of the restrictions imposed by childhood, ongoing or current caring and family circumstances (low income, parental illness/disability etc);
- career guidance up to the age of 24;
- flexible working arrangements;
- employers who have an understanding of the demands on carers and the transferable skills that caring can bring;
- employers who have developed appropriate packages of workplace support for working carers;
- assistance and services for the person being supported in order that the young adult carer can balance the demands of caregiving and paid employment, or in finding paid employment.

In the final Chapter we outline our recommendations for the development of service responses for young carers aged 16-17, for young adult carers aged 18-24 and for the development of adult carers services that are responsive to the needs of young adult carers.

Chapter 12 - Recommendations

In this final chapter research-informed recommendations are made for the development of services and support to young carers aged 16-17 and to young adult carers aged 18-24. We also make some recommendations about service developments for adult carers services. All of these recommendations are based on the premise that young adult carers should not have to take on, or continue with, inappropriate caring roles and responsibilities which have adverse effects on their health and well-being and which undermine their ability to achieve their potential. This requires there to be effective support for families and the person being cared for – an explicit aim within the National Carers Strategy (HM Government, 2008).

Box 12.1: National Carers Strategy 2008

“Our vision for 2018 is one in which professionals in our front-line services who are in most regular contact with young people have the knowledge they need to identify problems early and encourage young carers to come forward for the help they may need.

It is a vision where high quality targeted support is accessible to those who need it and based on sound evidence of what works.

Above all, it is one where preventing – protecting young people from falling into inappropriate caring – is the priority and a guiding principle behind the planning and delivery of services. Effective support for families and the person being cared for is at the heart of this” (p 125).

Service development for young carers aged 16-17

The findings from our study highlight a number of implications for young carers projects currently working with carers up to the age of 18, principally that they need to think about and plan for young carers leaving their service and empower them to be confident in finding and using other services post 16 (and especially post 18) years onwards.

We recommend that:

1. The aim of support and services should be to reduce the inappropriate caring roles undertaken by young carers wherever possible because the disadvantages that are experienced by some young adult carers are often rooted in their earlier experiences as young carers. Therefore early intervention and effective support for them and their families will help to prevent this disadvantage. The whole-family approach and key principles of practice for young carers, parents and their families (Frank and McLarnon, 2008) need to become embedded in the work and the approach of all those working with and supporting young carers and their families.
2. A key factor to be considered in the development of services and interventions for young carers aged 16-17 years should be concerned with outcomes rather than types of services and models. Commissioners and service providers of services/interventions for this group of carers should identify clearly the outcomes to be achieved and delivered for young carers. The key outcomes that services in England should deliver for all children are those as contained in Every Child Matters: be healthy, stay safe, enjoy and achieve, make a positive contribution, and achieve economic well-being. These last two outcomes become more important for young carers as they get older, and especially – as we have shown in this report – for 16-17 year old carers and those aged 18 plus (who are no longer ‘children’). Other ‘specific’ outcomes will need to be identified for young carers aged 16-17 and young carers projects will need to give thought to the balance between open-ended group work and activities, and more time-focused interventions, to deliver the specified outcomes.



3. A key principle for the development of all services should be that young carers, who wish to do so, are involved fully in planning services. While there are various models of 'user involvement', we recommend that young carers participate in service development as 'experts through experience'. Their accounts, as highlighted through this research report, give us confidence in making the rest of our recommendations.
4. Young carers services need to prepare young carers, especially around the ages of 16+, for the next 'phase' in their life. This might include signposting or referral to other service providers.
5. Young carers projects need to develop preparation programmes for young carers in transition – this should include the issues most pertinent to them such as job/course-search skills, grant applications for university, CVs, first aid, cooking, benefits, adult social care services etc. Other local agencies could participate in delivery, as this would help young carers to become more familiar with other sources of help and support aside from those more specifically aimed at carers. Chapter 11 provides comprehensive details of the issues that will need to be addressed in these types of programme.
6. Systems will need to be developed and put in place to monitor and evaluate interventions and outcomes, using robust measures, instruments and tools which enable comparison between interventions/services across time and place.
7. Young carers projects should continue to raise awareness of young carers' issues with schools, and also extend this to FE colleges and universities. Chapter 11 provides more details of the roles that schools, FE colleges and universities can play and some of the issues that they need to address.
8. Young carers projects and other service providers who have contact with young carers (eg health, education and youth services) need to provide them with information about their legal rights including the right to a carer's assessment from the local authority, or an assessment as a 'child in need' in appropriate cases.
9. Many young carers are well aware of the precariousness of the funding for young carers projects. This has a negative, unsettling effect on young carers and suggests to them that they are not seen as an important group deserving of long-term support. Projects need to continue to highlight this problem with those that fund them wherever possible. Commissioners of services need to think about how they can resource projects for more than one or two years at a time to allow for sustainability and continuity.
10. Young carers projects need to build relationships and bridges with local adult carers services to help adult services recognise and become more engaged with the needs of young adult carers.
11. Young carers projects in conjunction with adult carers services and other providers need to consider the best ways to provide 'seamless services' to young carers after they reach 18. Various models and examples are provided in Chapter 10.
12. Young carers projects need to consider the 'threshold' at which they provide a service to young carers. There was evidence that some young carers in contact with projects were providing low levels of care-giving. Such a threshold might include criteria based on the amount, intensity and regularity of caring, coupled with criteria that are concerned with the negative outcomes of caring on a child's wellbeing, health, education, development and relationships. Where the line is drawn will always be debatable, but specialist young carers projects should be providing services and support to young carers who need it most. Projects need to make good links with their local services, which may be able to support young carers with less intensive needs – thus allowing projects to work with young carers who require more specialist, intensive and outcome-focused support.

13. Universal services, such as schools and health care (including primary and secondary care) have a vital role to play in signposting and supporting young carers alongside more specialist services such as young carers projects. All schools should seek to identify and support young carers better, developing individual support plans for those most in need and identify ways to foster the educational achievement of young carers through a more flexible and personalised approach which also draws on extended school provision. FE colleges should also consider how they can identify and support young carers so as to enable them to stay engaged and complete their college course and to ensure they get access to careers information, advice and guidance.
14. Services providing careers information, advice and guidance should try to establish if a young person has caring responsibilities and the implications of these for their career and job choices. Young carers may need additional support, encouragement and the provision of other services for the person they are supporting if they are to realise their ambitions and in order not to be constrained into careers and jobs restricted to caring roles, although for some this will be a positive choice.

Service development for young adult carers

There is a clear need for policy and service development for young adult carers aged 18-24 years. There are a number of emerging models of specialist service delivery which were presented in Chapter 10, most in their infancy and very small in number, which include:

- A 'young carers plus' service whereby young carers projects extend their age range up to 24 or 25 years.
- Adult carers services proactively 'reaching down' to engage with carers aged 18-24.
- A 'partnership' approach between young carers services and adult carers services working to jointly deliver a young adult carers service.
- Better integrated carers services which bridge the gap between carers services for children and for adults.

Developing specialist provision for young adult carers is important but will not be sufficient by itself. Both universal and other targeted services need to take a more proactive role in recognising, identifying and engaging with the issues and challenges that young adult carers face in making a successful transition to adulthood and to adult services. These services would include Connexions/careers and Job Centre Plus; Targeted Youth Support; housing departments; health services (including mental health and drug/alcohol services); children's services (social care and education); adult social care; and services provided by the third-sector, for example, organisations that focus on specific health conditions or impairments. In this context, for example, universal services such as health can offer advice and information about young adult carers' own health needs, sexual health, and so on, as well as generic information about the illness/condition affecting the person being supported. Welfare rights services and Citizen Advice Bureau can provide information about money and benefits. Connexions, careers services and Job Centre Plus can provide much of the information that young adult carers need concerning careers, training and local jobs. Adult social care departments can assess the needs of young adult carers and provide support to meet their needs and enable them to continue to care – as they should do for *older* carers as required by law. All these service providers need to be more alert to the specific needs of young adult carers and find ways to deliver *their* particular service to them.

We recommend that:

1. The key factor to be considered in the development of services and interventions for young adult carers should be concerned with outcomes rather than types of services and models. 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.



2. 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. Their accounts, as highlighted through this research report, give us confidence in making the rest of our recommendations.
3. The development of outcome-focused services and models of intervention will require those working with young carers, and those in adult social care and adult carers services, to have a dialogue locally about how best to proceed to develop services for 18-24 year old carers. As we have said, this should include young adult carers themselves. This will also require discussion not just with specialist 'providers' and agencies, but universal and other services as well (see 4 & 5, below). Different models of service delivery should be tried and tested more widely to see which work best in delivering stated outcomes, for whom, in what circumstances and why.
4. Young carers projects and carers centres providing support to young adult carers aged 16-24 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.
5. Agencies that would not traditionally be associated with meeting the needs of carers also need to identify and engage with young adult carers. So, for example, colleges, universities, Job Centre Plus, employers, leisure services providers and others all need to be alert and sensitive to the needs and issues confronting this group of carers and which affect their opportunities for further education and learning, leisure, careers and paid work. Some young adult carers will be parents themselves and may need parenting support in this role because of their ongoing care responsibilities to others.
6. 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.
7. All agencies, but especially local authority services and carers 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 services and support for the young adult carer and their family.
8. 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 carers services.

Service development for adult carers services

Many adult carers services do not identify or focus on the needs of young adult carers and perhaps unintentionally 'exclude' these young adults from their service provision. They need to consider ways of developing their services to incorporate and address the needs of young adult carers and identify how best their service could reach and support this group to deliver desired outcomes. For some carers centres or services, this will pose major challenges about working with a group of carers much younger than they are traditionally accustomed to working with. Adult carers services will need to consider if this is best achieved by a partnership approach with providers of services to young carers, or other arrangements or models. Chapter 10 provides some models and examples. The ultimate service configuration will depend to some extent on the remit and reach of their own organisation and the outcomes that are to be delivered.

We recommend that:

1. The key factor to be considered by adult carers 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 carers services to consult young carers 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 carers 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 which enable comparison between interventions/services over time and place.
5. All agencies, but especially local authority services and adult carers 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.

The 290,000 carers in the UK who are aged 16-24 are a sizeable army of invisible carers. We hope that this research will help to give them a voice and bring them to the attention of the public, policy makers, service providers and others in powerful and less powerful positions, so that their needs, and rights, can be addressed more adequately. Developing services and interventions for this group will be a sound investment for the future, promoting the positive aspects of caring and reducing the negative outcomes, with all the associated costs and benefits these have for individuals, society and the economy.



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"We're real  people, with real  issues,  listen to what we say."

Young Adult Carers in the UK

Experiences, Needs and Services for Carers aged 16-24

"The data within this study provide new and important insights into the diverse experiences of what is often a 'hidden' group of carers... this study provides an evidence base for the development and delivery of more personalised support and better outcomes for a vital but often 'silent minority' of young people".

Dr. Philippa Russell, Chair, Standing Commission on Carers

Fiona Becker and Saul Becker's pioneering research report highlights the experiences, needs and service responses to young adult carers aged 16-24 in the UK. There are almost 300,000 carers of this age with a quarter of a million aged between 18 and 24.

The report draws on original data, including in-depth interviews with carers aged 18-24, focus groups with carers aged 16-17, surveys of young and adult carers services and secondary analysis of Census 2001 data.

The report reveals the number of young adult carers in the four countries of the UK; the changing nature of their caring tasks and responsibilities as they get older; their experiences of education at school, college and university; how they choose their friends and relationships; the restrictions on their leisure and lifestyle choices; their concerns about money, jobs and careers; their aspirations for the future; the challenges of leaving home and gaining 'independence'; the roles of young carers projects; emerging service responses specifically aimed at carers aged 18 plus; and how the needs of young adult carers in the UK can best be met.

The report also includes a series of recommendations for service development for those working with carers aged 16-17 and carers aged 18-24, and for those providing services to adult carers. These age categories have major implications for the commissioning and delivery of services in the UK and for whose responsibility it is for meeting the needs of children who are carers and adults who are carers.

Becker and Becker's research poses new challenges to all those concerned for, and working with, family carers and young people. This research report will be of interest to policy makers, commissioners, practitioners and researchers working in the fields of health and social care, young and adult carers services, education, children's and youth services, and adult social care.

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