



## Young Adult Carers in the UK

Experiences, Needs and Services for Carers aged 16-24



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### 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.



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### **Ethical approval**

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