

# Time to be Heard

A Call for Recognition and Support  
for Young Adult Carers



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# Acknowledgements

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We would like to thank all the young adult carers and Carers Trust Network Partners involved in the Time to be Heard campaign. We are grateful to the University of Nottingham for carrying out the research used in this report.

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# Executive summary

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Research shows the impact of caring for a family member or friend on young adults in education and when looking for work. From the first large-scale survey of this group we now have a fuller picture of the lives of the estimated 375,000 young adults in the UK who pick up the pieces when their families with care needs are left without adequate support.

In 2013, Carers Trust commissioned the University of Nottingham to undertake research examining the experiences and aspirations of young adult carers in the UK. A total of 362 people viewed the survey and responses from 295 young adult carers aged 14–25 were analysed.

Bringing these findings together, this report highlights the difficulties young adult carers experience in their education, employment, health and socialisation. They are not being identified and supported so they face multiple barriers that will have significant and lasting impact on their future.

The research (Sempik, J and Becker, S, 2013, 2014, 2014a) found that young adult carers:

- Miss or cut short an average of 48 school days a year because of their caring role.
- Were four times more likely to drop out of college or university than students who were not young adult carers.
- Miss work an average of 17 days per year, with a further 79 days affected because of their caring responsibilities.
- Have higher rates of poor mental and physical health than the average young person.
- Rarely receive the assessments they are entitled to, with only 22% of those surveyed receiving a formal assessment of their needs by the local authority.
- Experience high rates of bullying – one quarter reported bullying and abuse in school because they were a carer.

The Care Act 2014 which comes into force in April 2015, brings in new rights for young adult carers and heralds a change where children and young adults are identified earlier and supported to reach their own goals. Adequate funding of the implementation of the Care Act 2014 would be an important step. It would ensure that young adult carers are protected from excessive caring responsibilities and instead can put their energy into education, training and employment. This investment needs to be reflected in Government policy so that young adult carers are recognised as a vulnerable group who are prioritised for support to fulfil their potential.

Drawing on analysis of the research findings and consultation with thousands of young adult carers, Carers Trust is calling on the Government and public bodies to secure a positive future for the UK's young adult carers. It is young adult carers' Time to be Heard. This report focusses on recommendations for England, while forthcoming reports will address policy in Wales, Scotland and Northern Ireland.

## Key recommendations:

- The Government should provide sufficient funding and monitoring of the implementation of the Care Act 2014 and Children and Families Act 2014. Young adult carers and their families should receive appropriate assessments and the care needs of the whole family should be met. Young adult carers should not be unduly relied on to provide care.
- The Government should include young adult carers in additional financial support programmes, such as Pupil Premium, the 16–19 Bursary Fund and the criteria for university access agreements so that young adult carers are identified and given the support to do well in their education.
- The NHS and local government should support a national network of young adult carer services to improve young adult carers' wellbeing, ensuring their rights to assessment and support are respected. This is also necessary so that their views are represented within local and national decision making.
- Careers guidance, training and employability programmes should recognise young adult carers as a vulnerable group and provide sufficient information for them to plan for training and/or employment.

## About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of 116 independent carers centres, 55 Crossroads Care schemes and 99 young carers services. Together we are united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

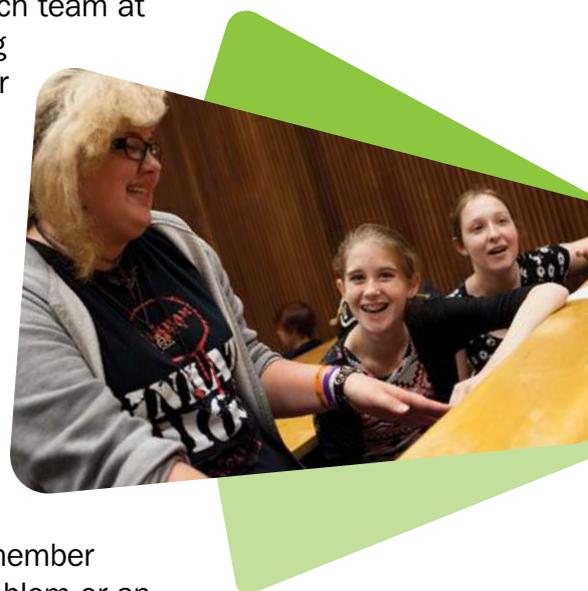
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# Evidence on young adult carers' health, access to support and experience of education and work

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In 2013, Carers Trust commissioned a survey of young adult carers to inform the Time to be Heard campaign. The campaign, funded by The Co-operative Charity of the Year, aims to transform the lives of young adult carers aged 14–25 by addressing the barriers that prevent them from reaching their potential. The survey was carried out by a research team at the University of Nottingham reaching 362 young adult carers of whom 295 provided responses for analysis (Sempik, J and Becker, S, 2013, 2014 and 2014a).

The research reveals the many obstacles on a young adult carer's path to adulthood. They face poorer educational attainment and chances in employment than other young people. This group is under pressure to pick up the pieces when adequate health and social care services are not available.



Young adult carers are young people aged 14–25 who care, **unpaid**, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Most of the survey respondents had been providing care to a family member for several years. The average age for becoming a young carer was ten years old. The majority that answered this survey were providing a very high level of care. <sup>1</sup>

The young adult carers responding to the survey were all caring for a family member. The person being cared for was a mother in 52% of cases. Other family members were a father (14%), a brother or stepbrother (17%), a sister or stepsister (8%) or both parents (4%). Those family members needing care had a wide range of conditions, most commonly physical disabilities, mental health problems, long-term physical illnesses and learning disabilities.

The research represents the largest data collection in the UK in relation to young adult carers, making this an important opportunity to look at their health, experience of education and chances for employment. This report considers lessons for policy in England. Forthcoming reports will put forward recommendations for Scotland, Wales and Northern Ireland.

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1 Based on measurement by Joseph, S, Becker, F, and Becker S, 2009.

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# Ensuring the health and social care system does not rely on young adult carers to pick up the pieces

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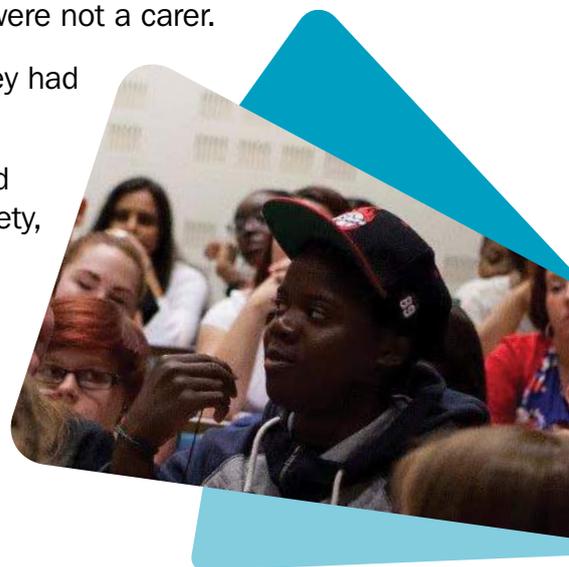
In the research we see that young adult carers are picking up the pieces of a health and social care system that is short of funds and does not always give joined up support to families. A young person's caring role develops when health and social care services leave their family member or friend without enough support.

## The effect of the current health and social care system on young adult carers

The survey results show the impact on young adult carers' health and opportunities when health and social care services are unavailable or inadequate.

For those young adult carers answering the survey:

- Only 22% have received a formal assessment of their needs by the local authority.
- 45% of those responding to the survey who had left school said that they would have got better grades if they were not a carer.
- 65% of those responding to the survey said they had one or more disability or health difficulty.
- 45% of those responding to the survey reported having a mental health problem, including anxiety, depression and eating disorders.<sup>2</sup>
- There was a link between providing a greater amount of care and regularly missing college or university.<sup>3</sup>
- Only 46% said their family received good support and services.



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- 2 The number of responses analysed were from 295 young adult carers. This included 61 still at school, 101 in college or university and 77 who had left school and were either in work or NEET.
  - 3 The data showed a weak to moderate but statistically significant correlation between level of care provision and attendance. There was a correlation coefficient of 0.29–0.41 depending on the measure of absence or lateness used.

Young adult carers reported the impact of their role on their education, chances for work, health and wellbeing. Young adult carers are developing health problems, including mental ill health, at a much higher rate than other young people.<sup>4</sup> Of the survey respondents, 38% said that their health was just OK or poor and 45% reported having mental health problems. Their caring role also had an evident impact on their attendance and grades at school, college and university.

The research findings support the case made by Carers Trust and young adult carers themselves that relying on young adults to provide high levels of care for a family member puts their health and their future at risk.

## Adequate funding of health and social care services to protect the rights of young adult carers

While the Government is bringing in new rights for people in England with care needs and for carers, support is focussed on those with higher needs (Department of Health, 2014). This means that only those with higher levels of care needs or those in crisis will qualify for support from their local authority. Unless adequate support is available to more families and funding is found to pay for it, the rights of many young adult carers are unlikely to be realised. The Government could be

leaving young adult carers to pick up the pieces of the health and social care system. Young adult carers need better funding of social care.

**“Carers are the ones that suffer in silence. You have mental health problems because you are keeping it in.”**

**Young adult carer**

In the survey sample, only 22% of young adult carers had received a formal assessment of their needs by the local authority. This means that the vast majority are missing out on the chance to have their needs considered and to hear about their right to be supported. Stronger rights for young adult carers in the Care Act 2014 mean that more are entitled to a formal assessment and can benefit from family assessments.

New duties for local authorities to support and consider the whole family, including young people, have the potential to improve the futures of young adult carers. The research found that currently less than half of young adult carers felt their family received good support and services. An increase in the number of assessments and the subsequent provision of support by local authorities will be essential to address the poor health, disadvantage in education and high unemployment rates seen in the survey results.

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4 Data for comparison includes the Office for National Statistics 2004 survey covering England, Scotland and Wales, which found that one in ten children and young people aged between five and 16 had a clinically-recognisable mental health disorder (Green et al, 2005). Another survey conducted in 2006 found that 20% of students aged 16 to 19 in sixth form or further education colleges reported experiencing emotional or psychological problems in that current term (Schools Health Education Unit, 2007).

Social care services have wide-ranging responsibilities to provide services to people with care needs and to carers but their budgets restrict the money available to pay for the necessary support. In 2014, the Association of Directors of Adult Social Services provided evidence that £3.5bn has been removed from the care system budget since 2010 (ADASS, 2014). Research commissioned by the Care and Support Alliance show the situation is getting worse for the families of people with a care need. Research comparing social care provision in recent years with levels five years before, finds that 350,000 fewer people received social care services. Factoring in the changes to the population, that would be equivalent to half a million people being denied access to social care services between 2008 and 2013 (Fernandez, J et al, 2013). The budget to pay for health services has been stretched as the population has grown. Experts such as the Kings Fund are predicting financial problems ahead for many parts of the NHS (Appleby, J et al 2014). This tightening of funding and criteria leaves those with care needs reliant on their family and people in their community, including young adult carers.

We are calling on the Government to adequately fund health and social care so that young adult carers are enabled to fully participate in education and employment opportunities, and live healthy and fulfilling lives.

**“If there were quality services for disabled people that is the best they could do. Mental health services have been cut so much.”**

**Young adult carer**

## **The need for support from specialist young adult carers services**

In the research, we found evidence that specialist young adult carer services can significantly improve wellbeing and educational attendance. Those surveyed said accessing specialist services had increased their confidence (72%), their feeling that they have friends (60%) and their grades and attendance (26%).

Services for young adult carers provide tailored support for young people with caring responsibilities to make decisions about education and employment. These services play an essential role in bringing groups of young adult carers together for peer support. Young adult carers can be supported to take part in local and national decision making. However, only a minority of young adult carers will have a specialist service in their area.

**“I got here [the young adult carers service] because I was referred by my mum’s nurse. The young adult carers services really gave me support.”**

**Young adult carer**

Support commissioned for young adult carers must recognise their particular needs and be provided by a skilled workforce.

## Recommendations

- The Government should commit to a new funding settlement for health and social care services to ensure that young adult carers are not relied on to care for family members and friends, putting their future at risk. The Care Act 2014 and the Children and Families Act 2014 should be implemented with sufficient funding so that young adult carers' rights to identification, assessment and support are realised.
- Local authorities in England should fulfil their duties in the Care Act 2014 and Children and Families Act 2014 to ensure that young adult carers are not providing an inappropriate level of care and have an equal chance to get an education, train for the future, have good health and enter employment.
- Clinical commissioning groups, NHS trusts and local authorities should fund and sustain young adult carer services for specialist support. This will contribute to young adult carers' access to information on their rights, the tools to improve mental health and wellbeing and their educational and employment outcomes.
- Young adult carer services and other organisations in contact with young adult carers (schools, GPs, local authority services, universities and colleges) should provide information on rights to assessment and support from the local authority for young adult carers and their families in the Care Act 2014.

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# Committing to identify young adult carers in education and provide appropriate support

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A large number of young adult carers in school, college or university had not told anyone that they were a carer or had received support. The most common reason for not communicating their caring role was that there was “no point”. Many of those who were identifying themselves found that this did not lead to the support in their education that they needed. Schools, colleges and universities must increase identification alongside addressing the lack of support that they offer. Schools, colleges, universities and, with their new duties towards young adult carers, local authorities will need to use different mechanisms to address this issue. Nevertheless, the goal is the same – to ensure that identification increases and that it links systematically to appropriate offers of support for young adult carers.

“They only realised [I was a carer] when I was being bullied then they gave me counselling.”

Young adult carer

## The consequences of not supporting young adult carers in school

School is a crucial time for young people but caring responsibilities were having a significant impact on the attendance and attainment of the young adult carers surveyed. Young carers have been identified by Ofsted as a group with protected characteristics in need of specialist support (Ofsted, 2014).

“I feel that my biggest issue is achieving grades when I have to spend time caring.”

Young adult carer



Some schools are taking positive steps to support young adult carers, while others lack the awareness to identify and support them. Young adult carers face inconsistency, with many missing out on the support needed to prevent them being disadvantaged in their education.

- On average each year, young adult carers miss ten days of school, start late 27 days a year and leave early 11 days a year.
- A quarter of young adult carers in school report being bullied or abused because they were a carer.
- The most common highest qualification for the young adult carers responding to the survey was a GCSE at grade D.

“I had to pay fines because I didn’t come to school. I called in but they said [my parents’ illness] wasn’t my problem: ‘We don’t believe you you’re just bunking off’. I had to pay £300 out of my savings.”

Young adult carer

All schools should identify and support young adult carers. This is important in order to address the educational disadvantage and the distressing experiences in school evident in the research findings.

## Early identification of young adult carers in schools and providing support

Identifying young adult carers is an essential step towards offering them support to learn, study and get the grades they need for further and higher education and employment. Without adequate identification and support young adult carers are left to balance the demands of education and caring, putting at risk their school qualifications and experience.

- 35% of young adult carers had not informed their school that they were a carer.
- 50% of young adult carers said there was a particular member of staff who knew they were a carer and supported them.

An ideal mechanism to secure the identification and support of young adult carers would be their inclusion in eligibility for Pupil Premium. This would enable schools to identify young adult carers within their population and to use the additional funding to support their attendance, attainment and wellbeing.

“Although I got good grades when I said I needed help, I needed help. Sometimes I could not do it all and would need some time just to stop.”

Young adult carer

Support in schools needs to be consistent and accessible. All young adult carers should be confident of their chance to benefit from their time in school with qualifications, skills and direction for the future.

## Identification of young adult carers in universities and colleges

Young adult carers tell us that they do not know how to identify themselves in college and university to access support.

- 25% of young adult carers at college or university had not informed staff.
- The most common reasons for not identifying themselves were that there was no point, no one asked or they did not know who to tell.
- 45% said they did not have a particular person at college or university who recognised they were a carer and helped them.

Many college and university students do not have a clear opportunity to identify themselves as a young adult carer, especially early on in their studies when support could have the greatest impact.



**“There have been a few times when I’ve had a breakdown, when I started my foundation year at uni. I was ill for nine weeks. YAC [young adult carer] service wasn’t starting up and I had left the young carers services because I was 19. I wasn’t introduced to it properly. I had no transition.”**

**Young adult carer**

The Government, Universities and Colleges Admissions Service (UCAS) and Office for Fair Access (OFFA) should ask universities and colleges to identify young adult carers through data collection systems and provide them with support in their education.

## The consequences of young adult carers at college and university missing out on support

Lack of support in universities and colleges, coupled with too much caring responsibility at home, had an impact on young adult carers' chances of accessing and fully benefitting from higher and further education.

- 14% of young adult carers in school said they could not go to college or university because of their caring role.
- 56% of the young adult carers in college or university were struggling because of their caring role.
- 17% said they may have to drop out for reasons associated with their caring role.
- 13% said they may have to drop out for financial reasons.
- Over half of the young adult carers in college or university were receiving a bursary but many were missing out.
- 29% of those who were not in education or employment had dropped out of a college or university course, four times the national average.
- Research conducted by National Union of Students (NUS) showed that any offer of help from colleges or universities for young adult carers often comes far too late for it to be effective (NUS, 2013).

These findings show a need for targeted support for young adult carers in college or university. Universities and colleges can draw on models of good practice and work with student unions to support young adult carers.

### Recommendations

- Schools should identify young adult carers at the earliest opportunity and support them to make sure they are not disadvantaged in their education because of their caring role. Schools should draw on best practice (see [www.youngcarersinschools.wordpress.com](http://www.youngcarersinschools.wordpress.com)).
- The Department for Education should include all young carers in the eligibility criteria for Pupil Premium and the vulnerable student criteria of the 16–19 Bursary Fund.
- The Department for Business Innovation and Skills and OFFA should ask for carers to be identified in university data collection systems, to be included in funding arrangements and to see an increase in support while at college or university.
- Admissions processes administered by schools, colleges, universities or local authorities should ask if the student is a young carer or young adult carer.
- UCAS should include a tick box on application forms for students to indicate if they are a carer. Universities and colleges will then be aware of the personal circumstances of those young people applying for courses. They can be flagged for support when they are considering and attending college or university.
- Colleges and universities should identify and support young adult carers in line with best practice. The National Network of Universities Supporting Young Carers, Carers Trust and the NUS can provide models of good support for young adult carers at universities and colleges.

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# Removing obstacles to training and fulfilling employment for young adult carers

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Many young adult carers are feeling the pressure of balancing their caring role and training or employment. Young adult carers also need more information about their options for the future so that they can make informed choices. Once in work their caring role can have a negative effect on their attendance and restrict their choice of courses or job. Young adult carers worry about the person they care for while they are at work so it is essential that local authorities and the NHS ensure that there is high quality support in place.

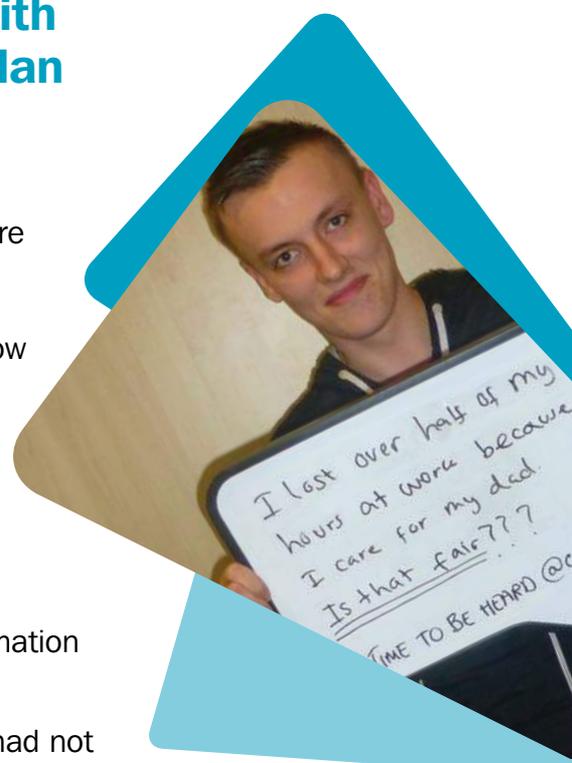
## Providing young adult carers with the information they need to plan for their future

Young adult carers need better advice about their options for the future. Many of those surveyed were uncertain about how they will be able to pursue further education, higher education, training and employment while they continue as a carer. The low number who had received an assessment from the local authority means that many are missing out on support to answer these questions, including the chance to consider whether they want to reduce their caring role with the support of social care or health services.

Young adult carers did not feel they had the information and advice they needed to plan for the future.

- 87% of those no longer in education felt they had not received good careers advice and many also reported that they did not get the advice they needed about how to look for a job while having a caring role.
- 24% of young adult carers in school said they could not afford to go to college or university, while 41% were unsure.
- 13% of those at college or university felt they may drop out because of financial difficulties.
- Few received state benefits (10% received Carer's Allowance and 28% received other benefits).

Taken together, it is clear that young adult carers have insufficient information about the resources and guidance available to them.



Careers advice for young adult carers should help them understand their options in the context of their caring responsibilities. This advice needs to be tailored, targeted and effective. With new rights to assessment and support services from the local authority when the Care Act 2014 is implemented, young adult carers in England should benefit from more support to consider reducing their caring role. There are also important duties for local authorities to support young adult carers to consider their options for further and higher education, including how the person they currently care for will receive that care if the young person begins study or work. This gives local authorities the remit to manage the transition of all young adult carers and to build their aspirations. It is essential that young adult carers are offered tailored careers advice. They should also have access to specialist support to consider and prepare for university, with an ongoing offer of guidance as they balance caring responsibilities and employment.

**“If you have trouble in school you don’t think about what you want to do in the future. It’s hard enough now. I wish you had more support in careers advice. I haven’t had the time in my life to sit down to think about what I want to do.”**

Young adult carer

## Enabling young adult carers to be part of the workforce

The research showed that being a young adult carer had a significant negative impact on employment.

- On average, young adult carers missed 17 days of work per year and had to start late or leave early on 79 days per year.
- 21% of the young adult carers who had left school were NEET.

The impact of caring on work attendance is likely to be holding young adult carers back in their working life. Many are risking their job security because they can struggle to balance their obligations to their employer and the person they care for.

Across the sample, a significant number of young adult carers had felt it was necessary to prioritise their caring role over their work choices.

- 44% chose their job because it was close to home.
- 38% chose their job because it offered the flexibility to fit it around their caring responsibilities.

**“My caring responsibilities feel like a barrier because I feel trapped and guilty for leaving my mum.”**

Young adult carer

The restrictions that caring places on their employment opportunities can also be seen in the high number not in work at all.

It was positive to see that those young adult carers who had completed a university or college course were more likely to be in a job because it fitted with what they wanted to do. The research shows that college and university is an important route to employment for young adult carers. This underlines the need to address young adult carers’ disadvantage in education and provide good guidance on their options in young adulthood.

Young adult carers are likely to be dealing with conflicting pressure from their employment and their caring. Health and social care services have new duties to offer support, as set out in the Care Act 2014 and Children and Families Act 2014. Local authorities are required to offer assessments and consider families' entitlement to support so that young adult carers do not miss out compared with their peers.

**“They [my manager] understand that if I have to go I go but make up the time later.”**

**Young adult carer**

At the same time, employers need to provide better support to young adult carers and to offer their employees flexibility. Being able to balance the demands on their time will

benefit the young adult carer and the organisation they work for.

Our research found that employers are generally aware of the caring responsibilities of young adult carers. The majority of young adult carers in work had told their manager about their caring role but for 41% of them their manager was not supportive. Collaborative work between employers, Government and young adult carers is needed to develop approaches for supporting young adult carers in work.

## Recommendations

- The Department for Education should require local authorities to oversee careers advice for all young adult carers up to the age of 25, in line with the duty for young people with disabilities, to ensure that young adult carers have sufficient information about funding, training and career options.
- Young adult carers should be prioritised for ongoing face-to-face careers guidance. Local authorities and schools should ensure that young adult carers have access to information when preparing for further and higher education that addresses additional questions that may arise as a result of their caring role.
- The Department for Business Innovation and Skills should set up a taskforce to develop recommendations and secure commitment for action from employers and Government departments to address the disadvantage experienced by young adult carers in training and employment. The taskforce should include young adult carers, employer and training provider representatives, and third sector organisations with expertise on young adult carer issues.
- Young adult carer services should identify sources of information on financing further and higher education and on applying for employment and training.
- Employers and providers of traineeships and apprenticeships should make clear the flexibilities and support available to young adult carers in employment, training or during apprenticeship.

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# It is young adult carers' Time to be Heard

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Over the last decade, Carers Trust's groundbreaking work has brought young carers higher up the policy agenda. There is more awareness of who young carers are and their support needs. The basic premise – understood and committed to by the Government – is that children and young people should not be relied upon to provide inappropriate care.

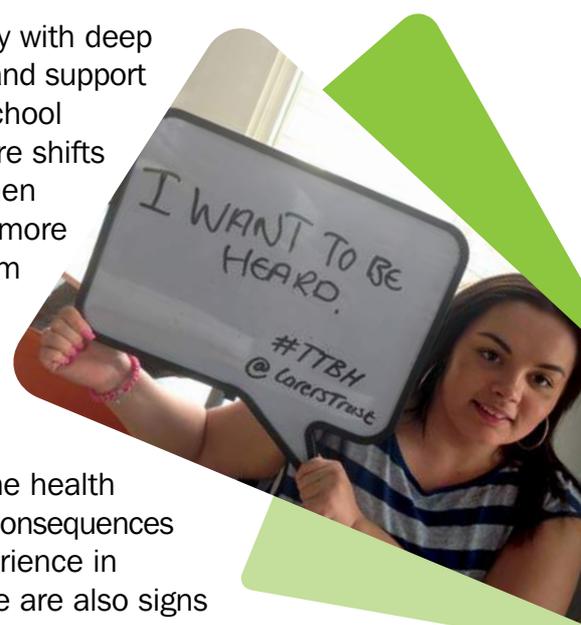
Those young people grow into adulthood generally with deep loyalties to their families. Yet statutory protection and support rapidly falls away as they transition beyond the school environment. The impetus to prepare for the future shifts to the young person and their family at a time when these young adults are often relied on to provide more care. Carers Trust is calling for a commitment from the Government and public bodies to implement policies and initiatives that prevent young adult carers from being disadvantaged in education, employment and their health.

Young adult carers are picking up the pieces of the health and social care system. There are severe negative consequences which can be seen in the disadvantage they experience in school, college, university and employment. There are also signs of the pressure placed on young adult carers, whose mental and physical health suffers when the NHS and social care services rely on them to fill in the gaps of disjointed and stretched provision. The consequences for young adult carers' wellbeing and chances for the future are unacceptable.

It is time for policy makers and the Government to hear the voices of young adult carers who are calling for:

- A social care and health system that does not rely on children and young people to provide inappropriate levels of care at the expense of their health and their future.
- Support in schools, funded by Pupil Premium.
- Clear and consistent offers of support, in terms of finances and academic studies, for young adult carers in colleges and universities.
- An equal chance to train and work.

Young adult carers are calling on policy makers to listen and to commit to ending the risks to their future. It is young adult carers' Time to be Heard.



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seven million  
reasons to care

The **co-operative**  
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## Carers Trust

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