

Young Carers: Aiming High!



A study looking at how young people are impacted by a caring role when attending or considering attending higher education



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www.thecarerscentre.org

Registered Charity No. 1015728 Registered Company No. 2758481



National Collaborative Outreach Programme



Contents

Page 01	Young Carers Aiming High
Page 02	The Context
Page 03	Methodology
Page 04	Challenges & Limitations
Page 05	Findings
Page 06	Interview Phase
Page 07	Related Quotes from Young Carers
Page 10	Infogram of our findings
Page 12	Impact
Page 13	Finance
Page 14	Focus Group
Page 15	Case Studies
Page 17	Summary of Findings
Page 18	Recommendations for improving practice
Page 19	The Team, Acknowledgements, References
Page 20	Dissemination Plan



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Are you a young person, affected by someone's health condition in your family?

Would you like to meet with other young carers, and access 1-to-1 emotional support, advocacy, advice and activities?

We are the Young Carers Project, we work with many young people like you, right across Brighton & Hove

To seek support for yourself or to refer a member of your family please contact us:



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Dissemination Plan

In addition to this written report, we have also produced an informative video report on the study. The reports will be circulated through The Carers Centre's and The University of Sussex's social media channels, professional networks and through a press release.

We will also champion our findings in person through a number of influential advisory boards and other opportunities.

Examples of specific forums/individuals which we can guarantee will be presented with our findings include:

- Policy decision makers at the University of Sussex
- Brighton and Hove Safeguarding Children Board
- Anti-bullying steering group
- Young Carers Steering Group
- Commissioner for Carers Services in Brighton & Hove
- The Carers Trust (national organisation)
- The Carers Centre's Schools Worker will incorporate findings into our ongoing pupil awareness raising assemblies and PHSE sessions (in academic year 2018-19, these sessions were attended by 3300 pupils)



Young Carers—Aiming High!

The Carers Centre for Brighton and Hove and The University of Sussex have conducted a research project into how young people aged 13 to 20 are impacted by a caring role when attending or considering attending higher education. We also explored the ambitions of young carers, the amount of advice they receive from family and school around their futures and whether concerns about finance factor into decisions about higher education.

All of the young carers who participated in the study support either parent or sibling with a disability, long term or terminal illness, a learning disability, a mental health condition or a substance misuse issue.

The Context:

The Context:

There is evidence that young carers are less likely to apply for, attend and complete Higher Education courses than their peers without caring responsibilities. Research conducted by Carers Trust found that 29% of young carers drop out of degree courses, occurring at a rate that is four times higher than the drop-out figures associated with non-caring youth (Alexander, 2014). Additionally, young carers can often temper their own ambitions for a variety of personal, familial, and financial reasons. In a quantitative, large scale study of 295 young carers between the ages of 14 and 25; 84% said they intended to go to college or university, but 24% thought that they would not be able to afford or attend (Sempik and Becker 2014). The high cost of accessing higher education exists as a significant barrier for young carers and their families. Families containing a young carer have on average £5000 less income per year than other families (Hounsell, 2013). This figure is likely to be significantly higher in the National Collaborative Outreach Programme (NCOP) highlighted wards on which we focused (see methodology), due to the severe economic and social deprivation in those wards.



Locally, we had discussions with 3 young adult carers, aged between 16 and 18, in preparation for this project. These consultations directly informed the development of research questionnaire and helped to guide the focus of this present research. They identified the following barriers to higher education:

- The management of independent study whilst juggling a caring role
- The physical and emotional toll resulting from the balance of care and educational responsibilities
- Feelings of guilt associated with leaving home and the cared-for person behind.

The young adult carers suggested they would be more likely to choose to study locally, if at all, because of fear of what would happen to their disabled relative in their absence. If they did leave home to study, they said they are more likely to worry about home whilst away and travel back and forth from university more regularly, increasing stress levels as a result.

The Team

The Aiming High Project was delivered by The Carers Centre for Brighton & Hove and The University of Sussex in partnership with the young carers of Brighton & Hove. The University of Sussex lead was Dr Feylyn Lewis. The Carers Centre team consisted of Lizzie Hovard and Tom Lambert with assistance from Mary Collins, Paula Melis, Ruth Sullivan and Nick Hudson.

The Carers Centre for Brighton & Hove provides information, emotional support and peer-group activities to unpaid family and friend carers across the city of Brighton and Hove. For more information about the centre's work, please visit www.thecarerscentre.org

Acknowledgements

The report writers wish to thank all the Carers Centre and University of Sussex staff and volunteers who helped make this project a success. We would also like to thank Sussex Learning Network and the National Collaborative Outreach Programme for supporting us to deliver Aiming High! Most importantly, we want to thank all the young carers who participated in the study for giving up their time and providing their invaluable insights.

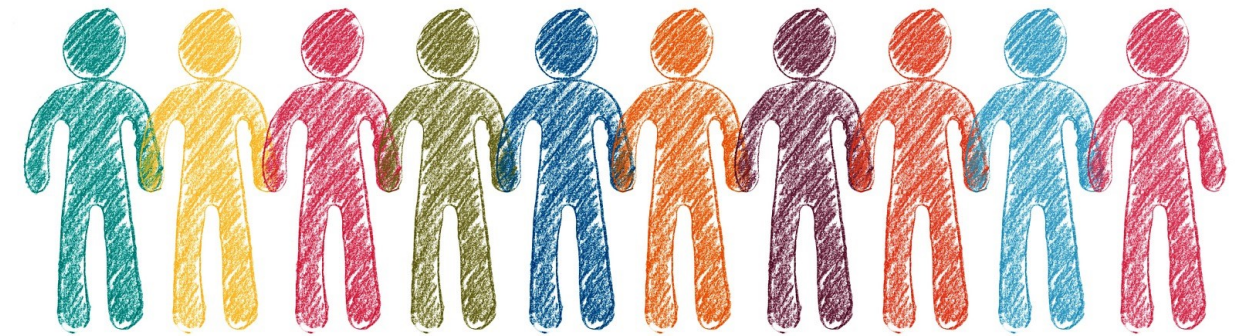
References

- Alexander, C (2014). Time to Be Heard: A Call for Recognition and Support for Young Adult Carers.
(London, Carers Trust)
- Arnett, JJ, Kloep, M, Hendry, LB, and Tanner, JL (2011). Debating Emerging Adulthood: Stage or Process?
(New York: Oxford University Press)
- Becker, F, and Becker, S (2008). Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24
(London: The Princess Royal Trust for Carers)
- Hounsell, D (2013). Hidden from View: The Experiences of Young Carers in England
(London: The Children's Society)
- Sempik, J and Becker S (2014). Young Adult Carers at college and University.
(London: Carers Trust)

Recommendations for Improving Practice:

- There must be more specific information applicable to young carers accessing higher education. This information must be clearly signposted on college and university websites and informational leaflets. The intense responsibilities shouldered by young carers often mean that they are a “time poor” group of young people. Therefore we advocate for explicit, clearly worded information on the support available to young carers at higher education institutions, so that a young carer does not have to engage in lengthy, time-consuming search for resources on formal support.
- Practical advice giving from schools, colleges, and universities must begin early. Our research shows that young carers begin thinking about their future aspirations at young ages, and we posit that they should be supported with accurate information appropriate to their age level about the process of attending higher education.
- Schools and colleges should actively promote opportunities for scholarships. For example, the University of Sussex has a first generation scholars scheme available that priorities vulnerable groups including young carers.
- Young carers need a safe person to talk to about their feelings and decision process on attending higher education. Ideally, this person must be on well-informed about aid available for young carers, and also a person external to the family unit.
- Young carers need financial assistance and campus tours, indicating that they have a focus on the practicalities of attending university. Universities should be encouraged to fund transportation costs for those young carers needing to make frequent trips back home to care for their family members.
- Young carers support services should actively work with university ‘widening participation’ teams. This can help to increase awareness amongst key staff and potentially provide group campus visits and experiences specifically for young carers.
- We support the ongoing campaigning work of young carers across the country in advocating for changes to the Carers Allowance guidelines. Currently, only carers no in full-time education or studying less than 21 hours per week are eligible to receive the Carers Allowance, prohibiting those young carers who are able to balance responsibility of caring and study. As our research indicated that financial barriers remain significant influence into young carers’ aspirations to attend university, we support a policy change to the Carers Allowance to allow greater numbers of young carers to receive this financial benefit.

Methodology:



Methodology:

This research project involved a brief assessment, semi-structured qualitative interviews and a focus group with young carers.

The interviews and assessments were conducted with 20 young carers aged 13-20. 12 of the 20 participants live in the 4 NCOP-identified deprived wards of Brighton & Hove. These wards are East Brighton, Hollingdean & Stanmer, Moulsecoomb & Bevendean and North Portslade. 13 of the participants were female and 7 were male.

The qualitative interviews featured a semi-structured interview guide, allowing participants the space to bring up issues and perspectives as desired. The brief assessment asked basic demographic questions and included two specific instruments which have been used internationally in the context of young carers: the Multidimensional Assessment of Caring Activities (MACA) and the Positive and Negative Outcomes of Caring (PANOC), in addition to questions on my family composition (including age, gender), education (e.g. institution attended, educational level) and caring role (e.g. who they care for, the condition of the person cared for).

The focus group provided an opportunity for the young carers to share their views on accessing higher education in an open, safe setting. It also enabled them to respond to initial findings from the interviews and explore the type of support they would appreciate in the presence of a University of Sussex representative.

Full ethical approval was acquired from the University of Sussex ethics institutional review board before the start of the study. Regarding the process of informed consent, the young carers were involved in the study on a voluntary basis, without coercing their participation directly or indirectly in any way. Each young carer was heard and his/her opinion taken into account (Oviedo Convention on Human Rights and Biomedicine). Every participant was fully informed about the study in an age-appropriate manner. Those young carers who wished to participate signed an informed consent form prior to the start of the first meeting.

Carers Centre and University of Sussex staff collated and analysed the responses received following the assessment, interview and focus group phases of the study. We were able to identify key, emerging themes and cross-reference responses across a number of areas such as assessment score, to whom care is provided (e.g., parent or sibling) and ward of residence.

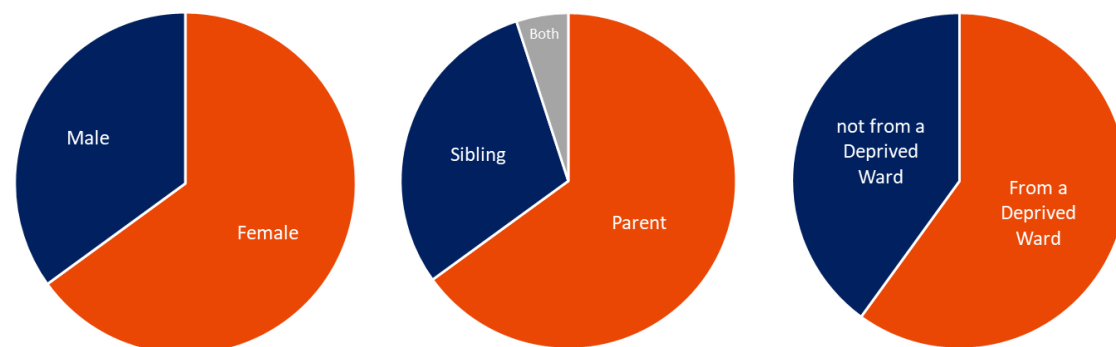
Challenges & Limitations:



Challenges & Limitations:

This research study intended to interview young adult carers enrolled in university in addition to young carers actively engaged with Carers Centre support. Part of the lack of participation from university students can be attributed to the timing of the research study recruitment. Following a delay owing to the university ethics approval procedure, much of the study took place in early summer at a time when most students have left campus for the summer. However, it also remains true that previous research with young adult carers and student carers has encountered similar difficulties in engagement. This indicates that further attention must be paid to this group of young people in transition, as they often “fall in the cracks” of child-to-adult service provision.

Additionally, this research recognises that this is a small-scale mixed methods study, utilising qualitative interviewing, focus groups, and quantitative assessment through questionnaires. Because of its small sample size, the findings contained in this report are not generalisable or representative of the entire population of young carers. Nevertheless, this research stands as the first-ever mixed methods research study conducted on Brighton & Hove young carers with a specific focus on higher education aspirations and access. The findings contained therein provide rich and unique observations on the barriers facing a local group of young carers in transition to adulthood and raises a number of significant issues for future study.



Breakdown of Carers who participated

Summary of Findings:

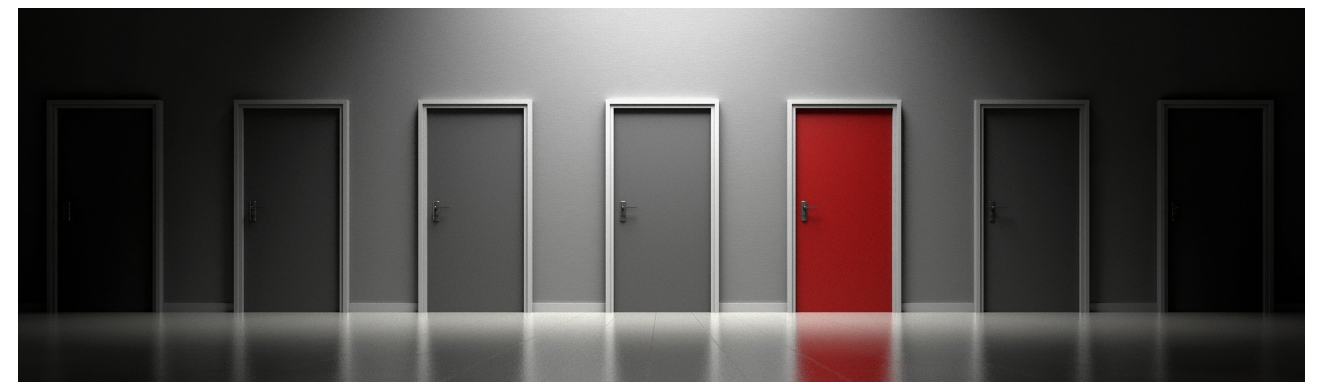
Summary of Findings:

Young Carers are young people with aspirations, dreams, and hope for their future. These are young people who have given serious consideration to their future and what career they would like to do. The interviews in this research serve as evidence against the myth that young people are aimless, clueless, and disengaged when it comes to their future.

“higher education is a stepping stone to accomplishing their career aspirations.”

At a young age, these young carers have recognised that higher education is a stepping stone to accomplishing their career aspirations. They have also recognised that higher education can be a marker of the transition into young adulthood. The belief that *“university is what young adults do”* is supported by previous research with adolescents and emerging adults, however their exists a class bias in this research, i.e., grounded on middle-class participants (Arnett, Kloepp, Hendry, and Tanner, 2011). For the young carers in our research study, the notion that higher education should (or could) be their next step in life may reflect class expectations, encouragement from teachers, parental/familial expectations, and wider social influences.

It is clear that the young carers in this research will not make decisions regarding higher education in isolation. Rather, their family, and to a lesser extent, their teachers, serve a critical role in their decision process. In the majority of the interviews with the young carers sampled in this research, the impact upon the family unit is at the forefront of their minds as their consider higher education. Furthermore, the actual decision to attend university is seen as a family decision. However, it may be that family discussions tend to centre on the young carers’ course of study selection, rather than the likely more sensitive topics of care coordination, guilt, the uptake of caring duties by younger siblings, etc (see Section 5b).



Barriers to accessing higher education also emerged as a significant theme with the young carers sampled in this research. Lack of money is the primary barrier, followed by geographic barriers.

- The financial barriers are very clear to the young carers. Indeed, for many, the first thought associated with university is the financial aspect.
- Secondly, young carers were also faced with the consideration of whether they could move away from home to attend university. Geography was intertwined with the issues of care; “who will care if they leave?” Guilt and the lack of support for the care recipient were identified as significant reasons for why young carers felt that they could not move away from home.

Case Studies:



Young Carer ‘B’

“helped me know what it’s like to be at uni.”

Young carer ‘B’ is a 14 year old female. She lives in East Brighton with her family and is in Year 9 at a local secondary school.

‘B’ cares for her younger sibling who has a cognitive impairment, and shares the caring role with another sibling. She carries out a high level of caring and feels like she would find it hard to leave her sibling if she moved away from home.

She has lots of ideas for what she wants to do in the future including travelling the world and possibly going to university. ‘B’ has some experience of university already; this year she took part in a first generation scholars programme with the University of Sussex. She thinks the programme was useful as previously she thought she didn't want to go to university but the experience “helped me know what it’s like to be at uni” and now it’s more of a possibility for her.

‘B’ emphasised that in her mind going to university would be as much as about gaining “life experiences” as getting an education. ‘B’ has already talked openly with her parents about her future choices and knows that she can also talk to her teachers at school.

Findings:

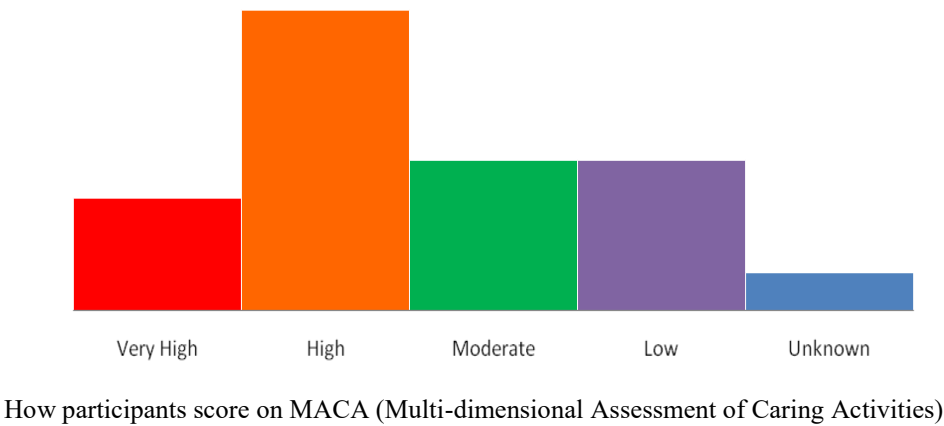
Assessment Phase—

As outlined in methodology, the brief assessments utilised the following tools:

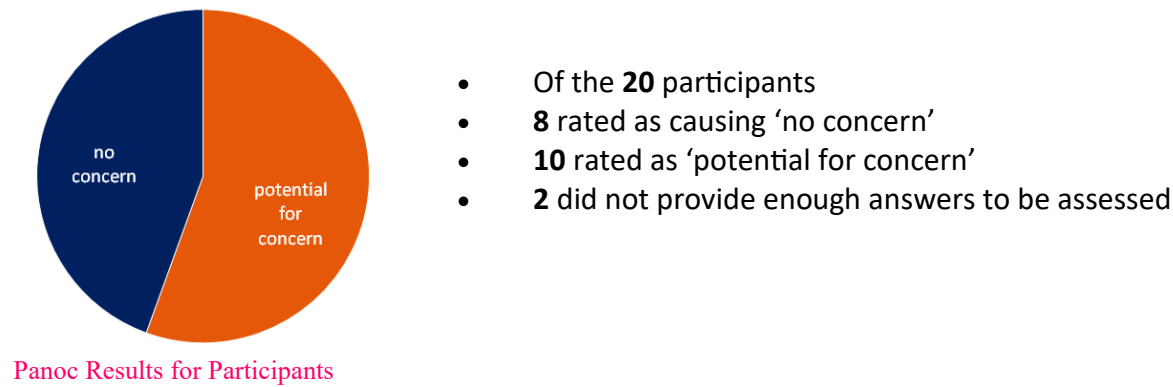
Multi-dimensional Assessment of Caring Activities (MACA) which measures the level of caring activities each young carer undertakes.

Of the **20** participants:

- **3** reported ‘very high’ levels of caring activity
- **8** ‘high’
- **4** ‘moderate’
- **4** ‘low’
- **1** did not provide enough answers to be assessed



The Positive and Negative Outcomes of Caring (PANOC) - is an instrument designed to provide a measure of the subjective cognitive and emotional impact of caring onto young people. The scores resulting from the administration of the PANOC can be used to determine a level of emotional distress, indicating a need for potential concern by practitioners and professionals.



The assessment outcomes and other demographic data were then cross-referenced with our four interview question categories to inform our findings:

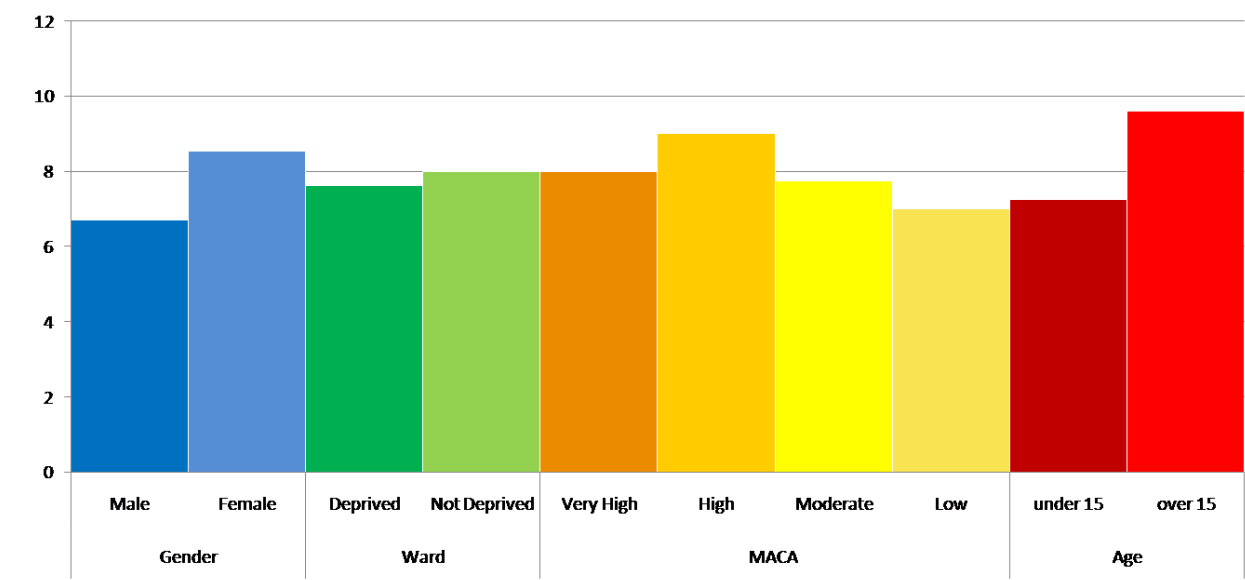
Interview Phase:

There were four categories of scored interview questions and responses. These were: Ambitions, Family & School, Impact and Finance. Each category also featured less structured questions which enabled participants to express personal experiences and their own recommendations.

Ambitions:

Ambitions: which included 6 questions such as ‘if you knew there was established support at your university, would this contribute to your decision of whether to apply?’

- Responses under Ambition produced a score between **0-12** with a high score being indicative of a young carer who is clear about their wishes for the future and who sees their goals as attainable.
- Several cross-referenced categories/demographics such as ward or level of caring activities did not radically change average scores in this area.
- The starkest statistic in this category was that female participants scored on average **27% higher** than their male peers. There are a number of possible explanations for why female participants appeared to possess more solidified views on attending higher education. The age of our sample may help to account of the gender differences: 30% of the female participants were aged 15 years or older in comparison to 14% male participants aged 15 years or older. It may be that older participants have a better grasp of their ambitions and views towards university because of their mature age, which may explain our finding that suggests more female participants have more concrete plans about higher education. Additionally, our female participants were 2 1/2 times more likely to agree with the interview statement “Because of caring, I have discovered what I would like to do in the



Cross reference of average scores for ambition across different categories

Case Studies:



Young Adult Carer ‘A’

“I feel like I made the right decision for both of us”.

Young adult carer ‘A’ is a 20 year old female. She lives in Brighton and is in her second year studying at university.

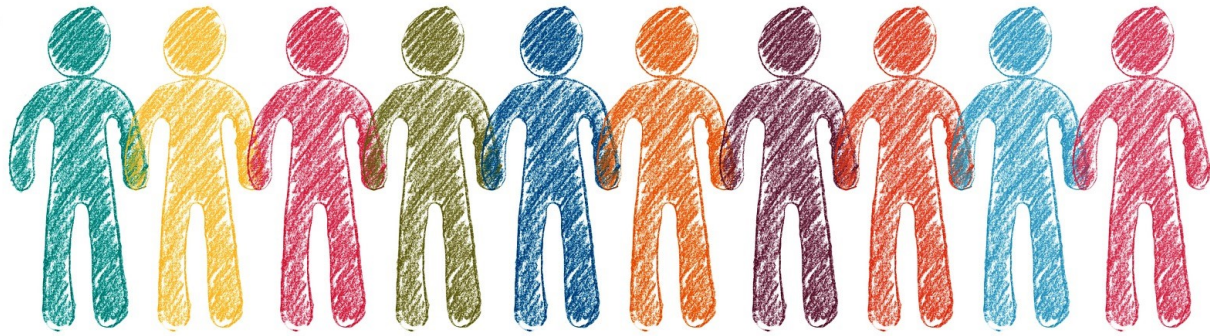
‘A’ cares for a parent who has a mental health condition and a cognitive impairment, and although she now lives away from her mother she still has an active caring role.

‘A’ decided at the age of 17 to study social work which was influenced by her own experience of having a social worker; having someone advocating for me”. She moved away from home for university but felt that her choice was influenced by her mother’s mental health as she knew she needed to stay close enough to still fulfil her caring role.

She also recognised that her family circumstances impacted on her own mental health and in moving away from home she found some much needed time and space for herself. ‘A’ said that a positive of starting university and moving away from home was that her mother’s support network has extended because she has not physically been there to provide care.

She acknowledges that when she is at university there are more barriers to providing emotional support for her mother however back in the family home she goes into “carer mode”. Reflecting on the decision to got to university ‘A’ says I feel like I made the right decision for both of us”.

Focus Group:



Our focus group session gathered 10 young carers together to share with them our initial findings from the individual interviews and assessments. Also in attendance were Dr. Feylyn Lewis from the University of Sussex and 3 Carers Centre workers. Some emerging trends came as a surprise to the group participants, whilst others reinforced their views.

The group were surprised that at the time of the session, 10 out of 15 interview respondents said that they knew what they wanted to do after completing school/college. The group agreed that a lot of young carers go into caring professions because of their background and personality.

Barriers to accessing higher education which the group highlighted were:

- “Worrying about the person you care for”
- “Lacking the energy because carers can be exhausted”
- “Prices” - the group agreed that money was a significant factor with one young carer pointing out that “a lot of our families have parents who cant work”

The group facilitators asked the following question: “**What would be different if you were studying away from Brighton?**” The answers included:

- “You cant come home to fulfil your caring role”
- “I’d spend more time worrying”
- “My younger brother and sister would have to take over caring”

Young carers were asked by facilitators what kind of support would make them feel more able to pursue university:

- “Study from home options”
- “Free travel passes”
- “Understanding and calm tutors. There to listen if you really need them”.

Dr Lewis addressed the group, advising that the University of Sussex will be responding to recommendations of this study. The university is keen to recognise and respect young carers’ home responsibilities and look into the possibility of enhanced support such as bursaries and travel expenses.

Related quotes from young carers:

“At 17 decided to study social work influenced by having a social worker, someone advocating for me”.

“I would like to be a paramedic”.

“I really do want to go to uni—I want to get a better education and a better job.”

- Higher education can be seen as a stepping stone and a marker of the entry into young adulthood

“Further study is a stepping stone to becoming an adult”.

- Young Carers in this research study rightly gathered that higher education can be more flexible and accommodating for their needs (see Becker and Becker, 2008).

“Different from school, days off, not going to lessons all the time”

“Free spirited—you choose what you want to do; it’s not a set curriculum”.

“Atm (At the moment) I feel like school is quite pointless—not what I want to do, doesn't help me with what I want to do”.

Family & School:

Family & School: which included 3 questions such as ‘Has your school/college given you any information or advice about going to university?’

- Responses under Family & School produced a score between **0-6** with a high score being indicative of a young carer who feels well informed about future options and comfortable discussing them with support networks.
- Young carers whose PANOC assessment rated as ‘potential for concern’ scored on average **46% lower** in this category than those whose PANOC raised ‘no concerns’. This outlines the importance of protective factors in a young carer’s life. Those who felt uninformed at school and uncomfortable talking about their future with family members indicated more negative impacts around their caring role than peers.
- These quotes show that external influences are key for young people in helping give them vision or example of what is possible for them.

“To be a mechanic I need the right qualifications. I need a good grade in maths. My brother is a mechanic and I like what he does”.

“At 17 I decided to study social work influenced by having a social worker, someone advocating for me”.

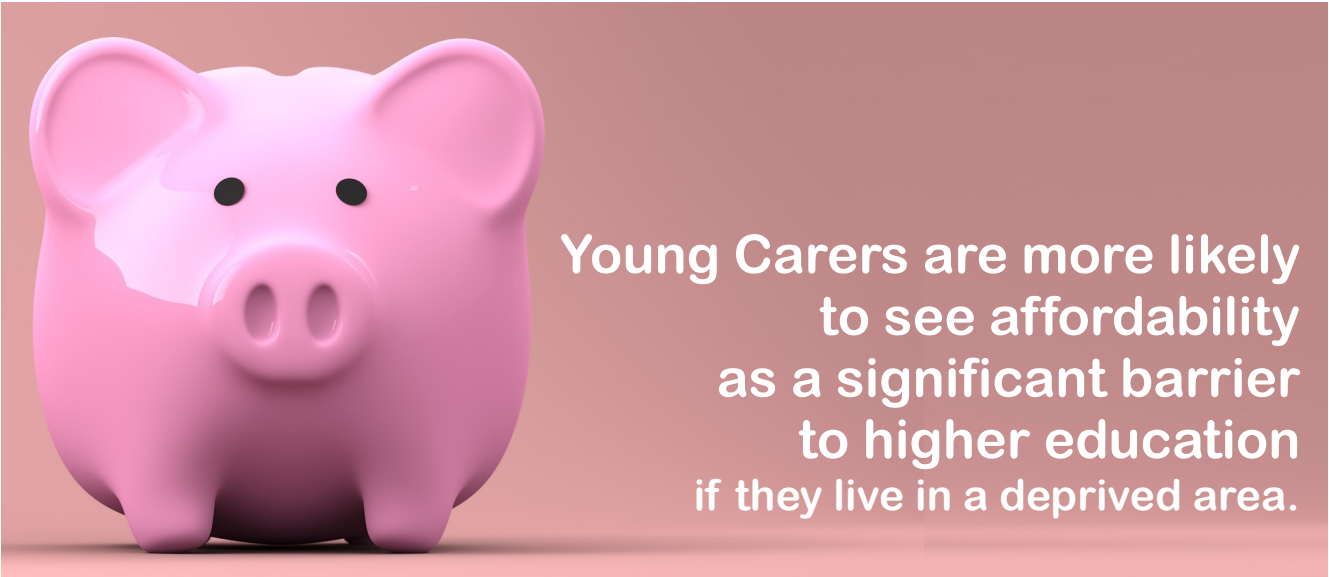
- **Other Barriers**—Family discussions concentrate on the selection of the young carers’ course of study and career aspirations. It is important to note that families are largely supportive of young carers. However, it is also likely that family discussions do not broach the sensitive topics of how the family will manage when the young carer leaves the home, who will take on caring duties in their absence, the lack of practical, formal support, and finally, the emotions of the entire family—guilt, shame, sadness. There may be a practice of silence on the more difficult, sensitive topics within the family unit. At least three young carers in this research study had negative experiences in family discussions.

“Felt guilty for looking into Unis. Told mum, felt horrible. Mum was scared that I was going to uni and didn't want me to study social work. Mum didn't have much experience of social work—didn't understand the process”.

“I’ve only told two of my friends so far. I don't want to talk to mum and dad about it”.

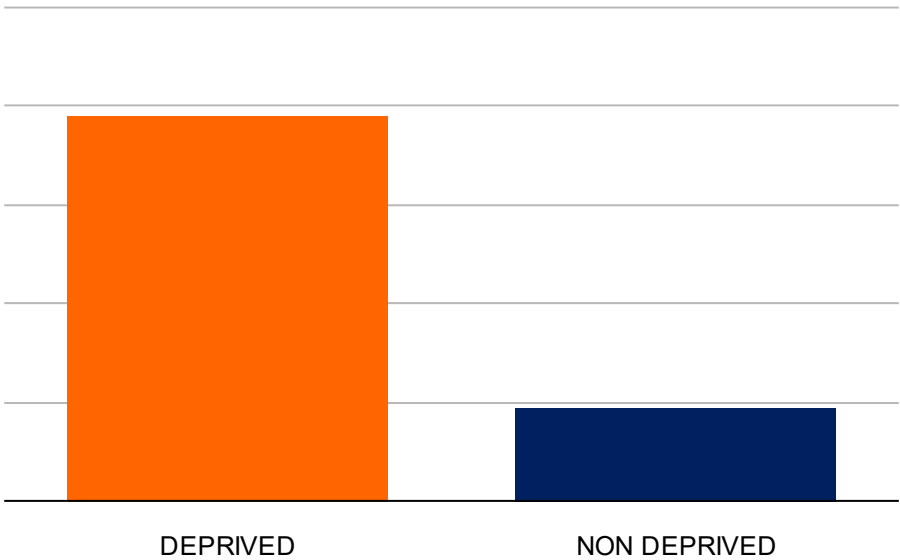
“Mum doesn't want to move far away”.

Finance:



Finance: which included 3 agree/disagree statements such as ‘Because of caring/my family circumstances, I wont be able to afford to go to university’.

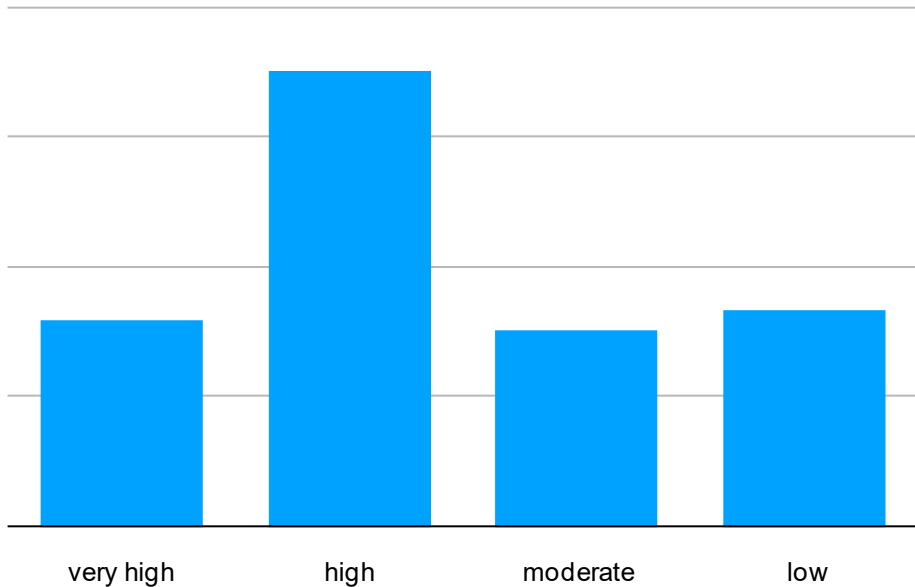
- Responses under Ambition produced a score between 0-6 with a high score being indicative of a young carer who feels that there are significant barriers to them accessing higher education that relate directly to their caring role.
- Young carers living in a ward identified by NOCP as having high levels of deprivation report on average 36% higher in this section than other young carers. This suggests that young carers are more likely to see affordability as a significant barrier to higher education if they live in a deprived area.
- **Other Barriers**—Money awareness, as a potential barrier to their career aspirations, was recognised early on by the young carers in this research study. What messages do we communicate to children when their first impression of higher education is of financial barriers?



Impact:

Impact: which included 6 agree/disagree statements such as ‘Because of caring I wont be able to leave home to attend higher education’

- Responses under impact produced a score between 0-12 with a high score being indicative of a young carer who feel that there are significant barriers to them accessing higher education that relate directly to their caring role.
- Young Carers who carry out a ‘high’ or ‘very high’ level of caring activities score on average 16% higher in this section than other young carers. This suggests that those young carers are less likely to feel confident applying for, attending or completeing higher education courses because of their responsibilities at home.
- Young carers who care for a parent score on average 54% higher in this sections than young carers who are supporting a disabled sibling. This suggests that those young carers are less likely to feel that they can move on and become independent, as there may not be another family member available or willing to uptake the caring responsibilities. One can infer that sibling carers are comforted that their parent(s) or other family members would continue to support their cared for sibling.
- Other Barriers—Geography was indicated as a primary consideration by young carers. Barriers named indluded ‘moving away’ and ‘feeling guilty’. Others saw challenges in studying at a local institution: “Life would be simpler if I went away”.
- University Support Requested by Young Carers:
 - “Publicised info—not me having to look for it. Drop in/support/counselling in the early days to support me”
 - “Bursaries; counselling; flexible open days; flexibility around deadlines if there’s an emergency.”
 - “Possible additional support with open days.”



“Young carers whose PANOC assessment rated as ‘potential for concern’ scored on average **46% lower** in this category than those whose PANOC raised ‘no concerns’.”

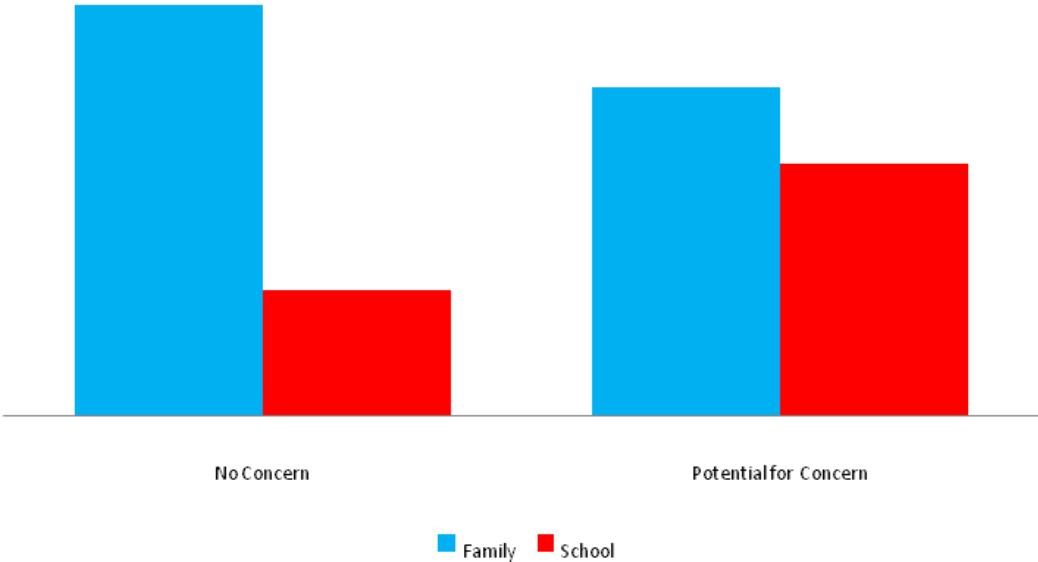


Chart showing average score by PANOC for Family and School Questions

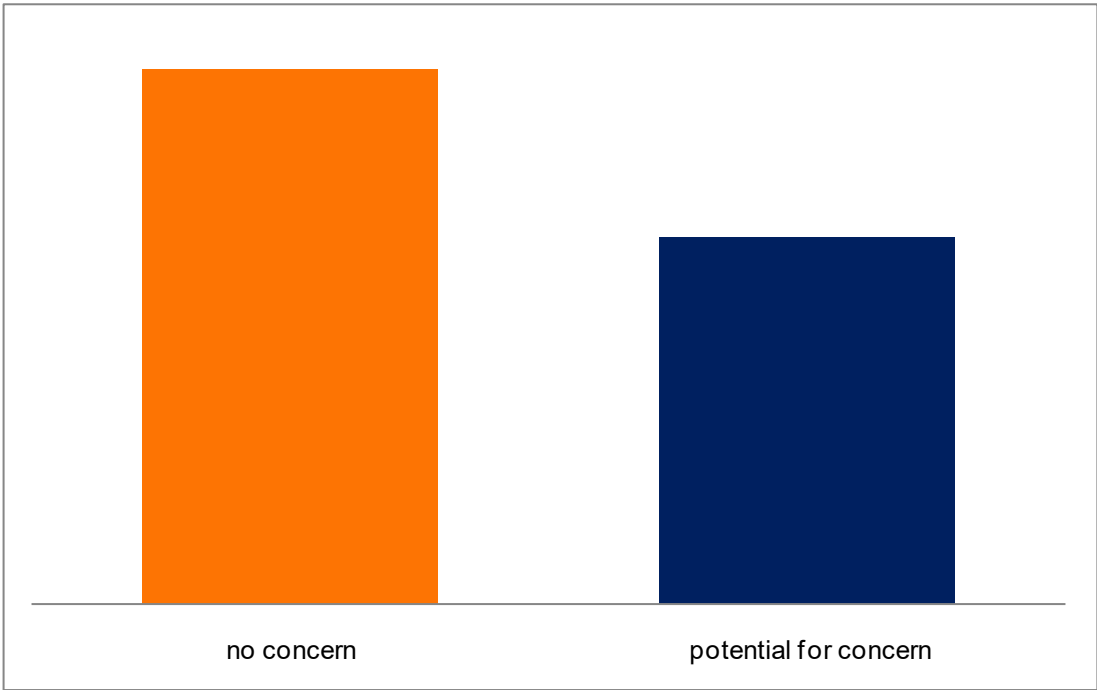
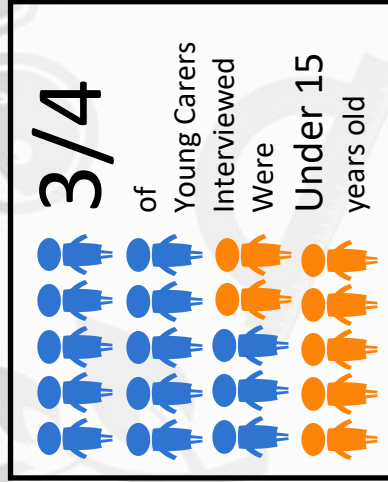
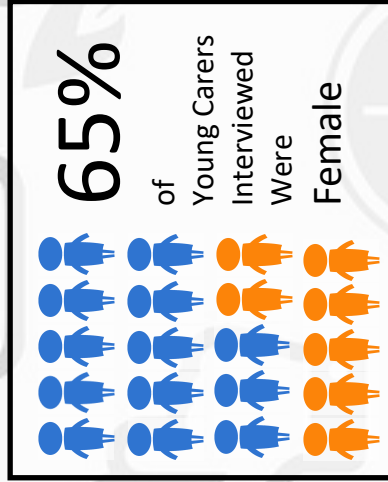
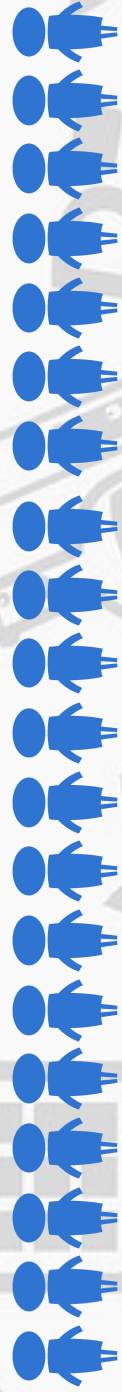


Chart showing average score by PANOC for Family and School Questions combined

Young Carers: Aiming High!

We asked 20 Young Carers age 13-20 about their thoughts and feelings about going to university to study, and what possible barriers there may be to stop them.

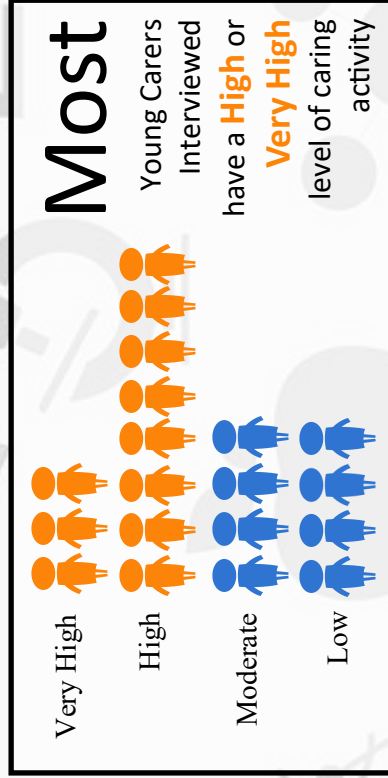
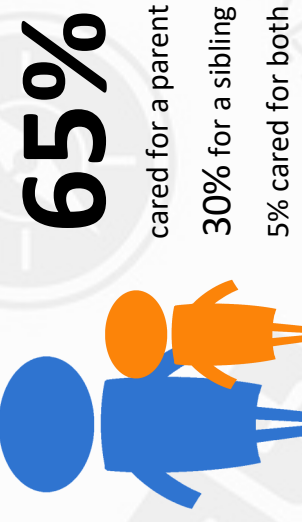
Here is what we found out:



"I would like to be a paramedic."

"At 17 I decided to study social work influenced by having a social worker, someone advocating for me."

"Further study is a stepping stone to becoming an adult."



Young Carers begin thinking about their future aspirations at young ages.



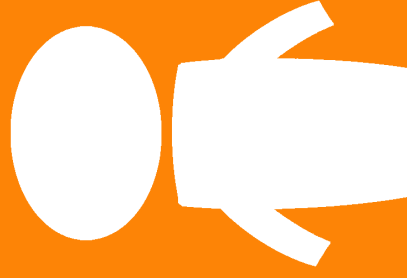
Young Carers who carry out a **'high' or 'very high'** level of caring activities are **less likely** to feel confident applying for, attending or completing higher education courses because of their responsibilities at home.

"Because of caring, I have discovered what I would like to do in the future."

Female participants were

2 1/2 times

more likely to agree with this interview statement:



"I really want to go to Uni—I want to get a better education and a better job."



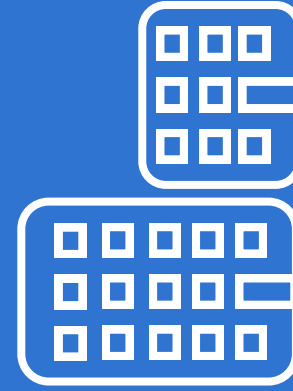
Lack of money is the primary barrier to accessing higher education for our Young Carers.

"Worrying about the person you care for."

"Lacking the energy because carers can be exhausted."



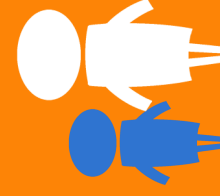
Barriers for our Young Carers
In their own words



Young Carers are more likely to see affordability as a significant barrier to higher education if they live in a deprived area.



Those who felt uninformed at school and uncomfortable talking about their future with family members indicated more negative impacts around their caring role than peers.



Young Carers who care for a parent are less likely to feel they can move on and become independent, as there may not be another family member available or willing to uptake the caring responsibilities.

"Young Carers are young people with aspirations, dreams, and hopes for their future"



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In association with:

