

# Types and aspects of support that young carers need and value, and barriers and enablers to access: the REBIAS-YC qualitative study

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## Scientific summary

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# Scientific summary

## Background

Providing care can negatively impact children and young people's education, employment, health and social participation, with associated costs to individuals and the government. Transition to adulthood can be particularly challenging. Recent years have seen improved legal rights for young carers, aiming to increase support provided and avoiding excessive or inappropriate care that might risk their emotional or physical health or life chances. However, there are substantial knowledge gaps regarding how best to support young carers in the current service and rights context and from the perspective of young carers and the people they care for.

## Objectives

To explore the following questions:

1. What types, components or features of services and other support are seen as helpful, valued and acceptable to young people who look after someone at home and the people they support? Conversely, what is found to be less or unhelpful?
2. What additional support is perceived as needed?
3. What are the barriers experienced by young and young adult carers in seeking and accessing services for themselves or the person they support?
4. What are the barriers and facilitators for practitioners in providing support and services perceived as valued, helpful and needed by young and young adult carers and the people they support?

## Methods

The study used in-depth qualitative methods including focus groups and semistructured interviews with young and young adult carers aged 9–25 years and parent care recipients and workshops with practitioners. Data collection methods in focus groups included group and paired discussions, use of flipchart and stickers, drawing, writing and annotation. Focus groups and interviews were structured around topic guides to explore perceptions of: what is helpful, unhelpful or could be improved about existing services; what additional support is needed and what needs would it cover; and barriers to accessing support. We recruited participants in four localities in England, representing different young carer and marginalised groups and different geographical and sociodemographic areas. The inclusion criteria for young carers were that they be aged between 9 and 25 years and providing unpaid care and, for care recipients, that they be aged 16 years or older and cared for by a young carer (not necessarily a young carer involved in the study). Participants were recruited through young carers organisations, schools and colleges in the four localities. Workshops were held with practitioners from each locality, recruited through partner organisations and their networks. Workshops were informed by preliminary findings from the focus groups and interviews and structured around key findings and questions about barriers and facilitators to their implementation.

Data included transcripts, fieldnotes and other written and drawn material and annotations. Data were analysed using deductive and inductive thematic analysis with the aid of NVivo 12 (QSR International, Warrington, UK) software. We set out with particular research questions, seeking to discover what acceptable intervention or support looked like, and for whom, how this related to what was currently on offer and what the barriers to access were perceived to be. Initial codes and themes were also informed by the theoretical frameworks and existing literature described elsewhere in this report. Coding also

took place inductively, with categories not pre-set but drawn from the data, allowing the development of unanticipated themes. Analysis of the focus groups and interviews with carers and care recipients took place prior to the practitioner workshops, so that preliminary results could be discussed with the advisory groups and used to inform workshop discussions.

## Results

The study sample was 150 participants of which 17 were care recipients. Young carer participants had varied caring and life circumstances and sociodemographic characteristics. Care recipients were parents with a range of physical and/or mental care and support needs.

We found seven key areas of support and services that were perceived by young carers and the people they care for as needed, valued when received, but often lacking.

Young carers and the people they care for valued having someone they trust to talk to. This person would listen, understand and be non-judgemental and would not share private information inappropriately and without consulting with them first. Trusted relationships were highly valued where they occurred. The trusted person could be a named person or named role in school or college or a school counsellor; a key worker in a young carers organisation; a social worker or family support worker; or their general practitioner.

Young carers and their families also wanted clear, early, accessible information about what to expect and not expect from a service or person. This might include information about the length of the waiting list for that service; how a service or person can and cannot help; expected number of sessions; and when and why information might need to be shared with others. Being transparent, and consulting with the young person about the sharing of information, helped build trust. Clear and well-managed endings mattered, including clarity about why support was ending, what would happen next and where to go should similar help be needed in future. Linking to other support, or new workers when existing staff leave, was also needed, and valued when received.

A wide range of support might be required. Accessible and multiformat information and advice about wider resources, and formal and informal support that might be available, were therefore needed. However, information alone was rarely enough. Support to access services was sometimes perceived as needed and valued by young carers and care recipients when received. Practitioners felt that linking to other services by an already-trusted practitioner could increase likelihood of take-up and engagement. Valued practice included helping with introductions, attending sessions or appointments with the young carer or care recipient, and checking in after first sessions to address barriers and concerns. Specific or generalised information about the care recipient's health conditions and treatment was also valued by young carers, although care recipients in the study did not always want this information shared.

The heterogeneity of the young carer population and their caring experiences means that support needed and valued will vary. Choice, flexibility and co-development of plans and solutions are key. This entails involving young carers in decisions and plans; a flexible approach to support; and allowing young carers and their families repeated chances to accept support from services. Timing is important to the young carers and their families; they are not always ready to access support when it is offered, or they need to return to support as circumstances or life stage changed.

Support that reduces young people's practical and emotional caring responsibilities was needed. It was valued when received, but was often absent or insufficient, resulting in considerable unmet need. Reduced caring responsibilities would enable young people to have more time for other things in their lives, such as education, social participation and hobbies, and to have less stress and sense of responsibility. In some cases, it was also perceived that support provided by others would improve the

health, happiness and independence of the care recipient. Support needed varied but could come, it was felt, from paid caregivers, adult mental health services, other family members, community groups, social connections and activities or aids and adaptations. It could involve long-term reductions, short breaks and/or emergency or crisis support for the person with care needs.

Support to reduce the need for children and young people to provide excessive or inappropriate care by providing more support for the person they care for should consider the whole family. While practitioners recognised the value of whole-family working, both practitioners and young people felt effective support could be given working with specific individuals only, and some young people valued having a practitioner who was 'just for them'. Practitioners also recognised the challenges involved in providing support for the whole family, such as eligibility criteria mismatches, differences of opinion within the family and different commissioning systems for children's and adult services.

In the absence of support that reduced or removed caring responsibilities, or in addition to it, support that helps with impacts of caring and/or young carers' other life issues was identified as needed and was valued when received. This included timely, helpful, accessible and young carer-aware mental health support and greater understanding at school, such as flexibility of deadlines for schoolwork and homework, although there was a recognition of the difficult balance between making allowances for the home situation and supporting the young person's educational progress. Opportunities to take a break at school were valued, as were systems where breaks could be taken without publicly having to give an explanation. Peer support from other young carers was usually valued, along with activities that were 'fun' and gave them a break, which were often provided by young carers organisations or sometimes young carer clubs in schools.

Greater awareness, recognition and understanding of young carers, what young carers do, and about disability and mental and physical illness, would be helpful to young carers. Although there were some examples where schools, particular school staff, or other students, had shown good awareness and understanding, this was often felt to be lacking. Children's mental health services needed to be more understanding of the interaction between mental ill health and caring responsibilities.

Young carers and the people they care for expressed numerous barriers to accessing the support they needed and valued: the support needed may not have been available and/or services were sometimes not accessible or approachable; there may not have been enough information about a service and how it worked and/or information may not have been communicated in accessible, user-friendly formats. Other perceived barriers identified in the study were service boundaries and lack of links between services. Young carers' and care recipients' lack of time and competing priorities such as school or caring responsibilities (for the young carers) and their mental or physical health could get in the way of support. Feelings of fear, mistrust, nervousness, embarrassment, fear of judgement or lack of confidence in seeking help were further barriers and ones that services could help overcome. Lack of transport prevented some carers and care recipients from accessing services, exacerbated by centralised, rather than local, hubs.

The findings have economic implications. Provision of care by young adult carers aged 16–25 years costs the state an estimated £1B annually. Recent, relevant and high-quality economic evidence on interventions supporting young carers, and which might alleviate impacts, is limited. In the extant studies found in the scoping review, estimated costs of interventions per person ranged widely from £121 to £778 for co-developed support planning and review; £1200 to more than £15,000 for family interventions; £265 to £385 for social prescribing; and £1100 for having a designated person at school. Return-on-investment estimates [calculated by dividing estimated benefits ('returns') by the cost of the intervention or support provided] ranged from £5 to £91 per £1 spent on whole-family approaches; and £8 per £1 spent for a designated person at school. Most of the 'returns' related to a societal perspective, including benefits to the government and to individuals (such as in the form of income gains).

## Conclusions

In-depth listening to young and young adult carers and their families has shown the types, aspects and range of support that young and young adult carers need, and value when received. The study shows much unmet need for support, and variation in type and quality of support received, including geographically. Many of the valued and needed aspects of support are already recognised and embedded in current legislation. Action is now needed to implement this legislation and to sustain and extend the areas of good practice that currently exist. Other aspects of good and needed support we identified are not currently reflected in legal rights, and are not consistently reflected in commissioning, service tenders or practice.

Implications for social care commissioners, practitioners and policy-makers

1. There needs to be more funding overall, and more targeted funding and allocation of resources nationally and locally, for adult social care and mental health services to fulfil the requirements of the 2014 Care Act, to prevent children undertaking inappropriate or excessive caring roles, which impact young carers' wellbeing, education and life prospects.
2. Funding needs to be directed at practitioners and organisations working with young carers and the people they care for to have time to provide the support young carers say they need and value and to allow time for building trusting relationships.
3. Commissioning of services and support in schools, adult and children's social care, young carers organisations and mental health services could be done in ways that enable continuity of valued support; flexibility of support is needed that responds to changes in needs and strengths over time, and as people's readiness to access support, and their circumstances, change.
4. There should be wider implementation of whole-family agreements, assessment and practice across and within adult and children's social care, mental health and the voluntary and community sector.
5. Policy or guidance should recommend a designated person(s) available in schools for young carers to talk to about their caring situation or if they are in need of extra help.
6. Wider roll-out of good practice is needed.
7. Greater use should be made of active linking to wider support, such as accompanying people to meetings or appointments.
8. More, and more accessible and multiformat, information about remit, eligibility, nature and how to access the support available needs to be provided. Advocacy to help people negotiate the system might be beneficial, but better communication is key.
9. Young carers are young people first and the impacts of the care they provide, the context in which they provide it, and the support they need and value varies; their views and individual experiences need to be taken into account.

Recommendations for research (numbered in priority order)

1. More research is needed from the perspectives of young and young adult carers and the people they care for, including those from marginalised groups of young and young adult carers, such as those from Roma and Traveller communities and refugee and migrant communities. There are key roles for peer researchers in this type of research.
2. Research is needed to identify and understand the good practice that exists, and how to improve wider implementation of the support needed and valued by young carers and the people they care for.
3. Future research could also valuably include economic evaluation of the support needed set against the costs of not providing it.

## Study registration

This study is registered as Current Controlled Trials ISRCTN13478876. <https://doi.org/10.1186/ISRCTN13478876>

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