

RESEARCH BRIEFING

UNDERSTANDING THE NEEDS OF YOUNG CARERS IN THE CONTEXT OF THE COVID-19 PANDEMIC



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APRIL 2020 - JUNE 2020

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WHY IS THIS STUDY IMPORTANT?

Young carers are often marginalised, their voices unheard, and their needs unrecognised. It is therefore vital to raise awareness of these concerns in the context of the COVID-19 pandemic.

There are an estimated 800,000 children under the age of 18 in the UK who come within the Care Act 2014 and Children and Families Act 2014 definition of providing excessive and/or inappropriate care. These young people provide essential care for their families, often 24 hours a day and over the course of their whole childhood. This can have a detrimental impact on their own social, economic and educational wellbeing as well as their physical and mental health, which may carry forward into adulthood.

The COVID-19 crisis has far reaching implications for young carers. The indirect impact of attempts to counter the spread of the virus are likely to have a major impact on their psychological wellbeing. Alongside this, support systems are struggling under increased pressure, potentially drawing the focus away from the needs of these marginalised young people.

AIMS OF THE STUDY

The study aims to benefit young carers during the COVID-19 pandemic in the following ways:

- Increase the recognition of young people providing care and of the impact of service changes on young carers.
- Capture the current views of young carers to inform urgent and effective support needs.

HOW WAS THE STUDY DONE?

To gain a rapid and holistic understanding of the issues facing young carers in the COVID-19 crisis, views were sought from a range of perspectives. 20 participants were recruited through young carer organisations and Twitter. Semi structured phone

or video conference interviews were held with 8 young carers, 5 young adult carers, 3 parents of young carers and 4 youth workers. Detailed notes were taken throughout the interviews. Data were analysed from each sub group and combined to inform 4 key emerging themes.

KEY FINDINGS

1. COMPLEXITY OF CARE

No two young carers are alike, nor is the complexity or context within which they provide that care. Several young people cared for their parents and their siblings who had a wide range of often competing physical and mental health needs. Care tasks were equally varied - from cooking, cleaning, organising bills, shopping and managing medication, to less easily quantifiable tasks such as emotional support - 'keeping him happy and calm', 'looking out for crisis points' and 'making sure mum doesn't hurt herself'. Young carers from a single parent household appeared to carry a greater level of responsibility. One parent described her son - 'becoming my everything'.

Youth workers said that caring responsibilities for older carers had increased exponentially during the pandemic. Often participants explained that their younger siblings did not understand about the virus or the reason for the lockdown which led to frustration and conflict. Olivia (17) described how the fear and insecurity inherent within the crisis has made her mother increasingly anxious 'it affects her sleep and then of course mine because she keeps waking me up so she is not alone'.

2. EXTERNAL SUPPORT

What was often an already uneasy relationship with health and social care services, with poor communication and a lack of awareness of the needs of young carers, has been compounded by the restrictions of social distancing. Hannah (20), returned from university to find her mother's

weekly contact with the community mental health team withdrawn, putting her back into a full-time care role.

Assessments, services and informal support had been cancelled or withdrawn. Essential services such as shopping delivery, child care and cleaning had fallen, at very short notice, to the young carers.

3. EDUCATION

The young people sorely missed the routine, respite and release provided by school. 'School has always been a place away that I can feel safe' (Olivia, 17). Teachers could make them feel that - 'someone noticed and someone cared' (Grace, 15). School support during the lockdown, however, was extremely variable, ranging from weekly phone contact, to taking 10 days to reply to an email. Some young carers were struggling with home learning, feeling unable to focus on themselves and their studies. 'I am struggling to focus on my college work or anything, even the smallest task makes me really tired, I have no motivation at all' Jessica (19).

4. MENTAL HEALTH/MANAGING STRESS

The restrictions of lockdown and the anxiety related to COVID-19 risks increased both the young carers' stress and their caring load. Several could not leave the house because of the physical vulnerability of the person they care for. One youth worker said the young carers' concern about the health of the person they are caring for can 'become all consuming' without any distraction or support to maintain a healthy perspective.

Despite these very difficult circumstances, many young carers felt unable to complain since 'moaning' about the pressures of caring would be 'selfish' and insensitive to the person they were caring for. Young carers are often stoical, not wanting to be an added burden - 'I look after myself, I have always tried to be as independent as possible so no one has to look after me, my parents are busy enough with my sister' (Grace, 15).

MESSAGES FROM YOUNG CARERS

Young carers were aware of the limited resources available and gave wider messages about what would help them.

- All felt that awareness should be raised about what it means to be a young carer. This is important for health, social care, school staff, the general public and also, their own peer group.
- They did not want assumptions to be made about their families, or themselves, for example Katie (18) felt that people assumed she could not be a young carer because she was not able bodied.
- All greatly appreciated support from their young carers' organisation, but were acutely aware of those young carers receiving no support at all.
- All young carers are different and should be able to define the service they receive, choosing when and how to engage.
- Many enjoyed the online support provided during the lockdown.

"I can't get a break, I can't even get 5 minutes, if I shut my door she is there and then verbally I just have to take it, there is nowhere for me to put it I just have to take it, she becomes anxious, then annoyed, then angry and neither of us can walk away now so I just have to take it"

KEY RECOMMENDATIONS/IMPLICATIONS FOR POLICY & PRACTICE

1. Continue to raise awareness of young carers, particularly within educational settings which can be a sanctuary and a safeguard. As schools reopen, teachers need to be mindful that some of their class may be young carers. They need to give careful consideration to the support they require to return to school and re-establish themselves within the curriculum, using the young person themselves to create an individualised plan.
2. From a social care perspective, the stipulation of both the Care Act 2014 and the Children and Families Act 2014 that no child should undertake inappropriate and/or excessive care should be given additional weight within this health crisis. Any child under the age of 18 living with a parent or sibling with substantial disability, physical health needs or mental ill health should be automatically regarded as a young carer and supported accordingly.
3. The work of young carers' organisations such as Caring Together are crucial for the health and wellbeing of carers. They are able to respond to young carers' needs in a flexible and proactive manner without the potential stigma of some statutory services. The value of their work should be recognised and funded.
4. Young carers' voices are central to understanding the impact of these responsibilities. Young carers should be involved in all aspects of research, as well as policy and service development.

STRENGTHS AND LIMITATIONS

The strengths of this project lie in its ability to present a rapid response to the needs of young carers, which has been made possible by the collaboration and support of Caring Together. The commitment of this organisation and the Targeted Intervention Team of West Berkshire Council meant that a wide range of young carers from across England were able to participate in a safe and supported manner. The restriction to comply with social distancing rules meant that no interviews could take place in person and equipment was not available to record the interviews, thus complete verbatim transcription was not possible. Future research should reach out to the many young carers not receiving support through young carers' organisations. The views of professionals from health, social care and education would also enrich subsequent research.

IMPACT

This rapid project has attracted interest from BBC news, ITV news, Channel 4, Mail on Sunday, LBC, Heart radio and Radio 4 Woman's Hour. It is hoped that the study will continue to raise awareness and form the basis of practice guidance.

FIND OUT MORE

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