

# The role of adult social care in improving outcomes for young people who provide unpaid care

## RESEARCH FINDINGS

Young people (16 to 25) who provided care were found to be: less likely to be in employment, have lower earnings from paid employment, and have poorer mental and physical health than equivalent young people who did not provide care

Costs to the state were an estimated £1 billion a year. Individual young carers also experienced financial costs

The association between receipt of care for the person with care needs and the impacts of providing care on young people's lives was mixed. Services could have negative as well as positive effects and, in many cases, were not in sufficient amount or the right type to prevent young people from carrying out levels of care that impacted on their employment, education and health

Aspects of services identified as helpful/less helpful included timeliness; access; involving the young person and taking into account their needs; relationship with practitioners; and continuity of care



# BACKGROUND

Current social care practice seeks to prevent negative impacts of caring on young people and improve their lives. Care Act 2014 and Children and Families Act 2014 provisions include an assessment of whether caring has an impact on young people's wellbeing, personal development, physical and mental health, and ability to participate fully and fulfil their aspirations in education and employment. Assessments must consider the option of the young carer's needs for support being met by providing services to the person they care for, especially in order to prevent the young person from undertaking 'excessive or inappropriate care and support responsibilities'.

Efforts to reduce the burden on young carers have mostly focused on those aged under 16. There is less information about those aged 16–25.

This study aimed to find out the impacts of caring on young people, including economic impacts, and whether and in what ways services provided for an individual with care needs can also support young people providing care, in particular their education, employment and health. It focussed on young people in England aged 16–25, caring for an adult.



## Methods

The study used three main methods:

- Analysis of data from three waves of the UK Household Longitudinal Study (2013 to 2017) and Health Survey for England. It compared employment, earnings and health impacts for 561 young adult carers and 6,342 non-carers aged 16–25 at two time points 12 months apart;
- An online and paper survey completed by 188 young adult carers;
- In-depth interviews with 14 young people who had also taken part in the survey to explore in further depth the relationship between social care service receipt for adults with care needs and outcomes for young adult carers seen in the national data and survey. Interviewees were selected to reflect a range of service receipt circumstances.



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The research investigated the impacts of providing care on young people and whether and how adult social care services for disabled or older people in England can also support the young people providing care for them. This included privately-funded and state-funded services.

## IMPACTS OF PROVIDING CARE

Analysis of national data, the survey and in-depth interviews showed the impacts of providing care on young people's employment, education, mental health and wellbeing and social participation, especially when caring for higher numbers of hours, providing personal and/or emotional care and/or being the sole carer.

Young people aged 16 to 25 who provided care were found – one year later – to be subsequently less likely to be in employment, had lower earnings from paid employment, and had poorer mental and physical health than equivalent young people who did not provide care (see Box).

### BOX: EFFECTS ON YOUNG CARERS

The results showed that, compared to non-carers, carers:

- were twice as likely to have left employment and become unemployed in the 12 month period
- had worse physical and mental health
- were about £160 worse-off per month
- paid £741 less in tax per year
- claimed £44 per month more in welfare benefits
- cost the health service £289 more per year.

Costs to the state associated with negative impacts of caring were an estimated £1,048 million annually in 2017. This comprised lower tax revenue (£497 million), welfare benefit payments (£357 million), and health service use (£194 million).

## THE ROLE OF FORMAL SOCIAL CARE SERVICES IN SUPPORTING YOUNG ADULT CARERS

In the survey and national data, the research team found that receipt of services by the person with care needs was associated with no difference in

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reported effects of caring on education or health after taking into account other factors that can affect these outcomes (carer's circumstances and type of care provision).

In contrast with previous findings on working-age carers, effects of caring on employment were reported more frequently in the survey and national data when services were received than when they were not, even accounting for carer's circumstances and care hours provided.

In interviews, the research team explored possible reasons for the associations seen between greater reported effects on employment and receipt of services and no difference in reported effect on education and health and receipt of services. Services being received or otherwise is not the whole picture. Preventing negative effects on carers requires services to be received at a level, type, and quality sufficient to reduce the need to provide care and prevent detrimental levels of care responsibilities.

## SUFFICIENCY OF SERVICES

In the survey, half (52%) of the young people felt that more services were needed by the person they supported and, despite receipt of services, the majority were still providing personal or emotional care and/or high hours of care. In some cases not enough services were received to start with. In others, service provision had not responded to changing support needs and/or changing family circumstances.

In the survey, not receiving enough services was associated with young people being more likely to report impacts of caring on their education, health, and social life. In interviews this was partly because they had to fill gaps in service provision and partly because experiencing the person they cared for not having their needs met was stressful and upsetting.

My mum not having support, it made me constantly worry. Because even now, when I know she's bad, I'm like, am I going to come home to find my mum's in hospital or worse?...Because it used to be that she could be left in the house on her own, but now she can't (Isabel)

It's been so hard to get her services over the years ....it's so stressful... just getting the help or the fact she's not getting the help she needs (Cleo)

Conversely, receipt of sufficient services had a positive effect on the young person's wellbeing and stress, ability to participate in education, employment and social and leisure activities.

She's a lot happier now... which is great and less stressful for me....It makes my life very much easier....it means I don't have to stay at home sort of looking after people for long hours of the day or on weekends (Maanya)

When they are here it's good for me because I know she's in good hands for at least, you know, a day. You know, she doesn't necessarily need me all day that day, so I could go out and do things that I want to do (Hannah)

They've helped massively. If we didn't have the carers then I wouldn't be able to work (Ashley)

Type of service was also important. Services that provided emotional support were particularly valued, and if not received, were identified as needed. In the absence of these types of services, in some cases, young people had to provide quite intensive emotional and mental health support. Providing emotional support was associated with higher proportions reporting negative impacts of caring on their education and health.

## EARLY INTERVENTION

Services also needed to be provided early and promptly. Many young people in the survey had been caring from a young age and during critical periods for their education, employment and mental health. The average age they started providing care was 12 years old, some were as young as four, and 40% started when they were still in primary school. Services therefore need to be provided early enough to prevent problems developing in the first place, particularly because of the potential for longer-term consequences.

Interviewees expressed that wait times and delays in receiving services were particularly problematic. In some cases the care-recipient's health and/or the caring situation deteriorated whilst waiting for services. Once received, the need for services was responsive to changing care needs and carer and family circumstances.

## QUALITY OF SERVICES

The interviews showed that other aspects of services could also be helpful or less helpful in alleviating need to provide care, reducing carer's stress, supporting their mental health, and reducing disruption to their education and work. These include:

■ **Process of accessing services:** The process of accessing services could be lengthy, time-consuming, stressful and distressing. Even when needs were

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recognised and help sought, there were often long waits. Getting turned down was particularly difficult:

Being turned away, for whatever reason, going 'I need help' and being turned away, can really knock a carer back (Freya)

■ **Involving the young person:** Young people wanted to be involved in discussions about service provision, and kept informed about services, how best to support the person with care needs and what to expect. They wanted to be taken seriously and recognised as a carer; on many occasions their young age counted against them. Taking into account carer's needs and opinions was experienced positively: it made the young people feel supported and gave them greater piece of mind.

■ **Relationship with practitioners:** Good relationships with practitioners reduced stress and had positive effects on carer's wellbeing. Difficulties in this relationship caused stress and, in some

cases, contributed to the care-recipient cancelling and/or subsequently reluctant to have services.

■ **Continuity of care:** Continuity of careworker, or care team, affected quality of relationships and quality of care. Lack of continuity could be detrimental because of the need to re-explain quite personal situations and to repeatedly have different people in the house.

There was a recognition by carers that problems they experienced with services often lay outside individual workers. For example, many interviewees mentioned funding cuts, difficulties of short visits, staff turnover, or agencies closing or changing.

value of, other services in conjunction with social care services. This included:

- age-specific carer support groups;
- help for their own mental health;
- assistance from school, college, university or employer;
- housing and transport;
- welfare benefits and financial advice;
- community services and resources such as youth groups.

## COMBINATIONS OF SUPPORT

Many young people providing care in the study had a range of needs, some arising from them having provided care from such a young age.

In interviews they described the additional need for, and, if received, the

## PROJECT POSTCARD OF KEY FINDINGS



# CONCLUSIONS & IMPLICATIONS

- The negative impacts on young people of providing often long hours and/or challenging types of care reinforces the strong moral, public health, and economic case for reducing or removing the need for young people and children to provide unpaid care.
- Preventing negative effects of care provision on young people requires services to be provided at a level, type, and quality sufficient to prevent detrimental levels of care responsibilities.
- How services for the care-recipient were accessed and provided was important in the effect services had on young people's education, mental health and employment. Services and the quality of their provision could have both positive and negative effects on young adult carers' lives.
- Services that provide emotional support to the person with care needs were particularly valued, and if not received were identified as needed. This could be, for example, mental health support or helping the care-recipient better access community resources and be less socially isolated.
- Young adult carers' needs should be taken into account when providing services for the adult with care needs although conflicts of preferences can make this difficult for service providers. Young adult carers would also like to be better informed about care-recipients' service plans and about their illness or disability.
- Early and prompt intervention is needed but services also need to be responsive to changing care needs and carer and family circumstances.
- A coordinator to help young people find information or access support could be helpful. In the study, this was often provided by young adult carer support workers but there is potential for this to come from other sources as well.
- Young people who provide care and their families' wide range of needs means that, as well as better services for the person with care needs, a holistic and system-wide range of support is required that also directly assists the carers.

## COMMENT

Within our Young Adult Carer Service we see first-hand the impact caring has on education, employment, emotional health and social connection. These young people are also disproportionately affected by public funding cuts both in terms of youth and carer support services, and services for the care-recipient.

These findings match our experience on the ground and highlight the potential for adult social care services to have a positive impact on the young adult carer. For this to happen we need:

- Early intervention to prevent inappropriate/excessive caring from occurring in the first place;
- Young adult carers' needs to be addressed when planning and providing support for the care-recipient – through statutory assessments that are worthwhile and translate into services;
- Services to be accessible, flexible, sufficient and the right type – accessing support can be time-consuming and stressful which can exacerbate rather than relieve impact on the carer;
- Better recognition of the value of services that provide emotional support for the care-recipient – this is often a key concern for young adult carers wanting to participate fully in education or employment.



### FURTHER READING

Brimblecombe N, Knapp M, King D, Stevens M, Cartagena Farias J (2020) The high cost of unpaid care by young people: health and economic impacts of providing unpaid care, *BMC Public Health*, 20, 1, 1–15.

National Institute for Health Research (2020) NIHR Alert: Missed life opportunities for young adult carers cost the UK £1bn every year, <https://evidence.nihr.ac.uk/alert/young-adult-carers-missed-life-opportunities-cost-one-billion-pounds-per-year>

Brimblecombe N, Stevens M, King D, Knapp M (2020) The role of formal care services in supporting young people who provide unpaid care in England, *Journal of Youth Studies*, 1–16.

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