



The
University
Of
Sheffield.



CROOK
*public service
fellowships*



STOP THE CLOCK: How can we prevent young carers undertaking inappropriate or excessive care?

SARA GOWEN SHEFFIELD YOUNG CARERS

Supported by DR ANDREA WIGFIELD, DR CAROLINE SAROJINI HART, PERMALA SEHMAR AND JULIE ASKEW, UNIVERSITY OF SHEFFIELD

Summary

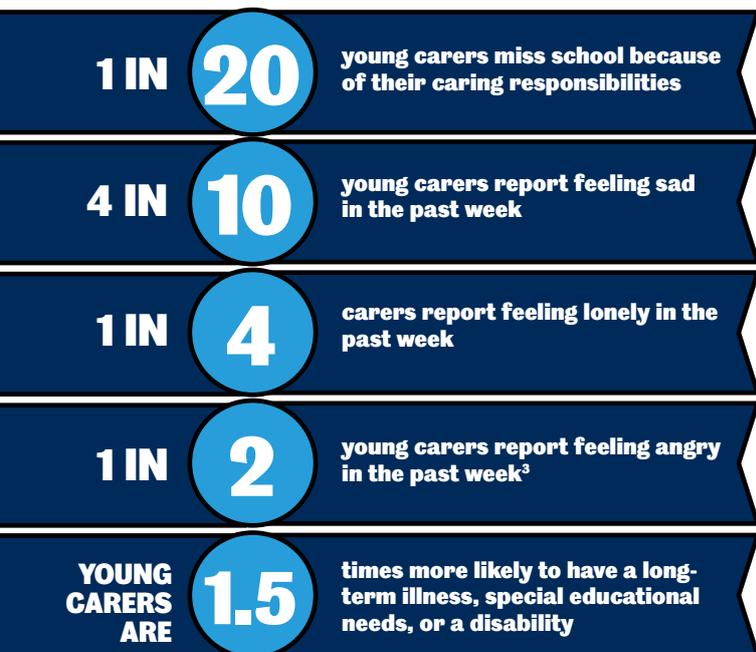
- The Care Act 2014¹ and Children and Families Act 2014² stipulate that no child should undertake inappropriate and/or excessive care. However, the concepts of 'inappropriate' and 'excessive' are not adequately defined and it is estimated that 1 in 12 children and young people in England and Wales are currently taking on medium to high level care for an ill or disabled family member.
- Young carers' voices are central to understanding the impact of caring on young people's lives. In May 2018, Sheffield Young Carers Action Group met with Prime Minister Theresa May to present their concerns and recommendations on what the government can do to improve the lives of young carers across the UK.

This briefing provides new research evidence from young carers about the challenges they face, highlighting the need for four areas of policy action. The four policy actions include i) early identification of young carers; ii) support for young carers so no child cares alone; iii) reducing excessive and inappropriate care by children through better assessment and service provision and iv) developing effective processes to support young carers' transitions to adulthood and independent lives.

Essential reading for MPs, policy makers and practitioners with responsibility for children and specifically related to: Care Act 2014 and Children and Families Act 2014

THE LANDSCAPE OF YOUNG CARERS

Young carers are a largely hidden group of children and young people who provide vital care for their families, often 24/7 and over prolonged periods of time. The nature and intensity of young carers' responsibilities often severely impact their own health, social, economic and educational well-being.



The prevalence of young carers in the UK is unknown and is indicative of the problem at the heart of the research⁴. We cannot identify the scale and scope of young caring in the UK if we do not hold both quantitative and qualitative data.

IDENTIFICATION OF YOUNG CARERS

Defining and identifying young carers is a crucial factor in supporting and safeguarding them. However, the lack of clarity and guidance on how to identify a young carer and what constitutes in/appropriate care makes it difficult for young carers and their families to get the support they need:

- Children caring for family members need support in their own right both as children and as carers
- Young carers need access to an enhanced range of health, social care and educational support.
- Many children do not acknowledge or disclose their caring responsibility and families may not identify their children as 'carers' due to fear, shame, stigma⁵ or because caring has become a normative part of family life.

"It is hard for people to tell if you're a young carer, you might look at someone and not know it."
Young carer aged 16

DEFINING INAPPROPRIATE AND EXCESSIVE CARE

Young carers undertake a range of tasks and responsibilities, often from a very young age. Many have normalised these tasks as something they think everyone does:

"When you think about it though, people think like, when someone's got used to it for so long you don't really realise that you're a young carer, unless someone goes 'you're a young carer you know.. Young carer aged 15"

To date legislation has failed to adequately define what is meant by 'excessive' and 'inappropriate' caring by children. In order to develop effective protocols to implement the legislation it is necessary to define ethical boundaries for what is understood by 'inappropriate' and 'excessive' caring. Our research aimed to give voice to young people themselves to gain insight into their everyday lives on this emotive and complex issue. The findings led to the development of provisional indicators.

INDICATORS OF INAPPROPRIATE CARING RESPONSIBILITIES

The set of indicators of inappropriate caring identified in our research include:

Parenting responsibility - e.g. a child acting in a parenting role towards the cared for person, siblings or other family members.

"I check in on my mum every night, I'll go into her room and be like 'I'll come and check on you in a bit but do you need anything for now?'"
Young carer aged 11

Global self-care responsibility - e.g. a child keeping their own emotions in check, keeping calm, tolerating parental anger, violence or excessive mental stress.

"Young carers need to be reminded about their own emotions and physical well-being as well as caring." Young carer aged 13

"This is hard because you have to be in control of them, you can't be angry or cry." Young carer aged 11

Personal care of the cared for person - e.g. bathing and toileting.

"I help with bathing and it's really not okay." Young carer aged 18

Strenuous physical activity - e.g. lifting, shopping (heavy bags), assisting cared for person, including moving and handling.

"I help with shopping because they don't leave the house, but it is heavy to carry." Young carer aged 9

¹ <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

² <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

³ Sources for figures: Still Hidden, Still Ignored, Barnardo's 2017; Hidden from View, The Children's Society 2013; Cheesbrough et al (2017) The lives of young carers in England omnibus survey report, Department of Education

⁴ https://www.bbc.co.uk/news/resources/idt-sh/Being_a_young_carer

⁵ Smyth, et al 2011

Responsibility for medication - e.g. collecting and administering medication, including giving the medication when the cared for person does not want to take it.

"I give medication to the person I care for but if they don't want it, I don't like forcing them." Young carer aged 13

Financial responsibility - e.g. maintaining the family budget, paying bills and worrying if there is enough money to pay them, using their own money to pay.

"Yeah sometimes my mum tells me to bring my money cos she doesn't have enough money." Young carer aged 15

Emotional support for the cared for adult - e.g. cheering them up, checking on them in the night, listening and lifting their mood.

"My mum sometimes feels scared or down about what my sister's doing, she normally asks me to stay in her bed with her for a night, so I do that sometimes." Young carer aged 12

This list includes two key indicators related to parenting responsibility and self-care responsibility that are absent in the Care Act. The research deepens insights into the way that inappropriate young caring is manifested in complex family lives.

If endorsed by government, these indicators could be used to develop a young carer 'well-being index' to help professionals identify what is inappropriate for each individual young carer and inform service development. We conclude that if a young carer is undertaking any or all of the above responsibilities and tasks, then this constitutes inappropriate care.

INDICATORS OF EXCESSIVE CARING RESPONSIBILITIES

Young carers never stop caring. According to national research 1 in 12 young carers provide care for more than 15 hours a week. The set of indicators of excessive caring identified in our research include:

Being the sole carer.

"You want to do so many things to help but (you) only (have) two hands and it takes a lot of brain space." Young carer aged 13

Length of time (over years) that child/young person has been caring.

"I don't know if this is bad, I don't know, anyway sometimes I think about having my own house and living by myself and being able to do stuff that I can't do at mum and dad's. I don't know if it's spiteful, ungrateful or anything." Young carer aged 15

Caring 24 hours a day.

"I don't sleep a lot but still keep moving." Young carer aged 9

Caring overnight.

"Randomly wake up and panic if you hear someone snoring, thinking your sister is having a seizure and needs to go to hospital. I don't like this, it is hard." Young carer aged 15

Level of responsibility a young carer undertakes for physical care.

"I do all the housework, I don't like to do it but it stops her from hurting herself." Young carer aged 11

Level of responsibility a young carer undertakes for emotional care.

"Yeah I think doing practical things, like cleaning or cooking, it's not a big deal, well for me it's not, but then having to worry all the time, that's just gets on your nerves to be fair." Young carer aged 15

The young carers in our research felt responsible for caring for their family member(s) 24 hours a day, 7 days a week, 365 days of the year. Young carers stated that caring through the night was the most challenging, as this entailed constant worry about something happening to their cared for family member during the night and that their home was not safe or secured for the night. The disturbed nights and lack of sleep have a profound impact on young carers' health, wellbeing and capacity to manage school/ college/ work and daytime caring, alongside the responsibility of caring overnight, every night. We conclude that the government needs urgently to 'stop the clock' on the 24-hour cycle of caring by young carers through more effective monitoring, support and, where necessary, intervention.



24 HOUR CARE EXAMPLES

YOUNG CARER AGED 12

6AM: Wake up and worry

9AM: School or at weekend - clean

12PM: If weekend - help make lunch, feed baby sister

4PM: Bus or tram home, clean, give meds to my mum, prepare food again

6PM: Give food to big bro when he comes home, change baby's nappy, play and talk with big sis

10PM: Med to sister and mum, change nappy, put baby to sleep

12AM: Lie in bed and listen out to see if big sis is having a seizure. Worry. Careful to not wake the baby. Walk around to make sure doors are shut, windows are shut. Try to sleep, it's hard

YOUNG CARER AGED 14

6AM: Get siblings up and ready for school

9AM: Going into school late as had to take siblings to school

12PM: Hoping my dad isn't lonely and my mum isn't going crazy

2PM: Worrying about going home - having to go straight back to caring

4PM: At home doing care things - cooking for siblings

6PM: Settle the kids down ready for bed, shower and bathe them

10PM: Make sure everything is okay, parents are okay and make sure the children are in bed asleep. Phone a friend, watch a movie, or read

12AM: In bed or just waiting till my Mum shouts me as she gets lonely

2AM: Awake or asleep because you are not sure

4AM: Sleep

Recommendations

In light of our research findings on the scale and impact of caring on young people's lives we strongly recommend that government takes immediate steps to develop and endorse more specific indicators of inappropriate and excessive care. We recommend that government develops urgent guidance, support and resource to enable health and social care services, non-statutory agencies and wider community networks to act to reduce young carers' burden of responsibility where it is deemed 'inappropriate' or 'excessive'. This requires urgent action to address the gaps in provision that lead to children becoming young carers in the first place. In terms of practical steps, we recommend:

1. Setting up a Department of Health and Social Care Select Committee Inquiry into the role of children and young people in providing care in England.
2. Setting up a group of Experts by Experience including young carers, young carers services, and education, health and social care professionals to feed into the Inquiry and subsequent recommendations for action.
3. Developing national statutory guidelines and a 'Young Carer Well-being Index' to define and assess inappropriate and excessive care, with the Experts by Experience.
4. Taking the opportunity of the upcoming green paper on social care to review the implementation of the Care Act 2014 and the Children and Families Act 2014.

Conclusions

The health and social care system in England places an unfair burden on children and young people to fill the gaps not met by the current provision. Our research highlights the way forward for the key challenges that must urgently be addressed. Children and young people with caring responsibilities need to be identified early; clear definitions and indicators of inappropriate and excessive care are essential; effective resource is required to facilitate urgent reductions in young carers' burdens of responsibility and support for young carers is needed throughout both their childhood and in their transition to adulthood.

The upcoming social care green paper provides an initial opportunity to identify the level of caring responsibilities and the impact of the lack of services have on young carers' life chances. A select committee inquiry will be able to draw up recommendations for action, including the development and implementation of clear guidelines and protocols for professionals to determine when a young carer is undertaking inappropriate and/or excessive care and how to act to 'stop the clock'.

ABOUT THE RESEARCH

The indicators and definitions of inappropriate care used in this policy paper have been developed through focus groups with 21 young carers in Sheffield aged between 9 - 18 years. All the young carers involved have received support through Sheffield Young Carers Project⁶. The aim of the research was to draw out: what types of care young carers see as inappropriate and/or excessive; the level and number of caring tasks they undertake; what activities and tasks they undertake during a typical 24 hours; and how they feel about carrying out these tasks.

Thanks to staff at Sheffield Young Carers and all the young carers who shared their views and spoke openly about their caring responsibilities.

⁶ www.sheffieldyoungcarers.org.uk

This research has been carried out by a multidisciplinary team as part of the Crook Public Service Fellowship scheme in the Faculty of Social Sciences. The scheme is funded by a donation from Professor Tony Crook and is supported by the ESRC Impact Accelerator Account. It allows future leaders in the public and not-for-profit sectors to work closely with academics on pressing policy issues to influence their sector and potentially wider society.

Sheffield Young Carers is a local charity, established in 1997. It works to identify and support young carers, aged 8-25, in Sheffield. It works to reduce the impact of caring and enhance the life chances of children and young people with caring responsibilities

About the key researcher

Sara Gowen has worked in youth and community work for 30 years, at a local and national level. She has been Managing Director of Sheffield Young Carers since 2014. Her work with young carers has inspired her to undertake this research to address the unacceptable level of caring responsibilities our children and young people undertake. Her commitment to the principles of young people's participation underlies all her work. For further enquiries and information, please contact Sara at sara.gowen@sycp.org.uk.