

THE ISSUE

The Children and Families Act 2014, Section 96, defines a young carer as ‘... a person under 18 (5–17) who provides or intends to provide care for another person. A person is not a young carer if the person provides or intends to provide care under or by virtue of a contract, or as voluntary work.’¹ With the Care Act 2014, it extended the rights to a needs assessment to all young carers under the age of 18 regardless of who they care for, what type of care they provide, or how often they provide it.²

A survey in 2018 asking 925 children in England to outline if they provide care, and to describe the care provided and to whom, reveals the extent of caring by children is much higher than previous estimates.³ If results of the research reflect the country as a whole, then there are over 800 000 secondary school children (aged 11–16 years) in England caring for an individual at home, and that approximately 7% of young people have a significant caring role in the home for an ill or disabled relative.

Of the 200 identified as young carers, 177 responded fully about the care they give. The scores from 56 (32%) of children showed them to be carrying out a high level of caring, with 16 (9%) of children doing a very high level of caring. The results show that most frequently responders cared for their mother (46%, $n = 91$) and siblings (40%, $n = 46$). Physical illness was most frequently cited as their reason for caring (35%, $n = 70$), followed by long-term illness (24%, $n = 48$). Mental health was also given as a reason by 24% ($n = 47$), with 6% ($n = 10$) highlighting drug or alcohol problems. Girls (59%, $n = 117$) were more likely to be carers than boys.³

The data reinforces the December 2016 report of the Children’s Commissioner for England that the vast majority of young carers (80%) are ‘under the radar’.⁴ Further, the report highlighted that ‘many do not get the help they need’, that this is ‘absolutely

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unacceptable’, and though ‘not all children with caring responsibilities will need support ... it is vital that those who do are properly assessed and the right help put in place.’ The Commissioner also added to the serious concerns expressed in the 2013 Children’s Society’s report *Hidden from View*⁵ that some of these children are ‘not only losing their childhoods ... they are also missing out on vital school and training, which will have a negative impact on the rest of their lives.’⁶

To help address the issue, the Government published in June 2018 the *Carers Action Plan 2018–2020*.⁷ Actions include improving the identification of young carers through better information sharing across agencies by the Department of Education (DfE); Department of Health and Social Care (DHSC) funding of a project focussed on young carers from disadvantaged and seldom heard groups; working with the Carers Trust to develop and deliver a ‘train the trainer’ model, and conduct a review of best practice in identification of young carers and access to support.⁷ As regards young carers, reference is made to the 2016 ‘Call for Evidence’⁸ report which included responses from 400 current or past young carers, in which 67% ($n = 268$) of responders outlined that they had not received any support as young carers.⁷

THE VALUE OF YOUNG CARERS

Relatively little is known about the economic costs and benefits of the range of interventions offered to the most vulnerable young carers. However, a report by the Carers Trust in 2008 estimated significant financial savings in social support which young carers projects contribute to

the economy: for an average cost of an intervention per capita of £2500, there is a saving of £6.72 for every £1 invested.⁹

Although the report makes no specific reference to GP practices, it is self-evident that their support should contribute to this situation. It should also result in improved care and health outcomes for patients and, over time, reduced demands on GP workloads. It is also worth considering the contribution of young carers to the economy. Though unquantified, given carers are estimated to save the NHS over £132 billion per annum, the figure is likely to run into billions.¹⁰

PRACTICAL ISSUES IN MEETING THE CHALLENGE

In 2017, the Acorn Practice and its Patient Participation Group embarked on a collaborative project to identify and meet the needs of its young carers. Located in the London Borough of Richmond, a primarily affluent area in South West London, it serves 8500 patients.

The process included: scoping the issue; developing a policy, workplan, and implementation strategy directed towards identifying young carers and providing support at the right time; ensuring that the level of responsibility taken on is appropriate to their age and maturity; ensuring understanding of the needs of the person(s) cared for, how best to help them, and the action required in the event of incidents or changes in their condition; and providing active signposting to further sources of help. In doing so, extensive use has been made of good advice published by the RCGP, including specific guidance on supporting carers in general practice, and e-learning materials for staff organising and providing support. At the July 2018 Care Quality Commission inspection, the project was rated as ‘outstanding’.¹¹

However, progress has been problematic, and, given that it has also been shared regularly with the Clinical Commissioning Group/Patient Participation Group (CCG/PPG) Network, it suggests that many, if not all, practices are likely to face similar

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practical issues in meeting the challenge of identifying young carers and addressing their needs.

The problems are considerable. First, there is a lack of data gathering and sharing between the various services involved, for example: Achieving for Children, Schools and Carers Centre. The reasons for this may include incomplete assessments and documentation, and restrictions imposed by the Data Protection Act and General Data Protection Regulation (GDPR). Instead, the Acorn Practice has been advised to make inquiries at the time of registration — fine for new patients but too late for all those already registered. Added to this, as the RCGP highlighted in 2013:

*Young carers rarely make themselves known to their GP and often avoid seeking help although caring can impact significantly on their lives.*¹²

Further, carers may not identify themselves as carers, nor may they, or those for whom they care for, be willing to give consent to being identified as such. Finally, and perhaps most significantly, young carers are rarely identified by practice teams, and patients are rarely asked who cares for them. That said, patients supported by a young carer are likely to visit their general practice at least once a year.

A question was posed at a Practice PPG meeting:

‘So, what is it that stops Acorn Group Practice staff asking patients the question: “Who cares for you when you are unable to care for yourself?”’

From discussion, the answer includes: finding the time within the appointment to raise the question, knowing whether and when to pose it, and remembering to do so. There are also concerns about resourcing these activities. Finally, there is an expectation that the whole business of providing services and support to young carers should be funded by the CCG.

Until such funding arrives, it is difficult to see how the aims of Acorn Practice’s policy can be implemented, and the legal rights and needs of young carers met. Further, given the Chair of the RCGP’s response to

the British Social Attitudes survey finding that: ‘satisfaction with GPs was at its lowest level ever’¹³ with the words:

*‘We know that general practice is currently facing intense resource and workforce pressures ... something we find just as frustrating.’*¹³ The Acorn Practice is unlikely to be alone.

This parlous situation also casts doubt on the likely success of NHS England’s June 2019 announcement that all GP practices would be invited to adopt a new package of services for young carers.¹⁴

REFERENCES

1. The National Archives. *Children and Families Act 2014*. <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted> [accessed 23 Sep 2019].
2. The National Archives. *Care Act 2014*. 2019. <http://www.legislation.gov.uk/ukpga/2014/23/contents> [accessed 23 Sep 2019].
3. Anscombe C. *New research suggests more than one in five children in England carry out some care for sick and disabled family members*. University of Nottingham, 2018. <https://www.nottingham.ac.uk/news/pressreleases/2018/september/children-england-care-sick-family.aspx> [accessed 23 Sep 2019].
4. Burns J. ‘Under the radar’ young carers denied support, says study. *BBC News* 2016; **27 Dec**: <https://www.bbc.co.uk/news/education-38381725> [accessed 23 Sep 2019].
5. The Children’s Society. *Hidden from view: the experiences of young carers in England*. 2013. https://www.childrensociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf [accessed 23 Sep 2019].
6. The Children’s Society. *Young carers*. 2019. <https://www.childrensociety.org.uk/what-we-do/helping-children/young-carers> [accessed 23 Sep 2019].
7. Department of Health & Social Care. *Carers action plan 2018–2020: supporting carers today*. 2018. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf [accessed 23 Sep 2019].
8. Department of Health & Social Care.
9. Crossroads Caring for Carers, The Princess Royal Trust for Carers. *Economic evaluation of young carers’ interventions*. 2008. <http://static.carers.org/files/finalfinal3-4040.pdf> [accessed 23 Sep 2019].
10. Buckner L, Yeandle S. *Valuing carers 2015: the rising value of carers’ support*. London: CarersUK, 2015. <https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015> [accessed 23 Sep 2019].
11. Care Quality Commission. *The Acorn Group Practice — Jackson*. 2018. <https://www.cqc.org.uk/location/1-572531131/reports> [accessed 23 Sep 2019].
12. Royal College of General Practitioners. *RCGP supporting carers in general practice. Summary report on GP practice journeys towards improved carer identification and support*. 2013. <https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/~media/EFE191B727514B66909FEED20FF23E1F.ashx> [accessed 23 Sep 2019].
13. Trigg N. Satisfaction with NHS ‘hits 11-year low’. *BBC News* 2019; **7 Mar**: <https://www.bbc.co.uk/news/health-47472472> [accessed 23 Sep 2019].
14. NHS. *NHS sets out ‘care for young carers’ offer in GP surgeries*. 2019. <https://www.england.nhs.uk/2019/06/nhs-sets-out-care-for-young-carers-offer-in-gp-surgeries> [accessed 23 Sep 2019].

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How can we improve support for carers? Government response to the 2016 carers call for evidence. 2018. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713695/response-to-carers-call-for-evidence.pdf [accessed 23 Sep 2019].