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## Young Carers:

Still Ignored or Do They Now Have  
Reason to Be Hopeful?

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**Special Report**  
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According to the 2011 census there are around 195,000 young carers in the UK, but this may be a long way shy of the estimated 700,000 young people who take on caring duties, according to research by the BBC and the University of Nottingham.

If correct, that latter figure would mean 1 in 12 secondary-school aged pupils would qualify as a young carer.

While much was done to strengthen the legal position of young carers with the Children and Families Act 2014 and Carer Act 2014, there are still many grey areas which the government is hoping to address through its Carers Action Plan 2018-2020.

This Special Report will set out the intentions of the 2014 Children and Families Act and Carers Act, highlight the issues raised by stakeholders since then, and consider the government's response as it looks to improve the offering of help and assistance available to young carers, by 2020.

### **Children and Families Act 2014**

Back in 2014, changes to the Children and Families Act and the Care Act offered hope to thousands of young carers and families, with the aim of reducing the burden of excessive caring on young people. The idea was that changes to these two pieces of legislation would work together, strengthening the offering to young people and ensuring they get the right amount – and appropriate type – of support for the whole family.

The changes set out in the Children, and Families Act 2014 include:

- Ensuring all young carers under the age of 18 have the right to an assessment, regardless of who they care for, how often they provide care, or the type of care they provide.
- A young carer will no longer have to request an assessment – although they can still do if they wish – nor will they have to be carrying out care that is defined as “regular and substantial” to qualify as a young carer
- The Act says that the needs assessment must include an assessment of whether it is appropriate for the young carer to provide, or continue to provide, care for the person in question, in the light of the young carer's needs for support, other requirements and wishes. The assessment should also consider to what extent the young carer wishes to participate in education, training and/or work

The Act also states that once the assessment has been carried out, a written record of the evaluation must be given to:

- The young carer
- The young carer's parents, and
- Any person to whom the young carer or a parent of the young carer requests the authority to give a copy

Additionally, if the person being cared for is under the age of 18, the written record must state whether the local authority considers them to be a child in need. The

Children and Families Act also defines when young people should not be classed as young carers, setting the boundaries as:

- If the young person provides (or plans to offer) care via a contract
- If the young person provides (or intends to provide) care as voluntary work

Furthermore, the Act considers how to provide a more holistic approach to care, thus recognising the young carer as part of the family unit. As a result, where the local authority is required to carry out a young carer's assessment **and also** other assessments on the young carer or the person that they care for, then these assessments can be, in certain circumstances, combined.

### **Relationship with the Carers Act**

With unusual foresight, The Carers Act was updated almost simultaneously, reinforcing these rights and helping to bolster the holistic approach to care the government was eager to implement.

The implications of the changes to the Care Act can be broadly summarised as follows:

- Local authorities' adults and children's departments should work together to ensure assessments are useful, and
- Local authorities should take a whole family approach to assessing and supporting adults so that any needs of young carers within the family are also identified

Broadly speaking, this means that when a child is identified as a young carer, the needs of everyone in the family should also be considered. If processed correctly, this would mean involvement from adults' and children's services.

While the ultimate aim may be to discover why the child is caring in the first place – and to find what support could be put in place to prevent the child from enduring too many caring responsibilities – in an age of austerity such ambitious aims are unlikely to be fully realised. However, by responding with a joined-up approach, the possibility of finding a suitable care package is much more likely than with a piecemeal response.

These changes to the legislation came into effect in April 2015, meaning there has been sufficient time to reflect on how successful they've been – and whether more needs to be done to protect the role of young carers in law.

### **Inappropriate or excessive care**

Indeed, since the amends to the two Acts, charities including [Barnardo's](#) and [The Children's Society](#) have published reports on young carers making a raft of recommendations – and some pointed criticisms – in the process.

One of the most significant objections levelled at the Children and Families Act and the Care Act is that, while both stipulate that no child should undertake inappropriate and/or excessive care, these terms are not adequately defined in law. In turn, this

creates a grey area for local authorities, making it difficult to judge what inappropriate care is, or how much care is excessive.

In their report [Stop The Clock](#), The University of Sheffield, Crook Public Service Fellowships and Sheffield Young Carers – led by Sara Gowen – attempt to establish a consensus around these terms, defining what they mean in order to help local authorities commission better services and to protect young carers from becoming overburdened. They estimate that 1 in 12 young carers might be taking on medium-high levels of care for an ill or disabled family member. At the upper estimate of 700,000 young carers in the UK, this would equate to more than 58,000 young people.

The report looks at what constitutes inappropriate or excessive care, highlighting some actions that could be considered under these terms. These indicators include:

- Parenting responsibility – e.g., a child acting in a parenting role towards the cared for person, siblings or other family members
- Global self-care responsibility – e.g., a child keeping their own emotions in check, maintaining calm, tolerating parental anger, violence or excessive mental stress
- Parental care of the cared-for person – e.g., bathing and toileting
- Strenuous physical activity – e.g., lifting, shopping (heavy bags), assisting the cared for person with things such as moving and handling
- Responsibilities for medication – e.g., collecting and administering medication, including giving the medicine when the cared-for person does not want to take it
- Financial responsibility – e.g., maintaining the family budget, paying bills and worrying if there's enough money to pay them, and/or using their own money to pay
- Emotional support for the cared-for adult – e.g., cheering them up, checking on them in the night, listening and lifting their mood

Additionally, the report includes three further policy action points to address the need for

- Early identification of young carers
- Support so that no young carer feels alone or isolated
- The development of effective processes to support young carers as they transition to adulthood

While these are somewhat vague, they do highlight the fact that there were some oversights when the amendments were made to the Children and Families Act and the Care Act, despite the government's efforts to marry up the legislation.

Finally, the report makes four recommendations:

- 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

- 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
- Developing national statutory guidelines and a 'Young Carer Well-being Index' to define and assess inappropriate and excessive care, with the Experts by Experience
- 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

### Barnardo's report on young carers

In December 2017, Barnardo's published their extensive report on young carers, titled **Still Hidden, Still Ignored**. The report – written in conjunction with YouGov – was based on a survey of more than 800 teachers as well as qualitative interviews with 40 Barnardo's Young Carer Practitioners and 79 young carers from across England. Additionally, focus groups involving young carers were held in Preston, Newcastle, and Liverpool.

Broadly, its findings were very similar to those of Sheffield University, acknowledging that many young carers give up on opportunities, even when the local authority is aware of their situation.

While the report made many recommendations focusing on teaching and schools (see below), it also set out some broader actions that it wanted local authorities to focus on, including:

- Working with partners, such as schools and health services, to identify and provide specialist support for BAME young carers. One of the key challenges here is the need to reduce stigma and fear of agency involvement from these communities. Additionally, services should be accessible and visible, and work to overcome any language and cultural barriers that may lead to BAME families not seeking support
- Local authority commissioners need to reassess funding structures to ensure that the focus and funding is not just on the identification and assessment of young carers, but also on sustainable and worthwhile support
- Local authorities and other agencies involved with their help must have clear embedded pathways for young carer support and should look to improve cross partnership working between all children and adult services
- Local authorities should appoint a designated officer within adult social care with responsibility for young carers, transition assessments, and support to ensure that there is a consistent point of contact for families and other agencies
- All local authorities and agencies need to adopt an outcome focussed follow-up approach, rather than referring young carers on and then closing the case
- Agencies must work together to provide joint, online support for young carers recognising this is a preferred and accessible method for many young people and how they would prefer to receive assistance

Barnardo's also looked at other services that might be able to provide more help and support, including GPs – where it was felt they could do more to identify and to support young carers – and in schools.

Indeed, schools were a particular focus of the report, as is emphasised in the following findings:

- A YouGov survey revealed that almost three quarters of teachers and 81% of head/deputy headteachers felt that schools had a responsibility to refer young carers, but only 45% of secondary school teachers said they did not feel confident that they would recognise a young carer. Furthermore, over a third (36%) said they did not feel sure about how to refer to any young carers they did identify to external support services
- One in 3 teachers (34%) said they don't think their school has any particular way to support young carers
- 93% of heads/deputy heads believe more should be done for young carers

So, while there is a will to help young carers in the school setting, it is clear that many teachers feel they lack the skills to provide appropriate support. Furthermore, this apparent black hole emphasises the need for agencies across the health, education and social care sectors to come together to find a consistent and viable approach to tackling the problems facing young carers.

### **Making change**

It does, however, seem like the Government is listening.

In June 2018, the government released its [Carers Action Plan](#), a document that sets out its plans to support carers and evaluate the services they receive – or would need to receive – if they are to access meaningful support.

The paper includes a bespoke chapter on young carers, acknowledging that they face a unique set of challenges. Pleasingly, some of the recommendations made by the likes of Sheffield University and Barnardo's are considered in the action plan.

The report sets out a two-year timeframe for action, running until 2020. An original call for evidence was launched in preparation for a carer's strategy – which was superseded by the announcement of an older people' green paper. In turn, this led to the government bringing forward the Action Plan and setting out the direction of travel for improvement over the next 18 months.

The Action Plan is a joint document, co-signed by the Department of Health & Social Care, Government Equalities Office, the Department for Digital, Culture, Media & Sport, the Department for Business, Energy & Industrial Strategy, Department for Work & Pensions, and the Department for Education.

Regarding young carers, the areas for attention as set out by the action plan are as follows:

- **Identification:** The Department of Health and Social Care is working with the Carers Trust on an identification project, developing a 'train the trainer model'

so that local areas can identify young carers and provide signposting to relevant services. This has a set delivery date for 2018/19

- **Best Practice Review:** The Department for Health and Social Care and Department for Education are conducting a review of best practice in identification of young carers and in access to support. This has a delivery date of Easter 2019
- **Seldom Heard Groups:** The Department of Health and Social Care is to fund a project that focuses on young carers from disadvantaged and seldom heard groups. It is hoped this will improve identification among Black, Asian and minority ethnic groups. It has a delivery date of 2019/20
- **Education:** The Department for Education is conducting a review of Children in Need, which includes young carers, to further understand the challenges facing these pupils and find out the support that can improve educational outcomes. This work is ongoing
- **Financial support:** In 2017, the Learning and Work Institute (LWI) and the Department for Work and Pensions launched customer information materials that laid out the rules for students claiming Carers Allowance. This activity is currently being evaluated
- **Young Carer Health Champions:** This programme, developed by NHS England and launched in 2015, was established to improve the confidence of young carers in using health services, and to develop the capacity of young carers to participate in the planning and development of young carer-friendly services. Events will run later this year, and the programme is ongoing
- **Mental Health Needs:** The mental health demands on young carers was recognised in the green paper Transforming Children and Young People's Mental health. The consultation on this green paper closed in March 2018, with the government writing its response in July last year. Sadly, there was no explicit mention of young carers, meaning this was something of a missed opportunity
- **Transition:** The Department of Health and Social Care will fund a project on transitions for young adult carers. The project will look to identify and disseminate effective practices to support and enable young adult carers to make positive transitions between the ages of 16-24 and identify the types of practical and emotional support that can allow a young adult carer to achieve a positive transition. It is hoped this project will be delivered before the end of 2019

### **Implications of the action plan**

While it's clear that work is taking place to understand further the challenges facing young carers, much of this is happening in the background. Even though it is imperative that this work takes place, behind-closed-doors reviews will do little to change the narrative for what is an often-forgotten group in our society.

But, as the government has set out a clear timetable for action, it should mean that by the end of that, we will be much better informed about how they intend to support

young carers – especially in areas such as identification, access to financial aid and mental health support, and supporting BME communities. Crucially, a plan for transition – often one of the most complicated times for social care support – should be in place, bringing relief and comfort to thousands of young carers.

It's perhaps prudent to acknowledge that the government has previously worked hard to support young carers – and changes to the Children and Families Act and the Carers Act both demonstrate this. It remains clear that a more targeted, bespoke approach and true partnership working between children's and adult's services will be needed if young carers are to receive appropriate ongoing help and support.

It's also prudent to remember that the Action Plan does not, in itself, contain any new service initiatives, but is instead a vehicle through which to make further discovery when it comes to understanding the challenges facing young carers. It will need to produce a number of specific and practical recommendations – and would almost certainly require an implementation plan to put in place these recommendations – if it is to lead to meaningful and lasting change. As such, this feels like the start of the process, rather than the end. For a group that has experienced enough false dawns in the past, let us hope this is not another one...

#### **About the author**

Rob Mair is the Managing Editor of the Pavilion journal *Leadership Issues in Social Care*.



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