



Young Carers' Rights

Making them real



LOUDER TOGETHER

Young carers and UK carer charities are concerned about the lack of clear support for young carers, and young adult carers, in the Health and Care Bill.

Young Carers National Voice is calling on MPs to support key recommendations that will ensure better identification and support for these children and young people, helping to ensure they can reach their full potential.

Contents

1. Young carers have rights	1
2. A lack of national action	2
3. An opportunity for change	3
4. Value for money	4
5. Action by Government	5

"I've cared for my Mum since I was six years old. She had severe depression, a borderline personality and quite a lot of substance abuse. And the thing I found, kind of, really hard about it was that I was kind of like her sole carer." Young carer

1. Young carers have rights

Young carers and young adult carers have certain legal rights as a result of campaigning by young carers and their supporters. These rights were introduced by The Care Act 2014 and Children and Families Act 2014 (amending The Children Act 1989).

The Children Act 1989 was amended to say that councils must:

- Identify young carers with support needs;
- Provide preventative services (like young carers support services);
- Undertake young carers needs assessments;
- There is also a duty to cooperate for the NHS, e.g. helping identify young carers or giving them information.

The Care Act 2014 says that councils must:

- Support young carers in transition to adulthood – this includes undertaking transition assessments for them;
- Undertake carers assessments for young adult carers (18-24 year olds);
- Take whole family approaches to assessment;
- Ensure that young carers are not left with inappropriate levels of caring responsibilities.

2. A lack of national action

"Before I was identified as a carer I felt quite isolated and spent a lot of time worrying about mum rather than concentrating in class, especially if she had to go to hospital for treatment." Young carer

Sadly, there has been little action by Government to make sure that these duties are actually met by councils.

This means that the rights are largely unknown to young carers and are not enforced – in fact they appear meaningless to most. A [report by The Children's Society](#) regarding transition assessments helps to illustrate this.

The [Children's Commissioner for England](#) found that, of '18,000 young carers brought to the attention of local authorities for the first time in 2015-16, one-third were rejected without ever being assessed.' Unfortunately, there does not appear to have been any follow up of this by either the Children's Commissioner or the Department for Education.

If these young carers' rights are to make any difference to the lives of young carers and their families, we need to see the Government introduce proper monitoring of the young carers assessments and support provided. This should be undertaken nationally and include collecting information on:

- Numbers of young carers needs assessments carried out;
- Care Act assessments for young carers in transition and for young adult carers aged 18-24;
- Numbers of young carers supported through young carers support services that are funded by councils;
- The number of young carers identified and supported by schools and colleges;
- The identification and support of young carers should also be included in local authority inspections. These are undertaken by OFSTED for schools and Children's services and the Care Quality Commission are responsible for health and adult social care.

"I also believe that being a carer affects mental health dramatically so it should also be seen that they are given extra support if needed for that. A carers assessment would help ensure mental health isn't affected too dramatically by their caring role and if it is they should be supported with options and support with this." Georgie

"Support needs to be monitored and the way in which councils operate should be reviewed annually. Government should be asking for the data for assessments requested, assessments delivered and assessments actioned - it's ok filling in pieces of paper but if there is no action or follow up there is no point of assessing." Young carer

3. An opportunity for change

Despite the essential role of carers and young carers in supporting our NHS and social care systems, there was no explicit mention of unpaid carers in the White Papers that made proposals for the Health and Care Bill. Alongside Carers UK and Carers Trust, we were very worried by this. Not only do young carers deserve to be recognised for the important support they provide, but the aims for integration between health and social care systems can only work if unpaid carers are visible, recognised and counted as part of the NHS.

We believe that the Health and Care Bill is an important opportunity to improve carers' rights within the NHS where their needs are all too often overlooked. The NHS depends heavily on carers in supporting people with long-term conditions and disabilities in the community.

"My mum is disabled. My siblings are Autistic and my dad works. I am 9. I can wash, cook, clean, look after the kids, make beds, sort uniforms and lunches. I also struggle coz I'm dyslexic and there's not much help at school. It's embarrassing always asking for help."
Young carer

Carers often undertake numerous roles simultaneously: administering medication, supporting daily activities such as eating, drinking, dressing, moving, supervision and cognitive support, through to more complex, specialised nursing care.

Carers' own health is often impacted by their caring role and they are twice as likely as non-carers to have ill-health because of caring. Without recognition and support, the wellbeing of young carers will be harmed, with damage to their future life chances.

We are calling for protection and improvement of carers' rights within the NHS as part of the Health and Care Bill. We welcome the Government's recent inclusion of carers in the new structures the Bill will create, including:

- A duty on NHS England to consult carers;
- New Integrated Care Boards being required to consult carers around planning and commissioning and also around preventative services;
- New powers for the Care Quality Commission to assess local authorities' performance in implementing The Care Act.

Unfortunately, the Bill currently takes away important rights at the point of hospital discharge which would be a very retrograde step.

We are calling for Government to include the following in the Health and Social Care Bill:

- Keep carers' rights at the point of hospital discharge, to ensure that the carer is supported, and the patient is safe to discharge;

- Place a duty on the NHS to consider carers in their own right and to promote their health and wellbeing;
- Introduce new provisions to strengthen carers' rights to a break and ensure adequate funding and supply of breaks services.

We want the Government make clear that new rights will apply to carers of all ages, **including young carers**.

"For the government to not include the most vulnerable cohort of carers within the Health and Care Bill shows the utter lack of understanding there is towards us as young and young adult carers." Young carer

4. Value for money

"Things have improved for me lately because one of the teachers has taken an interest and asked me how things were at home. I felt better once I told him, and I know he understands and will speak up for me if I get into trouble with homework or am late." Matthew

As well as a strong legal and ethical case to support young carers, there is also an economic case. Making young carers' rights both real and meaningful will save money rather than increase costs.

There have been several studies undertaken assessing the financial benefit of supporting young carers. For example, there was [a study that examined social return on investment](#) undertaken in Worcestershire in 2013-14. This highlighted the benefits to the wider community and suggested that every £1 spent would benefit society, saving an estimated a value of £8.69 for each £1 spent.

Economic research company Ecorys has undertaken two very relevant studies. The [first was with Sheffield Young Carers](#) which established the value of the direct benefit to young carers themselves.

This was followed by work with [Action for Carers Surrey and their Surrey Young Carers service](#). This estimated the savings to local authority Children's Services achieved by providing preventive support to young carers rather than responding where cases break down as a result of lack of support. They estimated that each pound spent would save £2.97.

"A more centralised approach, set out in the briefing, is what we need - not want - need. Government need to get to grips with this issue before thousands of children and young adults are plunged into a situation where they have to choose between their health or those that they care for or even sacrificing their future." Young carer

5. Action by Government

We want to see action by Government, NHS, OFSTED and local authorities:

On health and social care

- Young carers to be a clear part of the Health and Care Bill reforms that are being proposed by Government, and for carers to be explicitly referenced in the future legislation (the recent Health and Social Care Committee report also included carers in its recommendations).
- Care Quality Commission to include a focus on the whole family approach when checking that councils are implementing their Care Act responsibilities.

"The [school] day's good because it means I can just relax and don't have to worry about [the person I'm caring for]. And the school does a lot because the school runs a club for us every Thursday, so it gives me somewhere to go." Daniel

On education

- Department for Education to require schools to include young carers in the annual school census and in Pupil Premium – especially given the additional impact the pandemic has and will have on young carers' education.
- Young carer training to be mandatory for all school staff, including governors.
- Every school/college to have a system in place that flags who young carers are, and then to monitor their attendance/attainment (as for other vulnerable learners).
- A Young Carer Lead to be mandatory in every school/college. Acknowledged as part of their job – not a minor add-on.
- OFSTED to:
 - Include young carers as a specific group in all inspections.
 - Require schools/colleges to identify and refer young carers for support
 - Check whether and how young carers' needs assessments are undertaken and the impact these have (important that they don't just get done but actually make a difference/lead to positive change).

"It [school carer club] really helps; it gives me confidence. Some of the things I never thought I could talk about with anyone, I thought I'd keep secret to myself, I can talk about them. And the school has lots of events like bake sales which really helps to spread awareness to everyone in the school." Rose

"I think it would be really beneficial to offer training to the school receptionists/teaching assistants and lunchtime supervisory staff also, because they often play a more supportive role to students around the school while teachers may be busy." Charlotte

On training professionals

- Young carer training to be included in the university syllabuses for teachers, social workers and health professionals. Training should also be offered to existing staff and those recruited from other areas of work.
- Young carer training made mandatory and included in the induction process for all council staff, health professionals and the emergency services. It should also be included in safeguarding training which should be completed and refreshed yearly.

"I didn't feel that I had support throughout school or college with this, there was no willingness to adjust my college timetable to help me out." Charlotte

On young carers' rights, assessments and services

We want to see action by both Government and new Integrated Care Systems aimed at:

- Ensuring young carers and their families know their rights and what support is available to them in their local community – including specific young carers' services.
- Ensuring that councils have and allocate adequate funding to provide young carers' services that meet the need in their area.
- Ensuring that anyone who undertakes a young carer's assessment and transition assessment is properly trained and able to explain the benefits of the assessment to young carers and their families.
- Ensuring assessments are reviewed and updated so young carers and young adult carers can get additional support if things have changed.

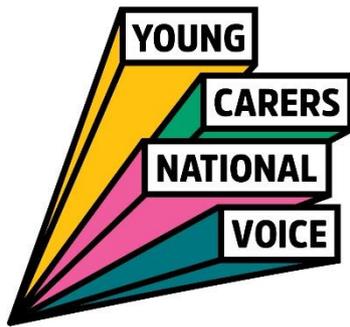
Taking Action Now

Young carers deserve their rights. The young carers who have made this call are owed action from Government and the Integrated Care System.

We call on all MPs and Councillors to address young carers' demands. On our part, we will work with you.

Join us and let's make young carers' rights available and accessible across the country to ensure that they are able to have the same life opportunities as their non-caring peers.

Young Carers National Voice



LOUDER TOGETHER

Young Carers National Voice is a growing network of local young carers organisations that are committed to promoting the voice of young carers. The aim of the network is to bring together young carers from across the country to campaign collectively on the issues that are important to them. It is predicated on a belief that together young carers' voices are stronger.

Contact: Laura Selby, Deputy Manager, Sheffield Young Carers laura.selby@sycp.org.uk Tel: 0114 258 4595, www.sheffieldyoungcarers.org.uk

**Document produced on behalf of
Young Carers National Voice by
Action for Carers Surrey**

Call us on 0303 040 1234

Email SYC@ActionforCarers.org.uk www.actionforcarers.org.uk

Action for Carers (Surrey) Registered Office: Astolat, Coniers Way, Guildford, Surrey GU4 7HL.
A Company Limited by Guarantee. Company Number 5939327. Registered in England & Wales with Charitable Status. Charity Registration Number 1116714. ©Action for Carers Surrey. ACS0115_09.21

