



**The
Children's
Society**

‘There’s nobody is there – no one who can actually help?’

**The challenges of estimating the number of
young carers and knowing how to meet their needs**

**Policy briefing
February 2016**

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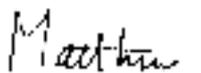


Foreword

Young carers today face a greater set of challenges than ever before, yet too often they remain unrecognised and unassisted by the very systems and services that should be there to support them. This is exactly why efforts to research and understand the issues and social landscape that young carers and their families face are so very important. We need greater knowledge about the lives of young carers, so that we can be sure we are taking the most effective measures to improve them. Getting things right for young carers now is crucially important for their immediate development as young people and their longer term chances to thrive as an adult.

If we continue to move forward without a proper understanding of the myriad complex pressures that young carers face in their daily lives, too many of them will carry on falling through the gaps, facing unnecessary hardships and remaining hidden from the support services they desperately need.

It is therefore vital that services make a concerted effort to work together to both understand and assist young carers in their caregiving wherever possible, and I am immensely proud that once again The Children's Society is at the forefront on this issue, leading a call for change and advocating a better life for these exceptional young people with the best possible chances to flourish.

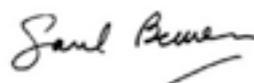


Matthew Reed, CEO
The Children's Society

There is a quarter of a century of social research on young carers that provides the foundation for this important study. The report reviews the different methodologies and estimates of the number of young carers in the UK and highlights the on-going challenges in trying, first, to identify young carers from different circumstances (including those considered 'hard to reach'), and second, to meet the needs of young carers and their families.

The qualitative element of the study shows that caring has significant impacts on the lives, education, health and development of young people. What remains clear, despite decades of research, is that there is still a long way to go to ensure that most young carers have adequate and appropriate support that reduces their vulnerability, caring roles and promotes their health, wellbeing and full potential.

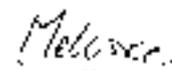
There are, however, some signs for optimism. New legislation relating to young carers, those they care for and the whole family, and reviewed here, has strengthened the rights of young carers today. Can our policy makers and service providers turn the hope offered by this legislation into positive outcomes for young carers and their families? The conclusions and ways forward offered in this report provide a framework for renewed action.



Professor Saul Becker,
Pro-Vice-Chancellor and Head of
the College of Social Sciences,
University of Birmingham

When I read this research, I was given hope. Despite Government cuts and pressures on local services, there are those out there who want to help young carers, and that help that will make a significant impact in someone's life. As a champion, I've been able to meet a lot of other young carers and the issues like the ones discussed in this research are exactly what we talk about. They've done a good job at telling others what a young carer's life is like at a glance, and of explaining the issues that surround identification.

I've known people that have been caring for years without ever hearing the term 'young carer', but the findings in this research have the chance to improve the way young carers are both identified and supported by those around them – and give them a chance to have as much of a normal childhood as possible. Research about young carers is important, not just to the young people themselves, but to the people they're caring for. With more information comes more understanding and more help, and that's all young carers want really. Caring becomes a part of life, but if there's a way to make that even a fraction easier, then we'll take it.



Melissa,
young carer

'There's nobody is there – no one who can actually help?'

The challenges of estimating the number of young carers and knowing how to meet their needs

Bina's story



Sabina, or Bina, is 17 years old. She lives with her father, whose vision is impaired and who is affected by depression. Bina helps to support him with a range of tasks. She helps with paperwork and applications, as he struggles with reading and writing. She gets him to hospital appointments and supports him emotionally, as he can find it hard to remember things and often feels uncomfortable leaving the house. In addition, Bina also helps to look after her two younger brothers, taking them to school and supporting them in lots of ways when her father is ill. She cooks, cleans and shops to ensure that the family have what they need – and she worries about finances and feels sad that her brothers don't have a higher standard of living.

Bina says her caregiving role started when her parents' relationship broke down and she moved with her father and

brothers to a new area (when she was about 13), but concedes that she's actually been helping to support various family members since she was a small child. However, as she explained when talking about the young carers service that she now attends, the concept of being a 'young carer' was alien to her:

'I didn't know what it was until I came to this service – you don't really think about it.'

So it's difficult for Bina to pinpoint exactly when she became a 'carer', other than when she was referred to the young carers service a couple of years ago.

Bina says that she used to find her caregiving role stressful, particularly taking on more responsibility for domestic

tasks at home after her parents separated. At the time this was compounded by other things happening in her life – she struggled to get a place in a new school, she felt isolated and didn't have many friends she could talk to – and she became depressed. She started getting stress headaches and went to the doctor, who gave her a prescription for painkillers. After a while she overdosed on her medication.

As a result, Bina ended up in hospital and was referred to a crisis mental health team – a process which she found upsetting and not particularly supportive. She can't recall anyone explaining the concept of 'young carers' to her, or suggesting that young people in her situation qualified for any kind of support. Eventually though, she was referred to a young carers service locally, which she finds invaluable. However, whilst Bina feels like she's finally got the support she needs as an individual, support and benefits her father accessed have been cut, meaning that she's worried about his welfare more than ever and plugging the gaps in caregiving herself.

Bina's got big plans. She's going to college and wants to apply for a scholarship to move overseas to study. But she's at a crossroads – her plans would mean leaving her father and her young brothers, and she doesn't think they would be able to cope without her.

Introduction

This policy briefing is about children and young people like Bina, who are navigating their way through life whilst taking on a duty of caregiving for someone they are close to. It is based on a one year research project which explored the support needs of specific groups of young carers thought to be particularly likely to struggle to access the support or services they need¹. The three groups identified for this project were young adult carers aged 18 to 25 years, young carers aged under 10 and young carers of any age from a black or minority ethnic (BME) group.

The Children's Society has a long history of research and policy development on young carers, spanning over two decades. In 2013 The Children's Society published *Hidden from View*, a report which identified that young carers were 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and were twice as likely to not speak English as their first language. It also found that young carers were more likely to be disabled or have a special educational need, or not be in education, employment or training between the ages of 16

and 19. In addition, it pointed to research and data which raised concerns that these groups of young people were less likely to be accessing targeted support for young carers.

The *Hidden from View* report provided the context for further enquiry into what was known about the young carer population, what their particular support needs were, and to explore potential barriers to accessing services.

Methods

The research employed a mixed methods approach to understand how support may be better targeted to particular groups. This included a scoping of literature on young carers and their prevalence, secondary analysis of 2001 and 2011 Census data, and semi-structured interviews with 45 young carers, six parents, and 13 workers from young carers services.

¹childrensociety.org.uk/Publications

1. What we already know

How many young carers are there?

Analysis of data from the two Censuses (in 2001 and 2011) suggested that there had been an overall increase in the reported number of carers of 20% but that this varied for different groups – for example, by age or ethnicity:

- A proportionate increase of 75% of reported young carers aged 5 to 9 years old
- A change in the reported numbers of young carers within ethnic groups – although the differences between groups were smaller than before.

However the 'growth' of young caregiving shown by the Census datasets may not represent an increase in the numbers of young carers but may instead reflect other factors – eg better familiarity amongst the public with the concept of 'young carer'.

There are also limitations with the Census methodology in terms of its suitability for estimating the prevalence of young people's caregiving (and changes in this) because, for example, collecting

data requires adults to identify caring roles, and to assess potentially arbitrary amounts of time spent 'caring'. Also, because these questions have only been asked on two occasions, it is possible that some results may be outliers.

Estimates of young people's caregiving in academic research provide a very mixed picture of its prevalence depending on the methods employed and the definitions used.

What is known about young carers from 'excluded' groups?

Little research has been done which has focused on the youngest young carers and their specific needs. With regard to 'young adult carers', studies have suggested that they may be conflicted between their caring role and their culturally-supported desires to progress into adult life (eg by attending higher education and/or seeking employment) – though these findings have also been challenged as being representative of a minority of young people's transitions. A

consensus from the literature was that young people approaching adulthood (at the age of 16 or 17) may increasingly experience difficulties around maintaining specialist support, as the remit of many services does not extend beyond childhood (legally ending when a young person reaches 18).

Research on young people's caregiving has, for the most part, not adequately attended to the particular issues for young people from minority ethnic backgrounds. The small number of studies that have explored ethnicity have produced contradictory findings – some advocating the need for segregated specialist services to meet cultural needs, others proposing combined, universally-accessible services. Themes that resonated throughout this literature were that young carers of BME heritage were likely to encounter the same barriers to access and engagement with services as their white counterparts, but that these were often compounded by racism, bullying, language barriers and a lack of understanding of the availability and nature of provision.

Other research (on excluded groups in general) has suggested that lack of access or engagement with services is rooted in a combination of three factors:

- Organisational barriers (related to how services promote themselves or how they operate)
- Families being 'hard to reach' (not knowing about or being unable to access services)
- Families being 'hard to engage' (unwilling or wary of using services)

The legal position for young carers and their families

The legal position and rights of young carers and their families have improved in the past two decades and the definition has changed over time. Early legislation which first acknowledged and offered a limited definition of a 'young carer' made provision for an individual assessment of need – but only at the request of a family. The Care Act 2014 introduced an explicit entitlement to a holistic assessment of need across all

members of a household where one family member has been identified as having a caring need or being a carer. This also gave a clear directive that the impact of caring should not be 'excessive' or 'inappropriate' for a young person, and that integrated services should be provided by local authorities to mitigate this, as well as to adequately look after the person whose condition requires care.

2. Identifying young carers and their support needs

From interviews with participants, it became clear that identifying and defining young carers by factors such as age or ethnicity is not a helpful approach. What was evident from the 45 young participants in this project was the different experiences and circumstances of each young carer's life. There are a number of key factors that may determine a young person's support needs:

a) The amount of responsibility for caregiving

- There were examples of young carers who lived alone with the person they cared for (sole carers), those who took on the majority of responsibility for caregiving, but lived with another adult or siblings (main carers), those who lived with others and where responsibilities were shared out amongst them (team carers), and those who had caregiving responsibilities but were not the main carer (secondary carers).
- In addition, the amount of informal support available from outside the home varied considerably. There were some participants who spoke of extended family, friends, neighbours and religious or community groups that supported them or their families, whilst others were relatively socially isolated.

- Also, the amount of professional support to families varied. Whilst all participants in this study were 'identified' young carers and had connections to young carers services, many had spent years providing support at home with no formal identification or referral. And many still described themselves as not having anyone who provided 'support', which may suggest a divide between professional involvement and interventions which feel supportive or helpful to the young person.

b) Family and home context

- For some young people, the physical conditions in their home added to their caring role or support needs. For example, interviewees spoke about sharing bedrooms with siblings for whom they helped to provide care, or the limitations of living in properties with only stairs when the person they provided care for had mobility issues:

'I have been ill quite a few times and have been in pain where she leans on me when I help her up and down the stairs.'

- Others talked about the additional worries and concerns that financial difficulties presented for them or their families. For example worrying about paying rent, affording groceries or other necessities like travel:

'The last few months mum has been short on money. She was struggling with things like rent and everything, groceries. So I had to lend her money.'

As well as reductions in access to services, some young carers described how changes to their family's income had indirect consequences:

'Even though it doesn't hit a young person directly, it doesn't mean it doesn't affect their lives. [Losing] DLA doesn't affect me directly, but it affects my life anyway. All this bedroom tax doesn't affect me because it's not my home, but still affects me.'

c) Self-recognition of care-giving role

The ways that young people in this study talked about their identity as a 'carer', how caring connected or influenced either their educational, social or personal life, or their feelings about needing support varied considerably. These included:

- Young people who identified very strongly as being a 'carer' and saw this as something they would always do, either as a career or for their family.
- Those who did not want help, and felt capable of coping and positive about their role and their wider life.
- Young people who recognised they might need additional help or support, but did not want to 'ask' for help, or who found it difficult to be proactive in identifying support.
- Those who saw their caregiving as a part of their everyday life, or did not see themselves as being 'a carer'.

3. Young carers' views on their support needs

Young people's views on the support they had received related to three key themes:

1. Ongoing relationships

Young people particularly valued having a long term relationship with a professional. Most commonly, this was a worker from a young carers service, but participants also talked about teachers or tutors, GPs and social workers.

This had the benefit of not having to retell their 'story' which invariably involved focusing on their caring role rather than their wider lives, worries, interests and experiences. It also allowed them to build relationships based on trust, which meant they felt able to ask for help when they needed it:

'I would just say to him [project worker] "I need to talk to you" and he'd just drive round and I would chew his ear off. You can just do that.'

These relationships also fostered familiarity over time, which meant that a young person could feel relaxed, could be quiet and reflective and that they did not have to always respond to different professional agendas:

'The first interview we had I didn't really talk, because I just find it so weird! But after she's not like...the way she talks to younger people it appears she's really calm, not nagging and stuff like that. It's easy to talk to her.'

2. Understanding, not pathologising

These types of relationships – where young people were able to build up trust with individuals – also meant they felt better supported in other parts of their lives. Participants also appreciated where professionals actively listened to them, understood their individual circumstances and were responsive in how they provided support. Examples the young people gave included teachers being flexible with deadlines and assessments, or being around simply as 'someone to talk to', even when the issue was not explicitly connected to their caring role:

'When I was younger, the more I held it in, the more angry I was...I felt like I was being judged. My learning mentor – she wouldn't judge me. She'd make jokes about the situations that made me angry. I used to get angry about the smallest things...'

Young people in the study explained the invaluable support that they had received from specialist projects, support which had offered many things that were not available elsewhere: respite and release from caring and responsibilities, opportunities to do things that would otherwise be out of their reach, care, learning and understanding. And, perhaps most importantly of all, giving them a feeling that they were not alone in their caring role:

'When nobody knew about me and I started coming to the club, I felt alone because none of my friends had somebody who was disabled or had problems with them. So I thought I was the only person and the odd one out. But then I started coming to young carers and it made me feel better.'

3. Support for the person needing care

Many young people particularly focused on the need for appropriate care and support for the person they provided care for, rather than support for themselves:

'If I'm at university, at least my mind's at peace, because if anything happens to my dad, he can contact [the emergency response team] and they can come out to him and help him whatever situation he's in.'

In addition, where professionals working with the person being cared for saw the whole picture, and checked in with the young person too, this was particularly appreciated:

'My doctor is really good. He acknowledges that I am a young carer – which is great, because he talks to mum about stuff, but he will talk to me as well, and ask, "Is that okay?" It's nice that he's not just talking to me – which excludes my mum – but is talking to us both.'

4. Barriers to meeting young carers' support needs

The interviews with young people suggested that there was a broad set of challenges for services and professionals in addressing the potential needs of young carers:

1. Personal resistance

As mentioned, young people's understanding and conceptualisation of being a 'young carer' varied considerably, as did their comfort with being given this 'label'. The difficulties that young people and their families had experienced in accessing help included their own perceptions and fears, and their assumptions about what was 'normal':

'It would be weird to ask for someone else's help.'

'There was a huge stigma when I was at school about depression and mental health – and if I then said I am a carer...I would have to say my mum had a mental health condition. That would send a flurry of Year Eight judgements because there was no understanding of carers or mental health. So that's why I didn't tell.'

2. Responses from professionals

Young people explained that professionals and services were often reactive rather than proactive in identifying a need for support. This could mean that if a young carer was reluctant to disclose information this remained hidden, and staff were ill-informed about how to respond:

'In Year 11 our English teacher asked us all to write an autobiography...She approached me afterwards and said, "I didn't know that was your situation"...There wasn't an, "I didn't know that was your situation, there's this and this [I can do]" it was just, "I have read about it, I know that's happening". And it was left at that.'

Where information was not shared between agencies this would lead to temporary loss of support. It could also have the knock-on effect of a need to retell their story to every new teacher, doctor or other professional whom they encountered.

Other young carers spoke of being 'blocked' or ignored by health professionals. Whilst it is may be necessary to safeguard children, and ensure that all patients are able to have a private consultation, some young people reported that they had been frustrated because they were not asked about their experiences, or kept informed of outcomes of consultations with the person being cared for – despite this being something that affected them in their day-to-day lives:

'So then he comes out [of the doctor's appointment] – he's got short-term memory loss – so he'll go, "He said...err, um... I can't remember". So I don't know what medication you're supposed to be taking, when you're supposed to be taking it, how you're supposed to be taking it. It seems to me that they don't accept that young people care for people.'

3. Organisational issues

Young people's and parents' accounts conveyed how difficult it could be to find accurate information, sometimes because this had become outdated, and also that accessible information was hard to come by:

'It's very difficult, because I don't know much English. I can't fill in the forms about benefits or different forms. And she [young person's mum] can't read or write, and I don't know how to register with the learning disability, where to go.'

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The challenges of estimating the number of young carers and knowing how to meet their needs

Other factors such as thresholds for support, catchment areas and age limits served to exclude some young people from accessing the help and support they needed, or jeopardised their plans:

'Because [an emergency support service] was in place, it gave me more peace of mind to go to uni. If that wasn't there would I have gone to uni? I don't know. Now I am going into my third year and it's been cut. Do I carry on with uni – which is what I want to do – but what if something happens?'

The frequency with which services were subject to change – including staff turnover, or sometimes loss/reduction of funding and restriction of services or, at worst, closure – was another issue which could cause some hesitancy on the part of young people and their parents to engage, because they felt that this could lead to an ongoing cycle of the requirement to repeat accounts of sensitive information to strangers and having to build new relationships:

'My dad's mental health worker went away... they started sending round different people each time to the house. Now we've been given a different support worker, but now they are refusing to come round on the grounds that it might be unsafe and things.'



Recommendations

The experiences of the participants in this study provided a great deal of insight into ways in which services used by young carers and their families could be improved to make them more accessible. Provisions in the Children and Families Act and the Care Act will no doubt address some of the key issues that mean that young people may not be identified or referred to appropriate services. How these are resourced and implemented locally will determine their success. The following recommendations consider how different sectors or groups may implement changes to make service provision more accessible.

Local authorities strategic leads

The Children and Families Act stipulated that local authorities must take reasonable steps to identify young carers and should take a 'whole family approach' when assessing and supporting adults. As such, it is essential that Cabinet members for children and adults take responsibility for promoting joint working and information sharing to embed legislation locally. Some specific ways in which local authorities may consider doing this include:

- Local Safeguarding Children Boards (LSCBs) and Local Safeguarding Adult Boards (LSABs) should compare their audits of children and adults caseloads to help to identify young carers and ensure appropriate referrals.

- Health and Well-being Boards (HWBs) provide the opportunity for leaders in the health and care sectors to work jointly to improve health and well-being. Therefore this may be a useful forum to focus specifically on local provision for young carers and assess local needs.
- Representatives from specialist young carer services should be included on LSCBs and HWBs as appropriate to ensure effective information sharing.
- Where relevant, local authorities should audit what provision is available for those outside the age range of local young carers services.
- Service providers and commissioners need to ensure that information about local provision is well-promoted, kept up to date and is accessible (i.e. available in different formats and locations).

Funders

Support needs to remain available, affordable and accessible for young people and their families.

- Commissioners in local authorities could explore joint commissioning of services with adult and children's services or across a number of geographical locations to maximise resources. Local authorities should explore

how provision for whole family working may be included as a part of the 2% social care precept, as announced by the Chancellor of the Exchequer during the 2015 Autumn Statement.

- Funding organisations could provide creative opportunities to deliver support on a more long-term basis such as:
 - Longer contract time frames to allow young people and their families to have a professional they can trust and for young people to have someone who knows about their individual needs as well as their caring role.
 - Developing a peer mentoring system for young carers providing a regular, ongoing (and low-cost) contact for a young person, and a development opportunity for the mentor.
 - Creating an 'innovation fund' for young carers services to try new approaches and improve knowledge transfer.

Frontline professionals

Some particular examples of how professionals in health, social care, education and specialist young carer services could improve their systems and processes or ways of working to meet the needs of young carers and their parents are given in the following sections.

Health settings

- Patients should be able to request a printed summary of the outcome of an appointment with any health professional – including changes to medication, other treatment and upcoming appointments – to put the carer's mind at ease and ensure that information can be circulated more easily to those involved in caregiving.
- Where a patient is known to have a family member who takes on a caring role, surgeries should book double appointments to allow for check-ins with carers.
- Where professionals in Adult Mental Health Services (AMHS) know that a patient has a child, they should make a routine referral to a local young carers service or local authority to ensure that appropriate assessments can take place.

Social workers

- Social workers are now required to carry out 'whole family' assessments. This should – where appropriate – ensure that all children and siblings of an adult are assessed (and later reviewed) individually, as some siblings may have different experiences to others or may be taking on more of a caring role and this may change over time.
- Assessments should include the appropriateness of the living environment and the family's financial health, as this may have an impact on the physical and emotional tasks for – or have other impacts on – young people in the household.
- Social workers should ensure they adopt child-centred lines of enquiry to find out about caring roles, rather than basing assessments on concepts or categories that may be difficult for a young person to understand or describe.
- Training should be provided for adult care social workers to ensure they are well supported in whole family work with children and young people.

Staff in education settings

- Young people may be reluctant to disclose their caring, or may not even be aware of it. Therefore teachers and tutors need to be proactive in identification and ensuring ongoing stable support for a young carer. This may include maintaining links with social care to update on potential referrals and to ensure that a young person's caring status is shared when they move from one school to another.
- Where possible, information about young carers should be held with a central, named staff member.
- The concept of 'caring' should be mainstreamed in lessons and discussions in schools and colleges to facilitate disclosure.
- Schools should consider obtaining 'Young Carers in Schools' accreditation. For more information, go to youngcarersinschools.com

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Young carers service practitioners

Young people were forthcoming in their interviews about how helpful, and sometimes how vital, the support of specialist young carer services had been. Some of them were also keen to point out that it was important to work closely with young people themselves when drafting communication materials and resources, to ensure that these were appropriately-worded and to avoid 'hero' or 'victim' connotations.

What this could have meant for Bina...

Had the Care Act and Children and Families Act been in place when Bina was younger, this may have helped to ensure that she had been identified sooner, as her father would have been in touch with adult services teams for his various physical and mental health support needs. The whole family approach would have highlighted that he had children, and provided the opportunity for identification and referral to support before it reached the critical level that it did for Bina.

If local authority services such as housing and the police understood that Bina took on additional responsibilities in her home, this might have meant that when she called to log repairs needed on their home, or ask for help to deal with anti-social behaviour in her neighbourhood, she would have been given better support with those issues.

Likewise, had there been systems in place that many schools have now adopted, there would have been the chance for her to get the help and support she needed at school when things changed at home and she realised she was becoming depressed and isolated.

And finally, if the young carers' services that Bina, and so many like her, have come to rely on were able to plan for longer-term support – rather than existing from one year to the next depending on what funding becomes available – then this would ensure that the support, friendships and fun that these spaces provide would be protected. Whilst these aren't what all young people need or want, more sustainable funding would also provide space for services to innovate in areas such as peer mentoring or generalist youth services, and to provide a better offer for a wider array of young people.

It is a painful fact that many children and young people in Britain today are still suffering extreme hardship, abuse and neglect.

The Children's Society is a national charity that runs crucial local services and campaigns to change the law to help this country's most vulnerable children and young people.

Our supporters around the country fund our services and join our campaigns to show children and young people they are on their side.

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Names used in this report have been changed to maintain anonymity. All photographs posed by models.

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