



Department
for Education

The lives of young carers in England

Research brief

February 2016

TNS BMRB

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Executive Summary

Overview

This document reports on the qualitative part of a programme of research conducted by TNS BMRB, in partnership with Professor Jo Aldridge, Director of the Young Carers Research Group (YCRG) at Loughborough University, investigating the lives of young carers aged 5 to 17 in England. This qualitative research was designed to find out more about the characteristics of young carers and their families; the nature of care they are providing; the impacts of caring responsibilities and the needs of both young carers and their families; experiences of support; and responses to support propositions developed in consultation with key local and national stakeholders.

The quantitative element of the research estimating the prevalence of young caring is ongoing and will be reported in due course.

Background

According to the most recent census (Office for National Statistics, 2011), there are almost 166,000 young carers (aged 5-17) in England. Young carers undertake a wide range of caring roles and responsibilities, including emotional support, personal care, housework and household budgeting. While research has found that caring can result in positive impacts, there is a relatively strong body of evidence on the adverse impact of caring on health outcomes, social activity, educational engagement and employment opportunities for young carers (e.g. Aldridge, 2008; Becker, 2007). As such, children who live with and care for parents or other family members who are ill or disabled may require support in their capacity as children and/or as young carers.

At present, young carers and their families have access to a range of different health, social care and educational support services, all of which should include needs assessments that support the identification and management of adults as services users, the support needed in their role as parents and, importantly, the support needs of their children. However, a significant proportion of young carers have not disclosed their caring responsibilities to their school, they are no more likely to be in contact with social services than are their peers, and only a minority have had an assessment of their needs or been informed about sources of help (Barnardo's, 2006; Dearden and Becker, 2004; The Children's Society, 2013). Many families do not recognise their children as 'carers' (Smyth et al., 2011), some children do not recognise or identify with the role, and there

can be a degree of reluctance, even anxiety, among families in disclosing caring responsibilities.

With the implementation of the Care Act 2014 (HM Government, 2014) and the Children and Families Act 2014 (HM Government, 2014) there is now a need for local authorities to identify and assess the support needs of young carers, regardless of the type of support they provide.

Methodology

This research involved 22 face to face research visits conducted with young carers aged 6-17 years old and their families between January and March 2015. A number of purposive recruitment approaches were used to sample a broad range of young carers including: targeted engagement with gatekeepers in young carer support services such as young carers' projects and young carer respite services; and screening from an online panel. Research visits lasted 3-4 hours and used a mixture of exploratory discussions with families, observations of family interaction, in-depth interviews with children who were providing care for parents/siblings, and interviews with parents/guardian and other family members e.g. a cared-for sibling. The research with young carers, and the support propositions tested, were informed by a rapid evidence assessment and 10 telephone interviews undertaken with individuals representing local authorities and national and local support organisations across England between October and December 2014. Finally, a 90-minute workshop was conducted with nine young people aged 11-17 years old who attended young carers' projects to validate key findings on the types of support local authorities should prioritise.

Key findings

Understanding the context of caring: young carers and their families

- Young carers were more likely to care for a mother than a father, and lone parent families were over-represented in the sample. This is aligned with findings from previous research (e.g. Dearden and Becker, 2004)
- Cared-for parents/siblings all had a single or dual diagnoses of physical or mental health illnesses/disabilities, however these were often also accompanied by other physical and/or mental health issues that had not been formally diagnosed. Parental mental health conditions were particularly challenging for children to cope with due to the unpredictability of the nature and extent of care support needed. This

unpredictability also had implications for the degree to which mental health services were able to provide timely support for parents with mental health problems.

- Parents could struggle to discuss their health conditions with their children, particularly where their conditions were complex or terminal, or where the child was young (i.e. those aged under 10 or 11). There was a clear desire among young carers of all ages to better understand the condition of the cared-for person – potentially through greater involvement in discussions held between health care professionals and their parents.
- Older young carers (those aged 16 and 17), and those in lone parent households, tended to take on greater caring responsibilities and felt more responsible for providing support than did younger carers or those children who had not disclosed their caring responsibilities. In most cases young carers stated that they were happy to provide caring support – even more personal forms of care - however there were some responsibilities, such as helping to manage household finances, where they indicated that they were less comfortable due to a lack of experience.
- School holiday periods were particularly challenging for most of the young carers due to an increase in their caring responsibilities at home and reduced opportunities to engage in other activities both inside and outside the home as compared to term-time.

Experiences and impact of caring on children and families

- Caring was seen to be a very rewarding role by the majority of the young carers – regardless of age or length of time caring - bringing with it a range of positive emotional and psychological benefits. However caring also had adverse effects: anxiety, stress, tiredness, strain within family relationships, restrictions in social activities and relationships, and under-engagement in education.
- The majority of parents were keen to reduce the impact of caring responsibilities undertaken by their children particularly in respect of social relationships and school engagement. There was a clear desire among parents for their children to receive support in making effective education transitions and in planning for the future. However, parents did not appear to be actively preparing for their child to cease caring responsibilities through explicit parent-child discussions of how caring needs could be fulfilled as their children grew older and became more independent.
- Young carers developed different coping strategies in order to lessen the impact of their caring responsibilities. Older young carers benefited particularly from social

relationships, whereas younger carers benefited from sharing their feelings openly with parents and some used tools such as worry books (introduced either by parents or school support staff) to communicate their thoughts and feelings. To reduce the impact of their caring role on their education, many young carers in secondary school tried to complete homework before returning home.

- Young carers known to local services did identify with the term 'young carer'. Young carers were proud of their caring role but also recognised that it was used as a label which carried with it negative connotations. Young carers not receiving formal support services did not self-identify with the term 'young carer' and parents of these children and young people expressed concerns about their child being labelled as a young carer – a label which they felt reflected negatively on them as a parent.

Young carer needs assessments and uptake of services

- Formal or informal support helped reduce the extent of young carers' responsibilities, however not all parents were comfortable disclosing their condition to health and social care professionals due to a fear of the potential repercussions for their family.
- There was confusion among both young carers and their parents as to whether children had received their own young carers' needs assessment. Children and parents believed needs assessments could be improved by ensuring they were conducted promptly following disclosure, in a private setting, in a mode preferred by the child (i.e. face-to-face or by telephone), and with clarity in respect of the outcomes of the assessment.
- Young carers typically accessed young carers' services via referrals from adult/children's social care, school, or adult/children's health services. Barriers to accessing support included parental concerns about the consequences of disclosure for families (and what this would mean for their children), lack of understanding of the nature of support available, and concern as to the appropriateness or impact of interventions and support services. Conversely, early and effective communication between professionals and families helped to allay parental concerns about the consequences of requesting/accessing support, and helped to facilitate access to young carers' projects.
- Young carers' projects were an important source of formal support and respite for young carers. Having caring in common made it easier for these children and young people to open up in conversation about caring – something that was valued by both

parents and their children. Projects also provided access to fun activities, as well as information, advice and advocacy, although the nature and extent of provision varied across the projects. As young carers became older it was evident that they sought to engage with a wider peer group, and relied less on young carers' projects. Young carers and parents both expressed a desire for young carers' projects to provide support for families to spend more time together.

- Schools provided support to those children who were identified as young carers, ranging from personalised teaching/pastoral support, access to homework clubs or afterschool provision, and greater flexibility in school/class attendance. Support for young carers in school varied considerably, in some cases support reduced the emotional and educational impact of caring, but in other cases it was inconsistently provided due to a lack of shared information/understanding between teachers.
- Social workers tended to have limited contact with young carers about their caring role, although some children did have a key worker who discussed the impact of caring with them and made referrals to young carers' services. There was a high degree of distrust of social services generally, and social workers more specifically, within families who had direct experience of support from social services in the past. In these cases both children and their parents were reluctant to disclose information about caring responsibilities for fear of potential repercussions in the form of interventions that might lead to family separations.

Support propositions: views of young carers and their families

- Parents and young carers identified a number of factors that would promote access to support for young carers. These included: increasing the inclusivity and availability of young carers' services (e.g. greater support for younger carers and enabling access through central locations or transportation to and from services); ensuring that health and social care support services communicate the availability and nature of young carers' services quickly and effectively; standardising age appropriate activity and information across young carers' services; and improving support for cared-for family members to help meet diverse needs.
- As part of this research, young carers and their parents were presented with a range of propositions for forms of support that may be beneficial to young carers and their families.

- Young carers and their parents identified benefits from having someone to talk to about concerns, relationships and the experience of caring, including other young carers of a similar age – those with a shared experience and understanding. However, framing this in the language of ‘taking a break from caring’, could reduce engagement in this form of support by children and parents who do not perceive a need for a ‘break’. Practical support through the provision of aids/equipment (for those families where parents or other relatives had mobility and social care needs) helped reduce the caring responsibilities of children and young people while information from professionals helped to alleviate their anxieties caused by a lack of knowledge around their parent or sibling’s condition.
- Parents and young carers were keen to mitigate the impact of caring on their ability to participate fully in school, and to achieve. Young carers identified that support from teachers to complete their studies as the main way in which schools could support them. This was best achieved through teachers having a clear understanding of the nature of children’s caring responsibilities and providing stronger support around stressful periods such as exams and transition points.
- Information about managing finances was most relevant for older young carers who were more likely to be providing this kind of support in families. However, younger carers also expressed an interest in learning more about money. Likewise, support with life planning was also seen by young carers and parents to be valuable support, although this was most relevant for older young carers nearing independence.

Discussion and conclusion

The results of this study confirm those of other studies in that children and young people with caring responsibilities experience a range of both positive and negative outcomes as a result of these responsibilities, and that these outcomes are directly affected by the level of informal or formal support they receive. There are a number of factors that were found in this research that had an impact on the identification, support and experience of young carers. This qualitative study into the lives of young carers helps provide an up-to-date understanding of the current context of caring among children and young people at a key point in time, with the introduction of the new legislative framework (the Care Act 2014 and the Children and Families Act 2014).

The research found that:

- the issue of identifying 'hidden' young carers was illustrated by the challenges that were faced within this research in engaging children and young people not currently accessing support services
- given the challenge that exists in identifying hidden young carers it is crucial that all services working with vulnerable children and adults take a holistic approach to assessing need as is supported through the Care Act 2014 and the Children and Families Act 2014
- social care, health and education professionals have a crucial role in identifying and assessing the needs of young carers in order for suitable support to be made available
- the identification of need can be a particular challenge given parents and children remain concerned about the consequences of disclosing young caring in families. The result being children and young people with caring responsibilities, and their wider needs, can go unrecognised and unsupported
- early interventions are critical in ensuring that children do not take on inappropriate caring tasks; the need for children to provide care is increased when services to ill or disabled adults (or other family members) are inadequate, inappropriate or missing and when family based interventions are not provided
- practical, emotional and informational support helps young carers (and their families) to moderate the impact of their caring responsibilities and to prepare for adulthood. Where support for either the young carer or their cared-for parent/sibling is inadequate this can exacerbate the adverse emotional effects of caring among children and young people, particularly where accompanied by a lack of understanding of the parental/sibling condition(s); and
- while young carers and their parents highlighted the valuable role that young carers' projects play in providing young carers with a social and emotional outlet these should not be offered in place of or simply in the absence of other health, education and social care support.

A common theme throughout the research is the importance of early intervention and the critical role that *all* statutory services have in assessing and supporting families holistically. The findings from this study are congruent with the principles and guidance set out in the legislative framework. These principles promote the need for whole family approaches when working with young carers and their families as well as the need for professionals to consider young carers' needs not only as carers but *a/so* as children (see also Association of Directors of Children's Services, Association of Directors of Adult

Social Services, Children's Society and Carers Trust, 2015; and Department of Health, 2015). These findings are consistent with previous research and echo the ongoing need for raised awareness and understanding of the need for holistic, whole family approaches to needs assessments and support among all professionals.



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Reference: DFE-RB499

ISBN: 978-1-78105-556-4

This research was commissioned under the 2010 to 2015 Conservative and Liberal Democrat coalition government. As a result the content may not reflect current Government policy. The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

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