Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks?

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Historically, research about young carers has focused on defining the tasks and responsibilities undertaken by children caring for ill or disabled family members and the impacts of such care, without reference to the domestic and caring work undertaken by children and young people in families where there are only non-disabled or well members. This study presents new evidence of what children and young people generally do to assist in the home and examines how the lives of young carers differ from children and young people who are not carers. It concludes by examining the implications of these research findings for evidence-informed policy and practice. © 2006 The Author(s). Journal compilation © 2006 National Children’s Bureau.

Introduction

The past decade has witnessed a growing interest in, and awareness of, the nature, extent and impacts of caring on some children and young people in the UK. A wide range of research and evidence from practice now exists which identifies the specific experiences and needs of children and young people who provide care, assistance or support to another family member who has care needs, and the effects of caring when children and families lack appropriate care support. These children and young people, commonly referred to as young carers, undertake specific caring responsibilities that are implicitly perceived as being unusual. Whilst some degree of caring and household responsibility is to be valued and encouraged in childhood (Becker and others, 1998) as a reciprocal part of family life and as a beneficial training ground for good citizenship, the nature and extent of such responsibility need to be congruent with age and the level of physical development and emotional maturity. Research has suggested that many young carers are involved in exaggerated levels or types of caring which often impact negatively upon them (Becker and others, 1998).

Much of the qualitative and quantitative research in this field has focused on defining the tasks and responsibilities undertaken by young carers, and the impact that inappropriate levels of caring has on the well-being and development of these children and young people. A number of consistent findings have emerged with regard to young carers’ experiences and the nature of their caring roles and responsibilities. The research has shown that young carers usually undertake a wide range of responsibilities within the home, including domestic tasks, personal and intimate care, emotional support, general care and childcare (see, for instance, Aldridge and Becker, 1993, 1994; Bilsborrow, 1992). These care tasks are the same,
whether young carers live in a rural area or in the city (Frank, 1995). Changes have also been identified in the nature of the caring tasks performed by young carers over time (Dearden and Becker, 1995, 1998, 2004). Dearden and Becker’s national survey undertaken in 2003, for example, suggest that there has been an increase in the incidence of emotional support offered by young people over time and a continuing, if not small, decrease in the proportion of young people performing personal intimate care (Dearden and Becker, 2004).

Research has also highlighted that the nature and extent of children’s caring responsibilities, within a family context, are influenced by the interplay between a combination of factors: the nature and severity of the illness or disability of the person with care needs; the level and frequency of the need for care, including the degree of personal autonomy and independence of the person with care needs; the age, gender, ethnicity, co-residency, power and status of the young carer; the structure and socio-economic status of the family unit and the nature and effectiveness of informal and formal support networks outside the family (Aldridge and Becker, 2003; Dearden and Becker, 1998; Frank, 2002). In consequence, the type of caring tasks and duties undertaken by young carers and the level of responsibility that they assume for such tasks is likely to be determined by their individual circumstances as well as by social and other external factors (Aldridge and Becker, 2003).

If a ‘continuum of caring’ (Frank, 2002) exists within which all children and young people will fit somewhere, at what point can we differentiate between ‘conventional’ and ‘exaggerated’ levels or types of caring? Becker and others (1998) have suggested that the domestic and caring experiences of young carers are different from that of children in other households and that what is likely to set young carers apart from their peers is their limited ability to exercise choice in undertaking caring duties in the home and the performance of intimate or personal caring tasks, such as bathing, using the toilet or dressing. Much of the existing qualitative and quantitative research in this field, however, has focused on defining the tasks and responsibilities undertaken by young carers without reference to other children and young people in the population. In consequence, the types and levels of domestic and caring tasks undertaken by young carers, compared with other children and young people in the general population has, until recently, remained unknown. No baseline exists for establishing normal expectations of children’s help in running a household (Social Services Inspectorate, 1995) and there has been no comprehensive study to date to compare child domestic and caring responsibilities in families where there are disabled/ill and non-disabled/well members. This has led some academics to question whether young carers are, in fact, doing anything more, or different with respect to household work or caring responsibilities, than children from other households do (Olsen, 1996; Olsen and Parker, 1997; Parker and Olsen, 1995). In particular, Olsen (1996) has argued that existing knowledge about who young carers are, what they do and how their experience differs from that of other children who might be called ‘non-caring’ children, is extremely limited. He has pointed out the lack of awareness of the work that any children might perform in a household and the lack of consensus about what constitute reasonable levels of child involvement in domestic and caring tasks.

**Research method**

The research discussed here specifically set out to address the current lack of knowledge about the types of domestic and caring tasks undertaken by children and young people within the home and the levels of responsibility they assume for such tasks. The aim of the
research was to examine how the lives of children and young people who are known to adopt caring roles might differ from other that of children and young people in the general population who are not looking after someone who is sick or disabled.

Adopting a quantitative approach, the study used face-to-face structured interviews to survey 390 children and young people aged 9–18 years, to find out their perceptions of what they do to help at home. Using a style of cluster random sampling, specific areas of one unitary authority were identified that would generate a large sample of children and young people. Targeted areas included the grounds or vicinity of youth clubs, educational establishments, the town’s main shopping centre and local residential areas. Three hundred and seventy-eight children and young people were then randomly selected from the general youth population in these identified locations. A further 12 children and young people living in the same town were selected on the basis that they were known to be young carers. Nine of these young carers had formerly participated in a qualitative research study undertaken by the researcher. A further six young carers were referred by professional agencies, of whom only three agreed to participate.

It had been hoped that more known young carers could have been recruited as research participants. Whilst much existing research has recruited respondents via specialist young carer projects (Dearden and Becker, 1995, 1998, 2004; Shah and Hatton, 1999), no such project existed in the target area during 2001 and, as has been documented in previous research (see, for instance, Thomas and others, 2003), difficulties were experienced in identifying known young carers through the health, social and education agencies in the area. This was, in part, because professionals do not recognise children’s caring roles (see Aldridge and Becker, 2003) but also because young people and their families feared that professional intervention could lead to family separation (see Aldridge and Becker, 1993, 1994; Frank and others, 1999).

The majority of the 378 respondents from the general population were aged between 11 and 15 years, the average age being 12.5 years. Fifty-nine per cent of these children and young people were girls and 41 per cent were boys. Three-quarters of the sample were White European. The majority of these children and young people lived in households where there were at least two adults and where at least one adult was employed either full-time or part-time. In the main, the profile of the 12 young carer respondents mirrored the categories from the general population sample with some important distinctions. The majority of the young carers’ ages ranged from 11 to 15 years, the average age being 13.8 years. The gender division was predominantly female, with eight girls and four boys. Most were White European, although five of the young carers were from backgrounds of dual heritage, mostly White/Asian. Three-quarters of the young carers lived in lone-parent families exclusively with their mothers and two-thirds lived in households where no adult was employed.

A set of questions based on the social survey carried out by the Office for National Statistics (Walker, 1996) was designed for use with the general population sample of children and young people and the comparative sample of known young carers. The survey questions were presented in the form of a short questionnaire. The purpose of the questions was two-fold. Firstly, they were intended to establish the nature of domestic and caring tasks performed, the levels of responsibility undertaken for such tasks and the extent to which children and young people were able to participate in leisure and recreational activities. Secondly, they were intended to identify children and young people, within the general popul-
tion who did not look after someone or give special help to someone at home who was ill, had a disability or other special needs, and children and young people who did show some evidence of being in a caring role.

The interviews were conducted in the grounds or vicinity of educational establishments, youth clubs, the main shopping centre and local residential areas between July and November 2001. The duration of the interviews varied but their average length was approximately 6 min. In order to protect participant’s rights and welfare, the research was conducted within a principled framework, taking full account of anti-discriminatory and anti-oppressive practice issues (Humphries and Truman, 1994).

Participation was voluntary and potential respondents were assured that they could refuse to take part or withdraw from the research process at any point. The children and young people were given as much information as might be needed to make an informed decision about whether or not they wished to participate. The potential respondents were encouraged to enter into dialogue about the research, to ask questions and to reflect on the information given before proceeding with interviews. Consent to take part in the research was obtained from the children and young people and, where appropriate, from parents, educational and community establishments. Due regard was given to the participants’ privacy and dignity, and care was taken not to cause distress to the respondents. The researchers were aware of the need to convey respect and empathy for the participants’ circumstances, and of the importance of asking questions of an intimate and personal nature without showing or eliciting any signs of embarrassment. The pre-interview discussion with the respondents also focused on ways of saying no, so that in situations where participants might not wish to reply or comment on issues raised, or when they felt the need to stop the interview, they could do so more easily.

Overall, the fieldwork yielded substantial, reliable data essential to the development of new knowledge and understanding the types of caring undertaken by children and young people within the family. The standardised schedule of questions, consistently applied, ensured that interviewer-related error was kept to a minimum (Bryman, 2001) and although some respondents were critical of the overall length of the schedule, most appeared motivated to participate in the research. Statistical analyses of the data collected were undertaken using a quantitative data analysis computer software package (spss for Windows, 1999).

Key findings

The study provides new knowledge about what young carers do to assist in the home, how they feel about what they do and how their experiences differ from that of other children and young people who are not carers. It also reveals, unexpectedly, the existence of a group of children and young people who sometimes perform more domestic and caring tasks than known young carers. It is not my intention to explore this second finding here but, as has been discussed elsewhere, it is important to acknowledge that this subgroup of young carers remains unidentified in their caring roles and consequently, unsupported in the community (Warren, 2004).

In what follows, I will explore how the lives of young carers differ from that of other children and young people in the general population, particularly with regard to the nature, frequency and time spent on domestic and caring tasks.

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Domestic tasks

The research provides insights into the nature and extent of domestic work generally undertaken by children and young people, while also highlighting the extensive range of tasks performed by young carers over and above what other children and young people do to assist in the home. Children who do not assume caring roles most commonly tidy and dust their own bedroom and make light meals such as a sandwich but rarely, or only sometimes, perform other domestic tasks around the home. Overall, they spend less time on domestic tasks than young carers, with over half those interviewed spending less than two hours a week. In contrast, young carers undertake a variety of domestic tasks in and around the home, in addition to tidying and dusting their own bedroom and making light meals. Most commonly, they vacuum-clean other rooms in the home, lift or carry heavy things, cook the main family meals and clear away afterwards. They are also more likely than their peers to shop for food, wash and iron their own clothes and those of other people in the family and mow the lawn. They are far more likely to take full responsibility for these tasks and to spend much longer hours (over six hours) performing these tasks each week than other children and young people in the general population — some spend in excess of 26 hours a week (see also Dearden and Becker, 2004). In the absence of additional support both from within and outside the family, there was a clear need for young carers in this study to adopt this extensive range of routine domestic tasks. The extent of these responsibilities, however, appeared to reduce the young carers’ capacity to tidy and dust their own bedrooms as frequently as other children and young people in the general population. In consequence, taking care of their own space had to assume less priority for these young carers than other domestic tasks that might be considered more essential to the everyday running of the home, such as cooking main meals, clearing away afterwards or vacuuming communal areas.

General care and other tasks

The young carers that we spoke to are far more likely than other children and young people in the general population to undertake regularly a range of general care tasks including paperwork, financial matters, taking someone to see their general practitioner or to the hospital and providing childcare. They also spend much longer hours (over six hours) performing these tasks each week than their peers. In contrast, children and young people who do not assume caring roles perform fewer general care tasks and spend shorter periods of time offering such care. Over three-quarters of non-caring children spend less than two hours each week on general and other care tasks. However, while these children and young people rarely offer such care, when they do, they most regularly provide childcare, typically child-minding or babysitting their brothers and sisters.

Personal and intimate care

Of all the domestic and caring tasks undertaken by children and young people generally, it is the provision of personal and intimate care that most clearly distinguishes young carers from other children and young people who do not assume caring roles in the family. Young carers are more likely than their peers to perform regularly a range of personal and
intimate care tasks, including giving medication or providing other health-related care (such as injections and changing dressings), assisting with mobility (including helping to walk, get up the stairs or get in and out of bed), dressing and undressing, washing, bathing, showering, using the toilet, cutting nails or helping with eating and drinking. They also spend lengthy periods of time performing these tasks each week (over six hours) – some spending in excess of 26 h. In contrast, non-caring children and young people perform few personal and intimate care tasks; the majority (97 per cent) spending less than two hours each week on such care. When they do provide personal care, these children and young people are more likely to give medication or other related health care and to assist with dressing and mobility, rather than assisting with more intimate tasks, such as using the toilet, bathing or showering.

Emotional support

The research also highlights the high emotional investment made by young carers over and above what other children and young people in the population provide to family members. Emotional support, in this context, is defined as a diverse range of emotional caring tasks that are undertaken in response to a careful observation of the emotional state of the person with care needs, to help in building and sustaining their emotional well-being and, where necessary, providing supervision. These tasks include keeping someone company (such as sitting with them, reading to them or talking with them); keeping an eye on someone to make sure that they are all right and accompanying someone to social activities outside the home (visits to friends or relatives or taking them out for a walk). The research suggests that children and young people who are not carers provide substantially less emotional support than young carers; rarely or only sometimes keeping someone company, keeping an eye on them or accompanying them on outings. They spend shorter periods of time providing such support — the majority (84 per cent) spending less than two hours each week on emotional care tasks. In contrast, young carers are more likely than other children and young people to provide regularly a range of emotional support and to spend more hours each week on such support (over 3 h) — some spending more than 26 h/week. While in this study, the majority of young carers took full responsibility for keeping someone company or keeping an eye on them, only a third accompanied someone they lived with to see friends or relatives or took them out for a walk. Notably, where support and services were being provided to assist parents with their illness or condition, this appeared to remove the need for children to take responsibility for accompanying a family member outside the home.

Children and young people's feelings about caring

This study also provides insights into the attitudes held by children and young people in the survey with regard to the help that they give, and the ways in which young carers’ feelings about their caring role differ from that of children and young people who are not carers. The research suggests that young carers are far less likely than their peers to say that they dislike helping at home. They are, however, far more likely than non-caring children and young people to say that they should not have to help at home as much as they do, and are less likely to feel that they ought to offer to do more at home, particularly when they get older. These findings need to be understood within the wider research evidence which shows that
overall, young carers do more to help at home than non-caring children and young people. They spend more time helping and are more likely to have sole responsibility for domestic and caring tasks that are largely undertaken by adults.

**Impacts of caring**

In addition to providing evidence of how children and young people's domestic and caring experiences differ, the interviews reveal some of the effects of these different experiences on young people's lives. In particular, this includes the extent to which the caring tasks performed and the responsibilities assumed affect children and young people's attendance at school, their peers' responses to them, their capacity to socialise and engage in leisure and recreational activities and their aspirations for the future.

With regard to the effects of helping on children and young people's educational experience, the data show that whilst young carers are more likely than non-caring children and young people to miss school because of their caring roles, a large majority of young carers, in fact, do not miss school. This confirms earlier and ongoing research findings by Dearden and Becker (1998, 2004). Similarly, whilst young carers are more likely to be late for school than children and young people who are not carers because of the help that they give at home, most young carers are, in fact, nevertheless punctual for school. The research does, however, suggests that young carers are more likely than non-caring children and young people to report that other children make fun of them or bully them because of the help that they give at home. This bullying can be directly related to other children's knowledge of young carers' domestic and caring roles, their parents' illness or disability or the fact that young carers are perceived as being different and so may not be accepted by their peers. As Crabtree and Warner (1999) have stressed, young carers may have fewer social skills as a result of their minimal social life experience and may find it harder to make and sustain relationships.

The data also provide evidence of the impacts that different types and levels of caring have on children and young people's capacity to socialise and engage in leisure and recreational activities. Young carers are, for example, more likely than non-caring children to be prevented from participating in social and leisure activities by factors associated with their caring roles and familial circumstances, such as needing to help at home, looking after someone in the family, the financial costs of caring and problems with transport. When young carers do participate in leisure and recreational activities away from the home, these activities are more likely to be based at school than in other community groups. In contrast, children who are not carers participate in a range of social and leisure activities. They are more likely than young carers to undertake mainstream hobbies and interests, to participate in sporting activities or to join community or specialist interest groups, such as a youth club, a music group, the Brownies or Guides. Most of these children and young people are less frequently prevented from going out than young carers, and when the social lives of 'non-caring' children and young people are restricted, it is more likely because they need to complete homework.

Perhaps one of the most poignant findings of the research was in relation to young carers' perceptions of the effects of caring on their future lives and their awareness of the social and economic factors that are most likely to restrict their future choices.
the majority of children and young people hoped to further their education at college or university, young carers are more likely to identify a need to work in order to financially support their studies. As previous research findings suggest, young carers live in families that are among the most likely to experience poverty, disadvantage and social exclusion (Aldridge and Becker, 2003; Dearden and Becker, 2000, 2004). Young carers’ perceptions, therefore, appear realistic both with regard to their future material disadvantage and to its impact on their access to continuing education. Moreover, the data show that while many young carers directly choose to continue to live at home when they leave school, as a group, they are more likely than non-caring children to experience ambivalence about where they will live in the future. As other research (see Dearden and Becker, 2000) suggests, leaving home is especially problematic for many young carers, particularly if they have to leave a parent who requires help and support. Continuing to live at home, therefore, may be the only course of action open to young carers in the absence of support from elsewhere.

The lack of choice facing young carers and their families has been highlighted previously in *Children & Society* where attention has been drawn to the social and economic limitations that affect the real choices facing these children and their families (Olsen, 2000). My data show that young carers are more likely than other children and young people who are not carers to identify a range of barriers that might prevent them from fulfilling their future ambitions. In order of priority these include a lack of money, a need to look after a family member and a lack of qualifications. In contrast, children and young people who are not carers report that their future ambitions may be restricted, primarily, by a lack of money.

**Messages for policy and practice**

The nature, frequency and time spent by young carers each week on domestic and caring tasks differs from that of other children and young people in the general population. Young carers are a distinctive group who spend more time on domestic and caring tasks and take more sole responsibility for helping and caring within the home than other children and young people who are not carers. Professionals across education, health care, social services, community and youth services need to be alert to the possibility that children and young people may have caring roles. This requires greater awareness among professionals of the domestic and caring tasks undertaken by all children and young people, and the differences that exist with regard to the types and extent of care work undertaken by young carers, compared with non-caring children and young people.

The primary messages for professionals, policy-makers and planners emerging from this research are not new, and have been highlighted in research papers, articles, books and at conferences across the UK for a number of years. One issue that frequently arises in the literature is the lack of recognition among agencies of the work that young carers do and its effect on their lives (see, for instance, Aldridge and Becker, 2003; Aldridge and Wates, 2005; Dearden and Becker, 2004; Thomas and others, 2003; Underdown, 2002). Awareness-raising strategies and the multidisciplinary training of staff in health, education and social care agencies, therefore, still need to be developed and sustained if professionals are to recognise and respond effectively to family circumstances where young caring might occur. Moreover, if professionals are to prevent children and young people slipping through the net, there is a
need for early intervention to ensure that these children and their families receive services at the first onset of problems.

Messages for professionals in education

Teachers, pastoral staff, learning mentors, education welfare officers and connexions advisers have a clear role to play in the early identification of young carers. They are well placed to recognise and monitor the behavioural indicators (absenteeism, lateness, difficulties in completing homework, lack of concentration in class, friendship difficulties, limited time for social and leisure activities) that are associated with the onset of children’s caring roles and can clearly signpost children and their families to suitable support services.

These professionals also have a role to play in supporting parents to enable their children to reach their full educational potential. Those children and young people who miss school or are at risk of doing so because of their caring responsibilities need to be targeted so that specialist support services can be provided to them and their parents. Personalised packages of learning tailored to young carers’ individual needs, aspirations and talents need to be developed and closely monitored. Support systems including study support, lunchtime and after-school activities, on-the-spot-advice and counselling could also ensure that young carers receive personalised learning, care and support. Schools also need to involve young carers in the development of policies that specifically address their needs in relation to educational issues and codes of conduct by peers and staff.

Messages for professionals in youth and community work

This study has confirmed the particular value to young carers of a range of curricular and extracurricular school-based activities provided by education, youth and community services during lesson times, lunchtimes and after school. These professionals, therefore, have an important role to play in providing affordable, structured and unstructured community-based recreation and leisure activities that enable young carers to spend time away from their caring roles. Youth and community workers are also well placed to provide young carers with information and avenues for accessing other forms of support, including counselling, befriending or advocacy services and, where appropriate, enabling young carers and their families to access the practical and emotional support provided by specialised young-carer projects.

Messages for healthcare professionals

Health professionals including doctors, health visitors and district nurses are also well placed to identify young carers and to enable parents and children to access appropriate information, services and support networks. This demands effective communication among the relevant welfare professionals, the collection and sharing of information across service boundaries and the recognition by professionals of the need to refer children and families to partner agencies. The experience of this study suggests that it should be the responsibility of all professionals to work with families to try to overcome any obstacles – particularly parental reservations or fears – to the provision of support services.
Moreover, where the children's own physical or mental health may be at risk through lifting and carrying, or due to the worry, uncertainty or anxiety associated with a parent's illness or disability, it is important that health professionals ensure that these children's needs are identified early so that regular health screening can be put in place.

**Messages for social work and social care professionals**

Social services departments and their partner agencies need to be more proactive in recognising and identifying children and young people's caring contributions within the home. Intra-agency work between adult and children's services and inter-agency work across statutory and voluntary sector services are important in ensuring positive outcomes for families as a whole (Aldridge and Becker, 2003; Jones and others, 2002). Better co-operation and coordination of services are needed so that practitioners can develop a shared understanding of assessment processes and procedures; service thresholds that trigger intervention and of service eligibility criteria.

The Children Act (HM Government, 2004) provides the framework for enhanced co-operation between local partners through the integration of education, social care and health services, the co-location of multidisciplinary services within the community, the development of systems to ensure more effective sharing of information and the development of a common assessment framework to identify children's needs. The findings from this research indicate that such partnership arrangements could be particularly beneficial to young carers and their families in ensuring an integrated and consistent approach to identifying, assessing and addressing families' needs.

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