

## **Young carers: still 'hidden' after all these years?**

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### **Abstract**

*Although legislation and policy guidance within the United Kingdom provide a framework for intervention and good practice with young carers, children and young people caring for ill or disabled family members continue to remain 'hidden' or 'invisible' in our communities. This paper reports key findings from doctoral research which identify a group of children and young people within the population who have not been formally recognised in their caring roles nor formally assessed as young carers. It highlights, for the first time, the differences in the nature, frequency and time spent on caring tasks by this sub-group of carers, compared with known young carers and 'non-caring' children and young people. Indicating a high level of unmet need among parents and other family members who are ill or disabled, these findings have important implications for professional policy, planning and practice across adult and children's services. The paper concludes that greater professional awareness of the work that all children perform in a household, earlier intervention and effective collaborative practices could do much to ensure that children, young people and their families receive the services that they need.*

**Keywords:** Children, disability, research with children, young carers

### **Introduction**

Over the past thirty years, a combination of factors has made it more likely that children will take on caring roles. These factors include the de-institutionalisation of care, advances in medical care, reductions in family size, an increase in privatised family life-styles and the adoption of policies in the United Kingdom, which place emphasis on informal care within the community (Olsen, 1996). The development of legislation and policy guidance relevant to the needs of these children and their families has provided a framework for intervention and good practice which, in theory, should enable welfare professionals to define when and how to intervene to provide services and support to families. Much of the qualitative and quantitative research in this field, however, continues to highlight the failings of agencies to provide adequate support to these children and young people, commonly referred to as 'young carers'. In particular, the virtual invisibility of these children and young people, the ongoing lack

of recognition among agencies of the work that they do and the impacts of caring when children and their families lack appropriate care support, are well documented (see, for example, Aldridge & Becker, 2003; Cree, 2003; Thomas *et al.*, 2003).

Building on such literature, this paper seeks to highlight the experiences of a group of children and young people in the general population whose caring roles and responsibilities remain hidden. Drawing on findings from doctoral research undertaken in 2001, the paper presents a profile of this sub-group of carers: who they are, what they do and how their experience differs from other children and young people who do not adopt care-giving roles and those who are known as 'young carers'. This is the first study to provide a three way perspective of children and young people's care-giving, as shown in Figure 1. The study suggests that children and young people who show signs of being in a caring role are potentially more vulnerable than *known* young carers, in that they do not appear to have been formally

recognised in their caring roles, nor formally assessed as young carers. Unidentified and unsupported, children's voices continue to be unheard, and their care-giving remains as hidden today as it did in 2001 (see Barnardo's, 2006). It is hoped that the findings presented in this paper will be of practical use to a range of professionals working in children's and adults' services, informing developments in policy, practice and research, for the benefit of young carers and their families.

## Background

### *Why do young carers remain 'hidden'?*

Previous research and practice guidance have suggested a number of reasons why young carers' contributions to family life in the United Kingdom remain 'invisible' and their needs unmet. There can be a lack of recognition of the child's role as a caring one by both the child and parent (Aldridge & Becker, 1993). There may also be reluctance, by family members, to admit to the presence of a child carer within the family, for fear of professional interventions that might lead to family separations (Bilsborrow, 1992; Aldridge & Becker, 1994). The perceived stigma associated with

alcohol misuse, HIV/AIDS, mental illness or caring more generally, particularly among young black and South Asian carers, may also affect families' openness about child care-giving (see, for example, Imrie & Coombes, 1995; Shah & Hatton, 1999; Aldridge & Becker, 2003). Significantly, the lack of recognition among professional workers about young caring as a welfare issue, combined with the ongoing lack of awareness among professionals of the potential for children and young people to assume caring roles, can result in failure by many professionals to recognise the potential 'triggers' for young caring (Aldridge & Becker, 2003). Furthermore, the myths and racial stereotypes associated with black and South Asian communities, which may lead some professionals to assume that, because of extended family networks, families 'take care of their own' (Shah & Hatton, 1999), combined with the discrimination and institutional racism experienced by black and minority ethnic families in accessing education, social and health services (Shah & Hatton, 1999; Jones *et al.*, 2002) are also impacting on professional recognition and identification of young carers.

## Figure 1 Classification of children and young people's care-giving

- **'Non young carers' ('non-caring')** - children and young people who do not look after, or give special help to someone at home who is ill, has a disability or other special needs. They undertake low levels of domestic and caring tasks considered appropriate for their age and level of maturity.
- **Known young carers** - children and young people who have been formally identified and recognised in their care-giving roles. They undertake a range of domestic and caring responsibilities which vary in amount, regularity, intensity and duration according to the context of care, and most importantly, the nature and effectiveness of services and support available from outside of their family (see Becker *et al.*, 1998).
- **Children 'showing signs of caring'** - children and young people who look after, or give special help to someone at home who is ill, has a disability or other special needs, and who undertake a range of caring responsibilities that are sometimes as substantial or more significant than known young carers, but who appear not to have been identified or recognised in their caring role.

*How many young carers are there in the United Kingdom?*

Historically, the hidden nature of child caring has precluded definitive conclusions about the extent of young caring in the United Kingdom. The 2001 Census (ONS, 2003), which presents the most accurate figures available to date on the numbers of children providing unpaid care within their family, shows that nationally 174,997 children and young people aged under 18 are carers (ONS, 2003), of whom 149,942 live in England and Wales (Becker, 2004). These statistics also show that more than 13,000 of these children are providing more than 50 hours a week of unpaid care (Becker, 2003) - longer than the adult maximum working week. Whilst these data are helpful in revealing what is known about the extent of unpaid caring for family members within the United Kingdom, concern has been expressed by academics and practitioners that many more vulnerable children and young people, not accounted for within these statistics, continue to provide care to family members without the services and support that they need (Barnardo's, 2006; Carpentieri, 2006). A recent survey of 83 young people aged 6-19, all of whom were supported by Barnardo's young carers' projects, revealed that on average each young carer had spent four years looking after a relative or parent before they received any support (Barnardo's, 2006), highlighting the extent to which children remain unidentified and unsupported in our communities.

*Defining children as 'carers'*

Over the past two decades, the social construction of children and young people as 'young carers' has helped to focus thinking on what might be considered 'normal' or 'appropriate' involvement of children and young people in domestic and caring work. This has led some academics to question whether children with caring roles do, in fact, do anything more or

different, with respect to household work or caring responsibilities, than other children and young people living in families where there are only non-disabled or 'well' members (Parker & Olsen, 1995; Olsen, 1996; Olsen & Parker, 1997). This lack of knowledge about the help that is provided by all children and young people in running a household, and the lack of consensus that has continued to exist with regard to differentiating 'normal' and 'inappropriate' levels of child involvement in domestic and caring work, provided the impetus for the research upon which this paper is based.

**Research methodology**

The research aimed to examine how the lives of children and young people who are known to adopt caring roles differ from other children and young people in the general population who, on the face of it, are not looking after someone who is sick or disabled. The intention was to provide quantitative data on the types and levels of domestic and caring tasks undertaken by 'non-caring' children and young people within the home, and then to compare and contrast these experiences with those of children and young people who were known to adopt caring roles.

A short, structured questionnaire, based on the social survey carried out by the Office for National Statistics (Walker, 1996), was designed for use in face-to-face interviews. A series of closed questions with multiple choice or scaled responses was used to seek specific information about: children and young people's perspectives on the nature of domestic and caring tasks performed; the levels of responsibility undertaken for such tasks; the extent to which they were able to participate in leisure and recreational activities, and their feelings about helping at home.

One fundamental definitional question which had to be addressed at the outset of the interview, centred on the need to

distinguish between ‘non-caring’ children and young people, and other children and young people in the general population who might show evidence of being in a caring role. Aware that children and young people do not necessarily think of themselves as ‘young carers’, a question was formulated that invited all children and young people to identify whether they looked after someone, or gave special help to someone at home who was ill, had a disability or other special needs. This question was important in helping to differentiate between those children and young people who lived in families where there were:

- non-disabled or well members;
- disabled or ill members who *did not* require their child(ren)’s assistance with care needs; and
- disabled or ill members who *did* require assistance with care needs from their child(ren).

These distinctions about the context of family care were important, for it was this willingness to listen to children and young people’s own viewpoints about definition and perception of their caring roles which, ultimately, generated the most striking and unexpected finding from the research study.

Data collection took place between July and November 2001 and was conducted within a principled framework that took full account of diversity and equality issues. Assistance was sought, for example, from indigenous community consultants and advisory groups regarding cultural needs, including religious festivals that might affect when, and how, the research was conducted. Consent to undertake the research was obtained, where appropriate, from a wide range of adult gatekeepers including head teachers, youth club managers, shopping centre managers and parents, before contact was made with children and young people. All respondents were informed that participation was entirely voluntary and that they could withdraw at any time during the interview.

Respondents were not asked for any personal details that could identify them in any way, and due regard was given to the participant’s privacy, dignity, rights, safety and well-being during the interview process.

### Research sample

Overall, a sample of 390 children and young people, aged between 9 and 18 years, was interviewed to find out their perceptions of what they do to help at home. Using a form of cluster sampling, 378 of these children and young people were randomly selected from the general population found in targeted areas of a unitary authority, including the grounds or vicinity of educational establishments, youth clubs, the town’s main shopping centre and local residential areas. An urban area of multiple deprivation, this authority has districts which have been ranked within the top 10% and 20% of all Super Output Areas (SOA) nationally (ODPM, 2004) and is one of the most ethnically diverse local authorities outside of London (ONS, 2003). A further 12 children and young people were selected on the basis that they were known, by education welfare and social services, to be young carers living in the same unitary authority. The lack of any specialist young carer project in the target area in 2001 and the lack of recognition of children’s caring roles generally among local health, social and education agencies, created difficulties with regard to identifying and recruiting a larger sample of known young carers.

Of the 378 children and young people from the general population sample who participated in the survey, 59% were female and 41% were male. Their ages ranged from 9-18 years, the majority (43%) being of secondary school age (11-15 years), with an average age of 13 years. Three-quarters of respondents described their ethnic origins as white European. The majority of children and young people who participated in the survey lived with at least two adults (84%) and in households where at least one of

these adults was in full or part-time employment (92%). Interviews were also conducted with 12 known young carers, 8 of whom were female and 4 were male. Their ages mirrored that of the general population sample, ranging from 9-18 years, the majority (8) falling within the secondary school band, with an average age of 14 years. Whilst most of these children and young people were white European, 5 young carers were from backgrounds of dual heritage, mostly white/Asian. However, in contrast with the general population sample, 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.

### Data analysis

Statistical analyses of the data collected were undertaken using a quantitative data analysis computer software package (SPSS for Windows, 1999). From the randomly selected sample, it became possible to categorise respondents into two groups: 'non-caring' children and young people, and children and young people who had defined themselves as looking after or giving special help to someone at home who was ill, had a disability or other special needs. This allowed analysis of the caring tasks and responsibilities undertaken by 'non-caring' children and young people, *known* young carers and those children and young people showing signs of being in a caring role, together with the effects of these experiences on children and young people's lives.

### Key findings

Whilst the research provided new knowledge about who young carers are, what they do and how their experience differs from other children and young people in the general population (see Warren, 2007), perhaps the most striking and unexpected finding was the existence of

a group of children and young people in the population who showed some evidence of being in a caring role through the provision of a range of domestic, personal and intimate caring tasks to family members. This group of children and young people, because their roles and responsibilities remained 'hidden', appeared not to have been identified in their caring roles, and were subsequently unsupported in the community.

### *How many 'hidden' young carers?*

Of the 378 children and young people who were randomly selected for interview from the general population sample, 34 (9% of the total sample) identified themselves as looking after or giving special help to someone at home who was ill, had a disability or other special needs. This unexpected finding has more recently been replicated by the Princess Royal Trust for Carers (PRTC, 2004). In an unpublished study of the experiences and views of a representative sample of over 1300 children and young people aged 7-19, the Princess Royal Trust for Carers found that around 12% of these young people showed signs of performing caring tasks within the home (PRTC, 2004). Together, these two pieces of research provide strong evidence to support the view that the 2001 Census data is likely to undercount the true number of young carers in the United Kingdom.

### *A profile of the 'hidden' young carers*

Fifty-nine percent of the children and young people in this survey who showed signs of being in a caring role were female and 41% were male. Their ages ranged from 9-18 years, the average age being 13 years. Just over half (59%) described their ethnic origins and background as black/black British, Asian/Asian British or dual heritage, the largest minority group being Asian/Asian British (44%). This may reflect cultural expectations expressed by extended family members in South Asian

communities regarding young people's duties to adopt caring roles (Shah & Hatton, 1999). The majority (91%) 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 (76%).

*What roles and responsibilities do these children undertake?*

Two main findings emerged from the research relating to the nature and extent of domestic and caring tasks undertaken by those children and young people who showed signs of adopting care-giving roles. First, this group of children and young people undertook a similar range of tasks in and around the home to those children and young people who were known to be young carers, which included domestic, general care, personal and intimate care, and emotional caring responsibilities. Moreover, the nature of these caring experiences and the level of responsibility assumed by these 'caring' children for such tasks, differed

from the experiences of other children and young people in the general population who were not carers. For example, as shown in Table 1, young carers and young people showing signs of caring were more likely than 'non-caring' children to tidy, dust and vacuum-clean communal areas of the home, wash their own clothes, wash and iron clothes for other people in the home, weed and maintain the garden and mow the lawn. They were also likely to perform such domestic tasks more frequently than 'non-caring' children and spent longer hours on these tasks each week. Overall, less than a third of those interviewed who showed signs of being in a caring role, spent under two hours a week on domestic tasks, compared with over half of 'non-caring' children and young people. Children and young people who did not adopt caring roles, rarely, or only sometimes, performed such tasks, spending shorter periods of time each week on chores such as tidying and dusting their own bedroom and making light meals such as preparing a sandwich.

**Table 1** Examples of some domestic tasks undertaken by non young carers, young people showing signs of caring and known young carers

	<b>% of non young carers</b> <b>n=334</b>	<b>% of young people showing signs of being in a caring role</b> <b>n=34</b>	<b>% of known young carers</b> <b>n=12</b>
Tidy/dust own bedroom	94	94	92
Make light meals	91	94	92
Vacuum clean communal areas	71	79	92
Tidy/dust communal areas	70	82	83
Iron own clothes	53	65	83
Weed/look after the garden	45	59	50
Mow lawn	36	47	58
Iron clothes for other people in household	34	59	50
Wash own clothes	28	47	50
Wash clothes for other people in household	20	32	42

n=390 Percentages are rounded to the nearest whole number.  
N.B. 378 children and young people were randomly selected from the population, of whom 334 were 'non young carers', 34 defined themselves as being in a caring role and 10 didn't know whether they looked after or gave special help to someone at home with an illness, disability or other special needs. A further sample of 12 young people were identified as 'known young carers' by professionals.

The data also showed that young carers and young people showing signs of caring were more likely than ‘non-caring’ children and young people to undertake regularly general care tasks such as paperwork, taking someone they lived with to visit their General Practitioner (GP) or hospital, and interpreting or signing for someone that they lived with. They also spent longer hours (over 3 hours) on these tasks each week than ‘non-caring’ children and young people.

Similarly, these groups of ‘caring’ children were more likely than ‘non-caring’ children and young people to give emotional support, such as ‘keeping someone company’, ‘keeping an eye’ on them to make sure that they were alright, or accompanying someone to social activities outside of the home (including visits to friends or taking them out for a walk). They also spent longer hours on emotional care tasks each week than other children and young people in the general population. Approximately 15% of children and young people who were not carers spent in excess of two hours per week on emotional care tasks, compared with over half of those young people showing evidence of being in a caring role, some of whom spent up to 15 hours per week.

Second, the research also highlighted that children and young people who showed signs of being in a caring role, sometimes performed more tasks and took full responsibility for these tasks more frequently than either known young carers or ‘non-caring’ children and young people. As shown in Tables 2 and 3, this group of young people performed more tasks of an intimate and personal nature such as giving assistance with washing, bathing, showering or using the toilet, and by giving medication, injections or changing dressings, than either young carers or ‘non-caring’ children and young people, and were more likely to take full responsibility for these tasks. This sub-group of young carers were also more likely than known young carers or ‘non-caring’ children, to provide child care (looking after brothers or sisters) or emotional support by, for example, ‘keeping an eye’ on the person with care needs. In fact, almost two-thirds (65%) of these young people accompanied the person with care needs to visit friends or relatives, or took them for a walk, compared with one third (33%) of known young carers in the study.

**Table 2** Personal care tasks undertaken by non young carers, young people showing signs of caring and known young carers

	% of non young carers	% of young people showing signs of being in a caring role	% of known young carers
Help to walk, get upstairs, get in and out of bed	9	56	25
Give medication	16	53	42
Help to dress/undress	9	51	25
Help to wash	6	44	25
Help to bath or shower	7	35	17
Help to cut nails	5	29	17
Help to eat and drink	4	27	17
Help to use toilet	4	24	25
Help to shave	1	12	0

**Table 3** Frequency of personal care tasks undertaken by non young carers, young people showing signs of caring and known young carers

	% of non young carers		% of young people showing signs of being in a caring role		% of known young carers	
	Always	Mostly	Always	Mostly	Always	Mostly
Help to dress/undress	0	2	12	9	0	8
Give medication, injections, change dressings	1	0	12	6	0	8
Help to walk, get upstairs, get in and out of bed	0	<1	6	12	8	8
Help to bath or shower	<1	1	6	12	0	17
Help to eat and drink	0	<1	6	6	0	0
Help to use toilet	<1	0	6	6	0	0
Help to wash	<1	0	3	18	0	25
Help to cut nails	0	1	3	6	0	0
Help to shave	0	0	3	0	0	0

Although an explanation for this needs to be tested by further research, these findings suggest that the families of children and young people showing signs of being in a caring role may not be receiving the support needed to allow them to reduce their reliance on their children, with regard to the provision of emotional support and personal and intimate care tasks. Where adequate support and services were provided to assist parents with their illness or condition, the need for children to take responsibility, for example, for accompanying a family member outside of the home, appeared to be removed (Warren, 2007).

*What support do these children and young people receive?*

Overall, the research findings indicated that young people showing signs of being in a caring role were supported by fewer health and social care services than households with young carers. Only one in ten of these households appeared to access the support and services of social work and social care professionals. Many of these young people, for example, gave assistance with washing, bathing or showering, without the services and support of a social worker, home care agency or community/district nurse. In

contrast, in this study no known young carers, living in households with regular social work contact, undertook comparable intimate care tasks. Similarly, young people showing signs of caring undertook full responsibility for a range of domestic tasks without the additional support of a home care agency or cleaner. These findings suggest that this group of children and young people is particularly vulnerable, as their families appear less likely to have contact with a social worker who might otherwise assist them to access appropriate community care services, thereby reducing or preventing altogether the need for these children and young people to adopt caring roles.

Whilst research indicates that nationally around 18% of young carers have been assessed under legislation and the proportion of young carers providing personal and intimate care has decreased from 21% (in 1997) to 18% (in 2003) (Dearden & Becker, 2004), the findings from this study suggest that many other young carers may be undertaking less intimate and personal care tasks than those young people who show evidence of being in a caring role. If this sub-group of children and young people are not identified and

defined by professionals as young carers, and their parent(s) do not receive services to assist them with caring, then they could be potentially in a worse position than known young carers with regard to some kinds of care tasks. Existing research has demonstrated that such caring roles can have negative outcomes for children and young people's psycho-social development and transitions into adulthood (Dearden & Becker, 2000).

### **Messages for policy, practice and research**

Up to 9% of children and young people in the general population may be showing signs of being in a caring role. This suggests that in a UK population of approximately 11.66 million dependant children (ONS, 2004), up to 1.05 million may provide care that remains hidden. The study shows that many of this sub-group of young carers appear to be from black and Asian backgrounds (59%), which suggests that in the UK, where approximately 1.45 million dependant children are from black and minority ethnic backgrounds (ONS, 2004), as many as 619,000 of these children and young people may be undertaking caring roles and responsibilities that remain hidden and unrecognised. Given that the proportion of children from black and minority ethnic backgrounds in the sample population is approximately 25% compared with 12% of the population as a whole, this figure is more likely to fall within the range of 309,000 to 619,000. Clearly, this is an area that requires further investigation and no claims are made that these findings can be generalised more widely. However, this sub-group of young carers is potentially more vulnerable than *known* young carers in that, because they have not been recognised, nor formally assessed in their caring roles, they continue to provide a range of domestic, social, emotional, intimate and personal care tasks to family members who are, themselves, less likely to access the services and support of health and social

care professionals. This suggests that the extensive network of young carer projects that exists currently within the United Kingdom could potentially be working at the less 'severe' end of 'young caring', which, in turn, poses challenges for health and social care agencies in both the statutory and voluntary sectors.

A very clear role exists for social workers, their organisations and their partner agencies in promoting a more proactive response to the recognition and identification of children and young people who show signs of adopting caring roles. Greater awareness is needed by professionals of the work that all children and young people perform in a household, including the levels of child involvement in domestic and caring tasks, so that those children and young people showing signs of caring can be recognised and identified in their caring roles. Any child who has been recognised and identified as a 'young carer' can then be assessed either as a 'child in need' or in some cases as a carer requiring professionals to use the legislative and policy framework to meet the needs of the child and their family. Early social work intervention is, therefore, crucial in ensuring that these children and their families receive appropriate services at the earliest opportunity.

The current moves to integrate education, social and health care services in the United Kingdom could prove particularly beneficial to families where children's caring roles remain hidden and unrecognised. As 'children in special circumstances' who often remain 'invisible to the system' (DoH, 2004) and whose needs are not always fully recognised by staff working in the statutory sector, these children and young people require a high level of co-operation between staff in different agencies. The development of an integrated, consistent and co-ordinated approach is, therefore, important in identifying, assessing and meeting the needs of families where children's caring roles

remain unsupported. Multi-disciplinary training of staff in health, education and social services needs to be developed and sustained to equip professionals to recognise and respond to these families' circumstances. Better co-operation and improved co-ordination of services is needed to ensure that families receive services at the first onset of problems so that children and young people showing signs of caring are not obliged to take on inappropriate levels of responsibility. Other ongoing developments will also be important in ensuring that children and their families receive the services and support that they need. These include: the development of multi-agency practice guidance to help in recognising situations where children may be caring; the development of protocols for information sharing; the embedding of the national Common Assessment Framework (DfES, 2005) to identify children's needs early, and the development of a more systematic approach to improving access to multi-disciplinary, community-based services. To this end, services and support which are co-ordinated around individual and family needs, and which take account of children and young people's views, are important in enabling professionals to respond to these children and young people, both in relation to their role as carers and to their needs as children.

Finally, we need to know far more about this 'hidden' group of 'caring' children and young people and how their needs and experiences may differ from known young carers and other young people in the population. In particular, we need to know more about the specific needs and experiences of black and minority ethnic communities whose families do not access professional support and services - why these children and young people become young carers and how support and welfare services can respond more effectively to their families' needs. Further research with this 'hidden' group of young carers and

their families has an important part to play in informing the future direction of policy and practice.

### Acknowledgements

Sincere thanks are due to Professor Saul Becker, University of Nottingham, who supervised this research and kindly provided informal advice on the preparation of this paper. Thanks also to Dr Caroline Currer and an independent referee for their helpful comments on an earlier draft of this article.

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### **Notes on Contributor**

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