

# Statistical Profiles of Young Carers

## A report on the first two Young Carers Research Group's (CCFR) quantitative surveys of young carers

### Summary

In 1995 the first ever quantitative survey of young carers was undertaken. The survey included data about 641 young carers, supported by 36 designated projects across Britain. In 1997 the survey was replicated. By this time there were more support projects for young carers and data were collected about 2303 young carers from 69 projects.

These two surveys enabled researchers for the first time to statistically analyse data such as age, ethnicity, caring tasks, cared for person etc. Prior to this the 'invisibility' of young carers meant that previous research had been small-scale and qualitative in nature.

- The young carers in both surveys ranged in age from two to 18 years, the average being 12. There were only slight differences in the distribution of age between 1995 and 1997: those in the 5-10 age range increased from 28 to 32%; those in the 11-15 range increased from 50 to 54%. Analysis of the 1997 data indicates that the likelihood of children being involved in domestic chores and general and intimate care increases with age. For emotional support and child care, the differences relating to age were less marked.
- Between 1995 and 1997 the gender division became more equal: in 1995, 61% of the sample were girls, by 1997 this was 57%. Further analysis of the 1997 data confirms that girls are more likely to be involved in all aspects of care, particularly in relation to domestic chores and intimate care – those tasks traditionally associated with women.
- In 1995, 90% of the sample was white; in 1997 this had reduced to 86%, suggesting that projects were beginning to make more contact with black and minority ethnic carers. However, some projects do not support any young carers from minority ethnic communities, while others, notably those in London boroughs, support a high proportion of black and ethnic minority carers.
- Both surveys indicate that the majority of young carers live in lone parent households: 60% in 1995 and 54% in 1997. Furthermore, most care for ill or disabled mothers. Since the incidence of lone parent families is increasing and most are headed by women, caring by children is also

likely to increase if the lone parent becomes ill or disabled.

- Most care recipients had physical health problems or disabilities (60% in 1995, 57% in 1997), some had mental health problems (29% and 25%), learning difficulties (6% and 11%) and sensory impairment (4% and 3%). The nature of the illness/disability of care recipients dictates, to a certain extent, the caring tasks performed by children. For example, intimate care is most closely associated with physical illness/disability whereas emotional support is more common when caring for someone with mental health problems.
- Many young carers miss school as a result of their caring responsibilities. Some also have other indicators of educational difficulties such as receipt of educational welfare services, educational psychology services, additional educational support or are referred to projects by educationalists because they need additional support. Although there were some improvements between 1995 and 1997, educational difficulties remain an important, negative aspect of young caring. In the 5-10 age group 17% were experiencing educational problems (20% in 1995); in the 11-15 range the figure was 35% (42% in 1995). Overall, of all school age children, 28% had indicators of educational difficulties, a slight improvement on the 33% recorded in 1995.
- Between the two surveys the Carers (Recognition and Services) Act 1995 came into force. Data were therefore collected on children assessed either under this piece of legislation, or under the Children Act 1989 for the 1997 survey. In total only 11% of children had been assessed under either piece of legislation.
- In 1995 a fifth of the young carers and their families had no outside support services other than the young carer project. By 1997 this had increased to a quarter.
- In 1995 10% of young carers were caring for more than one person. By 1997 this had risen to 12%.

## Project aims

The aim of the surveys was to provide a more detailed statistical analysis of young carers around the UK. Previous research had, of necessity, been small scale and qualitative and was therefore unable to generalise about other young carers. Many questions remained regarding, for example, the average age of young carers, the gender breakdown, who they were caring for and why. Only a large scale quantitative study could provide these types of data. An additional aim of the 1997 survey was to investigate the number of young carers who were being assessed under legislation intended to protect them and to promote their well-being. The surveys add to our knowledge of young carers' issues and complement the various estimates of the numbers of young carers nationally (see Box 1).

## Methodology

The samples for both surveys were drawn from Young Carers Projects around Britain. All such projects were asked for information and the response rate was 93% in 1995 and 80% in 1997. Cooperating projects were asked to provide data for each child supported by them. This included age; gender; ethnicity; family composition; relationship to person cared for; nature of illness/disability; caring tasks undertaken; whether in compulsory education and, if so, whether missing school as a result of caring responsibilities; other people in household; services received (by the whole family as well as the young carer); source of referral to the project; and, in 1997 only, whether they had been assessed and if so under which piece of legislation.

In addition to collecting this statistical data, a small number of young carers were interviewed to gain further insight into their own feelings and experiences of providing care to a family member. In the 1995 survey nine young carers were interviewed; in 1997, 22 young carers were interviewed, half of whom had received a formal needs assessment.

## Understanding caring – what children do

Young carers undertake a range of tasks from basic, domestic chores, such as washing dishes, cleaning, making drinks, cooking etc.; through general caring tasks, such as assisting with mobility, giving medication etc.; intimate personal care, such as bathing and assisting with toileting; emotional support; and providing child care for younger siblings. Some also provide additional assistance such as translating, doing administrative tasks, managing the household budget, paying bills etc.

Most young carers perform domestic chores – 65% in 1995, 72% in 1997 – although this is also influenced by the nature of illness/disability of care recipients. In 1997, 71% of those young people caring for someone with physical health problems or disabilities performed domestic tasks compared to 49% of those caring for someone with learning difficulties. General caring tasks were performed by 61% in 1995 and

57% in 1997, but again this was statistically more likely when caring for someone with physical health problems and less likely when caring for someone with mental health problems or learning difficulties. Intimate, personal care tends to be associated with physical health problems. In 1995, 23% and in 1997, 21% of young carers were providing this type of care – that found least desirable by parents and children alike. Further analysis of the 1997 data indicates that 26% of those caring for someone with a physical illness provide this type of care, compared with just 9% of those not caring for someone with these problems. Emotional support, however, is statistically much more likely where the care recipient has a mental health problem. Overall 25% in 1995 and 43% in 1997 provided this type of support, but when we concentrate on just those young people caring for a relative with mental health problems the figure becomes 62% (in 1997).

## Support services

One in five young carers and their families received no outside support services in 1995 other than their contact with a young carer project. By 1997 this figure had reached one in four. Clearly this lack of outside services has an impact on the level of care provided by children. Social work support was the most commonly received service, received by half the sample in 1995 and 47% in 1997. Although this represented a slight decrease, receipt of other services increased over the period: homecare increased from 14% of total service receipt in 1995 to 16% in 1997; respite from 5% to 9%; community psychiatric nurse provision from 5% to 7%; and visiting nurses (including district nurses, health visitors and Macmillan nurses) from 5% to 9%. The incidence of educational support and educational welfare services remained unchanged and accounted for 5% of all services provided despite such a high proportion of young carers showing signs of educational difficulties.

## Understanding caring – why children care

The main reason why children undertake inappropriate caring roles is a lack of adequate support services for their ill/disabled relatives. If appropriate and adequate support services are not provided, most of the care and support required falls to family members. If a lone parent requires support, then there is no other adult available to adopt the role of carer and caring falls, by default, to other family members, including children. However, even where there is another adult in the household this does not preclude children from adopting this role. In families where a mother is ill/disabled, a father may well continue to work full-time to provide the family with an income, thus relying heavily on children to provide care and support.

In the absence of adequate social care support, there is a complex interplay between several factors that determine how and why some children become carers. As indicated above, family structure is a significant determinant. Where

there is more than one child 'available' to care, or children of both sexes, then choices, preferences and family norms will be important.

The 1997 survey demonstrates that the likelihood of children being involved in all aspects of care (apart from supporting younger siblings), increases with age. This was not as apparent in the smaller survey of 1995, with the exception of 16-18 year olds who were more likely to provide intimate, personal care. In some ways this conforms to social norms: we would expect children to take on additional responsibilities as they mature, in preparation for adult life and independence. However, most young people would not be expected to provide intimate care to a parent, or to be giving injections and other medications. Furthermore, the gradual adoption of tasks tends not to happen where children have caring roles – they are more likely to take full, significant or substantial responsibility for tasks at an earlier age, rather than to extend them more slowly.

## Assessing young carers' needs

When the 1995 survey was conducted, the Carers (Recognition and Services) Act 1995 had not been fully implemented. The Act allows for the carer's needs to be assessed when the person requiring support is assessed or reassessed under community care legislation. The Act encompasses all carers regardless of age. The Children Act of 1989 also makes provision, under section 17, for the assessment of children in need – a category into which many young carers fall. During the 1997 survey data were therefore collected relating to young carers' assessments under either Act.

Just 11% of the young carers in the 1997 survey had received some form of assessment. Of those who had been assessed, 43% were assessed under the Children Act, 35% under the Carers Act, 9% under both Acts and in 12% of cases it was not known which Act had been used. Comparisons between those children who had been assessed and those who had not showed no clear differences in relation to age, gender, ethnicity and, surprisingly, tasks undertaken.

There were, however, some indicators that were associated with a greater likelihood of assessment. Overall, young carers caring for someone with mental health problems were more likely to receive an assessment and this was more likely to be under the Children Act. 14% of carers from lone parent families had been assessed compared with 8% in two parent families. Those who had indicators of educational difficulties were almost twice as likely to receive an assessment. Although assessments were rarely conducted, when they were they did result in positive outcomes, usually with an increase in services or the introduction of services where there had previously been none. More worryingly, young carers seemed unaware in some cases that they had been assessed at all, and the process of assessment varied widely from good to poor.

## Implications for policy

The surveys raise many points for policy and practice. Definitions of young carers need to be broad and inclusive and terms such as 'regular and substantial care' (as used in the Carers Act) should not be used to prevent children from being assessed. Professionals need to look at the impact of caring on children, in addition to the extent.

Awareness-raising continues to be necessary, not only within social care agencies, but also in education and health, to include GPs, nurses and teachers.

Professionals need more knowledge of the ways in which children in some families are drawn into adopting inappropriate caring roles. While illness/disability may trigger this, there is also an interplay between other factors such as age, gender, ethnicity, family norms, values and customs. However, the critical factors are the provision, or lack of provision, of adequate support services to ill and disabled people and low income within these families.

Support for the whole family is critical. Neither the child nor the ill/disabled family member can be considered in isolation since support services need to meet disabled parents' parenting needs, in addition to their health and social care support needs, if their children are to be enabled to develop fully. Professionals need to acknowledge, value and respect the reciprocal and interdependent nature of caring within families.

Too few young carers are receiving an assessment of their needs and the process of assessment is variable. Parents and children need to be made aware of their rights under various pieces of legislation and be more actively involved in the assessment process.

National standards for the quantity and quality of support services are required to ensure that young carers and their families are assessed and receive appropriate and adequate help based on need rather than geographic location.

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- The Young Carers Research Group (YCRG) is now part of the Centre for Child and Family Research (CCFR)

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- The Calouste Gulbenkian Foundation, The Gatsby Charitable Foundation and Carers National Association (1997)

## Where to find more evidence

**Dearden, C. and Becker, S.** (1995) *Young Carers – The Facts*, Sutton: Reed Business Publishing.

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The CCFR will be conducting a third national survey of young carers in contact with projects in 2003.

Full details of other outputs can be found in the CCFR brochure or on the website: [www.ccfrr.org.uk](http://www.ccfrr.org.uk)

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### Box 1: What we know about numbers from other studies

Findings %	Numbers involved	Numbers involved
23% of children aged under 16 live in families with one family member 'hampered in daily activities by any chronic physical or mental health problem, illness or disability'	Approximately 3 million children under 16 live in families with illness/disability in the UK	Eurostat, 1997 (Becker <i>et al.</i> , 1998)
Between 0.27% and 0.72% of all 8-17 year olds will be young carers	19,000 – 51,000 young carers (aged 8-17) in Britain	Office for National Statistics (Walker, 1996)
4% of all 18-24 year olds will have regularly cared for an ill or disabled relative during their own childhood	173,040 young people aged 18-24	NSPCC (Cawson <i>et al.</i> , 2000; Cawson, 2002)
17% of carers aged 16-35 had caring responsibilities before their 16th birthday	212,000 adult carers (aged 16-35) cared during their own childhood	1985 General Household Survey (Parker, 1994)
1% of all family carers in Scotland are young carers	6,000 young carers aged under 16 in Scotland	The Scottish Executive (The Scottish Executive, 2001)

Source: Aldridge and Becker, 2003