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Citation: DEARDEN, C. and BECKER, S., 2004. Young carers in the UK: the 2004 report. London: Carers UK

Metadata Record: <https://dspace.lboro.ac.uk/2134/627>

Publisher: © Chris Dearden and Saul Becker

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Young Carers in the UK



the 2004
report

Chris Dearden and Saul Becker

CARERS UK



First published in September 2004 by:

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© Chris Dearden, Saul Becker

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN 0 907274 36 6

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Acknowledgements The authors acknowledge with gratitude the assistance of all the young carers projects and young carers workers who took part in this survey. This study was funded by a generous grant from ADM Investor Services International Ltd.

Citation This report should be cited as:
Dearden, C. and Becker, S. (2004)
Young Carers in the UK: The 2004 Report
London: Carers UK.

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Executive summary of main research data and findings

This is the report of the third national survey of young carers who are being supported by specialist young carers projects across the UK. Throughout the report, where appropriate and for comparison, we refer to the two previous surveys conducted in 1995 and 1997 (Dearden and Becker, 1995, 1998).

The 2004 Report is based on data collected from 87 projects concerning a total of 6,178 young carers – the largest survey of its kind.

- 56% of the sample are girls, 44% are boys. The average age is 12.
- 84% of the sample is white; the largest minority group being African Caribbean.
- 56% of young carers are living in lone parent families.
- People with care needs have a range of illnesses or physical or mental health problems. Half of all conditions are of a physical health nature; 29% are mental health problems; 17% are learning difficulties and 3% are sensory impairments.
- The majority of people with care needs are mothers; this is especially true in lone parent families where mothers account for 70% of people needing care. In two parent families almost half (46%) of people receiving care are siblings.
- Just under two-thirds (63%) of siblings with care needs have learning difficulties.
- Only 4% of adults with care needs are in employment (where data available).
- Where there is at least one adult in the home (in addition to any adult with care needs) only slightly more than half of these other adults are also in employment (where data available).
- Two thirds of the young carers provide domestic help in the home; 48% provide general and nursing-type care; 82% provide emotional support and supervision; 18% provide intimate personal care and 11% also provide child care. The recognised incidence of emotional support has increased dramatically since 1997.
- Intimate care is most commonly provided where the person with care needs has a physical health problem or disability. Emotional support is far more common where the person has mental health problems.
- One in ten young carers is caring for more than one person.
- Overall, girls are more involved in all types of caring tasks, especially as they get older.
- Half the young carers are caring for 10 hours or less per week; one third for 11-20 hours per week; and 16% for over 20 hours per week. Some (2%) are caring for more than 50 hours each week.
- The overall incidence of missed school and educational difficulties has reduced, decreasing between 1995 and 1997 and again between 1997 and 2003. However, 27% of all young carers of secondary school-age are experiencing some problems, and the equivalent proportion of young carers of primary school age is 13%. Four in ten children caring for someone who misuses drugs or alcohol have educational difficulties.
- 18% of young carers have been assessed, an improvement on 1997. Young carers from minority ethnic backgrounds are more likely to have been assessed, especially under the 1989 Children Act. Those caring for someone with drug/alcohol problems are more likely to receive an assessment under the Children Act (28%).
- Caring can be a very long-term commitment for many children, and can start at an early age. One third (36%) of young carers had been caring for 2 years or less; 44% for 3-5 years; 18% for 6-10 years and 3% for over 10 years.
- One fifth of young carers and their families receive no other support except for their contact with a specialist young carers project. Social Services support is the most common external service received.

Young Carers in the UK: the 2004 report

This is the report of the third national survey of young carers who are being supported by specialist young carers projects across the UK. Throughout the report, where appropriate and for comparison, we refer to the two previous surveys conducted in 1995 and 1997 (Dearden and Becker, 1995, 1998).

The 2004 Report is based on data collected from 87 projects concerning a total of 6,178 young carers – the largest survey of its kind.

Methodology

This is the report of the third national survey of young carers who are being supported by specialist services across the UK. Throughout the report, where appropriate and for comparison, we will refer to the two previous surveys conducted in 1995 and 1997 (Dearden and Becker, 1995, 1998). Data collection took place during 2003, analysis and writing up during 2004. The survey includes data relating to young carers being supported by specialist projects around the UK – we have no information about those young carers who have not come to the attention of projects, other than data from the 2001 Census, which suggest a figure of 175,000 young carers nationally.

Young carers' support services across the UK were contacted and asked to provide information about each young carer using their service. Drawing on our own database of such projects and those of colleagues in Carers UK, The Children's Society and the Princess Royal Trust for Carers, we identified and contacted 232 projects and received replies from 87, a response rate of 38 per cent.

As with the two previous surveys, projects were asked to give the following information about each young carer using their service: age; gender; ethnicity; family structure (lone parent or two parent family); whether the young person was in education, employment or other and whether those of compulsory school age were missing any school as a result of their caring responsibilities; the source of referral to the project; their relationship to the person with care needs; the nature of the illness/disability of the person with care needs; any other adults and children in the home; and any support services received by the family. In common with the 1997 survey we also asked whether the young people had received a formal assessment and, if so, under which piece of legislation.

In addition to the information outlined above, for the first time we requested additional information about how many hours each young carer spent caring per week, the number of years they had been caring and also whether any adults in the family home were in employment. Although we were not confident that all projects would record such information, we received sufficient replies to generate some interesting findings.

In total we collected and collated data relating to 6178 young carers, all aged 18 and under. All of these data were coded and analysed using a statistical computer package (SPSS).

Young carers' characteristics and caring relationships

Gender, age and ethnicity

Of the 6178 young carers, 56 per cent were girls, 44 per cent boys. All were aged 18 and under, with the average age, both mean and median being 12. Over half (57%) were between the ages of 11 and 15 and in compulsory secondary education. Less than one per cent of the sample was under the age of five, 29 per cent were aged five to 10, and 14 per cent were aged 16-18. Eighty-four per cent of the sample was white; the largest minority ethnic group being African Caribbean, although this only accounted for three per cent of the total. Over half of the young carers (56%) were living in lone parent families.

Caring relationships

Twelve per cent of the young carers were caring for more than one person and the total number of people with care needs was 6992. Table 1 shows the relationship of people with care needs to young carers.

Table 1:
Relationship of people with care needs to young carers, as a proportion of all people with care needs

| Person with care needs | % |
|------------------------|--------------------|
| Mother/step-mother | 52% (3617) |
| Father/step-father | 14% (959) |
| Sibling | 31% (2142) |
| Grandparent | 3% (197) |
| Other | 1% (77) |
| Total | 101% (6992) |

Note: Percentages do not add up to 100% due to rounding

In common with both of the previous surveys (Dearden and Becker, 1995, 1998), the majority of people receiving care were mothers. Table 1 shows that 52 per cent of all the people receiving care were mothers, followed by siblings (31%), fathers (14%) and then grandparents (3%). However, if we focus on the proportion of children caring for different relatives (i.e. the total sample of young carers [6178] rather than the total number of people with care needs), the picture is slightly different. Furthermore, if we then compare lone parent and two parent families, some significant differences occur. These are shown in Table 2.

Table 2:
Family structure and people with care needs

| Person with care needs | Lone parent family | Two parent family | All families |
|------------------------|--------------------|-------------------|--------------|
| Mother | 70% | 44% | 59% |
| Father | 7% | 26% | 16% |
| Sibling | 24% | 46% | 33% |
| Grandparent | 6% | 4% | 4% |
| Other | 2% | 3% | 3% |

Note: n = 5386, 792 missing cases. Figures will not add up to 100% as some young carers are caring for more than one person

As Table 2 shows, in lone parent families 70 per cent of people receiving care were mothers and seven per cent fathers, whereas in two parent families the figures were 44 and 26 per cent respectively. This reflects the fact that most lone parents are women but also indicates that, in the absence of another adult in the home, children are more likely to become involved in caring for their parents. In two parent families, caring for a parent may be shared with the other parent – this is not an option in lone parent families. What is also striking is the fact that children within two parent households are more likely to be caring for siblings. Almost half of young carers in two parent families are helping to care for a sibling compared to a quarter in lone parent families.

Paid employment in the family

One of the questions we asked was whether adults with care needs were in paid employment. Although comparatively few projects collect such data, we received replies for 1024 cases (15%). Of these people receiving care only 43 (4%) were in employment. Although this is only a small proportion of the sample, the number involved (over 1000) is not insignificant, and demonstrates that very few adults who receive care from their children are likely to be in employment. There were 3931 other adults living with the people receiving care. These were mainly adult spouses/partners but some were other adult relatives or adult children living in the same household. Data relating to 2308 (59%) of these indicate that only slightly more than half (54%) were themselves in paid employment. These findings reflect those of smaller scale studies (see for example Dearden and Becker, 2000; Aldridge and Becker, 2003) where it has been suggested that a lack of adult employment – and therefore income – in families can result in the whole family being vulnerable to poverty and social exclusion. Furthermore, Morris (2003) argues that disability benefits do not take into account the additional costs of parenting for disabled adults, further exacerbating family poverty. Our data also indicate that even in two parent families the second parent may be in employment and therefore less ‘available’ to provide care. Furthermore, we know that in some families an adult spouse or partner ‘opts out’ of the caring role, which falls by default to children within that family (Dearden and Becker, 2000).

Care needs within the family

The people with care needs had a range of illnesses and disabilities and more than 8000 conditions were recorded.

For ease and to enable comparison with previous surveys we coded these into physical health problems and disabilities, mental health problems (including alcohol and substance misuse), learning difficulties and sensory impairment. Table 3 shows the distribution of conditions.

Table 3:
The health problems of people with care needs

| Illness/disability | % |
|-----------------------|------------|
| Physical health | 50% |
| Mental health | 29% |
| Learning difficulties | 17% |
| Sensory impairment | 3% |
| Total | 99% |

Note: Percentages do not add up to 100% due to rounding

As Table 3 indicates, half of the people with care needs had physical health problems although a significant proportion had mental health difficulties. Learning difficulties were less common and most likely to be experienced by siblings rather than parents. The incidence of children caring for people with sensory impairment was low.

While Table 3 shows the breakdown of all of the people with care needs, it hides some significant differences. Table 4 looks at the proportions of people with care needs and the nature of their illness or disability.

Table 4:
The nature of illness/disability of people with care needs

| | Physical health | Mental health | Learning difficulty | Sensory impairment |
|-------------|-----------------|---------------|---------------------|--------------------|
| Mother | 57% (2056) | 50% (1799) | 7% (239) | 4% (153) |
| Father | 65% (625) | 43% (414) | 7% (72) | 8% (81) |
| Sibling | 49% (1048) | 10% (222) | 63% (2029) | 3% (61) |
| Grandparent | 88% (174) | 19% (37) | 5% (14) | 6% (19) |

Note: Figures will not add up to 100% since many people had more than one recorded condition

So, for example, 63 per cent of siblings with care needs had learning difficulties. Conversely, parents and grandparents together only accounted for a fifth of those people with learning difficulties, and of the mothers and fathers with care needs only seven per cent of each had learning difficulties. We can see from Table 4 that parents – both mothers and fathers – were more likely to have physical and mental health problems.

Caring tasks

The young people perform a range of caring tasks:

- **Domestic tasks** refer to household chores such as cooking, cleaning, washing, ironing etc.
- **General care** refers to nursing-type tasks such as giving medication, changing dressings, assisting with mobility etc.
- **Emotional support** refers to observing care recipients' emotional state, providing supervision or trying to cheer them up when they are depressed etc.
- **Intimate care** is washing, dressing and assisting with toilet requirements.
- **Child care** refers to helping to care for younger siblings in addition to other caring tasks.
- The category **other** refers to tasks such as household and other administration, bill paying, translating for non-English speaking relatives, accompanying to hospital etc.

Allowing for up to four caring tasks per child, a total of almost 12000 caring tasks were reported. Table 5 shows the tasks that the young people were performing and enables comparisons over time.

Table 5:
Percentage of young carers providing different caring tasks 1995, 1997 and 2003

| Caring tasks | 1995 | 1997 | 2003 |
|-------------------|------|------|------------|
| Domestic | 65% | 72% | 68% (3493) |
| General | 61% | 57% | 48% (2443) |
| Emotional support | 25% | 43% | 82% (4197) |
| Intimate | 23% | 21% | 18% (913) |
| Child care | 11% | 7% | 11% (574) |
| Other | 10% | 29% | 7% (337) |

Note: n = 5116, missing cases 1062. Figures do not add up to 100% since most carers are performing several caring tasks

As Table 5 shows, there have been changes since the first national survey was conducted in 1995. The most striking feature is the increased incidence of emotional support offered by young people. However, the proportion of young people performing personal intimate care has continued to decrease, down from 23 per cent in 1995, to 21 per cent in 1997 and, in 2003, down to 18 per cent. Since personal care is the type of care work most disliked by both parents and children, this decrease is very welcome.

Table 6:
The association between caring tasks and the nature of illness/disability

| Illness/Disability | Domestic | General | Intimate | Emotional | Child care |
|--------------------|----------|---------|----------|-----------|------------|
| Physical | 62% | 50% | 20% | 64% | 8% |
| Mental | 59% | 29% | 9% | 77% | 10% |
| Learning | 46% | 38% | 15% | 68% | 15% |
| Sensory | 62% | 40% | 8% | 63% | 9% |

Note: Figures will not add up to 100% since most young carers perform several caring tasks

The nature of the illness or disability experienced by people with care needs has an impact on the type and level of care offered by children. Table 6 shows the association between caring tasks and the nature of illness/disability. Not surprisingly, intimate care is most commonly associated with physical health problems and disabilities and is provided in 20 per cent of such cases compared with just nine per cent of cases where a person with care needs has mental health problems. Conversely, emotional support is more common where a person with care needs has mental health problems – provided in 77 per cent of such cases. While domestic tasks are provided in around 60 per cent of cases involving physical or mental health problems and sensory impairment, they are provided in fewer than half of cases where a person with care needs has learning difficulties. This may reflect the fact that where care is provided to people with leaning difficulties this tends to be siblings, so parents may require less assistance with domestic tasks.

Overall, girls are more involved in all aspects of care but this is especially marked in domestic and intimate care, both of which have traditionally fallen to women. As Table 7 shows, 75 per cent of girls, but only 65 per cent of boys are providing domestic care while 22 per cent of girls and 13 per cent of boys provide personal, intimate care.

Table 7:
Gender and caring tasks 1997 and 2003

| Caring task | 1997 Male | 1997 Female | 2003 Male | 2003 Female |
|-------------|-----------|-------------|-----------|-------------|
| Domestic | 63% | 71% | 65% | 75% |
| General | 52% | 56% | 44% | 45% |
| Intimate | 15% | 23% | 13% | 22% |
| Emotional | 39% | 42% | 77% | 78% |
| Child care | 6% | 7% | 8% | 12% |

Note: n = 5116, missing cases 1062

If we look at age in addition to gender, Table 8 shows that children become more heavily involved in caring as they get older. This is true of all caring tasks, but less so of childcare, since younger siblings will also be growing older and require less support. The difference in gender becomes more pronounced as the carers grow older; in the 16 to 18 age group 85 per cent of girls are performing domestic tasks compared to 69 per cent of boys, while a third of all 16 to 18 year old girls are providing intimate care compared to just 17 per cent of boys.

Table 8:
Gender, age group and caring tasks

| Caring task | Age 5-10 Boys/Girls | Age 11-15 Boys/Girls | Age 16-18 Boys/Girls |
|-------------|---------------------|-----------------------|----------------------|
| Domestic | 52% (371)/60% (445) | 67% (846)/77% (1298) | 69% (176)/85% (344) |
| General | 39% (274)/43% (337) | 50% (635)/50% (840) | 55% (141)/51% (208) |
| Intimate | 11% (76)/13% (104) | 15% (191)/22% (370) | 17% (44)/32% (129) |
| Emotional | 81% (580)/80% (622) | 81% (1023)/82% (1387) | 85% (218)/87% (354) |
| Child care | 11% (75)/10% (76) | 10% (123)/13% (220) | 10% (25)/13% (52) |

Note: n = 5102, missing data 1076. Data relating to under five age group accounted for <1% and have therefore been excluded

Time spent caring

We were interested to know how many hours per week young people spent caring, but very few projects monitor this type of information. However, we received data in 2149 cases (35 per cent of the sample). Table 9 shows the results.

Table 9:
Hours spent caring per week

| Hours caring per week | % |
|-----------------------|-----------|
| 5 hours or less | 15% (332) |
| 6-10 hours | 34% (737) |
| 11-15 hours | 17% (361) |
| 16-20 hours | 16% (347) |
| 21-30 hours | 10% (210) |
| 31-40 hours | 4% (79) |
| 41-50 hours | 2% (39) |
| Over 50 hours | 2% (44) |

Note: n = 2149, 4029 missing cases

As the figures in Table 9 indicate, almost half of the young people are caring for ten hours or less per week. However, a third care for between 11 and 20 hours per week and 18 per cent care for more than 20 hours per week. Becker (2004) recently conducted secondary analysis of the 2001 Census data on young carers. Although not entirely comparable due to different time ranges, the findings are broadly comparable (See Table 10). Becker (2004) calculates that nationally 84 per cent of young carers spent between one and 19 hours per week caring. In the 2004 survey reported here, 82 per cent of young carers were caring for 20 hours or less per week. Becker’s analysis suggests that nine per cent of young carers nationally care for 20 to 49 hours and seven per cent for 50 hours or more. In this sample 16 per cent were caring for 20 to 50 hours per week but just two per cent for over 50 hours.

The Census data records all households, whereas this survey is of young carers who are being supported by specialist projects. As such, one might have expected the young carers in this sample to be caring less as they have support. However, this would appear not to be the case. While a smaller proportion of the young carers in this survey are caring for over 50 hours per week, a considerably higher proportion are caring for 20-49 hours. We do not know whether this reflects the fact that young carers caring for very long hours have no time to attend young carers projects; whether there are no projects in their locality; or whether contact with a young carers project reduces the number of hours spent caring. We can, however, see from Becker’s (2004) analysis of the Census data (reproduced as Table 10) that the largest numbers of young people caring for 50 or more hours per week are aged 16 to 17. This age group constitutes 35 per cent of all young carers recorded in the Census data. However, in our sample, 16 to 17 year olds account for only 14 per cent of the total. This is the same proportion as in the 1997 survey and reflects the fact that as young carers get older they use projects less. This is to be expected since young carers projects are for children, few are funded to work with adults, and young people’s need for the social activities and support on offer decreases as they become more independent. Conversely, as Table 8 indicates, as young carers get older, they also take on more caring tasks of all kinds. This suggests that there may be a need for specialist support for ‘older’ young carers (those aged over 16) and younger adult carers (aged 18-24) who commenced their caring roles during childhood (Becker, 2004).

Table 10:
Age and number of young carers in England and Wales, by hours caring per week (2001 Census)

| | 1-19 hours | 20-49 hours | 50+ hours | Total number | Total % |
|-------|------------|-------------|-----------|--------------|---------|
| 0-4 | 0 | 0 | 0 | 0 | 0 |
| 5-7 | 4,161 | 512 | 792 | 5,465 | 4% |
| 8-9 | 6,361 | 610 | 863 | 7,834 | 5% |
| 10-11 | 13,727 | 1,180 | 1,360 | 16,267 | 11% |
| 12-14 | 39,983 | 3,429 | 2,982 | 46,394 | 31% |
| 15 | 18,265 | 1,865 | 1,272 | 21,402 | 14% |
| 16-17 | 43,179 | 5,717 | 3,684 | 52,580 | 35% |
| All | 125,676 | 13,313 | 10,953 | 149,942 | 100% |
| All % | 84% | 9% | 7% | 100% | |

Source: Becker (2004)

An additional question we asked in 2003 concerned the number of years young people had been caring. Again, we were not sure how many projects would be able to provide this information, but we received replies in 4028 cases (66 per cent of the sample). Thirty-six per cent had been caring for two years or less; 44 per cent for between three and five years; 18 per cent for six to ten years and three per cent for over ten years. Given that all of the young carers were aged 18 and under, the findings suggest that caring may be a long-term commitment for many of them, and can start at a very early age. However, we must add a note of caution about these data. Caring may be reported by projects as having commenced at the onset of parental illness or the birth of a disabled sibling. However, caring does not always begin dramatically but may be a gradual process, so some children may have been ‘helping out’ initially, before adopting what we would understand to be a caring role.

Educational impacts

High levels of caring can have an adverse impact on young carers, resulting in friendship difficulties, limited time for social and leisure activities, limited time for school work and home work, and can limit opportunities and make transitions into adulthood more problematic (see for example Aldridge and Becker, 1993; Dearden and Becker, 2000, Frank *et al.*, 1999).

The two previous national surveys indicated that a high proportion of young carers miss school as a result of their caring responsibilities. In these surveys we also used referral to a specialist young carer project by a school, teacher, educational welfare officer or educational social worker as an additional indicator of educational difficulties. Table 11 shows the changes over time.

Table 11:
Young carers missing school or experiencing educational difficulties 1995, 1997, 2003

| Age group | 1995 | 1997 | 2003 |
|-----------|------|------|------------|
| 5-10 | 20% | 17% | 13% (212) |
| 11-15 | 42% | 35% | 27% (845) |
| All 5-15 | 33% | 28% | 22% (1057) |

Since the 1997 survey there has been much more awareness of the educational difficulties experienced by young carers. Many project staff now work within schools to raise awareness of the issues and to work with teachers and others to improve young carers' educational experiences and outcomes. It is therefore reassuring to see that, once again, the overall incidence of educational difficulties among young carers has decreased. However, where children are caring for a relative with drug or alcohol problems, the incidence of missed school and educational difficulties is much more marked; 34 per cent were missing school and 40 per cent in total were missing school or had other indicators of educational difficulties. In previous surveys the incidence of drug and alcohol misuse has been too low to further interrogate the data, but in this survey there were 432 (7%) cases of children caring for a relative with drug or alcohol problems, sufficient for this further analysis.

At more than a fifth of all young carers, the overall proportion experiencing educational problems is still high. This remains more marked in the 11 to 15 age group – the age when young people are making educational decisions, taking formal examinations and preparing for their future. Furthermore, those children helping to support a family member who is misusing drugs or alcohol are especially vulnerable to the risk of missing school and experiencing educational difficulties.

Assessments of young carers

In 1997, following the introduction of the Carers (Recognition and Services) Act, we included a question on assessment. We were interested to know whether social services departments were assessing young carers and, if so, under which piece of legislation. At the time they could be assessed under Section 17 of the Children Act (1989), as children in need, or as carers – at any age – under the 1995 Carers (Recognition and Services) Act. Since then the introduction of the Carers and Disabled Children Act (2000) now offers an opportunity for carers over the age of 16 to receive an assessment and services, including direct payments, in their own right.

In total, 18 per cent (885) had been assessed, most (11%) under the Children Act. This is an improvement on the 12 per cent of young carers who had been assessed in 1997. There were no significant differences between those who had been assessed and those who had not in relation to gender, age or caring tasks. The only statistically significant difference relates to ethnicity; young carers from black and ethnic minorities were more likely to receive an assessment, 25 per cent had been assessed compared to 17 per cent of white young carers. Overall, while 11 per cent of all young carers received an assessment under the Children Act, the proportion rose to 21 per cent of those from black and minority ethnic communities; conversely, those from black and ethnic minority communities were less likely to receive an assessment under the Carers Act – only three per cent had received a carer's assessment compared to six per cent of white young carers. Children from lone parent families were more likely to be assessed under the Children Act – 14 per cent compared to eight per cent from two parent families – and two thirds of young carers from black and minority ethnic young carers were living in lone parent families, which might explain their increased likelihood of receiving a formal assessment.

Children caring for a relative with drug or alcohol problems were also more likely to receive an assessment; 28 per cent of these young people had been assessed, 24 per cent under the Children Act. Of these particular children, 68 per cent were living in lone parent families.

The findings suggest that living in a lone parent family increases a young carer's likelihood to receive an assessment of their needs – usually via the Children Act. This is particularly true in black and minority ethnic families and in families where a relative has a problem with drugs or alcohol.

There were no statistically significant differences between children from white and black families in relation to the number of hours spent caring. Nor could we find any significant differences between those children from lone parent and two parent families other than the fact that they are more likely to care for a parent rather than a sibling. There were no other discernible reasons why black young carers and those from lone parent families were more likely to be assessed. However, because the majority of assessments were conducted via children's legislation, we do not know whether they were to acknowledge the vulnerability of these children as carers, or whether there were child protection concerns. This is particularly true of young carers caring for a relative with drug or alcohol problems. We can hypothesise, based on previous studies and experience (see for example Aldridge and Becker, 2003; Dearden and Becker, 2000), that concerns over a parent's drug or alcohol use, especially if accompanied by mental health problems, may lead to child protection procedures. This might explain the high rates of assessment under the Children Act.

Services received by the family

Finally, we asked about the receipt of services by young carers and their families. Twenty-one per cent received no additional services other than the young carers' contact with a project. Social services support was the most common external support service received, accounting for approximately a third of all services received. It is also pertinent that social workers were the main source of referral to young carers projects. It would appear that while social services departments are the main provider of services to young carers and their families, and the agency with a statutory responsibility to assess disabled people, children in need and carers, they also recognise that young carers need support in their own right and refer them on to specialist projects. This is a salient point given the often precarious funding of young carers projects; they are often located within the voluntary sector and have little or no mainstream funding. It is clear that, without such projects, social services departments would be the main source of support and contact for most of these families.

The lack of parenting support offered to disabled parents has been identified by the Social Services Inspectorate and others (SSI, 2000; Wates, 2002). Our findings suggest that in many families there are no external support services being received, although we do not know whether they have ever been offered. Some families refuse external services for a variety of reasons, for example cost, quality, preference etc. (Dearden and Becker, 2000). However, disabled children are automatically considered to be 'children in need' as defined by the Children Act 1989 and may be entitled to support and services. Disabled adults may also be eligible for services if they meet local authority assessment criteria and a community care assessment identifies a need for such support. However, Morris (2003) suggests that disabled parents have unequal access to health and other mainstream services for themselves and their children. In some families this will lead to children taking on inappropriate caring roles.

Concluding remarks

This is the largest database to date specifically of young carers in contact with dedicated support projects, providing data relating to more than 6000 young people. Many of the findings replicate the two previous surveys. For example, there are few differences in the age, gender and ethnicity of young carers being supported by projects and the incidence of caring within lone parent families remains fairly constant. While the distribution of caring tasks may have changed, with an overall reduction in the proportions of young people involved in all aspects of physical care, the tasks themselves remain constant and are related to the nature of the illness or disability of people with care needs.

There have, however, been some improvements over time. For example, the incidence of missed school and educational difficulties, while still standing at 22 per cent overall (27% for 11-15 year olds), has improved since 1997. Equally, the proportion of young carers providing personal, intimate care has also decreased slightly to 18 per cent from 21 per cent in 1997. More young carers are being assessed, although the numbers remain low, but 18 per cent of this sample had received a formal assessment compared to just 12 per cent in 1997.

The improvements over time may reflect the work of young carers projects and the increased awareness of young carers' issues. During the ten years since the first national survey was conducted the number of young carers projects has grown rapidly, from 36 in 1995 to more than 200 in 2004. Many more young carers are receiving support and practitioners from across the board, including social workers, nurses, doctors, teachers etc. are becoming better at identifying and supporting them within their own practice.

There is still some way to go, however. A fifth of families remain without any support services at all apart from their children's involvement with a project. Children continue to provide a high number of care hours each week, and they perform caring tasks – particularly intimate personal care – that many families (and children) find unacceptable. Children caring for relatives with drug or alcohol problems are especially vulnerable to educational difficulties. We have seen that, despite an improvement in the general picture since 1997, many young carers continue to experience educational difficulties and too few of them have had a formal assessment of their needs. For example, almost three quarters of children caring for parents who misuse alcohol or drugs have still not been assessed despite the fact that 40 per cent of them have educational difficulties.

Many children care for several years and some will be committed to caring for many years. It is apparent that services need to better meet the needs of disabled adults, particularly those adults with parenting responsibilities, and that more assessments of disabled parents and of young carers need to take place in order to meet needs and to prevent young caring from becoming established within the family. Professionals in health, education, social services and the voluntary sectors must continue to work towards supporting young carers and their families, and aim to reduce the incidence of inappropriate care that continues to take place.

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Young carers in the UK

the 2004 report

Chris Dearden and Saul Becker

This is the report of the third national survey of young carers who are being supported by specialist young carers projects across the UK. Based on data for more than 6,000 young carers, the report provides a detailed and intricate statistical profile of what young carers do in terms of their caring roles and responsibilities, and of the care needs of the people for whom they provide support. It shows that:

- The average age of young carers in contact with projects is 12.
- 56% of young carers are living in lone parent families.
- Nearly one in five young carers provide intimate personal care, a small improvement since the second national survey conducted in 1997.
- One in ten young carers is caring for more than one person.
- Almost one fifth of young carers are providing more than 20 hours of care each week.
- More than a quarter of young carers of secondary school age are having problems in school, a slight improvement since 1997.
- Almost three quarters of children caring for parents who misuse alcohol or drugs have not been assessed despite the fact that 40 per cent of them have educational difficulties.

These and other key statistics presented in the 2004 Report demand to be read and to be understood by all those concerned for, and working with, young carers and their families.

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