

Cite this download as:

Dearden, C. and Becker, S. (1998) *Young Carers In the United Kingdom Executive Summary*, London: Carers National Association.

Executive Summary

Young Carers in the United Kingdom: A Profile

By Chris Dearden and Saul Becker

Published by Carers National Association

6 May 1998

Young Carers in the United Kingdom is the largest survey to date of children with care-giving responsibilities. The book contains information on over 2,300 young people, all aged 18 and under, who provide care and support for ill or disabled family members and who are also in contact with a specialist young carers project. It combines a statistical profile of these children with case studies of 22 young people, half of whom have been assessed by social services, half who have not.

The book draws comparisons between the position of young carers now and in 1995 when a similar survey of a smaller number of young carers was conducted (see notes below). While the situation shows some improvements, notably in a two per cent reduction in the numbers providing intimate personal care, and a five per cent reduction in those experiencing educational difficulties, young carers as a whole remain a vulnerable group of children. Specialist support projects, of which there are now over 100 in the UK, are greatly valued by young carers and their families. These projects help young carers to achieve their rights and to access other avenues of support which will both reduce the incidence of children as carers and ensure that ill and disabled family members also receive the support to which they are entitled.

In the past young carers have been largely ignored in community care legislation, but the Carers (Recognition and Services) Act of 1995 allows them to seek an assessment in their own right when the person they support is being assessed. The

Children Act 1989 also protects children in need and many local authorities now accept that young carers fall into this category and should be supported as such. The book discusses the incidence of assessment under both Acts and case study material provides an insight into how children and young people experience both the process of assessment and its outcomes.

Key survey findings

Age

- The average age of young carers supported by projects is 12.
- 86% are of compulsory school age (5 - 15).
- Over half are between the ages of 11 and 15.

Educational experiences

- A fifth of all young carers of compulsory school age are missing some school.
- 28% are either missing some school or have other indicators of educational difficulties, such as receipt of additional educational support or education welfare services.
- Of those at secondary school (age 11 - 15) over a third either miss school or have educational difficulties.

Gender

- 57% are girls, 43% boys.
- Girls are more likely to be involved in all aspects of care, especially domestic tasks and intimate care.

Ethnicity

- 86% are white European; black African and black Caribbean young carers are the largest minority ethnic groups.
- Those from minority ethnic communities are more likely to care for members of their extended family; they are also more likely to care for mothers rather than fathers.
- A larger proportion - 61% - of minority ethnic young carers are girls.
- Young carers from minority ethnic communities are more likely to live in lone parent families (60% compared with 54% overall).

Family Structure

- Over half (54%) of all young carers live in lone parent families.

Care recipients

- 12% of young carers are caring for more than one person.
- 58% of all care recipients are mothers; this is more marked in lone parent families.
- Most have physical health problems but over a third of young carers care for someone with mental health problems.

Caring tasks

- Most young carers perform domestic chores and a fifth are involved in personal, intimate care such as bathing or toileting.
- The nature of the illness or disability of the care recipient influences the tasks performed by young carers.

Services

- 25% of young carers and their families have no outside support services other than their contact with a young carers project.
- Social work support is received by almost half the young carers and their families.
- Educational support and education welfare services account for just 5% of the total number of services received. Given the high proportion of young carers with educational difficulties this figure is surprising low.
- The availability and quality of external support to young carers and their families, coupled with the adequacy or otherwise of a family's financial resources, are the most important determinants of whether or not a child will become a young carer and what tasks they will have to perform.

Young carers and assessment

- Only 11% of young carers have received any form of assessment; 5% under the Carers Act.
- There are no significant differences between those who have been assessed and those who haven't in relation to age, gender, ethnicity or caring tasks. Thus, those young carers performing intimate care are no more likely than others to receive an assessment of their needs; nor are very young children who have caring roles.
- Of those assessed, the likelihood of a Carers Act assessment increases with age while that of a Children Act assessment decreases.
- Of those black and Asian young carers assessed, more had been assessed under the Carers Act than the Children Act.
- Those caring for someone with mental health problems are most likely to be assessed, particularly under the Children Act.

- 14% of young carers in lone parent families have been assessed; 8% in two parent families.
- Those with indicators of educational difficulties are twice as likely to be assessed under either piece of legislation.
- The provision of services following assessment decreases the level of care provided by children.

Recommendations

- Definitions of young caring need to be broad and inclusive to ensure that terms such as 'regular care' and 'substantial care' are not used to prevent and exclude some vulnerable children from receiving an assessment of their needs. The likely impact of leaving children to care unassisted should be the prime consideration of professionals when deciding whether or not to make an assessment.
- Awareness-raising needs to be on-going, not simply within social care and social work agencies, but also especially within education, health and youth services.
- The relationship between illness, age, gender, ethnicity, family structure, co-residence, power and status, and poverty needs to be better understood. These factors, in combination, influence how and why some young people become carers. However, the critical factors are the nature, extent and quality of external support services and the level and adequacy of income maintenance.
- Support of the whole family should be seen as a priority, rather than a focus on parents or children in isolation.
- Care must be taken to acknowledge and value the diverse cultural, religious and social expectations and experiences of families from minority ethnic communities whilst acknowledging the rights of children.
- Young carers projects are a valuable resource for children and families, but many parts of the UK remain without this specialist support. There is scope for young carers projects to take a more active role in supporting whole families and for family centres to work more closely with young carers and their families.
- Social services need to ensure that young carers and their families are aware of, and understand, their rights to assessments under the various pieces of legislation. Currently too few young carers are being assessed under any Act.

Case studies

The book contains full case studies and quotes from 22 young carers. Below are a small selection.

Shazia

Shazia is 17 and lives with her mother and two younger brothers aged 12 and 15. Her mother has diabetes, visual impairment, back problems, angina and is incontinent. Her mobility is limited and she is unable to do housework, shopping etc.

Shazia has now left school and is attending college. She has had an assessment of her needs as a carer under the Carers Act and, following assessment, the family received homecare for two hours a day, Monday to Friday. In addition to this, the young carers project worker arranged and paid for an additional two hours every weekday evening and visits at the weekend. The family now has homecare twice a day, seven days a week, which includes help with cooking, ironing and housework. The family also has a social worker who visits regularly and a nurse visits to assist with the mother's incontinence. Prior to assessment, Shazia was cooking all the family meals and doing all the housework and shopping. Shazia's mother speaks little English and Shazia accompanies her on hospital visits etc. and translates for her.

Tanya and Leanne

Tanya and Leanne are 11 and ten respectively. They live with their father, their mother died when they were both very young. Their father has arthritis in his spine and phlebitis and ulcers to both legs. This has resulted in restricting his mobility and making it painful for him to bend and lift heavy weights. Although his mobility is restricted, he can manage most activities of daily living alone.

Tanya and Leanne are involved in domestic tasks in the home, such as washing and ironing, cooking and doing the dishes. They shop together as a family, but they carry the shopping as their father cannot manage this. Both girls have been assessed as children in need under section 17 of the Children Act. Following assessment the family received homecare once a week which was increased to twice a week after their father had a period in hospital. The provision of homecare has considerably reduced the amount of work the girls do in the home. In addition to homecare, their father also received a bed and chair to ease his back problems and is now in receipt of Disability Living Allowance and Mobility Allowance. The assessment was arranged by social services who also invited the girls to join the local young carers group.

Gary

Gary is 15 and lives with his mother who has multiple sclerosis (MS), which was diagnosed two or three years ago, and depression. She is quite unsteady on her feet and uses a walking stick outside. She also tires very quickly and gets frequent headaches. Gary's grandmother also had MS and he and his mother cared for her until she died.

Gary cooks three or four times a week, does the dishes most days, helps with the shopping and the washing and used to help his mother in and out of the bath. The family now has a shower, following an assessment of their needs, and Gary no longer has to help his mother into the bath. The only other support they receive is a community psychiatric nurse who visits his mother weekly in relation to her depression. Gary received a carer's assessment when his mother's needs were assessed.

Tom and Geraldine

Tom is 13 and Geraldine is ten. They live with their parents and younger sister. Their father has cerebral palsy and, following a car accident before the children were born, he sustained spinal injuries and now uses a wheelchair. He requires some assistance with washing, dressing and toileting. Their mother has a part-time job and acts as his main carer, but both children are involved in domestic tasks such as doing the dishes and helping with the housework. Geraldine also helps to get her younger sister ready for school in the mornings.

The family has no outside support or services other than the young carers project for the children, but their mother does receive some benefits, including Invalid Care Allowance. The children don't think their mother or father have ever requested any support and they have never discussed their own roles in the home with any professionals.

Marianne

Marianne is 14 and lives with her parents and 21 year old sister. Her mother has had multiple sclerosis (MS) for the past eight years and has been using a wheelchair for the past four years. She needs assistance with washing and dressing and is incontinent. Marianne's father takes responsibility for most of her mother's personal care needs. During the day while her father and sister are at work and Marianne is at school, her mother receives homecare, which includes help with ironing and cleaning and preparation of the family's evening meal.

After school Marianne takes responsibility for her mother's care until the rest of the family come home. She helps her mother to the toilet and changes her incontinence pads and every night she undresses her mother and helps her to get ready for bed. She also does some clothes washing, helps with the shopping, and does some cleaning and cooking at weekends.

Marianne has never received an assessment of her needs and has not been consulted or involved in any discussion with professionals.

Martyn

Martyn is 13 and lives with his parents and older brother. He also has an older sister who has left the family home. His mother has multiple sclerosis (MS) and angina. The MS was diagnosed about 11 years ago but Martyn does not know how long his mother has had angina. Martyn's mother uses a wheelchair, but cannot stay in it for long periods, and therefore spends most of her time in bed.

Martyn's father does not go out to work and is the main carer for his mother, who needs assistance with personal care and cannot do household tasks. Martyn helps by sorting out his mother's medication, doing some cooking, particularly at weekends when he tends to make his own meals and the occasional meal for his mother, helping with housework and shopping, and emptying his mother's catheter.

The family receives homecare every day to assist Martyn's mother, but this does not include any help with domestic tasks, only caring tasks.

Martyn has never received an assessment of his needs as a carer and nobody has ever discussed his caring role with him other than the young carers project worker.

Notes

1. Chris Dearden is a Research Associate and Dr Saul Becker is the Director of the Young Carers Research Group, Department of Social Sciences, Loughborough University, LE11 3TU. Tel 01509 223379/223352.
2. The survey was funded by generous grants from the Calouste Gulbenkian Foundation and Carers National Association.
3. Comparisons are drawn between 1995 and 1997. Data from 1995 are taken from *Young Carers - The Facts* (1995), by Chris Dearden and Saul Becker, published by Reed Business Publishing.

Young Carers in the United Kingdom: A Profile (1998) is written by Chris Dearden and Saul Becker and published by Carers National Association.
ISBN 1 873747 06 3, Price £11 (includes p&p).

Copies of the book are available from Carers National Association, 20-25 Glasshouse Yard, London EC1A 4JS. Telephone: 0171-490 8818.
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