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The capital carers: an evaluation of capital carers young carers project

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Final Report prepared for
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by Betty Newton and Saul Becker
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An Evaluation of Capital Carers Young Carers Project

Betty Newton and Saul Becker

“Very worthwhile and long overdue ... because they give the carer an outlet, a bolt hole, it gives them someone else they can turn to and it also brings out the fact that there is a need for supporting young carers to show how valuable they really are and that they are not taken for granted ... It also gives the young carer an interest outside the home somewhere to go to where somebody sympathises and understands what their problems are. If it carries on the work it may need to expand because there are an awful lot of young carers out there who haven't emerged yet.”

Max, a care recipient

“The project has helped because we are mixing with other young carers. Even though we don't talk about the work that we do as young carers it helps us because we have a common background.”

Debbie, a young carer

“It is really nice when you refer a young person to something and that it has worked out really well and was successful and I am really pleased that in this instance it's made a huge difference to his life.”

A social worker



Acknowledgement

Setting up the Young Carers Project at Capital Carers would not have been possible without the dedication and commitment of a number of individuals and organisations who have helped to make the Project both a reality and a resounding success.

A big thank you to the following organisations who had sufficient faith in us to help us financially:

**Cicely Northcote Trust
King's College Rag Committee
Lambeth, Southwark & Lewisham Health Authority
London Docklands Development Corporation
National Lottery Charities Board
Private Sector Housing Unit in Southwark
South East London Community Foundation
Southwark Social Services**

Special thanks to the Board of Trustees at Capital Carers who had the vision and drive to set up this new Project. To Cathy McNicholas, the Young Carers Development Worker, for her commitment beyond the call of duty to making it happen. To the members of the Development Group who helped to get it off the ground. To Dr. Saul Becker and his team at the Young Carers Research Group for their ongoing evaluation of the Project. And to all those people in Southwark who have worked with us to meet the needs of young carers in the Borough.

Our final thanks and special mention, however, must be reserved for the young carers themselves and their families. This report bears testimony to the contribution they have made to the development and success of the Project in its first three years. It is fitting that they should have the final say in these thanks:

**"I wouldn't give up coming to the Project for anything.
It's brilliant." [8 years]**

**"Young carers need a break from all their hard work
and that's what the Project's for." [10 years]**

**"Capital Carers is the place to be,
What you do is have loads of fun.
The way to join is really easy,
All you have to do is care." [11 years]**

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Section One: Introduction

In December 1996 Capital Carers established a Young Carers Project in Southwark. They employed a development worker to set up and manage the Young Carers Project and ensure the achievement of its aims and objectives. During the first three months of the Project's life the emphasis was on setting up the structure of the scheme, awareness raising, making contacts and general publicity. The Project itself was formally launched in March 1997.

Prior to the launch a Young Carers Development Group was established in January 1997 to guide and assist the Project towards meeting its aims and objectives. This multi-disciplinary group was drawn from both the voluntary and statutory sectors and comprised the development worker and representatives from Capital Carers senior management, the Cicely Northcote Trust, Social Services, and the Education and Health Departments. The group met monthly during the first six months and then at three monthly intervals thereafter. Throughout 1998 the group met less regularly as the Project became more established. It was the intention of the development group that a review should take place towards the end of the first year of the Project and then its work would discontinue. Even though the group does not have managerial responsibility this procedure has served it well.

Funding Framework

The funding came about as a result of a successful joint finance bid in October 1996 by Capital Carers (formally Southwark Crossroads) from the Joint Consultative Committee (Social Services and Health) to fund a development worker and to cover the core costs of the Project. Further resources were acquired in January 1999 from the National Lottery Charities Board to enable the scheme to employ a project worker for three years. Funding for the Project's activities programme comes from a variety of funding bodies including: the National Lottery Charities Board, London Docklands Development Corporation, South East London Community Foundation, King's College Rag Committee and Southwark Private Housing Renewal. A successful bid was also made to the Cicely

Northcote Trust for this research and the publication of this evaluation report.

Evaluating Capital Carers Young Carers Project

One of the main aims of the development group was to commission an independent evaluation of the Project over a three year period. The Young Carers Research Group (YCRG) at Loughborough University was commissioned to monitor and evaluate the Project. This followed a study commissioned by Southwark Social Services Department to identify young carers within the borough and examine their experiences and needs.

The aim of the monitoring and evaluation was to provide staff, young carers and their families as well as local professionals with an opportunity to comment critically on the service provided. Statistical information on all aspects of the service provision was collected by the development worker and analysed by the YCRG in such a way as to provide a comprehensive profile of the Project. This analysis shows the extent to which the Project was meeting its stated aims and objectives. It also made useful comparisons with national profiles of young carers (Dearden and Becker, 1995, 1998).

An independent evaluation was considered essential to prevent any conflict of interest on the part of the Project's staff and to ensure impartiality. Such an evaluation also had the merit of accessing more easily those negative as well as positive comments on the nature of the service, comments which are essential to the future development of the Project.

Methodology

This evaluation combines both qualitative and quantitative research methods. The quantitative element uses data relating to the Project's young carers collected by the development worker using referral monitoring forms. These forms were collected on three occasions over the three year period before being collated and analysed by the YCRG to give a statistical profile of the young carers supported by the Project. Information was also taken from the young carers development worker's

awareness-raising monitoring returns as well as the Project's policy and procedure documents.

In addition to the quantitative element, three phases of field work took place enabling the research team to interview in-depth the Project staff and volunteers, the young carers, parents, as well as the professionals who had made referrals to the Project. This field work was carried out shortly after the data collection in order to investigate any significant findings from the quantitative information. The young carers and their parents interviewed for this evaluation were reassured about the confidentiality of the research and the names used in this report have been changed to protect their identities.

The qualitative element was crucially important in that it allowed the research team to explore in detail how young carers and the local professionals responsible for referrals viewed the services offered, and how the Project and its staff were meeting their aims and objectives. It also provided the young carers, their families and the professionals with an opportunity to offer critical comments about the Project and any changes they would welcome. Considerable attention was given to collecting the views of local professionals. Their perceptions of the Project are crucial as they must have confidence in the Project, its worker and staff members if they are to continue referring vulnerable young people to them for help and support. Interviews with parents were also important especially in the light of recent debates by some disability rights authors (e.g. Keith and Morris, 1995) that disabled parents may feel undermined by the work of young carers Projects. While the primary focus of the Project is to support children and young people who act in a caring role, it also works directly and indirectly with other organisations and agencies to ensure that families receive all the support to which they are entitled. Parents were interviewed to ascertain their feelings towards their children receiving the support of the Project and also to monitor the ways in which the Project had assisted them.

It was planned to carry out a longitudinal study of two young carers and their families. The purpose of this aspect of the study was to elicit their perceptions of the Project and to gauge how young carers felt about any changes to the Project, whether their needs were being met, if those needs

had changed, and how they viewed any changes in staff and service provision. The interviews were conducted on two separate occasions with five young carers at intervals of approximately one year. Initially it was envisaged that the parents of these young carers would also be interviewed, but as Bryman has pointed out: "when this type of longitudinal research is conducted there is often a loss of respondents" (1989). This was indeed the case and it proved particularly difficult to interview the parents due to hospitalisation, deteriorating conditions due to their illness and other circumstance outside the research group's control.

The development worker was interviewed three times at different stages of the evaluation. She was invited to report on any changes in direction and to offer an overall view of the Project's progress. In total, forty interviews were conducted with young carers, parents, the development worker, volunteers and professionals. The analysis of these interviews forms the basis of this evaluation.

Aims and Objectives

The development group identified five main aims and objectives for the Young Carers Project. These were:

- To raise awareness of the existence and needs of young carers in the relevant social services departments, voluntary, educational and health services and other relevant agencies.
- To promote the Young Carers Project and to identify young carers in the borough ensuring that young carers from all communities were identified.
- To provide a single point of contact for young carers that would provide information, support, advice, social and recreational activities.
- To assist young carers in identifying their own needs, supporting each other and informing future service provision.
- To act as an advocate for young carers, promoting and safeguarding their rights as children.

These aims and objectives are examined individually in the report to assess the extent to which they are being met.

Young carers in Context

It is well known that young people have been providing care for other family members throughout the centuries. However, it is only in recent times that this has been acknowledged in any public way and that research has been conducted into its extent and nature. We can get some glimpse into this "hidden world" through literature, especially the novels of Dickens and Hardy and the writings of the Irish writer, Maria Edgeworth, who, along with her father, "brought up her 16 younger brothers and sisters" (Robertson, 1974:421).

Much of the early research into the experiences of young carers was descriptive in character and it wasn't until the mid-1980s that qualitative research began in earnest. The two earliest and best known studies of this period, the Thameside (O'Neill, 1988) and Sandwell (Page, 1988) studies, were, however, rather limited in scope and only designed to stimulate interest into the incidence of young caring and its effects on children. It wasn't until 1990 with the setting up of the Carers Project at Carers National Association (CNA) that systematic research began. The earliest studies of this period, Grimshaw (1991), Elliott (1992), Segal and Simpkins (1993) and Alexander (1995), dealt mostly with the experiences of children caring for someone with a particular illness or disability. Since then there has been a steady stream of publications and studies.

However, since these first studies appeared in the 1990s, there has been a significant shift in terms of emphasis and research methods. As already mentioned, the early studies were strongly descriptive with the focus almost entirely on the tasks of young carers. Meredith, for example, began his work at the Carers National Association defining the children who provided care almost entirely in terms of their duties and responsibilities: "children and young people who have responsibilities for the care at home of a relative with a disability or mental illness" (1991:14). A brief look at much of the early research on carers (O'Neill, 1988; Page, 1988; Meredith, 1992; Bilsborrow, 1992) shows the extent to which attempts at definition focused on particular aspects of the work and condition of young carers. Grimshaw (1991), for example, focused attention on the impact on children of parents with Parkinson's disease, Tyler (1990) on Huntington's disease, while later in 1993 and 1996, Segal and Simpkins highlighted the effects of parental multiple sclerosis on family life. More

recently, attention has been drawn to children affected by HIV/Aids (Imrie & Coombes, 1995). It should be pointed out, however, that some of this early research was remarkably forward-looking in some of the insights and recommendations offered. As early as 1990, Meredith, for example, promoted issues like advocacy and befriending which are now at the centre of service provision plans for young carers.

The nature of much of the early research with its analytical distinction between 'primary' and 'secondary' caring has changed over the years and given way to studies reflecting the experience of young caring as well as its nature. It soon became clear that there were fundamental differences in the conditions and effects of young caring which suggested the need to establish and apply new and more appropriate models of caring, relating specifically to age distinctions. The work of the Carers National Association Young Carers Project, originally funded by the Department of Health, has been a cornerstone in awareness-raising as well as an enabling and empowering process for young carers throughout the country. The Young Carers Project endorsed a child-centred approach and highlighted the social impact of caring in terms of the quality of life of young carers. As a result of this awareness-raising it was possible for the first national survey of young carers to be produced by the Young Carers Research Group at Loughborough University (Dearden and Becker, 1995). This survey, which studied 641 young carers supported by Projects around the UK, offered a statistical profile of young carers with information about age, gender, ethnicity, caring roles as well as case studies. It also included material from interviews with young carers and project workers.

A good indication of the growth in the number of young carers projects can be gleaned from the fact that when the original Young Carers Handbook appeared in 1995 there were 37 projects nationwide, whereas by March 1998, the updated Handbook contained information on 110 such projects. This Handbook as well as listing the projects provides an overview of some of the projects illustrating the diversity of approaches and ways of working with young carers. Within a relatively short period of time, young carers have become increasingly recognised as a group with their own particular needs and rights.

A number of recent studies, (Frank, 1995; and Mahon and Higgins, 1995) have successfully combined quantitative and qualitative research methods, and reinforced the general findings and conclusions of earlier similar research work. Both the small scale in-depth studies and the larger surveys confirm a number of patterns which have emerged more generally in the literature in relation to the caring experience, the nature of caring roles and responsibilities, and the impact of caring on children and their families. Frank, for example, found that young carers' tasks were "the same whether a child lived in a rural area or in the city" (Frank, 1995:38). Dearden and Becker's (1998) survey of 2,303 young carers found that the majority of them were involved in domestic chores, over half were performing general caring tasks, one-fifth were providing intimate care and almost half were providing emotional support. At the time this survey was conducted, the needs and experiences of young carers had begun to be recognised in both policy and practice, following the Department of Health's young carers initiative and the implementation of the Carers Act.

Issues surrounding health and development and education have been more to the fore in recent surveys and reports. Aldridge, Becker and Dearden's *Young Carers and Their Families* (1998) discusses the effects of caring on health and development as well as offering guidance on policy and legal matters. In addition there have been two major Department of Health Reports (1996) on young carers, one a report on workshops using a family approach to identify young carers, and the other a report of the Social Services Inspectorate fieldwork project on families with disabilities or illness. However, while these and other studies by the CNA and the YCRG have emphasised the impact of caring on children and young people, the definition of young carers promoted by the Department of Health (1996) still defines them by reference to the extent and frequency of their caring responsibilities.

From the different types of literature on young carers a picture is emerging which identifies several factors which appear collectively to set young carers apart, both from adult carers and from other children within families who do not take on caring roles. Among these factors are the following: young carers are usually under 18 years old; their parent(s) are usually either chronically sick or disabled; and their duties and

responsibilities impact significantly on their education, their social life and experience of childhood as well as their health and future prospects of employment. Many have often been neglected and ignored by welfare professionals and have not been in receipt of the necessary support services. As a result many of them have foregone some of their rights both as carers and as children (Dearden and Becker, 1995; Newton and Becker, 1996).

Many of the factors and issues raised by the growing literature on young carers are to be found in the research analysis which follows.

Section Two: Project infrastructure

In the early stages of the Project the emphasis was on building a solid foundation and creating an infrastructure. This involved the preparation of policy and practice guidelines, the production of volunteer and befriending packs, drawing up the roles and responsibilities of staff, as well as awareness raising sessions and making contact with local statutory and voluntary agencies and organisations. Only when this foundation work had been completed and the Project was reasonably well established and recognised as an appropriate and professional agency to which young people could be referred, could direct work with young carers and their families begin.

The Project has a comprehensive list of principles and policy documents many of which are generic to Capital Carers and deal with a wide range of issues including equal opportunity policies, confidentiality, data protection and health and safety. Of particular relevance to young carers is the child protection policy which was specifically written for Capital Young Carers by the development worker and which has now been adopted by the whole organisation. There is also a code of practice for volunteers and a special code of guidance for those volunteers engaged in befriending. The Project's equal opportunities policy extends to young people, staff and volunteers and includes a commitment to staff training and development.

The Project's confidentiality policy protects young carers' rights to confidentiality in all circumstances except those pertaining to abuse or endangerment. An important aspect of the Project's code of practice is that all young people supported by the Project are informed of their right to confidentiality while staff, including volunteers, are trained in issues surrounding confidentiality and child protection. One professional referrer commented as follows on the Project's confidentiality policy:

The Project is excellent and the worker is a professional and I trust her confidentiality. There is one particular case which is HIV and the children don't know anything about it and I'm very confident that she [the development worker] will keep that confidentiality and work with me around those issues. I feel very comfortable with that. (EWO)

A parent commented:

Initially I had reservations about the Project. I thought they would be running to social workers all the time telling them ... what was going on in this family, but they are just interested in the children's welfare and have made that quite clear, but they would report you if they see the children abused. (Jane)

The referral procedure has been kept as informal as possible with the minimum amount of paperwork. A professional referrer commented favourably on this approach:

It's not a formal process and I'm glad I don't have to make a written referral and that's really good. I can speak to the parent and young person, explain the Project, show the flysheet and leaflets, get in contact with the Project and it's out of my hands and then it's up to the parent and child to decide. It makes accessing the Project so much easier and you want to do it because in a sense you don't actually have to do the work and you are also enabling parents because you have all the information. It's for us professionals to have all this information for parents to access and once the process is complete it's then up to the parents and the family.

I don't feel it's a drawback and I keep a record on my file. I like the confidentiality as there isn't contact as such. Once I make a referral I often contact the [development worker] to ask if the young carer has been attending. It's not necessary that she contact me and I think that's right. I like the confidentiality of the referral procedure because it isn't a contract between myself and the family. It's something for them. (EWO)

Those professionals who took part in joint visiting with the worker felt that they were working in partnership with the Project:

We have done some joint visits and [the development worker] is always available for that. For example, one particular family was in a crisis situation and I thought it would be useful for [her] to come with me and explain the Project as I didn't feel I could. She came with me and spoke to the father. She gave them information and then followed it up for them. A cab was arranged to take up the young carer to the group activities. This was very helpful to me. (EWO)

Location

The Project is based within the premises of Capital Carers - a voluntary sector care provider and parent group of the Project. Young carers are welcome to drop in and visit the development worker in her open-plan office. An interview room for personal meetings and confidential discussions is also available. Group activities are held at the Coplestone Community Centre where a number of different community groups meet. The young people are picked up by mini-bus and taken to the centre and then home again at the end of the evening's activities. Because of the size of the borough, it can take up to one and a half hours to collect all the young carers.

Project Management

The Project is managed by Capital Carers Management Group and the director is the line manager of the Young Carers development worker. The director in turn is responsible to the management committee of Capital Carers. Initially, the Project was to focus on two key areas - research and development. In the first year the development worker's brief was to concentrate on identifying young carers in Southwark and undertake research into their needs.

Staffing

The Project has one young carers development worker and seven part-time volunteers giving support to the young carers using the Project. The role of the volunteers is to assist in the planning and provision of group activities, outings and weekend breaks as well as to befriend the young carers. The volunteers generally assist with group activities; three have the task of befriending. All volunteers have an induction evening where the policy and procedures of the Project are discussed. In addition, all the volunteers meet once a month as a group.

While there is no specific policy on the recruitment of volunteers, each applicant is interviewed by the Young Carers development worker. In addition, the volunteers are subject to police checks and have to submit two or more references regarding their suitability for the work. The volunteers are also subject to a three month probationary period before making a six month commitment to the Project. Their work is subject to ongoing supervision by the development worker. The majority of

volunteers have had some experience of working with children and a number of them want to take on the role of befriender. They are entitled to have a nominated representative on the Development Group. Throughout their period of service at the Project they are subject to the parent organisation's discipline and grievance procedure as well as having access to the same procedure themselves. All staff members and volunteers are expected to comply with the organisation's code of conduct and policies relating to Confidentiality and Disclosure and Data Protection.

Befrienders are subject to further training and meet with the Young Carers development worker every two weeks for a progress report. Their work is monitored closely for the first three months after which they are subject to a three monthly progress review. All the befrienders are "matched" with young people and work not only on a one-to-one basis, but also where there are two or more young carers in one family. They can also take on some small group work in specific localities under the supervision of the development worker. All befrienders have to gain parental consent to work with the young carers. They are introduced to the families by the development worker who initially prepares the parents and children for their involvement. During their induction sessions volunteers receive an induction pack containing copies of all relevant documentation including grievance and discipline policies and procedures. The befrienders also receive a Befriending Pack. An open door policy allows volunteers to gain access to the Young Carers development worker to discuss problems any time during office hours.

Section Three: A profile of Southwark Capital Carers Young Carers

Data taken from the monitoring returns supplied by Capital Carers are presented in this chapter. The main characteristics of the Project were assessed between March 1997 and December 1998 (the period of the evaluation) and comparisons made with figures from the national study of young carers Projects across the United Kingdom (Dearden and Becker 1998). There were 73 referrals to the Project between March 1997 and October 1998.

A closer examination of the figures shows that there were significant differences between the young people using the Capital Carers Project and those making use of other Projects throughout the country.

Age

The age of young carers supported by the Project ranged from 6 to 18 years, though more than half were in the 11 to 15 age group (see Table 1). During the period of the evaluation, the 5 to 10 age group increased significantly by 18 per cent; at the same time the percentage of young carers in the 11 to 15 and 16 to 18 age groups decreased. Overall, the Project users were slightly older than those in the national survey.

The average age of young carers who were helped by the project was 12: this is in line with the national profile.

Table 1: Age of young carers

Capital Carers Project compared to the 1998 national survey

Age	October 1997	April 1998	October 1998	National
under 5-	-	-	-	1%
5-10	18%	29%	36%	32%
11-15	53%	49%	44%	54%
16-18	29%	22%	19%	14%
Total	100%	100%	99%	101%
Number	17	60	73	2,303

Figures are rounded to the nearest whole number and therefore may not add up to 100 per cent.

Gender distribution

In the early days of the Project there was a strong gender imbalance which has since changed (see Table 2). In October 1997, 75 per cent of young carers using the Project were female but over the period of the evaluation the percentage of male carers increased moving closer to the national profile (Dearden and Becker, 1998). The issue of gender will be discussed further in the section dealing with family structure together with its impact on tasks and responsibilities.

Table 2: Gender distribution

Capital Carers Project compared to the 1998 national survey

Gender	October 1997	April 1998	October 1998	National
Female	76%	65%	59%	57%
Male	24%	35%	41%	43%
Total	100%	100%	100%	100%
Number	17	60	73	2,303

Ethnicity

Over the period of the Project's evaluation the number of young carers from the White European community was significantly below the national profile of 86 per cent (Dearden and Becker, 1998). Nationally, the number of young carers from minority ethnic communities being supported by Projects increased from 10 per cent in 1995 to 14 per cent in 1997 (Dearden and Becker, 1995 and 1998). However, as Table 3 shows the Young Carers Project in Southwark attracted a much higher proportion of

young carers from the black African and black Caribbean minority ethnic communities compared to other projects nationally. This is significant because it does not reflect the demographic profile of the Borough of Southwark which has a 72 per cent white and 20 per cent black population (London Research Consortium, 1998).

Table 3: Ethnic distribution
Capital Carers Project compared to the 1998 national survey

Ethnicity	October 1997	April 1998	October 1998	National
White European	47%	53%	47%	86%
Black	53%	44%	51%	7%
Other	-	4%	3%	
Total	100%	100%	100%	100%
Number	17	57	68	2,303

Ethnic status was not recorded for four young carers.

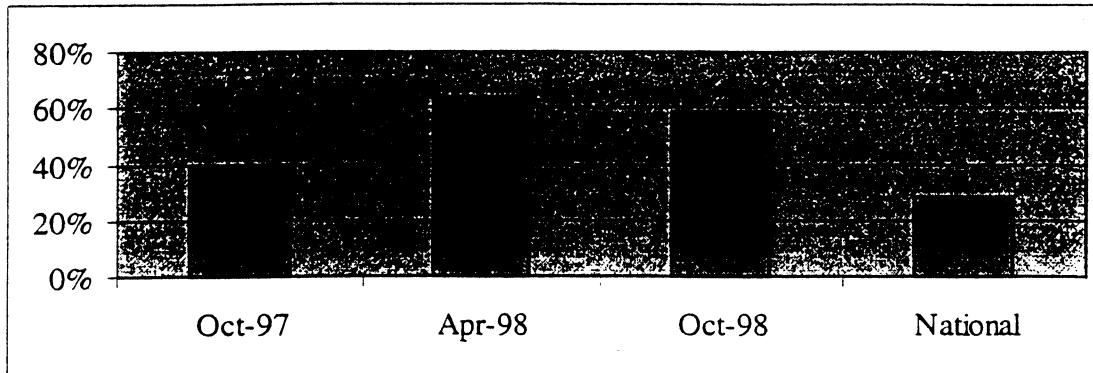
Educational experiences

Eighty-six per cent of the 73 young carers attending the Project were of compulsory school age. The proportion of young carers attending the Project and experiencing educational difficulties such as absenteeism, homework problems, arriving late at school, bullying (which will be discussed later), or in contact with the educational welfare service, is significantly higher than the national profile. With the exception of October 1997, the percentage of young carers with educational problems was more than twice the national average. The trend over the two national surveys in 1995 and 1998 would suggest that the number of young carers of compulsory school age experiencing educational difficulties declined from 33 to 28 per cent (see Table 4). However, the figure for the Project's young carers (59 per cent) remained very high. There may be a number of reasons for this. It could be that some other characteristics of the families exacerbated the educational problems experienced by the young carers: for example if they were caring for a lone parent, or if they had experienced problems such as bullying at school, or had fathers in employment who were unable to care during the day. Other reasons may have to do with issues arising from poverty, class and social exclusion, as some 86 per cent of the Project's young carers and their families live on income support. Sixty two per cent of the the borough of Southwark is

recognised as deprived and three of its most deprived districts are the fifth worst in the country (Community Care, 1996).

Table 4: Educational problems

Capital Carers Project compared to the 1998 national survey



The comments of children and their parents offered some explanations why young carers might miss school.

For example, when Dennis's mum is in the manic phase of her manic depression and when she is hyperactive, Dennis has to stay off school to administer her medication, ensure that she does not overdose and also monitor her condition in case she has to be hospitalised:

Sometimes I have to miss school ... When she is not well I have to take days off and look after her. (Dennis aged 15)

Dennis wants to go on to further education but sometimes struggles to do his homework at home which quite often has to be completed during the school break.

A parent commented on why she felt her son had not attended school for over three years:

There was a problem about him going to school and a lot of this was because he felt he couldn't leave his dad. Sometimes he used to worry about what would happen if his dad fell. I then became ill, had a breakdown and he [young carer] took on a double role because he was sort of caring for me as well. (Susan)

A social worker also described the effect that staying at home to look after his parents had on this young carer:

I think he was the primary carer for his mother who had major separation issues with him emotionally... He hadn't been to school for almost three years and I was concerned about the fact that he was staying most of the time with his mother and becoming socially isolated.

One young carer did not miss school because of her caring role but she could not settle and worried constantly about leaving her mother:

Now that her spine is so bad and sometimes at school I really worry about her and want to come home and the next day I don't want to go to school. One time I was really upset and started to cry in the classroom, the teacher asked me why but I kept quiet. I didn't really want to speak to anybody. (April aged 10)

Due to the intervention of the worker, the school is now aware of this young carer's problems and sympathetic to her needs. The head teacher gives her the opportunity to phone home during the day for a progress report on her mother's health. Support and recognition from teachers has also been helpful and lessened the stress on this young carer.

The development worker commented on how the caring role affected the young carers' ability to cope with homework and the lack of understanding shown by some schools:

The older ones have difficulty managing the workload at school and with what they have to do in the home...they get really stressed.

Some young carers fall behind on their work because of their home situation and require additional support. One parent commented:

Joe's education has been affected by his caring role but he is getting help now.

A number of young carers do well in their exams and go on to further education. However, the stress of caring can result in the young person giving up on further education. A social worker said:

This particular young carer had been involved in a college course but the stress of trying to be around for mum was such that she gave up college after the first year despite [the development worker's] best efforts and mine to persuade her to hang on in there.

Family structure

Table 5: Family Structure

Capital Carers Project compared to the 1998 national survey

Family Structure	October 1997	April 1998	October 1998	National
Lone parent	76%	80%	74%	54%
Two parents	24%	20%	26%	46%
Total	100%	100%	100%	100%
Number	17	60	73	2,303

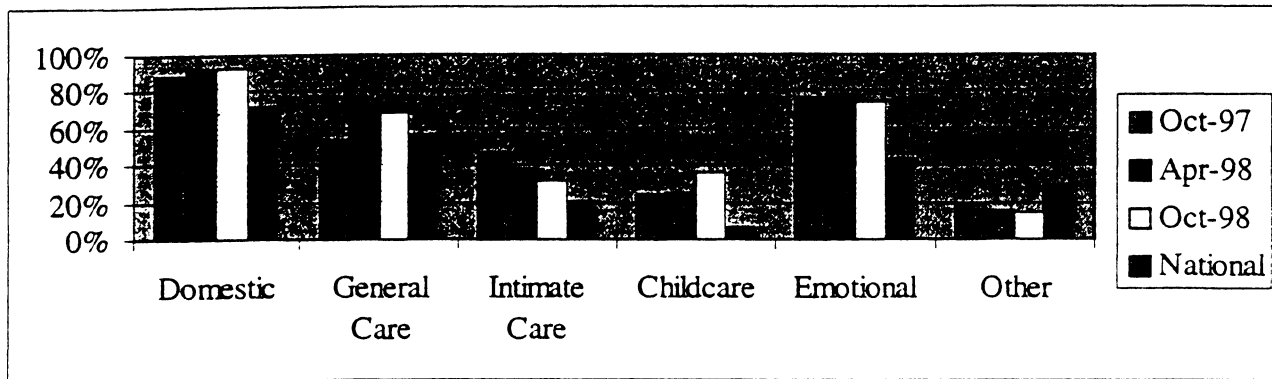
As Table 5 shows almost three quarters of the young carers live in lone-parent families, a figure which is significantly higher than the national young carers profile (Dearden and Becker 1998) and also above the national figure for lone-parent families in general. Haskey (1998) estimated that in 1995, 23 per cent of all children were living in lone-parent families.

Caring tasks performed

Almost all the young carers using the Capital Carers Project were performing a variety of domestic tasks such as cooking, cleaning, shopping and preparing meals, as well as more intimate caring tasks such as washing, showering, bathing and toileting. Many young carers also provided emotional support and cared for other siblings.

Table 6: Caring tasks

Capital Carers Project compared to the 1998 national survey



However, given that many young people are now expected to engage in some domestic work, it is difficult to know how much of this work these carers would normally be performing if they were not providing care. As Table 6 shows, the number of those engaged in both domestic work and intimate care increased in the period of the evaluation and overall was significantly higher than the national profile. Many of those interviewed felt that the amount of domestic work undertaken by the young carers was excessive.

There were significant changes during the period of the evaluation. In particular, there was a slight increase in the number of young carers involved in domestic tasks which is now well above the national profile. The decrease in the level of intimate care is in line with national trends but the proportion of young carers in Southwark carrying out intimate tasks is still higher than other projects nationally (Dearden and Becker, 1998). Child care has also increased over the period of the evaluation and is now four times that of the national profile. Emotional tasks are nearly twice as high as the national profile. With the increased awareness of young carer's issues and their recognition in legislation and policy, together with the increase in the number of support services available to them, a significant decrease in the proportion of young carers involved in intimate care tasks might have been expected. Below we discuss each type of caring task in more detail.

Domestic tasks

This study found that 92 per cent of the young carers were involved in domestic tasks, a significantly higher percentage than the national profile

(72 per cent). Both young carers and their families felt that the young carers were doing too much.

Three young carers told us:

... We make the dinner, wash up, do the hoovering, wipe the table mats. Put the clothes in the washing machine or on the line. Sometimes we cook our main dinners (Toni, Joy and Emma 11, 10 and 8).

April lives in a lone parent family and is the sole carer for her mother. She is sometimes fearful of getting burnt when cooking and often has to climb eight floors with the shopping. She spoke of the type of domestic chores in which she is involved:

I Hoover, and polish, wash up and do the cooking... I go shopping and when the lift is broken I still have to bring all the shopping up. I really don't like doing the cooking because I don't want to get burnt because I know I have to look after mum and if anything happens to me I'm going to feel upset because I don't really know who is going to look after mum. (April, 10).

Leona has a similar level of responsibility, particularly when her older brother is not available:

I do the housework, I have to wash the clothes and tidy the washing machine. I wash the dishes, clean the kitchen, the bathroom and my room, I do the cooking when [Dennis] is not here to do it, I cook sausages, meat, bacon and eggs. (Leona, 9)

General

The national profile shows that 57 per cent of all young carers assisted with mobility and administering medication. This type of care is more common where the care recipient has a physical impairment (Dearden and Becker, 1998). Sixty eight per cent of Capital young carers were involved in these tasks, just above the national profile.

Penny has manic depression and at times is unaware of her surroundings. She therefore cannot be relied on to take the correct dosage of medication, and sometimes hallucinates and becomes incontinent:

When I'm high [hyperactive], he [Dennis] will give me my medication because I'll sometimes take more than I'm supposed

to take or take it at the wrong time. I've actually taken an overdose and not been aware that I was doing it.

Emotional Support

Many young carers also provide emotional support. Again, data from the national study show that 43 per cent of all young carers provide emotional support of some kind (Dearden and Becker, 1998). However, in the Capital Carers evaluation, over three quarters (78 per cent) of young carers were providing emotional support in the home. Eighty eight per cent of those caring for someone with a mental health problem provide emotional support.

It makes me sad when she is down, I just try and comfort her... if she's like that I don't really go out. (Dennis, 15)

When she [mum] is upset I give her a cuddle and say it is all right and stuff like that. (Martin, 13)

Helen cares for both parents but is the primary carer for her mother who is partially sighted, epileptic and hemiplegic. Helen commented on the emotional support she gives her mother:

I need to watch her all the time and try to pick her up when she is down or whatever. Also, because of mum I have to give more emotional support to dad to make sure that he is alright as well. He sometimes gets depressed because she gets depressed and takes it out on us. He gets more angry with her and then we have to be supportive of each other at these times. (Helen, 15)

Intimate caring tasks

Intimate caring tasks are performed by 32 per cent of the young carers compared with the national profile figure of 21 per cent. The figure for Capital Carers was even higher - 47 per cent - at the start of the evaluation period. A study by Aldridge and Becker (1993) showed that this type of care is the most difficult for both parents and children because of the embarrassment it can cause.

Sylvia has lupus and a blood disorder. Sometimes her joints are so painful she can't walk or use her hands which restricts her ability to wash and use the toilet. She told us:

There are days when I can't get upstairs to use the toilet and have to use a plastic bucket for whatever toileting I have to do

that I can't get out. She has to try and help me out and it's so hard.

Helen who cares for her mother who has epilepsy and is severely disabled is quite pragmatic about the intimate tasks she performs for her mother:

I still have to change her catheter bag and put in a new one and see that it works okay and occasionally I have to bathe and dress her but it's not too bad really.

Profile of care recipients

The profile of care recipients is very similar to the national profile, with slightly fewer young carers in Southwark caring for fathers. The only significant difference is in the category of 'others', which is significantly higher (see Table 7). Thirty three per cent of Capital Carers young carers were caring for more than one person which is significantly higher than the national profile of 12 per cent. Also many of the care recipients have multiple illness such as epilepsy, hemiplegia and visual impairment.

Table 7: Care recipients

Capital Carers Project compared to the 1998 national survey

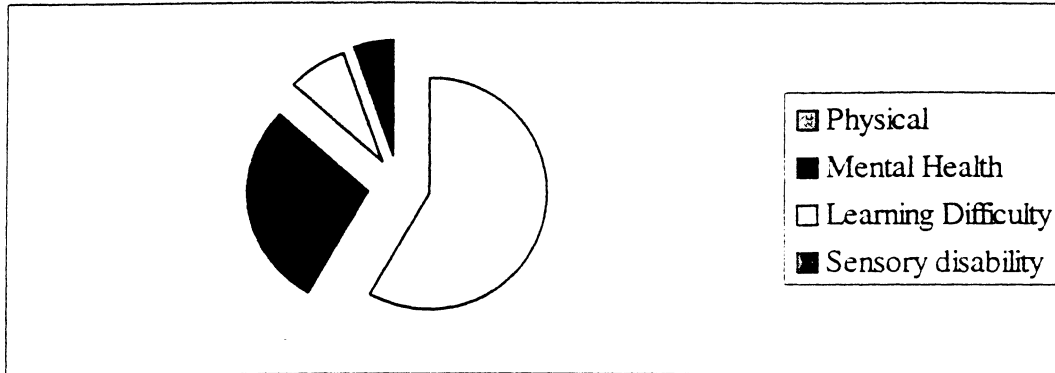
Care recipient	October 1997	April 1998	October 1998	National
Mother	56%	58%	54%	58%
Father	11%	13%	9%	13%
Sibling	26%	19%	26%	24%
Grandparent	-	4%	4%	4%
Others	7%	6%	7%	1%
Total	10%	100%	100%	100%
Number	27	79	107	2,588

Some young carers are caring for more than one person. Therefore there are more care recipients than there are young carers.

As Table 8 shows most of the care recipients have physical health problems, the most common conditions being: cancer (11 per cent), blood disorders (eight per cent), muscle wasting diseases (eight per cent), back injuries (three per cent) and Lupus (three per cent). Almost one third of care receivers have mental health problems. Dearden and Becker (1998) found that children providing care for someone with a physical condition

were more likely to provide higher levels of all types of care, other than emotional support, than those caring for someone with other types of condition.

Table 8: Nature of condition
Capital Carers Project



Note 'Physical health' includes physical illness and physical disability; 'mental health' includes mental health problems and substance misuse; 'learning difficulty' includes specified conditions such as downs syndrome, Alzheimer's disease and autism; 'sensory disability' includes visual impairment. Also some care recipients have more than one illness or disability.

Services received

The most common service received was social worker support. This accounted for 27 per cent of all services and was received by 58 per cent of young carers and their families. Eleven young carers (ie fifteen per cent of all young carers and their families) did not receive any services other than the help they got from the young carers Project. A major problem with the statutory service provision is its fragmented nature and the fact that there is little or no co-ordination. Health and social services, for example, who serve the same family, often don't know whether the other is involved. There is an obvious need for co-ordination.

Table 9: Services received
Capital Carers Project

Service	Number	Percentage of all services received
Social Work Support	42	27%
Home Care Services	15	10%
Educational Support	10	6%
Occupational Therapy	1	1%
Community psychiatric nurse	24	16%
Respite care	6	4%
Voluntary organisations	15	10%
Daycare centre/workplace	8	5%
Visiting nurses	9	6%
Therapy/clinical psychologist etc	13	8%

Figures are rounded to the nearest whole number and therefore may not add up to 100%. Some families are receiving more than one service.

Unfortunately, few of the families we interviewed spoke highly of the services received from social services or other service providers.

Sylvia (a mother with Lupus and a blood disorder), for example, does not have a social worker and has not been able to get an assessment of the family's needs:

When I went into hospital the neighbours looked after the children, social services provided a car to take the children to school... but it was the neighbours, a mother and two daughters who took it in turn to sleep over with the girls. It was really hard because none of them was well [the neighbours] and one of the daughters was a sickler [sickle cell]. If I had to move away the support just wouldn't be there.

Debbie and Ryan's parents are visually impaired and their sister has Myalgic Encephalitis (ME). They used to have home care for 10 hours per week. The parents were dissatisfied with the quality of home care and cancelled the service. Now Debbie and Ryan have extra caring duties:

We have no other services except for filling in forms which is done by volunteers from Home Start.

Heather was very critical of the level of support given by social services:

In the past before I was diagnosed as being ill, I had support from social services, things would just be going right and then they would pull out all the support and we would tick along for a while and then we would crash again...Trying to deal with social services ended in me breaking down and going into hospital...they were supposed to give me two weekend respite care and came up with one...I ended up in hospital.

Vanessa, who has severe back trouble and mobility problems, described the support offered to her by social services:

They said they could send some drivers to take me to the supermarket. But what's the point of taking me to the supermarket and dropping me off there if I can't walk around to pick up my shopping. I was so angry that I didn't bother... she [the social worker] just reeled off some numbers for me to phone. But I said that's not going to help me with my shopping.

If community care is to be meaningful it is essential that the services requested are of an acceptable standard and meet the specific needs of the individual carer and their family. The views of the families in this study suggest that the services offered sometimes do not meet these criteria.

Section Four: Meeting Aims and Objectives

The aims and objectives for the Project were set by Capital Carers and included five core aims: raising awareness of the existence and needs of young carers in the relevant social service departments, voluntary, educational and health services and other relevant agencies; promoting the young carers Project and identifying young carers in the Borough, ensuring that young carers from all communities are identified; providing a single point of contact for young carers offering information, support, advice, social and recreational activities; assisting young carers to identify their own needs, supporting each other and informing future service provision; acting as an advocate for young carers, promoting and safeguarding their rights as children.

The extent to which these aims were met by the Project is examined in this chapter.

1. To raise awareness of the existence and needs of young carers in the relevant social services departments, voluntary, educational and health services and other relevant agencies.

Once the development worker was in post she developed an awareness-raising programme over the first few months so as to give information about her role and the role of the Project and how young carers could be referred to it. This was done through presentations to social work teams, school assemblies and voluntary agencies as well as meetings and contacts with education welfare officers, visiting nurses, occupational therapists, community psychiatric nurses and other key personnel.

Between late December 1996 and December 1997, the development worker attended 15 small group meetings (each with an audience of fewer than five people), and made 43 larger group presentations, reaching a combined audience of 1,751 people.

Helping professionals to identify and refer young carers was an important part of the awareness raising programme.

Our evaluation suggests that:

- The Project has been very successful in terms of awareness-raising. The first referral was in March 1997 and by December 1998 the total number had risen to 73. Some awareness-raising continues but less than during the early months due to the large number of referrals already generated by the Project and the length of time needed to 'process them'. This is time-consuming work which adds considerably to the pressure on the development worker, who is the only person dealing with it.
- The focus of the awareness raising changed to a more informal and personal approach which seeks to put a young carer in touch with a range of specialist agencies including health, education and social services as well as voluntary agencies. There are also plans to work with the Education Action Zone, comprising two schools in the borough, in the hope that this will further develop agency networking. The development worker is a member of the Southwark Advocacy Group which has been very supportive of the Project's work with young carers. She is also involved with the Social Inclusion Group. Her involvement with the development group has the advantage that the Group uses her knowledge and information for further awareness raising among its constituent members. Moreover, networking presents funding opportunities. There is an obvious need for it to continue.
- Since January 1999, a Young Carers Project worker has been in post with responsibility for running the activity programme and the training and recruitment of volunteers. This should enable the development worker to spend more time on the Project's overall development work at a strategic level.

2. To promote the Young Carers Project and to identify young carers in the Borough, ensuring that young carers from all communities are identified.

From its beginning the Project has identified and supported a total of 73 young carers most of whom have been referred through the social, health and education services. Even though the identification and promotion work was directed at all the ethnic groups in the Borough the non-white

carers are predominantly from the black African and Afro-Caribbean communities.

- The development worker has tried to access other minority ethnic groups but has found this difficult due to the lack of information on young carers from Asian and Chinese/Vietnamese ethnic groups. As part of her outreach work to these communities, the development worker has made contact with the Cultural Unity Group in the borough and provided the LEAT with leaflets for distribution. She also tried to access some of these young carers through presentations to school assemblies. A major difficulty with this work is that because of cultural and family expectations some of these young carers feel it is their absolute duty to care for their relatives (Aldridge & Becker's 1998). It would be a mistake, however, to interpret this as meaning that all such carers have the automatic support of their extended family.
- There are still a significant number of young carers from the Asian and other communities who are not taking up the Project's services. The development worker addressed some 50 women from the Southwark Muslim Women's Association. However, to date, there have been no referrals from this community. To some extent this group and others from the Asian community constitute a hidden population and need to be specifically targeted. Closer contact with the Cultural Unity Working Group might help to ensure that the needs of young Asian and Muslim carers are met by the Project's services in future. Now that there is a project worker in place, outreach work to these and other communities could be intensified.

3. To provide a single point of contact for young carers that will offer them information, support, advice, social and recreational activities.

The development worker endeavours to provide young carers with a single point of access, offering support as well as information about relevant services. She has become known as someone who does things for young carers and who can access the relevant agencies on their behalf for help and information. The development worker is finding that some referrers are referring young carers to the Project in the hope that she will refer them on to other agencies.

- The development worker has collaborated with Southwark Carers to produce an information pack for young carers. This includes a copy of the Project leaflet, a Carers National Association magazine, fact sheets on how to access social services, health and state benefits, how to use complaints procedures and how to find someone to talk to. It also contains information on HIV and Aids networks and a copy of the Child Protection Policy document. There is a fact sheet informing young carers of their right to a community care assessment and how to start the process. The pack also contains information for young carers on all policies and procedures governing the Project.
- Respite care is provided by Capital Carers to some of the young carers' families to enable the children to participate in social and leisure activities. This respite care is on a 'request and demand basis' and is paid for via a social services agreement with the parent organisation Capital Carers. To date, seven young carers have received respite care (sitting service) provided by the parent organisation to enable them to take part in the social and leisure activities. For example, one family has received respite care to enable the three children to take part in these activities. Weekend respite care is being organised to ensure that one young carer who cares for both parents is able to take part in a weekend outing. The parents greatly value the existence of this service and are pleased to see their children get a break for social and leisure activities.
- The social and leisure activities programme has been one of the most successful features of the Project. The programme provides carers with a much needed 'time out' break to take advantage of activities they might not otherwise have access to. For example, some young carers who went on the weekend breaks had never been away from home before. All the young carers interviewed had been on trips and outings with the Project. These activities include ten pin bowling, ice-skating, an outing to Chessington Zoo and a number of trips to 'fast food' restaurants. In addition, there have been seven weekend breaks to the New Forest and a trip to Disney Land, Paris. All the young carers participate in the planning of these outings and activities which they greatly value and enjoy.

- Initially the group's Thursday night meetings were held on alternate weeks with one week for the 8-11 age group and the other for the 12-17 age group. These Thursday evenings were given over to social and leisure activities including games, group discussions, team activities and a supper. The children were collected from their homes by the development worker in a mini bus and taken to the Copleston Centre and then dropped off home again after the evening session. Since April 1998 the number of young carers has grown and there are now 4 groups, two for the younger and two for the older children meeting on a monthly basis.
- As well as the social and leisure activities, the Project also offers issue-based group work on a regular basis. Issues covered include sexual health (in the form of a game for older young carers), bullying (role play on feelings organised by a Southwark Carers Counsellor), and first aid training. Even though the decision on whether or not to participate is left to the young carer, it is considered important that the young carers are present to offer feed-back and information.
- Consideration is also given to the needs of young carers who may need to speak one-to-one with the development worker. For example, one stressed teenager was taken out to a local health club which gave her the opportunity to talk to the worker alone and receive some much-needed 'pampering'. Although the Development worker is unable to offer individual support to all the young carers referred, she can point them in the direction of the relevant agencies and services. This 'networking' is of particular importance to young carers and their families.

4. To assist young carers in identifying their needs, supporting each other and informing future service provision.

The fact that the Project's work is child-centred is very important. Young carers are consulted about the type of service they require and how they want it delivered. Future plans include the setting up of a counselling service (to help with issues such as bereavement) and mutual support groups related to geographical areas as well as grouped according to the nature of the disability. A befriending scheme is already under way and, to

date, has been modestly successful. The development worker has put together an excellent befriender's pack based on Young Carers Research Group literature, which supervises, supports and encourages the befriender. The scheme, however, lacks a formal training programme which is essential if it is to develop and achieve its objective.

- Since April 1998 the Project has offered a six week induction session for new young carers covering a wide range of issues including school, health and disability, and counselling. An occupational therapist was available for one of these sessions. For existing young carers there will be outings instead of meetings at the centre and reunions of previous groups of young carers. One young carer and his parent expressed concern about the reduction in the Project's leisure and social activities. However, given that 73 young carers are being helped by the Project, it may be somewhat unrealistic to expect these activities to be provided on a regular basis.
- One event which did much to help the young carers talk about their experiences and give them some self confidence was when 7 of them along with others young carers from other projects in the London area took part in the LWT Teen Challenge television session with the London Bubble training. As part of the programme they had to perform a drama about not wanting to care any more.
- Two young carers were part of the interview panel for the new project worker. As representatives of the user group, they drew up their own questions and took an active part in the interview process.

5. To act as an advocate for young carers, promoting and safeguarding their rights as children.

Advocacy work is crucial to the objectives of the Project but due to the pressure of work (itself an indication of success) it has not been possible to give it the prominence it deserves. The development worker is a member of the Southwark Advocacy Group. She also engages in collaborative work in relation to particular families over a range of issues helping them to gain access to the services they need. She helps with general advocacy work, but on more complex matters refers to specialist workers in the

field. For example, in education matters where young carers are having problems with school, she talks with the school authorities. Most of the schools, however, are now more aware of the issues surrounding young carers.

Some of the advocacy work done to date includes: advocacy on behalf of a young carer who was being bullied at school; consultation with the Health Authority to get a young carer moved up the waiting list for an operation because she was missing school; representations to the housing department in an effort to get one young carer and her mother moved to more suitable accommodation; and liaising with professionals across different statutory sectors to get escorts for young carers who were missing school or arriving late, or who were unable to travel long distances to school. The funding issue involved went all the way to the Director of Social Services level. At another level, the development worker accompanied young carers to the Benefits Agency office so that they could be made aware of their rights and know which questions to ask. She also held a meeting with the Head of Assessment at the Social Services Directorate about a number of issues surrounding young carers.

- Advocacy work can often overlap with helping the young person access practical support. However, while much of this advocacy work will undoubtedly continue to be done, there is also a need for a more formal and structured approach. This might entail, for example, the development worker working more closely alongside the young carers and assuming the role of advocate for them to secure the rights to which they are entitled under existing legislation. The development worker has written some documents and reports for Case Conferences and submitted letters to court in addition to regular reports to social workers on child support issues. She has also been invited to attend some Child Protection conferences. All advocacy work done on behalf of young carers is done with the consent of the families and quite often at the request of the parents to the benefit of the whole family.
- Now that a new project worker is in place the development worker is hoping to get more involved in inter-agency discussions with a view to playing a more active part in the advocacy and befriending aspects of the Project.

To date, a considerable amount of work has been done to meet the Project's aims and objectives, most of it successfully. The case for such a Project has been well made and it now remains for the Project to build on the foundation established and develop a number of key areas (see Section Six).

Section Five: Perceptions of the Project

Any evaluation should involve the views of those who use or are in any way affected by the Project. Interviews were conducted with some of the young carers who make use of the Project, some of their parents, a number of the professionals who referred the young carers to the Project and some of the Project volunteers.

Table 12: Sources of referral

Source of referral	Number	Percentage
Social Services	26	36%
Family	10	14%
Education Welfare	7	10%
Community mental health team	4	5%
Occupational therapist	4	5%
Voluntary Sector	4	5%
Social Services mental health team	3	4%
PACE	3	4%
School Counsellor	3	4%
YCRG	3	4%
School	2	3%
Self	2	3%
Bloomfield - Child guidance	1	1%
School nurse	1	1%
Total	73	99%

Note: Figures are rounded to the nearest whole number and therefore may not add up to 100 per cent.

The children and their parents were asked how they came to know about the Project and what their perceptions of it were.

Sylvia, who has Lupus and a blood disorder, said that she heard about the Project through a letter from the development worker:

At first when I was told about the Project, that was through the children receiving the citizen of the year award, I had the letter through the police, [the development worker] sent the letter through them as she didn't have my address. When I got the letter I was a bit wary, you know social services, fostering of kids. I had a lot of doubt. One day when I was really down and was in

a lot of pain I took the letter out and said 'well I'm going to ring her and have a talk and ask her to come and see the girls', and she did...She explained it all out.

Penny who has manic depression first heard about the Project through her social worker:

I think it's a brilliant idea because the children need to know what the real world is like ...When I heard the name Crossroads, immediately it went back to me about that programme that they had on television...and I read some literature that [the development worker] gave to me and I thought it was a really interesting and a good thing for the kids to do.

Jane, who is suffering from depression and has misused alcohol and other substances, first heard about the Project through her community psychiatric nurse:

The young carers Project was one of the things that the boys needed... it's been a lifesaver for this family.

Heather first heard about the Project through her son's social worker:

She [social worker] actually introduced us to the Project because she wanted Mehmet to attend it. [The development worker] came along with [a befriender] to talk to us about it. They wanted [the befriender] to work along side Mehmet on a one to one and spend some time alone with him. I had quite a lot of worries about that but [she] reassured me that all their voluntary workers go through a vetting system but I wasn't completely reassured at that.

Views of young carers

The young carers told us that they valued the Project because it gave them someone to talk to, contact with other children who shared the same experiences and as a source of information and learning.

Social and leisure activities

Here are some comments:

It [the project] takes us out to places, like it takes us bowling and things like that. I don't usually go out when my mum's in hospital but when I go out with Cathy my mum doesn't get worried because it's only for a couple of hours. (Dennis, 15)

You get to do things you wouldn't normally be able to do with mum like go to Chessington zoo and everyone goes on the rides and it isn't like going on your own which I normally do to please mum and dad. With the project I go on with my mates. I've enjoyed the weekends away to the New Forest and I'm really looking forward to going to Disney Land and Paris with the group for three days in February. (Helen, 15).

Helps us enjoy ourselves, we meet new people and have fun, we are taken to lots of activities. When she [Cathy] took us to McDonalds with Leona and Alice she told us a joke and everybody started laughing. (Joy, Toni and Emma)

We went with the project to Chessington zoo, it was great fun because Cathy got wet. (Debbie, 14)

Kennedy, [the befriender] has taken them to the aquarium and they have gone bowling, skating and the cinema. It's a treat for them that they don't get off me because I can't afford it they have a great time get taken for a meal and come back bouncing. It not only gives the children a break but me as well. There's also a holiday coming up in the Summer and they are going together, that will give them a weekend away which I couldn't have afforded. (Jane, Peter and Andrew's mother)

It hasn't taken away from me [as a parent]. In fact I feel like I'm gaining and the children are gaining. It picks up on the bits of motherhood that I might fall down on, like the day trips and lunches out. We used to do those things when I was working and was healthy, but we don't do these things much anymore and I'm glad that they've got somewhere to go and other children to be with. When the kids come home after an evening out with their group they are happy and full of beans, they are bouncy. It just raises their spirits. (Penny)

Joe enjoys his activities at the Project and looks forward to 'time out' from his caring tasks:

I enjoy it, we play basket ball, frisbee, bowling, ball games. I enjoy the activities and all the good times they give me. I would like to say thank you for all the time they have given me. (Joe, 10)

Joy said how much she and others valued the support of the smaller group:

We have a little group all to ourselves us three and another girl. We go out with two adults to places and it's so much easier. We all get to choose where to go. Last Thursday we went to the Pizza Hut and sometimes we go bowling or to the cinema. (Joy, 12)

Someone to talk to

One of the great benefits of the Project is the opportunity it affords young carers to talk about their experiences and concerns. One young carer spoke of why the Project played such an important part in her life:

[The development worker] is great, especially when my mum is down and then she is really good...She supports the whole family; mum sometimes rings her up just to talk to her. She listens to both mum and dad, especially mum, when she is down. So I know when I need help I can just call on the Project. (Helen, 15)

She's [the development worker] young and they can relate to her, they are more relaxed with her...if they need to speak to someone I know they will speak to [her] because they are relaxed with [her] and feel confident. (Sylvia)

Mixing with other children with similar experiences

Not surprisingly, children with similar experiences said they benefited greatly from having the opportunity to talk to each other about their situations and concerns. Parents too said how much they valued the help and support their children received from outside the family. It helped them realise that they were not so isolated and that there was nothing abnormal about their experience of living:

They talk about it [the Project] and they're excited and Leona can't wait until she sees her other friends in the group. She tells me about her other friend in the group whose mother has cancer and things like that. When I hear about other children who are coping with their parent's illness that makes me feel I can still cope at this level and that they [Dennis and Leona] can get support from other children, that they can share problems ... so they have benefited from it a lot. (Penny)

Meeting other young people and knowing that I'm not alone, everybody has a different problem but everyone is caring for someone close to them which is good. It's good to meet with other people in similar situations. (Helen, 15)

The Project has helped because we are mixing with other young carers. Even though we don't talk about the work that we do as young carers it helps us because we have a common background. (Debbie aged 14)

Ryan, who is Debbie's brother, went on to add:

This helps because we feel that they understand our situation unlike some of our school friends ... I sometimes have problems with people asking me what we do at home as if I was different from them. The only difference is that we help out a lot more at home. (Ryan, 12)

When he was interviewed again, almost a year later, Ryan said how much the Project had helped him open up his feelings to people.

One young carer talked about his 'lost childhood' and how the Project helped him partially regain it. He said that going out with the befriender helped him and was something he looked forward to:

When I go out with Kennedy I can actually be a child again.
(Andrew, 13)

Other aspects of the Project

Some of the young carers commented on the useful information and skills they learned from Project:

The first time Cathy came to visit us she discussed it [caring process] with us and gave us information and leaflets. (Andrew, 12)

We did a session on first aid and talked about what was wrong with our parents and how to deal with them. We also talked about bullying in school and watched a video and talked about the issues afterwards. I enjoyed them both and the first aid one was quite good. (Helen, 15)

We enjoy learning new things. I think it was when we went with Cathy and there were two women teaching us first aid. We learnt how to put a bandage on and to put people in the recovering position ... We would like more people to come and do sessions like first aid. More people to come in and give talks and visits. (Joy, 12)

Views of parents

The Project is child-centred but the involvement of the family (by agreement) is also important. In recent years some researchers have argued that the provision of such services would not be necessary if disabled people received adequate services in their own right (Keith and Morris, 1995, and Olsen, 1996). As part of the evaluation it was important to ascertain how parents felt about the Project and whether or not they felt threatened or undermined by it.

Most of the parents interviewed valued the fact that the Project helped young carers develop relationships with other people:

Joe may not want to upset me and talk about serious problems such as bullying at school to me but he would actually talk to Cathy and I'm happy to know that he talks to someone now. (Bernadette)

No, I've never felt undermined by the Project. I'm only grateful that they take April out for an evening. I also asked if they could help as I am the kind of person who has problems spelling, writing, reading and that kind of thing. I asked Cathy for help as April is changing schools next year. She filled in the forms for me and as I can't walk to take her to visit her different schools Cathy and another person [volunteer] actually took April round some schools so that she could make her choice which was great for me. (Vanessa)

Parents also valued the respite care offered by the Project. One parent spoke about how grateful she was for the sitting service provided by the Project:

When they go out on a Thursday I've got a carer who comes in and sits with me for three hours and she keeps me company and it's good. My feelings about the Project are very positive. It breaks down a lot of barriers. It's given me peace of mind to know that they are away from me, away from the fetching and the carrying and they can be children and have a laugh, just to be normal. You know when they are at home fetching and

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carrying for me they are like mini adults. So it helps them fit into their peer group and they look forward to meeting with other children. It's brilliant. (Sylvia)

One of the volunteers who is also a care attendant with Capital Carers had this to say:

When the children went to Margate I didn't get to go with them because I had to provide for one of the children who went. He wouldn't have been able to go because he looks after a 2 year old child and his mum even though he is only 8.

When asked about how worthwhile they thought the young carers Project was and how they would feel if it didn't exist, the children and their parents were very positive in their responses. All of them said that they felt the Project to be very worthwhile and 'long overdue'. An important reason given was that it provided the carers with a respite from their everyday caring tasks.

One parent said:

Very worthwhile and long overdue because they give the carer an outlet, a bolt hole. It gives them someone else they can turn to and it also brings out the fact that there is a need for supporting young carers to show how valuable they really are and that they are not taken for granted. It also gives the young carer an interest outside the home and somewhere to go to where somebody sympathises and understands what their problems are. If it carries on the work it may need to expand because there are an awful lot of young carers out there who haven't emerged yet. (Max)

Another commented:

I find the Project extremely good. It breaks down a lot of barriers. What I like about the Project is that the letters are not addressed to mum or dad but the children. It feels like there is somebody out there, somebody who listens and cares. I'm just glad they have that support. (Sylvia)

The views of professionals

The six professionals interviewed - two social workers, a community psychiatric nurse, and education welfare officer and a school youth worker

described how they heard of the Project, its usefulness and the referral process.

Learning about the Project

Some of the professionals involved had heard of the Project from literature they received from the development worker and others through Capital Carers and the launch of the YCRG research in Southwark. A few learned about it via awareness-raising exercises given by the development worker and from colleagues. One youth worker said:

I heard about the Project when we [school] got some material through the post and it came directly to the head teacher who then passed it on to me as the youth worker.

Others commented:

It came through the work that I do here in the sense that I knew there was a Project being set up. My team manager was actually involved in the management committee, so I knew about it from her. I guess also the flyers and information leaflets which are also useful.

I heard about the Project via the Crossroads carers' group in Southwark and I'd already referred this particular young person to Crossroads Care.

Reasons for referral

The majority of the professionals we spoke to had referred more than one child to the Project and had a variety of reasons for doing so. For example, a social worker referred one young carer (who cared for both his parents) to the Project because he had missed school for almost three years and had become socially isolated. She was looking at different ways of helping to get him back into school and thought the Project might be able to help. She also felt that the Project would give him another adult in his life and provide him with the opportunity to engage in social and leisure activities with other young carers who were children of his own age.

Another social worker highlighted the case of a young carer who was under considerable stress due to the volume of caring work she had to do at home and the emotional strain of caring for her mother who had dementia. In particular, the stress involved in looking after her mother

was so great that she was forced to give up college after the first year. The social worker referred her to the Project which was able to help her by putting her in touch with other young carers in the same situation. In cases like these the Project was able to strike the right balance in meeting-the needs of the young carers by providing practical help as well as emotional support.

The Educational Welfare officer who referred four young carers to the Project felt that it was an important resource for alleviating social isolation and helping to create much-needed peer group relationships:

Here he is being supported and is not on the fringe of things. He actually mixes with other children and does things. The other young chap is now 12 and he was spending a lot of time at home caring for his mum and dad and that has been so successful. If you had seen him two years ago I think you would have had no hope, but now he is a different person. For me as a worker, it's wonderful.

The same Educational Welfare officer said that because of her experience of the Project she would in future be more inclined to consider caring roles at home as a reason for childrens' absenteeism from school. If she found that children's education was suffering as a result of their caring roles, she would have no hesitation in referring them to the Project for help and emotional support.

All felt that their own objectives in referring the children had been met.

The value of the Project

A community psychiatric nurse who had referred three children from two different families felt that the real benefit of the Project was that it offered young carers the opportunity to engage in ordinary social activities like going to the cinema, or bowling, or just 'having fun' from time to time. He saw this as an important counterpoint to their experience of looking after someone with mental health problems. He said:

I am pleased that there is a link up, that all three children are going out and are happy, so I think in the objectives of having

fun and providing activity and healthy exchanges the young carers Project is doing its job.

A social worker described how highly she valued the Project:

It has certainly assisted this young carer. This young person's mental health was severely under pressure, but Cathy was very good at gauging when it was just right for this young carer to have time to herself with Cathy even to suggesting an individual outing. Another time she was really quite keen to encourage the young carer to meet others. So I think she got the balance really well.

The youth worker had referred one young carer to the Project and was considering referring two or three others. She greatly valued what the Project had to offer young carers and felt that it added another dimension to the kinds of support available to young people. In particular, she felt it was a great benefit to have workers who had access to the young carers outside of school and who were also in contact with their families.

The youth worker also mentioned the confidence she had in the Project:

Once you refer someone you have a sense of confidence that it will be followed up very thoroughly. The family will be fully involved and everyone will be consulted as much as possible and the young person will benefit. It's very reassuring.

A social worker felt that the value of the Project for the young carer she referred was that it reduced his social isolation and validated the fact that he could get on with other children. It also helped him to realise that he was not alone in being a carer, and it gave him a sense that he was important and could have some independence. The social worker said it had been very successful and 'made a huge difference in his life'. Another social worker commented that the Project has made a significant impact on the young carer and was a very good link in getting him back to school.

The community psychiatric nurse believed that the Project helped young carers to address 'what they are' and what they were doing. The professionals considered that the Project fulfilled a particular role and gave a service no other group could offer:

I think we would be reverting back to the kinds of levels of frustration that if it's not social services then who is it? Certainly the young people would not have the support outside the other institutions and they would be disadvantaged. Having been identified [as young carers] I think it's vital that their needs continue to be met. (youth worker)

I initially referred via the counselling service for carers that Crossroads have set up ... but I said 'I don't know whether it's going to be appropriate for this person who is sixteen'. I think this [the Project] achieves the same result but is pitched at the right level for young people. In this particular young carer's case she would either have myself, as social worker, or the psychiatric nurse who was really there far more for her mum and dad so I think it was better because she knew the Project was there for her. (social worker)

Most of those interviewed could not think of an alternative to the Project. They felt that it was a vitally important resource for young carers and one which by the help and emotional support it provided greatly enhanced the quality of their lives. When asked how they would feel if there was no carers Project, the Educational Welfare officer said:

It would be another resource taken away. I would be quite upset because I know from my own experience the effect it has had upon children. They need it. This kind of caring work is such a hidden thing which is why so many young carers find it difficult to talk about it. The Project is there for them, not just like another youth club but a place where they can get understanding and help. A youth club can't offer that.

An indication of the success and importance of the Project can be gleaned from the fact that all the professionals interviewed were of one mind in saying that they would have no hesitation in referring young carers to it and would certainly not want to lose it.

Section Six: Issues raised and Conclusions

This evaluation shows that the Project has met its main aims and objectives. Over the past three years it has managed to identify a large number of young carers from many of the communities in the borough and raised awareness amongst professionals, and a wide range of agencies about the needs of young carers and their families. It has been particularly successful in providing a single point of contact for those young carers identified and providing them with support and advice, and with social and leisure activities. Young carers have been encouraged to identify their own needs and have been shown ways in which they can support each other and inform future service provision.

Awareness raising

Now that a project worker is in place, the development worker will be free to resume awareness raising about the Project and the needs of young carers. While the Project was busy processing the large number of referrals the awareness raising work was scaled down. It now needs to be resurrected and carried out in a more strategic and carefully targeted manner. In particular, such targeting will have to be directed at schools and social services and at certain ethnic groups to highlight the key issues surrounding the needs of young carers.

Assessment

The development worker has written a document on assessment and providing services to young carers and their families. This contains ideas and suggestions for a more holistic approach and was disseminated to the relevant social services sections in Southwark. Copies were also sent to the Strategic Joint Planning Group which is a multi-agency group comprising social services, health, the community health care trust and the voluntary sector. Care provision from the social services is still very fragmented and emanates mostly from the adult sector. There needs to be greater co-ordination of service provision and more attention paid to the barriers and gaps highlighted by the development worker in the document she provided for them. The development worker might also consider producing a pack informing young carers of their rights under the

different legislation. All this will need to be part of a fresh targeting programme aimed principally at the adult section of the social services.

Young carers are acknowledged in both the Children Act (1989) and the Carers (Services and Recognition) Act 1995. In particular, the Carers Recognition Act gives the carer the right to ask for a separate assessment of their own needs. However, none of the young carers in this study appear to have had an assessment. In the national profile (Dearden and Becker, 1998) only 11 per cent were recorded as having had such an assessment. Even though young carers have the right to an assessment their own needs continue to be overlooked. An annual review of young carers would ensure that they are being supported appropriately and that their specific needs and those of their families are being met by the project and/or by other sources of support. This is borne out nationally by a study conducted by the Department of Health into local authorities' policies on young carers which found that there were still problems relating to services for young carers in the current legislation (DoH, 1996).

Education

The development worker has been particularly active in the sphere of education. However, notwithstanding the large number of school visits undertaken by the development worker and the talks given, the referral rate from schools has been very low. Much more strategic work needs to be done here to raise awareness amongst staff and pupils to help foster a more positive and understanding climate around issues like bullying, homework and absenteeism.

Bullying

Bullying can pose a particular problem for young carers because of the pressure of their responsibilities and their lack of a social life (Crabtree and Warner, 1999). The development worker has done valuable work on this issue conducting sessions for young carers as part of their six week induction programme. Her work in this area has been so positive that she herself has been invited to work with two schools in the north of the Borough as part of the Education Action Zone initiative. However, much more work needs to be done on this growing problem in close liaison with schools, education welfare, youth service and youth counselling staff. For example, schools could be invited to have one member of staff to 'act as a

link between young carers, the education welfare service, social services and young carer's Projects' (H. M. Government, 1999, p. 79).

A number of those interviewed including a volunteer, a professional, the development worker and young carers made some pertinent comments on the subject of bullying.

Young carers do not really have much of a social life. They go to school and then go home and so they don't really mix with a lot of other kids and because of that they are seen as different and I don't think other children understand and so they bully young carers. A lot of them are quite mature for their age and they find it difficult to talk about it and you can see they are upset or hurting and you don't know how to broach the subject. We did have one boy who was being bullied and suffered a lot because he was a young carer but ever since he started the project he has opened up a lot. (volunteer)

A lot of them are bullied, some if it is because other children have found out about their situation and some of it is because they are not very confident. Also the older ones are having difficulty managing the work load at school with what they have to do in the home. (development worker)

Being young carers creates differences in them that show. A young boy who I just referred because he is socially isolated and outside the home has no life skills he is being bullied and he doesn't have the skills to cope. It can happen if a young carer is placed in a group of young children who have no idea what stress they [young carers] are under. In a group like the young carers project this issue can be addressed. (EWO)

I get bullied at school but I don't like talking about it. Talking doesn't help. (Ryan, 13)

Some people at school bully me ... they just make it go on and on for days and days. (Peter, 11)

Health

Health is another area where more focused work might be undertaken. The development worker has already contributed to the local health authority training pack on carers. She has also tried, without much success, to access the health action zone initiative. However, more work needs to be done in relation to primary care groups and health action

zones. The Department of Health confirmed the value of young carers Projects when they stated in their report that 'Specialist young carers Projects were highly valued by young carers and their families, particularly for their focus on the child and their highly independent status' (1996, p.34). In addition, the National Carers Strategy (H. M. Government, 1999) looked at a wide range of issues in relation to young carers, especially education. It suggested that these issues be joined up for implementation at local level, and offered new money to local authorities to provide for carers as well as well as new legislation to address their needs directly.

Ethnicity

The Project has been very successful in accessing young carers from the Black community but not so successful with other ethnic groups especially within the Asian community. This may be because of cultural differences concerning the concept of 'caring'. This, combined with cultural beliefs and assumptions about family obligations, makes accessing young carers from these communities particularly difficult. It may be appropriate to take a different approach with these young carers and their families.

A fresh attempt needs to be made here making more use of a multi-agency approach, which would involve working with front line workers who have specific responsibility for Asian families. The Saraha Young Carers Asian Project at Greenwich could be contacted for advice on how to access young carers from this community. Leaflets and information packs could also be provided by a volunteer from the community who speaks the language. Such a person could also accompany the development worker and help her gain the trust of families or act as a link person who is known to the family. The development worker must continue to network with key individuals already working within these communities and make good use of the Cultural Unity Working Group. She has had some success, with the help of a council interpreter, in accessing young carers from the Turkish Cypriot community. A great deal of cultural sensitivity is required in working with people from ethnic minority groups. Now that there is a project worker in place, outreach work to these and other communities could be intensified.

Social Isolation

One of the main issues for young carers is the sense of social isolation many of them feel on being deprived of the time and freedom to participate in normal childhood activities. The Project plays a vitally important role here in providing young carers with the opportunity to participate in social and leisure activities. The provision of these activities is so important that it has been highlighted in the National Carers Strategy (H. M. Government, 1999).

Another aspect of caring which is easily overlooked is the degree of maturity it confers on young carers (Becker, Aldridge and Dearden, 1998). This is the case with many of the young carers attending the Project. Because of the nature and intensity of their caring tasks, many young carers grow to be older than their years, which in turn militates against their being able to engage in normal childhood activities. Many of them have, in a real sense, lost out on their childhood years. It is here that the Project has been of enormous help through its excellent activities and leisure programme. The only concern about these activities is their infrequency due to staffing problems. However, the Project and its parent organisation needs to ensure that this essential provision is not curtailed any further.

Family based approach

Even though the Project is child-centred, it tries, where possible, to meet the needs of the wider family. However, its primary focus must continue to be child-centred because, as Becker Aldridge and Dearden (1998) have pointed out, support for the individual carer automatically enhances the quality of life for the whole family. The greatest service the Project can offer to the families is its provision of breaks and leisure activities for the young carers.

The Project is ideally placed to take a more family based approach because its parent organisation is Capital Carers. To some extent this is already happening because of the way the development worker acts as an advocate on behalf of the whole family, helping them access services and entitlements, and providing the parents with some 'free time' through its sitting services and befriending scheme. Even though it is still crucial that young carers have access to support for themselves in the form of

befriending, counselling, personal help and advocacy, there is a need to work towards a more structured and holistic approach in line with other young carers projects like the one at St Helens, where the needs of young carers and their disabled parents are addressed in the context of the whole family. The setting up of a family support group, for example, could be based on 'the principle of self help to enable families to enjoy life together or with others of similar interests' (Aldridge and Becker, 1998). It should be relatively easy for the Project to move in this direction given the high esteem in which it is held by so many of the young carers and their families as well as the professionals interviewed.

Without the help of this Project many young carers and their families would not have any outside support at all. For this reason alone, it is imperative that the work of the Project continues and develops. The good record of this Project, however, is in contrast to the overall lack of services to young carers and their families in other parts of the UK, which has been confirmed by the national survey (Dearden and Becker, 1998) and a Department of Health survey (DoH, 1996).

Staffing

It is quite remarkable how much has been achieved by the Project to date given the staffing levels and budgetary constraints. Over the period of this evaluation the Project has been managed by just one full-time worker and one full-time member of staff with seven volunteers. There is a limit, however, to the amount of work that can be carried out by such a small team of workers. The fact that so much has been achieved is a tribute to the hard work and initiative of those involved in running the Project. Ideally, more full-time staff and volunteers are needed to help the Project meet its current needs, to say nothing of any future developments.

Funding

Closely allied to the staffing issue is funding. The Joint Finance core funding for the Project runs out in September 1999 leaving its future financially insecure. Even though it has received Lottery funding for a Project worker, there are now real fears for the future financing of the Project. This, unfortunately, is a situation all too common for such Projects. According to Becker, Aldridge and Dearden (1998), a proper funding strategy which gives priority to the needs of young carers and

their families is essential if these needs are to be met in a consistent and secure manner. In this study, Project staff have said that it was unacceptable, given the precarious nature of the funding, to raise hopes and expectations regarding services which might not be fulfilled. It would be a tragedy if the individual case work and face to face work currently conducted with young carers and their families in this area were to cease due to lack of proper funding. The work of this Project (and others) is too important and valuable to be solely dependent on short term funding and the vagaries of the Lottery.

Conclusion

This Project has in a short space of time established itself as a very successful service, highly valued by the young carers, their families and the professionals who refer to it. Much of the credit for this must go to the development worker who has placed her own enthusiasm, energy, initiative and inter-personal skills at the disposal of the young carers and their families. The project continues to meet the needs of a growing number of young carers, providing them with help and assistance not available elsewhere in the borough. A great deal has been achieved and much remains to be done. However, unless the project is put on a secure and long term financial footing, a much needed and valuable resource for young carers and their families in the borough of Southwark will disappear.

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