

Young Carers in Southwark

The Hidden Face of Community Care

Final Report
Prepared for the London Borough of
Southwark Social Services Department

by Betty Newton and Saul Becker
Young Carers Research Group
Loughborough University

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"I never go out to play ... I never have time to go outside and play with my friends or do the normal things a child would do, like go over to their friends and see how they are ... If my mum was well I could just go out to play and do the normal things a normal child would do."

Bafikile, aged 11, caring for three brothers and a mother with AIDS

"I was about 13 or 14 when I took an overdose and everything because I didn't want to go home no more. I just hated life ... I was so young and my freedom was just cut off completely. I couldn't go out and nothing like when I came home from school ... I look after my brother and everything."

Paula, aged 15, caring for a two year old brother with Down's Syndrome

"I would like someone to talk to about things and help me ... just help me."

Jodie, aged 13, caring for a mother with mental health problems

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Executive Summary
Young Carers in Southwark: The Hidden Face of Community Care

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1. Definition and Extent

1.1 Young carers are children and young people under the age of 18 who are helping to care for a parent or other family member with a physical disability, learning difficulty, mental health problem, HIV/AIDS, other long-term illness, misuse of alcohol or drugs. As primary carers they spend a substantial part of their time in day to day care or are involved in personal and intimate care of another person.

1.2 There are no precise figures on the number of young carers nationally or in Southwark. However, analysis of the General Household Survey of Carers suggests that in Southwark there are about 1,000 *adult* carers who started caring in their childhood (before their sixteenth birthday). Southwark Social Services may wish, at a future date, to seek out some of these adult carers to explore how their needs as carers have changed during childhood and into adulthood.

2. Scope of the Southwark Study

2.1 The statutory services in Southwark have had difficulties in identifying significant numbers of young carers in their area and there was growing concern that a group of vulnerable children were not having their needs met. Identifying young carers appears to be a problem that many statutory authorities are confronted with; many young carers and their families are worried that if their situation becomes known to social workers there is a danger that young carers may be taken away from their parents, or *vice versa*.

2.2 In fact, Southwark Social Services Department and other agencies in contact with young carers were not identifying and defining them as such. The Department *is* likely to be in contact with many young carers and their families, through its home care and other services. Moreover, many young carers do not define themselves as 'young carers', thus exacerbating problems of identification for statutory service providers.

2.3 This study, commissioned from the Young Carers Research Group by Southwark Social Services Department attempts to examine the experiences of young carers in the borough, to identify their needs, and to outline some of the policy and practice implications for the Department.

3. Methodology

3.1 Young carers were identified by the Young Carers Research Group over a period of six weeks, starting in February 1996. Many organisations, including those from black and minority ethnic communities, were contacted by letter, fax and telephone, and given details about the aims and objectives of the research.

3.2 In total, more than 70 letters/faxes were sent and over 210 telephone calls made to identify 27 young carers in the Borough and to go on to interview 12 of them for this report. Five respondents were from black and minority ethnic groups. All interviews were either conducted in the young carer's home or at another mutually agreeable venue in Southwark. The report provides extensive accounts of young carers' experiences in their own words.

4. The Respondents

4.1 The twelve young carers range in age from 9 to 17. The average age is 14.

4.2 The average age at which caring started was 8. The youngest age at which caring started - for three of the 12 respondents - was five years old. The gender breakdown showed that of the 12 interviewed, 11 were girls.

4.3 The average length of time for which the children had been caring was 5.9 years. Many had been caring for considerably longer (12 years in one case - a girl currently aged 17).

4.4 Between them the children are caring for a wide range of relatives, including mothers, fathers, siblings and grandparents, with a range of conditions and illnesses, including HIV/AIDS, epilepsy, learning difficulties, mental health problems, physical impairment, visual impairment and dementia.

5. Tasks Performed

5.1 The tasks performed by the young carers range from basic domestic duties to intimate caring responsibilities.

5.2 Specifically:

- 83 per cent of the young carers are involved in domestic tasks (compared with 65 per cent nationally)
- 50 per cent are involved in more general caring tasks such as assisting with mobility and administering medication (61 per cent nationally)
- 42 per cent performed intimate caring tasks such as toileting (25 per cent nationally)
- 50 per cent provided emotional support in the home (25 per cent nationally)
- 42 per cent provide childcare to their siblings (11 per cent nationally)
- 58 per cent are involved in other administrative and escorting related tasks, such as accompanying parents to doctors, translating, filling in forms etc. (10 per cent nationally).

6. Effects of Caring

6.1 Two thirds of the young carers said that they missed school because of their caring tasks and responsibilities (compared with a quarter nationally).

6.2 Caring also has emotional consequences which can severely restrict a child's social life and friendships.

6.3 Some young carers experience 'courtesy stigma' - stigma by association where their parent has an illness or condition which carries a high degree of stigma, as in

the case of HIV/AIDS or mental health problems. These young carers, and their parents, often have the greatest fear of becoming known to statutory authorities.

7. Young Carers' Needs

7.1 Young carers' needs can be classified under three broad headings:

- the need for information
- the need for support and someone to talk to
- the need for practical services.

8. Policy and Practice implications

8.1 A Rights Based Approach: Young carers are children first and carers second. They have rights which are protected by law (Children Act, NHS and Community Care Act, Carers Act and the UN Convention on the Rights of the Child), but which are all too often overlooked. These rights include the right to a secure and stable childhood and the right to realise their full educational potential. It should be the duty of professionals to ensure that young carers receive the services and support to which they are already entitled, and to develop provision which meets their needs in a sensitive way.

8.2 An Interprofessional Approach: Young carers' needs must be met by professionals from social services, health, education, youth services, leisure services and from the voluntary sector, working together across professional boundaries. Statutory and voluntary organisations can offer information on a whole range of services. The need for someone to talk to and for emotional support can be met by the setting up of befriending and support schemes involving youth and community counsellors. Practical services can be provided to young carers and/or the person for whom they care by social services under the Community Care, Carers and Children Acts

8.3 Allaying Fears: There was considerable anxiety and fear about statutory agencies, particularly social workers, who it was felt might intervene in family life in a punitive manner. This 'image' problem will need to be addressed by Southwark Social Services Department if it is to be effective in identifying further young carers, in assessing their needs and in providing support. The Department needs to let young carers and their families know that they will receive a sensitive response if and when they become known to the Department. Publicity information (leaflets etc.) would help here.

8.4 Identifying Young Carers: Social services and social workers do have a problem in recognising and identifying young carers. Many of the young carers identified by the Young Carers Research Group were already in contact with social services, mainly through domiciliary services provided to adults in need, but the Department had not defined them as 'young carers'. There will be many young carers and their families already in contact with the Department, and many more who are not.

8.5 Specific awareness-raising and training strategies on Young Carers: These are a matter of urgency and must be developed for social services staff and others outside the Department.

- Joint sessions across professional boundaries facilitate the exchange of information and ideas and provide the greatest opportunities for developing an interprofessional approach.
- **In-Service Training:** This could incorporate young carers' issues to help staff in the recognition and identification of young carers. Examples of such issues are: the awareness that any family with children which has a member with an illness or disability may also have young carer(s); that when in contact with these families social services staff, particularly in the adult division, need to ascertain *who* is doing the caring and not make assumptions that parents are caring for disabled children or that adults are caring for their partners; and that fear of professional intervention can be allayed if the existing legislation is used, and seen to be used, to promote the maintenance of the family unit rather than its fracture.

8.6 Assessment: Young carers have the right to request an assessment under the Carers Act but their needs cannot be looked at in isolation - the needs of the whole family must be assessed. This will necessitate the provision of care packages to families in receipt of no services, and the review of existing, possibly inadequate care packages to others. Joint training and awareness raising will enable professionals to work together to identify young carers and to arrange for assessment of their individual needs.

8.7 Services Required: Notwithstanding anxieties about statutory agencies, young carers said that they would welcome more support from the social services in the borough. What they wanted included: respite care, help with simple household tasks such as laundry, cleaning and shopping, and help with general and intimate caring tasks. These can be provided or arranged by social services under the Community Care and Children Acts. For example, if young carers are deemed to be children in need, services can be provided to the family as well as the child under the Children Act. Practical services can include home care, meals on wheels, day centre provision, equipment and adaptations in the home and respite care.

8.8 Respite Care has a particularly important role to play in enabling young carers to get to school and to find time and space to do activities necessary for healthy childhood development. What is needed are strategies to ensure that young carers are able to get a break from caring either through the provision of respite care for the adult they are caring for or the consideration of more innovative schemes to give the young carers a break. Currently respite care services on the children's side are specifically for children with disabilities - young carers would not be eligible for these services.

8.9 Provision of Information: Information can be provided by a range of agencies. Social services departments can provide information on how to access services, claim benefits etc. Health care professionals and voluntary organisations can offer information on specific illnesses, prognoses, care management etc. Voluntary organisations can offer more general advice and information services, advocacy etc. Information needs to be child-centred and must take into account language and literacy abilities.

- Advertising the existence of respite care and other support and services might help in bringing 'out' many young carers who previously had little, if anything, to come 'out' for. The provision of services and support would help the Department to identify young carers. Provision of services is a necessary precondition to the success of wider identification strategies.

8.10 The need for someone to talk to: Counselling and emotional support could be met by initiating befriending and support schemes, possibly from outside social services which may be perceived in a less threatening light. Befriending may be better provided by youth and community workers or by trained and vetted counsellors/befrienders, monitored by voluntary agencies.

8.11 Other Help: Staff in social services should also familiarise themselves with other services available within the borough. A knowledge and awareness of what is available will enable staff to work with other agencies and with children and families to find acceptable services and support for them.

8.12 Charging Policies: Social Services should monitor the impact of charging policies on young carers.

8.13 A Designated Project: Specific young carers projects such as the new one in Southwark funded through Joint Finance, can be a valuable way of meeting young carers' needs. Ideally projects should be child-centred and the services provided to suit the circumstances of individual young carers.

- However, projects cannot by themselves deal with all the needs of young carers and their families; establishing a young carers project should not be seen as an opportunity to pass on all young carers' issues to such a project. Young carers need to be 'owned' by a number of departments and agencies, and seen as an important area of work for all professionals in the field. Unless this is the case young carers and their families in contact with the Department will continue to be overlooked - as they will still not be defined as young carers.
- There should be effective mechanisms in place to ensure that the views of young carers are sought, listened to and taken into account. Feedback can be sought through consultation and/or the establishment of user groups which will inform the development of the Young Carers Project. They need to be involved at every level if service provision is to meet their needs. The project should have a set of practice guidelines for work with young carers and should be monitored and evaluated to ensure it meets needs in as effective and efficient a manner as possible, given limited resources.

8.14 Ethnicity and Culture: Of the twelve respondents, 5 are from black and minority ethnic communities.

- When identifying young carers, assessing their needs and providing services, professionals must be sensitive to ethnicity and culture, gender and age. The specific cultural, religious and ethnic needs of young carers and their families

must be identified and responded to in a sensitive and appropriate manner. Only those services which are culturally acceptable to the whole family should be offered.

- There are real challenges for service providers when responding to young carers from these communities. There is a widespread belief that Asian and other ethnic communities tend to 'look after themselves' because of their extended family network and culture, and that services need not therefore be provided to support carers. This is a myth. Children from black and minority ethnic cultures do provide extensive and intimate care, and, like white children, experience the same effects - the denial of childhood, educational problems and so on.
- Young carers from black and minority ethnic cultures are often used as interpreters and translators within the family group, often as the link between their parents and the various agencies or services. All too often they have to interpret and translate information relating to official forms about which they have little knowledge or understanding. Young carers should not be taken advantage of in this way.
- It was difficult to access young carers from black and minority ethnic backgrounds (especially Vietnamese/Chinese and Asians) for a wide range of reasons, including cultural identity, suspicion, fear and family honour and tradition. Service providers need to make extra effort to identify young carers from these communities and meet their needs in a sensitive and non-threatening way. Liaison and close cooperation with established black and minority ethnic groups and community organisations is likely to provide the best way forward for this.

8.15 Gender: Although gender is not the major factor in determining which children within specific families become young carers, it can play a part in some families. Professionals too can subconsciously assign traditional gender roles. Care must be taken to ensure that assessment and service provision avoid and remedy such gender stereotyping.

8.16 Age: Many young carers start caring at a very early age. This needs to be acknowledged when identifying, assessing and providing services to them. While needs are broadly similar, some will be age-specific. The age and level of understanding of the child must be considered at all times.

8.17 Prompt and continuing action is required to prevent young carers remaining the hidden face of community care in Southwark.

Section One: Aims, Objectives and Methodology of the Study

The statutory services in Southwark had been unable to identify substantial numbers of young carers in their area and there was growing concern that a group of vulnerable children were not having their needs met. This study was commissioned by Southwark Social Services Department to examine the experiences of young carers in the borough, identify their needs and outline the policy and practice implications for the Department.

Young carers are children and young people under the age of 18 who are helping to care for a parent or other family member with a physical disability, learning difficulty, mental health problem, HIV/AIDS, alcohol or substance misuse, or other long-term illness. Southwark Social Services is particularly interested in the experiences of two groups of young carers:

- those who are primary carers and/or spend a substantial part of their time in day-to-day care;
- those who are involved in the personal and intimate care of another person.

Because of the ethnic diversity of the borough, Southwark Social Services Department requested the inclusion in the study of at least two young carers from black and minority ethnic communities as well as some young carers under the age of twelve.

Methodology

The process of obtaining names and addresses of known young carers in the borough began on 1 February 1996 and lasted some 6 weeks. Organisations, including many from black and minority ethnic communities, were contacted by letter, fax and telephone, and given details about the aims and objectives of the research (Appendix 1 provides a list of all organisations and agencies contacted). In the first instance some 100 telephone calls were made to professionals and volunteers. Some of these then contacted parents on our behalf seeking permission for us to approach young carers.

As a result of these contacts **twenty seven** young carers were identified and **twelve** agreed to be interviewed. In total, more than 70 letters/faxes were sent and over 210 telephone calls made to identify and access the 12 young carers interviewed for this Report. The interviews were carried out over a period of six weeks and involved the researcher visiting Southwark on five occasions, staying for two days at a time. All interviews were either conducted in the young carer's home or at another mutually agreeable venue in Southwark.

The interviews with the young carers were semi-structured and relaxed, designed to elicit as much personal and biographical information as possible from them about their lives as carers, as well as their experiences of outside support services. All those interviewed were reassured about the confidentiality of the research and the names used in this report have been changed to protect their identities. As well as providing an insight into their caring tasks, the interviews also provide information about the nature of the illness or disability of those for whom they care. All the interviews were recorded on tape by the researcher and transcribed and analysed thematically, as with previous Young Carers Research Group studies (Aldridge and Becker, 1993; Dearden and Becker, 1995).

A number of other identified young carers declined to take part in the study, for example, one primary school had a young carer who looked after his mother who had mental health problems. The mother, according to the head teacher, refused to let her son be interviewed. Two other children, who looked after their disabled father who is a wheelchair user, were keen to be interviewed but withdrew at the last moment. A further two young carers were identified by the education welfare services. These two were going through a traumatic time and the EWO felt that this would not be a good time to interview them. A 14 year old girl living with foster parents also agreed to be interviewed, but when the researcher arrived to meet her she had returned home. Further cases involved two young carers looking after mothers who were suffering from terminal cancer. It was considered by the social worker involved that it was too soon to interview them as they had only recently been informed about their mother's condition. Finally, another social worker drew attention to the case of a 14 year old boy who was caring for his severely disabled mother and was doing practically everything for her including the most intimate caring tasks. We could not interview this young carer because of a departmental change in personnel.

Section Two: Literature Review

Young Carers: Then and Now

It is known that children have been providing care for other family members across 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. This has a lot to do with the 'hidden' world many young carers inhabit. One study of children in history (McLaughlin, 1976) tried to make sense of "the still unbroken silence that conceals the fortunes of the vast majority of children and parents" (McLaughlin, 1976:139). As far back as the 11th century, she reports, there is evidence that children carried out caring roles usually in response to the death of one or both parents. This continued throughout the 13th and 15th centuries in response to the changing conditions in society and particularly the practice of apprenticeship which continued right up to the 16th century. It is difficult to understand from the vantage point of the late 20th century what life must have been like for children who lived in another age. But the little archival evidence we do possess suggests that the practice of caring for parents, and sometimes whole families, was quite widespread. A useful source of information here is literature, especially the novels of writers like Dickens and Hardy. Dickens' *Little Dorrit* (1857) and Hardy's *Tess of the D'Urbervilles* (1891) are perhaps the best known examples, as are the works of the Irish writer, Maria Edgeworth, who, along with her father, "brought up her 16 younger brothers and sisters" (Robertson, 1976:421).

In spite of this descriptive literature, remarkably little research has been conducted into analysing the experiences of young carers. Indeed it has only been since the mid 1980s that qualitative research has been generated. The two earliest and best known studies of this period were the Tameside (O'Neill, 1988) and Sandwell (Page, 1988) studies. These, however, were rather limited in scope and only intended to stimulate interest into the incidence of young caring and the possible effects it had on young children. It wasn't until 1990 with the setting up of the Young Carers Project at Carers National Association (CNA), that more systematic research began. Since then there has been a steady stream of publications and studies including those by Bilsborrow (1992), Aldridge and Becker (1993), and Frank (1995). These have for the most part concentrated on the needs and experiences of young carers. Other studies, including Grimshaw (1991), Elliott (1992), Segal and Simkins (1993)

and Alexander (1995) have dealt with the experiences of children caring for someone with a particular illness or disability.

These studies, along with the growth of services and the numerous articles in academic and other journals, have made it possible to collect information on a large number of carers and have contributed to an awareness-raising process. 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).

A prominent feature of much of the earlier research was that it tended to be descriptive rather than analytical in nature. The first study to adopt a more analytical approach was the Sefton study (Bilsborrow, 1992). This provides a picture of the experiences and needs of young carers by giving them a voice of their own, and in doing so it set a pattern for much of the research which followed. It has now become clear that there are fundamental differences in the conditions and effects of young caring which suggest 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. In particular the Young Carers Project has made an invaluable contribution to the continuing recognition of young carers as a distinct group of carers. Its work has now progressed to co-ordinating research development as well as offering membership and a contact point for children and young people. It also provides policy consultation for local authorities along with support and advice to workers in contact with young carers. The Young Carers Project endorses a child-centred approach and highlights the social impact of caring in terms of the quality of life of young carers. Such an approach is based on the view that these young people are 'hidden' carers because of a complex range of factors, including fear and their ability or reluctance to see themselves as 'carers'.

Meredith (1990) promotes advocacy and befriending and places a high priority on supporting local development work as a way of addressing the complex issues surrounding welfare provision for young carers. He has also been instrumental in highlighting the opportunity presented by the Children Act and the Community Care legislation as useful vehicles for putting young caring on the agenda and hence facilitating service provision.

Qualitative research was essential when young carers were generally ignored by policy makers because the hidden nature of the issue meant it was impossible to identify a representative sample of young carers. Such studies adequately compensate for their lack of quantity by providing rich data which is both powerful and moving. Because most young carers are 'hidden' there has been a temptation among some researchers to contact professionals who are in contact with them rather than dealing directly with young carers themselves. The problem with this type of approach is that it removes the need to find and identify young carers and obviously lacks the perspective of the young carers themselves. Professionals' perceptions of the effects of caring, for example, may well be different from those of the children in question.

Medical Literature

There is now a substantial body of medical literature relating to specific illness and disabilities which adopts the care receiver's perspective, or focus on the care receiver's disorder, but which incorporate children who care because of the nature of the particular medical condition. This work is particularly important because it addresses the experiences and needs of the child as a carer and as a child at risk (from both the effects of early caring and the risks of disease). Because of the severity of certain disorders and their physiological effects on adults, the impact on the family as a unit - and therefore the child - is considerable. For example, where Parkinson's Disease affects a parent in the family environment, it has a subsequent impact on the child. Similarly with Huntingdon's disease, where the effects can be even more complex (see Harper, 1986; Tyler, 1990). In these cases the nature of the disease enforces action on the part of both medical and welfare professionals. It inevitably imposes a child-centred view, with the result that the more severe the condition, the more attention is focused on those affected by it. Tyler (1990), for example, highlights the effects of Huntingdon's and how it can compromise the parental role, resulting in stressful home conditions and an extra burden of responsibility on the child. The nature and severity of the adult's illness or disability is not only a determining factor in the emotional or physical effects on the child, but also on the level of responsibilities (i.e. caring) the child must undertake. Stafford (1992) examines the effects of parental alcoholism on children and Grimshaw (1991) focuses specifically on the child's perspective where Parkinson's Disease affects a parent. Honigsbaum's (1991) work on HIV/AIDS and children is also particularly relevant. As the incidence and prevalence of HIV and AIDS increases, it is reasonable to assume that the number of young carers in such situations is also set to

rise. This has already been confirmed to some extent by Alexander (1995) and Imrie and Coombes (1995). The plight of these young carers looking after parents with HIV/AIDS has further been emphasised by Geballe *et al* (1995), who have described them as 'the forgotten children of the Aids epidemic' (p.xi). A major criticism, however, is that such research tends to talk rather abstractly about the issues rather than directly with the young people about their experiences.

Some facts and figures

There are no specific national figures for the total number of young carers, only estimates based on regional surveys. The earliest of these were based on the 1988 studies in Thameside and Sandwell which suggested that there might be around 10,000 young carers nationwide. A more recent survey of projects on Merseyside by Mahon and Higgins (1995) suggested that the real figure might be much higher, somewhere between 15,000 and 40,000.

Gillian Parker's (1992, 1994) secondary analysis of the 1985 General Household Survey suggests that approximately one fifth of all **adult** carers nationally are aged between 16 and 35 years. Given that there are some 27,000 carers in Southwark over the age of 16, it is reasonable to assume that a fifth of these would be in the age group of 16-35. This would result in a figure of 5,400 in the 16-35 age group. Parker's analysis also suggests that 17 per cent of these will have been caring **before** their sixteenth birthday. Applied to Southwark, this suggests that there could be about 1,000 adult carers (aged 16 and over) in Southwark who started caring in childhood (before their sixteenth birthday). Southwark Social Services may wish, at a future date, to seek out some of these adult carers who started caring in childhood to ascertain their views about the caring experience and their needs, and how these needs have changed as they have moved through their late teens into adulthood.

In the remainder of this report we present the findings of detailed interviews with twelve young carers in Southwark.

Figure 1: Details of the Twelve Young Carers Interviewed in Southwark - Summary

Young Carers' Details

	Valerie	Bafikile	Tony	Nicola	Nuala	Paula	Jodie	Khabo	Helen	Kiran & Manisha	Debbie
Age	17	11	9	14	15	15	13	17	13	16 & 17	13
Country of Birth	England	Zambia	England	England	England	England	Barbados	Sierra Leone	England	England	England
Ethnicity	White European	African	White European	White European	White European	White European	Afro-Caribbean	African	White European	Asian	White European
Care For	Mother, Brother & Grandmother	Brothers & Mother	Father	Mother	Brother	Brother	Mother	Brothers	Mother	Mother	Mother/Father Brother
How Long Providing Care	Brother 12 Yrs Grandmother 2 Yrs	'For many years'	2 Years	7 Years	5 Years	3 Years	8 Years (Intermittently)	6 Years	8 Years	5 Years	6 Years
Age Started Caring	5	Since can remember	7	7	10	12	5	11	5	11 & 12	9
Current Education	6th Form College	Primary School	Primary School	Not Attending	Comprehensive	Comprehensive	Comprehensive	FE College	Comprehensive	Comprehensive & FE	Comprehensive

Care Recipient

Relationship to Carer	Brother, Mother & Grandmother	Brothers & Mother	Father	Mother	Brother	Brother	Mother	Brother	Mother	Mother, Father, Brother	
Illness/ Disability	Autism, Learning Difficulties & Dementia	HIV/AIDS	HIV/AIDS	Epilepsy	Incontinent, Blood Disorder, Learning Difficulties, Hyperactive	Learning Difficulties	Mental Illness	Hole in Heart	Severely Disabled, Epilepsy	Epilepsy	Visually Impaired/Blind/ Dyslexic
Current Work	None	None	None	None	None	None	None	Domestic	None	None	None/Sick Leave
Housing	Council House	Housing Assoc.	Council Flat	Council House	Council House	Council House	Unknown	Council Flat	Council House	Council House	Council House

Family Members

Brother	One, 15	Three, Younger Twins 5, Baby 1	None	None at Home	One, 5	3, at Home(one older 23, & two younger 3 & 5)	None	One (older 21)	None	One, 9	3, Younger Twins 2½ One 11
Sister	None	None at Home	None	One, 13	None	None at Home	None	Two (younger, 14 & 6)	None	1 (Older 17) 1 (Younger 16)	2 (Older, 16 & 17)
Parents	Mother	Mother	Father	Mother	Mother	Mother	Mother	Mother	Mother/Father	Mother/Father	Mother/Father

Section Three: Pen Profiles of Young Carers in Southwark

This section of the report provides a brief profile of the twelve young carers interviewed for this Report. Figure 1 also provides an 'at a glance' summary of each respondent's biographical details and caring responsibilities.

The twelve young carers range in age from nine to 17 with an average age of 14. The average age at which caring started was eight. The youngest age at which caring started - for three of the 12 respondents - was five years old and the average length of time for which the children had been caring was 5.9 years. Many had been caring for considerably longer (12 years in one case - a girl currently aged 17). Between them the children are caring for a wide range of relatives, including mothers, fathers, siblings and grandparents, with a range of conditions and illnesses, including HIV/AIDS, epilepsy, learning difficulties, mental health problems, physical impairment, visual impairment and dementia.

Nicola is 14, and, along with her 13 year old sister looks after her mother . They have recently moved to a new council house and live on income support. Nicola undertakes the primary care of her mother who is epileptic with some help from her sister. Whenever her mother has an attack she often falls over and hurts herself. Nicola has been caring for her mother since she was seven. She undertakes a range of domestic and general chores like helping her mother with the stairs, in and out of bed, as well as more personal and intimate tasks such as washing her back and hair and helping her with toileting. She also helps with any necessary paperwork as all the family have learning difficulties. Nicola herself is dyslexic and hasn't been to school for four months. The main reason for her poor school attendance is that she is afraid to leave her mother on her own in case she has another attack or takes an overdose. Her mother took an overdose when Nicola was 11 and Nicola had to call an ambulance. Her mother has become very dependent on Nicola and has told her she can't cope without her. She feels reassured when she has Nicola at home with her. Nicola now sees herself as the person who should be looking after her mother.

During the Interview

The family had just moved to a new council house and the interview was conducted there. Nicola was late for the interview because she had to collect her mother's income support (her mother is unable to leave the house). At first Nicola was

hesitant about being interviewed and had difficulty remembering such details as the family having a social worker. Nicola was very concerned that her lack of education and fear of leaving her mother would restrict her ambition to become a police woman.

Nuala is 15 years old and lives in a council house with her mother and five year old brother. She has the primary responsibility of looking after her brother who is incontinent, has kidney failure and is hyperactive with learning difficulties. The whole family suffers from a genetic blood disorder [HTT] and her mother worries a lot because of this. Nuala herself has a kidney disorder. She has been looking after her brother since she was 10/11 years old because her mother, who is also unwell, can't cope with him on her own. Her work with her brother includes calming him down whenever he has a tantrum, changing his sheets and incontinence pads, bathing him, making his bed, tidying his room and watching over him when he plays. She also gets up during the night whenever he has a nose bleed. Her brother attends a special needs school during the day for a few hours. Two years ago Nuala was taken into foster care when she took an overdose. The overdose was mainly a cry for help as she felt she was being overlooked because of her brother's disabilities and the role she had to play. There are often arguments between Nuala and her brother which cause tensions within the family.

During the interview

Nuala was very shy about being interviewed. However, she gradually opened up as the interview progressed and became more talkative. She is very bright and entertains ambitions of further education. She writes poetry and one of her poems was entered for a poetry competition. Nuala sometimes resents having this caring role and she feels she has no choice in the matter. She has a very close caring relationship with her mother.

Paula is 15 years old and lives in a council house with her mother, five brothers and sisters, and her step-father. Her step-father abuses alcoholic and is violent towards her mother. Paula has the primary responsibility for caring for her two year old brother who has learning difficulties and is asthmatic. She performs a wide range of caring tasks including getting him up in the morning, feeding him throughout the day, changing his nappies, giving him his medication, eyedrops, asthmatic pump, as well as regular portage exercises three times a day for 20 minutes. Paula has been

caring for him since she was 12 years old. Because of her brothers learning difficulties the intimate caring tasks she performs for him are likely to be long term. Paula's mother now suffers from depression which started when one of her children died at the age of 12, from spina bifida. She has a bad back and a dislocated knee and suffers occasional mood swings related to her depression.

Because of her caring role in the family, Paula has missed out on schooling. Her overdose of some years ago was the result of an unhappy home life and her lack of personal freedom. Paula doesn't have a good relationship with her mother who argues with her and occasionally beats her.

During the interview

The interview with Paula took place in a friend's house. Paula was a very willing interviewee and talked as though the experience itself was therapeutic. She loves caring for her brother and has made a lifetime commitment to doing so. However she finds it very hard going and sometimes feels depressed by the responsibility. She resents the fact that her mother has "abdicated her role as a parent" and forced it on her with the result that she has very little time for herself and friendships.

Jodie is 13 and lives with her foster mother. Jodie's mother has mental health problems and lives on income support. They have no other family members or relatives in this country. Jodie attends the local comprehensive school but missed out on a lot of schooling in her first and second years. She has been in and out of foster care since she was five years old when her mother first arrived in Britain from Barbados. Her mother subsequently became ill and violent towards her. However, Jodie sees herself as the only carer for her mother. She loves her mother very much and worries when she is away from her, especially when her mother is depressed. She takes her mother shopping and does many of the domestic chores. Jodie is very unhappy because she is not presently living with her mother, who she believes needs her.

During the interview

Jodie failed to turn up for the first interview because she went to visit her mother. At the second interview she was apprehensive about being recorded on tape and felt shy and uncomfortable. Most of her answers to the questions were monosyllabic. She was very soft-spoken. Towards the end, when the tape was turned off, Jodie seemed happier talking about her circumstances and experiences. She is a very

lonely child in need of someone to talk to. Even though the researcher explained the purpose of the interview, she still thought the interviewer was there to find someone to befriend her. It was a particularly difficult interview to conduct.

Tony is nine and lives in a flat with his father who has AIDS. He has been caring for his father since he was seven. His parents are separated. When his father is very ill Tony goes to a foster family, and only visits his father on Saturdays. He is currently staying with this foster family (he has been there for four or five weeks.) Tony sees himself as having the responsibility of caring for his father and wants to return home to be with him. When he is at home he cooks for his father and himself, does the shopping, reads to his father and plays games with him. However, he has to get himself ready for school in the mornings as his father is usually too ill to get up.

During the interview

Tony was hyperactive and found it difficult to concentrate on the questions with the result that the interview had to be curtailed. The content of the interview also had to be somewhat restricted as Tony does not know the nature of his father's illness and the interviewer had to agree in advance with the referring professional not to discuss with Tony anything relating to his father's condition.

Bafikile is 11 and lives with her mother and three brothers in a housing association house. She cares for her three brothers as her mother, a native of Zambia, has AIDS. Bafikile also has an older sister who lives in a children's home. Bafikile and her three brothers spend every second weekend with foster parents. Whenever her mother is unwell Bafikile takes on the parenting role for her twin brothers (aged five) and baby brother (aged one). She also looks after her mother especially when she is feeling fatigued. Her mother, who has poor eyesight, is quite ill at present. Bafikile's caring role consists of a range of domestic and child care tasks including helping her mother prepare the food, feeding, dressing and bathing her three brothers, getting up during the night when they are disturbed, cleaning and tidying the house. Bafikile is not a willing carer and feels the experience has robbed her of her childhood. She is one of the very few children who has been told that her parent has AIDS and of the likely outcome. Bafikile often has to miss days at school because her mother is too ill to look after the boys.

During the Interview

Bafikile came across as an intelligent, outspoken and articulate young person. She was very willing to talk about her caring role and how she feels the role was imposed upon her. Bafikile was confused about the length of time she has been caring but seemed to have little recollection of 'pre-caring' days.

Valerie is 17 and lives in a small council-owned maisonette with her mother and younger autistic brother. She has the main caring responsibility for her 15 year old brother though her mother also helps. She has been caring for him since she was five. Valerie has to be there for her brother whenever he has a tantrum to calm him down. He is bigger and stronger than Valerie and needs a great deal of attention. Up until two years ago her brother lived at home full time, but for the past few years he has gone to boarding school five days a week. However, he is at home at the weekends from Friday evening until Monday morning. He is also at home for the holidays at Easter, summer and Christmas, when looking after him becomes a full time job. These are crisis periods for the family as he is constantly on the go, never sitting down and in need of constant supervision. Valerie also has to deal with the necessary paperwork for her mother (who has few literacy skills) and for her aunt, who is illiterate. When she was 13 Valerie was involved in caring for her grandmother who had dementia. For approximately two years until her grandmother's death she was involved in performing personal tasks such as washing and toileting. At present Valerie is attending a sixth form college where she is studying for two 'A' levels. She has obtained a provisional place at a local university to study for a degree in mental health nursing. The family live on income support.

During the interview

Valerie was very happy to talk about her experiences of caring for her brother as she enjoys looking after him. She was less happy to talk about her role in supporting her mother especially when it came to dealing with officialdom and related paperwork. Valerie belongs to a very closely-knit family and was reluctant to mention that her mother had learning difficulties, this information had to be teased out of her. She tended to minimise her caring role in relation to both her mother and her brother.

Khabo is 17 and has cerebral palsy. She finds it difficult to walk and does so with the aid of crutches. She lives with her mother, elder sister, and two younger

brothers. Khabo looks after her younger brothers, especially the youngest who is six and has a hole-in-the heart. Khabo has had the primary care of her brother since he was born. The family originally come from Sierre Leone. Her father was deported in 1992 and the family is currently fighting a deportation order. Khabo is at FE college studying drama and the performing arts, but has missed out on many years of schooling because of her caring role and because of the difficulty in finding an appropriate school that would be sensitive to her own disability. There is very little money coming into the home as the family live on the mother's earnings as a domestic worker plus Khabo's disability allowance. The use of this disability allowance for general household expenditure is a source of friction between Khabo and her mother. Her mother is often depressed and Khabo - who does not have a good relationship with her mother - is somewhat frightened of her.

During the interview

Khabo welcomed the opportunity to talk about her caring role. She was very angry about having this role thrust upon her since, in her opinion, she is physically unable to cope with it. Khabo also wanted to talk in-depth about her financial situation and the fact that she was being kept very short of money.

Helen is 13 and an only child. She lives with her parents in a council flat. Helen cares for her mother who has epilepsy and is severely disabled. She has been caring since she was five and used to share some of the caring tasks with her father. However, she now has the primary responsibility of caring for her mother as her father (who has a history of heart attacks) recently suffered a stroke which left him unable to help. In fact, as a result of her father's stroke Helen now finds that she also has to perform some caring for her father. As well as cooking the family meals, Helen undertakes a number of personal hygiene tasks for her mother, such as bathing. After her father's stroke Helen became afraid to leave her mother alone and stopped attending school. She had been attending the local comprehensive school and had entertained ambitions of becoming a nursery nurse. However, she believes that she may have difficulty realising this ambition given the severity of her mother's disability, depression and her frequent threats of suicide. She is fortunate in having very good and supportive neighbours.

During the Interview

Helen came across as a very friendly and open young person who was very philosophical about her caring role. She was happy to talk about her responsibilities

and so concerned was she about the accuracy of her comments that the answers she gave to the questions were particularly careful and thought-out.

Debbie is 13 and lives in a small terraced house with her parents, three brothers and two sisters. Both her parents are visually impaired and her 11 year old brother is dyslexic. Debbie used to help her 16 year old sister with the caring tasks until about six years ago when her sister contracted ME. Since then Debbie has taken on the main role of carer to the whole family. Her tasks include ironing, Hoovering, shopping with her parents, reading and answering correspondence, filling in official forms, etc. Debbie attends the local comprehensive school.

During the interview

The interview was conducted with all the family members present in a rather noisy and rumbustious setting. Debbie herself was quite happy to discuss her caring role and did so without any inhibitions in front of her parents. It was obvious that she found her parents very supportive and understanding about her role as the family carer.

Kiran and Manshia are sisters aged 16 and 17 respectively. They live with their parents and younger brother in a ground floor council flat. They have been taking care of their mother who has epilepsy and high blood pressure for over five years. Their parents originate from Bangladesh and the mother speaks very little English. The two girls do most of the household chores such as Hoovering, dusting, washing up as well as the preparation and cooking of the family meals. They also translate for their mother on her frequent visits to the doctor. Kiran attends the local comprehensive school and would like a career working with computers. Manshia attends a further education college and is undertaking a GNVQ in Nursery Nursing.

During the Interview

This was the third attempt at an interview. The two girls were most reluctant to be interviewed. They were very protective of their mother and very guarded in what they said about their caring roles. They only agreed to be interviewed if their mother was present. Both girls seemed to be suspicious of an ulterior motive behind the interview. The whole family seemed to be suspicious and fearful of any social services involvement. The mother was only present for part of the time but insisted on having all the questions interpreted for her by both girls until the health project manager took her to another room. The mother insisted that it be recorded in the report that it was the father who had the major responsibility for caring in the

family. However, during the interview it transpired that his role was very limited and amounted to little more than occasional shopping. In fact, both girls were the primary carers of their mother in spite of their reluctance to talk about their work. They both shared a strong belief that it was their duty as children to look after their parents.

Section Four: Caring: Tasks, Responsibilities and Effects

The young carers talked frankly about their lives. In many respects these seemed to be dominated by a daily round of caring responsibilities and related household tasks. In this section of the Report we explore some of the themes and issues that arise from the detailed interviews with the young carers in Southwark.

The responsibilities of the young carers include:

- cooking, cleaning, preparing meals, shopping;
- more general caring tasks such as helping with mobility and giving medication;
- intimate caring tasks such as washing and toileting, etc.;
- emotional support;
- childcare - looking after younger members of the family;
- other more general tasks such as dealing with officialdom and paperwork.

Domestic Tasks

Caring tasks are strongly influenced by the nature of the illness and disability of the care recipient (Dearden and Becker, 1995). The national survey of young carers (ibid.) shows that 65 per cent of all young carers are involved in domestic tasks in the home. In the research carried out in Southwark, 83 per cent of young carers interviewed were involved in domestic tasks. Jodie and Tony, for example, have many domestic tasks to perform:

“All the tidying up in the house ... ironing my school uniform, hoovering and cleaning up the kitchen, washing up and putting away the dishes ... go to the shops for her ... and stuff like that.” Jodie

“I make him cups of tea and get his food. I make my own food... Just make some beans in the microwave. I can make some toast. I do get some stuff from the shops. Not the shopping centre. I just get like bread, butter, sugar and cakes.” Tony

For many young carers undertaking such domestic chores is something they take for granted:

“I do cleaning, I do the washing up ... tidy the house, clean the cooker, tidy up everywhere ... do the ironing, cook the dinner. You’ve got to wash the kids’ uniforms on a Saturday and iron them on Sunday, take them to the barbers ...” Khabo

Debbie’s day is also a full one:

“I run the Hoover around, I do the ironing, help change the boys’ nappies and things. I sort the washing out. I do the things that wouldn’t get done otherwise ... I go shopping with my parents and read them the labels ... I read everything on the shelves that makes it easier. I just go through everything, groceries and things, quite a lot of things could be left off the list if you don’t read them off the shelves.”
Debbie

General Caring Tasks

As well as domestic tasks there are more general caring tasks such as assisting with mobility and administering medication. The national survey showed that this type of caring is more common where the care recipient has a physical impairment. Nationally, 61 per cent of young carers are involved in general caring tasks (Dearden and Becker, 1995). The Southwark interviews show that 50 per cent of the respondents are involved in these more general roles. Paula told us of her mother’s difficulty with lifting:

“She [mother] has a dislocated knee and can’t do as much as she could ... She can’t bend down because of her bad back ... Sometimes she can’t even lift my brother up in her arms ... I think she has tennis elbows, her arms are really weak, she can’t pick him up or anything ... Down’s Syndrome children have strength in them. When you try to give him his asthma pumps and his eyedrops he wriggles ... He tenses himself so that he don’t move and it’s murder.” Paula

Nicola helps her mother because a fall (after an epileptic fit) damaged her back:

“I have to help her upstairs because she can’t manage and it’s trouble getting her into bed and that ... She can’t pick anything up if she wants it or bend down. I have to pick it up for her.” Nicola

Helen also helps with lifting her mother:

“We recently got a hoist for the bath which helps an awful lot ... It’s just basically lifting mum in and turning like a tube and it gradually comes up and you undo the clip and swing it over the bath and just wind it down again. It’s a bit arm aching ... but it’s not too bad it takes the weight away. There’s no more back strain to lift her out like I used to have to do me and my dad.” Helen

Nicola, Paula, and Helen’s comments illustrate a common feature of the general household and caring tasks young carers have to perform, namely, that they are physically demanding and hard work. This is particularly true in the case of a parent or a younger member of the family who has a physical disability. The national study by Dearden and Becker (1995) showed that the incidence of general caring responsibilities is almost as high as that for domestic tasks.

Intimate Caring Tasks

These tasks are performed by some 23 per cent of young carers nationally (Dearden and Becker, 1995). In the Southwark study 42 per cent of the young carers interviewed were involved in intimate care. A study by Aldridge and Becker (1993) found that this type of care is the most difficult for both children and parents because of the embarrassment it can cause. Valerie has to provide intimate care for her brother and also cared for her grandmother for two years before she died. Her grandmother lived with Valerie’s uncle who had schizophrenia:

“When he’s [brother] is in the bath I might have to wash his hair ‘cause he doesn’t rinse it properly himself. My nan had dementia and I had to look after her until she died two years ago. I was going round there and cleaning her and everything. I had to clean her all the time because she could not use the toilet or anything ... it was really bad”.
Valerie

Helen displayed a rather pragmatic approach to the very intimate caring tasks she has to perform:

“Do the bathing ... wash her hair ... If mum has a pessary I might have to do that ... the catheter attached to her tummy I have to change that. If it gets really infected I have to clean it out and give washouts and things like that ... If she has an accident in her knickers I have to put her in the bath and clean it all off and things like that.” Helen

Nicola also has to perform intimate caring tasks for her mother which she finds difficult at times:

“I have to help her onto the toilet and if she can’t get up on her own she calls me to help her. She can’t get into the bath ... I help her wash her back and her hair but she can wash her other parts and that herself.” Nicola

On the subject of how she feels about performing these intimate tasks, Nicola said:

“ Well, you really get used to it after a while, but sometimes when you hear your mum call, you feel oh no, not again and that but you’ve got to do it because she can’t wash her own back and that. It hurts me deep down inside ... to see her like that ... and I feel like crying but I can’t.” Nicola

Nicola’s comment is not untypical of many young carers who have to perform intimate personal tasks. They may not like having to do them, but often they simply get on with them out of love for the parent or sibling or because there is no one else available, or willing, to help.

Emotional Support

In addition to their domestic tasks and general or intimate caring responsibilities, many young carers also provide emotional support for the recipients of their care. This is also an important aspect of caring, even though it is difficult to define. Again, data for the national study showed that 25 per cent of all young carers provide emotional support of some kind (Dearden and Becker, 1995) In the Southwark interviews 50 per cent of young carers were providing emotional support in the home. Nicola and Jodie, for example, provide emotional support for their mothers, who both suffer from depression:

“I’m frightened to leave her in case she goes into a fit or something. When we were little ... she got really down and started taking overdoses and that really scared us ... When she’s really down she says I’m going to take an overdose ... I’m frightened to leave her.” Nicola

Jodie sees it as her responsibility to look after her mother. She said:

“I love her very much and care for her and I don’t want anything to happen to her ... It makes me very sad to see her like that ... I just want to go home and look after her ... I’m the only one she’s got really.”

Jodie

Childcare

As well as performing these domestic and intimate tasks, many young carers provide some form of childcare. The national survey showed that 11 per cent of all young carers were also involved in looking after siblings (Dearden and Becker, 1995). In the Southwark interviews as many as 42 per cent of the young carers were involved in childcare. Khabo has been looking after her younger brother since he was born six years ago:

“When my little brother was born my mother took a couple of weeks off work and then she had to go back to work. Me and my sister were looking after him at that time. I was about 11. My mother used to leave us with the baby and we ... didn’t know exactly what we were doing ... We coped because we thought we had to help in the family. We would look after the baby, change the nappies, feed the baby and go out for a walk and all the rest of it.” Khabo

Paula sees herself as the main carer for her younger brother even though she finds the work very difficult:

“When mum has a bad back ... She puts him [brother] in my bed and when he wakes up .. I’ll feed him, change his nappy ... sit him down and play with him ... I’m the main carer ... It’s because my mum says ‘You’re his Godmother and everything so you sort him out.’ But I think my mum should. When my mum had the baby I thought this is going to be good ... but all the work that goes with it ... screaming, waking up at night, feeding ... its terrible really.” Paula

Bafikile and Nuala also have to look after the younger members of their families. They see themselves as performing duties their mothers should be doing. They find this work very demanding and in some cases physically tiring, especially Nuala, whose younger brother is hyperactive and needs a great deal of attention. As with other caring tasks, they feel they have no choice in the matter.

Other Tasks

Many of the young carers interviewed are also performing other tasks. Dearden and Becker's (1995) national survey show that 10 per cent of young carers are involved in other tasks, such as accompanying parents to the doctor or hospital, filling in benefit, grant and medical forms, and generally dealing with officialdom. The Southwark study show that 58 per cent of those interviewed are involved in similar tasks. Valerie, for example, has to deal with the paperwork because her mother has limited literacy skills and can't easily relate to the social worker who visits:

"She [mother] hasn't had much education ... I mean most of my family are like that ... they are not very well educated about mental illness or anything like that ... But I think my mum, she just doesn't know how to express things and when she does see official people I don't think she can relate to them. Where I might understand but not totally understand ... she may get a little confused and stuff ... Whether its doctor's forms or grant forms I have to do this ... She worries about her handwriting and spelling so I have to do it for her." Valerie

Paula sees accompanying her mother to the hospital as something she should be doing anyway as she is the one who has care of her brother:

"I go to the hospital with my mum ... She brings me along because she thinks I should go there as I'm the one who should know what's going on. I should be the one to look after my brother." Paula

Part of Helen's caring work is more technical in that she has to monitor daily her mother's epilepsy:

"I keep a monitor, we have a sheet and do a tally and dates and if she had more than eight fits in 24 hours... it's a cause for alarm, when it gets to nine that's the point I take action really ... I phone an ambulance. I might phone the doctor first and see what he thinks but normally I just phone for an ambulance." Helen

Debbie finds filling in forms for her visually impaired parents and other members of the family particularly trying and time consuming:

"I fill in forms ... forms like child benefit form and other benefit forms ... housing forms and things like that ... They [the forms] are often complicated ... You would be surprised at the amount of forms, even the little rubbishy forms that you get home from school. All those silly little forms that seem to go on forever. I fill in the forms which make

sense. The major problem is that everyone sits back and assumes that the kids will do it." Debbie

Effects of Caring

One of the most visible effects of caring responsibilities on young carers is poor attendance at school. The national survey (Dearden and Becker, 1995) discovered that one in four young carers of compulsory school age miss school as a result of their caring work. Studies by Aldridge and Becker (1993) and Marsden (1995) found that the majority of young carers identified had experienced educational difficulties, usually to do with punctuality, poor attendance and problems with homework. In the Southwark interviews as many as 66 per cent of those interviewed said that they missed out on schooling because of caring tasks. The same proportion told of how their education had suffered because of caring responsibilities. Paula commented:

"I think when my mum had the children it interrupted it [schooling]. Everything just changed completely. My brother wasn't allowed out in cold weather and I just stayed in with him. I think I have grown out of the way of going to school. I'm so used to looking after my brother that I didn't want to go back to school ... I've just started to go back to school. I've been there two weeks in a trot. I'm going to stay there now but I've had five months off." Paula

Khabo's education has been severely disrupted by both her caring role and her own disability:

"I missed out on my education for six years ... not just because of bringing the family up ... it was also because I didn't have any school that would take me because of my disability. I was missing school and went to tutorial centres and I didn't like it 'cause I thought I wasn't getting anywhere." Khabo

Helen's education has also suffered recently as a result of her father's stroke. She now feels unhappy about leaving her parents at home on their own for any length of time:

"Since my dad's had his stroke I didn't go in [to school] because I had to be here to look after mum ... She was at home on her own and I wouldn't go in at all. She was like 'You'd better go back to school'. I said 'No way I'm not going in', that was it, I wasn't going in until I knew where mum was ... I went back to school ... and a neighbour came up to get me because my mum had been fitting pretty badly ... she had about eight while I was at school ... I had to go home ... There was no-one else." Helen

Others, like Jodie, feel that they can't attend school regularly because their parent is dependent on them:

"I missed school a lot ... especially my first and second year at secondary school ... I used to just stay at home and spend a lot of time with my mum ... just really helped her ... I didn't really leave her because I knew she was having problems at home." Jodie

Bafikile and Nuala's problems with schooling have not been helped by the fact that their childcare responsibilities leave them feeling tired and drained. Bafikile has to attend to her five year old brother when he wakes up in the night crying and has to be taken into her bed. Nuala finds doing her homework difficult after a long day providing for both her mother and her younger brother:

"It's difficult when I have got to look after him or when I've got to make sure he is alright or if he's here it's really difficult to get on with school work ... I have a lot of school work ... sometimes I'm finished about 12 o'clock or one ... it depends on how much work because sometimes I might finish a bit later." Nuala

Emotional Consequences of Caring

Caring can severely restrict a child's social life and friendships. In many cases this amounts to young carers being deprived of their childhood. Bafikile is a young carer in Southwark who feels this acutely:

"I never go out to play ... I never have time to go outside and play with my friends or do the normal things a child would do, like go over to their friends and see how they are ... If my mum was well I could just go out to play and do the normal things a normal child would do." Bafikile

The stresses and strains of childhood caring can often prove too much for some young carers. In Southwark two of the twelve young carers interviewed had taken an overdose in the past two years. Both mentioned the stress of their caring roles as a contributing factor:

"I was about 13 or 14 when I took an overdose and everything because I didn't want to go home no more. I just hated life ... I was so young and my freedom was just cut off completely. I couldn't go out and nothing like when I came home from school ... I look after my brother and everything." Paula

Paula's might be an extreme case but it does highlight some of the damaging consequences of excessive caring in childhood. In Nuala's case, her overdose had to do with her feeling that she was being passed over because of her younger brother's disability and age:

"It was as if I was just there to look after him and my mum wasn't paying any attention to me at all." Nuala

Helen sometimes finds that the stress of caring gets too much for her:

"The stress mounts up a bit ... I've got health problems where I wet the bed ... I get very nervous." Helen

Child carers have also been identified in families where alcoholism and drug-related problems and AIDS problems are experienced (Stafford, 1992; Alexander, 1995). The lives of these children are often dominated by stigma and secrecy. Goffman (1963) was the first to discuss this - issue what he called 'courtesy stigma' experienced by individuals in close association with those who are ill. Young carers can appear to find themselves stigmatized due to the social implications of their parents' addictions or condition. A new generation of stigmatized young carers is currently being identified (Imrie and Coombes, 1995). These are the uninfected but 'affected' children who are caring for parents with the HIV virus. As victims of stigma they often find themselves coping alone, ostracised even by close family and friends (Nagler *et al*, 1995). With regard to the Southwark research, considerable difficulty was experienced in accessing some young carers because of their parents having AIDS. In some cases, the children themselves did not even know that their parents had AIDS. It was something that parents and professionals kept hidden from children.

Those children who did know carried 'the secret' around with them, with few people or no-one else, to share it with.

Bafikile was the only child interviewed who knew that her mother had AIDS:

"Most parents don't really tell their children. I think they are just scared about what their child is going to think. They would probably think they were taking drugs or something like that."

Bafikile finds that the secrecy surrounding AIDS affects her relationship with the few friends she has as well as her wider family circle:

“My friends don’t know. I find it quite difficult to keep it from my friends but I have to because of my mum.”

“When my dad died of AIDS they [his family] knew he had AIDS and they didn’t want to know. I’ve never met any of them.” Bafikile

Ethnicity and Culture

Service provision for young carers and the recipients of care have been criticised for failing to meet the special needs of people from minority communities (Dominelli, 1989; Atkin, 1991; Local Government Information Unit, 1991).

Young carers from black and minority ethnic communities present special challenges when it comes to service provision. It is, for example, something of a myth outside Asian communities that because of their extended family network, young carers will always receive support. This, sadly, is not necessarily the case. Many young carers from black and minority ethnic communities feel caught between two very different and competing cultures. Service provision for such young carers need to take this fact on board and tailor services accordingly. For example, information about support services may be inaccessible to people whose first language is not English. This can result in people losing out on benefit, social services and housing. Because of their cultural identity and family traditions, some young carers may not even see themselves as carers. They may just see that what they are doing is the accepted and ‘responsible’ action for their families:

“Firstly she’s our mum and we feel it’s our duty to help her. If we don’t care for her who would. We are her own blood, her own flesh so we should care for her.” Manisha

“ I think that every Asian girl, and Asian boys as well, they help their parents. They find this a duty. It’s not like they have to do it, but everyone just do it. ” Kiran

As has already been noted, children often act as interpreters between the adults involved and the service-providing agencies. This too can cause problems where complex information needs to be communicated.

Some young carers experience difficulty communicating to doctors and others the precise details of their parents’ ailments:

“Whenever my mum goes to the doctors it’s mostly my sister [Kiran] is going and as my mum can’t speak good English so she [Kiran] will have to tell to doctor all her illness and everything. So like every time my mum goes to the doctors we have to go with her ... When we try to explain it [the ailment] to the doctors they have to examine her before they listen to us because it has to come from the patients. Like what we say is it could be even worse but we are just saying it but she’s the one who actually has the pain so its quite hard [translating].” Manisha

The research in Southwark found that it was difficult to access some young carers from black and minority ethnic backgrounds for a wide range of reasons including cultural identity, suspicion, fear and family honour and tradition. Some of those accessed were rather unwilling interviewees and less than forthcoming with information about their caring roles and experience. This is clearly an area which calls for more research and greater social awareness on the part of those providing services.

Section Five: Young Carers' Views of Professionals and their Own Needs

A characteristic of being a young carer is the absence of choice (Aldridge and Becker, 1993). Young carers have little or no choice in taking on caring responsibilities. All the young carers interviewed in Southwark felt they had no other option but to perform the necessary caring roles. Almost all of them were living in families on income support and most of them had lost some education as a consequence of caring.

Paula is a young carer who feels trapped by her responsibilities towards her younger brother and her mother. She has strong views about her situation:

"I would like to take my GCSEs and to go to college but ... my mum said 'Wouldn't you rather he [brother] lived with you?' But the point is that if he does live with me it's like taking him to school in the morning and picking him up ... it's pretty hard because mum said I could be his carer ... I know he has a hard life ahead of him but I shall be there for him all the time. But I do have a life of my own as well. I want to do things with my life. It's a hard decision to have to make and I'm not even sure what I'm going to do." Paula

Young carers like Paula want to be **listened to and taken seriously** as children and as carers. Valerie is particularly concerned that she is not listened to by welfare professionals:

"I just think they should try to understand and listen, because I think that if someone has listened to you and hasn't depersonalised you, have actually looked you in the eye and listened to you, then you feel a whole lot better." Valerie

This **distrust of professionals** is not just confined to medical and health professionals. Studies by Aldridge and Becker (1993, 1994a) show that amongst young carers there is a high distrust of social workers. Many young carers, and their parents, fear that social worker interventions will lead to the family being broken up and members separated. This is a very real fear, which even if inaccurate, influences strongly young carers' perceptions of social workers and social services.

The young carers in Southwark had mixed views about their experiences of social workers. Valerie thought that they could have given the family better information about their entitlement to services and grants, while Nuala and Debbie rarely, if ever, saw their social workers:

“My mum’s not that keen on him [the social worker] she hasn’t got a good relationship with him ... they never told her about any of the cash she could get or the services available ... I think there was an attendance allowance she never knew about that.” Valerie

“I did have an allocated social worker and ... but I’ve never met her. I spoke to her on the ‘phone ... She was the woman who sent me the letters explaining everything after my overdose. She told me that if I needed to talk to ring her ... But I’ve never met her.” Nuala

Debbie finds that her role as a young carer in the family is not acknowledged by the social workers and that she is not consulted about decisions:

“They don’t really come [social workers], but when they do they talk to my mum, they don’t want to talk to us [children]. They don’t find out what we need and how we feel about things ... They don’t stop and think about the whole family, the whole family unit. They come in and home in on the ability or lack of ability of the parents to be parents.”

Sometimes interventions by social workers can be difficult and painful for the young carers. This was true in Jodie’s case:

“It got awkward. It made me feel angry ... angry because they took me away from my mum.” Jodie

Nicola hadn’t seen a social worker for over six months:

“Well, we did have a social worker until we moved, not to here, but to the other place and then I think we got another one, we don’t really see her or hear from her or nothing. The last time I saw my social worker I think it was when I went down to social services with [educational welfare officer] for a meeting ... It was about my sister and me and how we get on and that and the way I kept beating her up because she was winding me up.” Nicola

The most important need of those interviewed in Southwark was for **someone to listen to and talk to them**. This was highlighted quite pointedly by Jodie:

"I would like someone to talk to about things and help me ... just help me." Jodie

The young carers interviewed said that they would welcome **more support from the social services** in the borough. The nature of this support ranged from specific provision such as respite care (in Valerie's case, for her brother), to help with simple household tasks like cleaning and shopping, to help with general and intimate caring tasks. Valerie said that there was a shortage of places at the respite care centre when the family needed them. According to Valerie, the respite care centre showed some reluctance to take her brother as they said he needed two people to look after him because of his tendency to run off. Once when he did run off he got hit by a car and was sent home to Valerie:

"We need more support for the actual people we care for. I mean it's difficult as I said, you see, you are caring for this person and they are not giving you any support at all. I mean I'm not just saying this for them [social services] to give them something to do. I think that it would cheer a carer up to see the person they have been caring for has gone out and done something and that they [the carer] have had a break themselves. I think that is the most important thing. And maybe some kind of grant or something, I don't know ... I know some young carers have no chance of going and getting into higher education or anything like that. I just think that it's really the support which is most important because we all need a break really." Valerie

Debbie believes that much more help should be available to herself and her family:

"The home help comes in three times a week for three hours ... I think there should be somebody to come in to help a bit more often than just the nine hours a week. It's quite hard sometimes to get the homework done and things." Debbie

Helen's experience highlights the extent to which some families have to go before help becomes available. In her case this coincided with the arrival of a new social worker:

"It's taken my dad to have four heart attacks and a stroke for them to actually get up and do something. The last social worker we had was the person who got us this place [ground floor flat] but since then we have really had no one. My mum's gradually gotten worse and my dad had his fourth heart attack then ... he's had a stroke and it's taken till then ... a lot more anxiety and things like that and valiums and health problems for them to actually get up and hear us ... A social worker was sent from social services and said she was there to help. She filled in loads of forms, filled one in for my mum and another one

for my dad. She came back when dad was out of hospital and well she fixed up all the care and things like that.” Helen

Bafikile’s mother does receive some services such as ironing, but there are problems with finding someone from the same cultural background to take on other domestic tasks. The only outside help Nicola’s mother was offered by social services was some help with shopping for two hours per week, and for this service there was a charge. A consequence of such charges is that families might choose to do without the service if they feel they cannot afford to pay or do without other things. According to Dearden and Becker (1995) if low income families have to do without these services the result is often that children end up performing these additional tasks. As Nicola observed:

“Social services did offer my mum somebody to come and help go shopping, but that only lasted a week and my mum had to pay for that out of her own pocket and she couldn’t really afford it. ... I ended up doing it.” Nicola.

Section Six: Conclusions and Implications

This Report is based upon detailed interviews conducted with twelve young carers in Southwark. From these interviews it is possible to make some observations about policy and practice implications. The interviews show that there is a great need for young carers to receive recognition and support in their own right. They require practical support in a variety of caring tasks, ranging from basic domestic assistance to very intimate caring tasks. Young carers' needs are complex and diverse and we should not assume that all have the same needs.

The first point to emphasise is that young carers are children first and carers second. They have rights which are protected by law (the UN Convention on the Rights of the Child, the Children Act, the Carers Act) but which are all too often overlooked. These rights include the right to a secure and stable childhood and the right to realise their full educational potential. Any programme which aims to support and help young carers must firstly take note of their needs as children and ensure their rights. It should be the duty of professionals to ensure that young carers receive the services and support to which they are entitled. It is the responsibility of professionals to see that young carers have access to information and services as well as education. They should also ensure that young carers are included, rather than excluded, in all discussions and decisions relating to care management and service delivery. Young carers are more than capable of articulating their own needs, when asked.

There are three policy issues which require social services' attention: the identification of young carers; the assessment of their needs; and the provision of services to them. These are examined in turn.

Identifying young carers

Many of the young carers identified for this research are, or have been directly or indirectly in contact with a range of different social services staff. While some undoubtedly fear professional intervention, others are already in receipt of some services from the Department. The problem lies in the recognition and identification of young carers. Social workers and other social services staff are clearly failing to identify many children as young carers, particularly at the assessment of a person in

need. This was quite clearly the case for some carers where the Department had had difficulty in identifying them as such. In fact, there was contact with young carers all the time - but the Department was not recognising this and/or young carers were themselves not necessarily defining themselves as such.

Clearly, awareness-raising and training for social services and other staff are essential. Many professionals from different spheres, not just social services, are in contact with families where children provide care. We would suggest that Southwark Social Services Department should arrange a seminar for professionals in health, social services, education and the voluntary sector as the first step in awareness-raising. Joint sessions such as this facilitate the exchange of information and ideas. For example, it is important to increase awareness among educationalists that poor school attendance or lack of concentration may be due to caring responsibilities rather than lack of commitment or ability. Multi-disciplinary seminars have proved highly successful in other parts of the country.

Secondly, in-service training could incorporate young carers' issues to help staff in the recognition and identification of young carers. Examples of such issues are: the awareness that **any** family with children which has a member with an illness or disability **may** also have young carer(s); that when in contact with these families social services staff need to ascertain **who** is doing the caring and not make assumptions that parents are caring for disabled children or that adults are caring for their partners; and that **fear** of professional intervention can be allayed if the existing legislation is used and seen to promote the maintenance of the family unit rather than its fracture or breakdown.

Assessing young carers' needs

Guidance is already in place in Southwark which will facilitate joint assessment (by adult and children's services) of the needs of young carers. Young carers have the right to request an assessment under the Carers Act but their needs cannot be looked at in isolation, the needs of the whole family must be assessed. This will necessitate the provision of care packages to families in receipt of no services, and the review of existing, possibly inadequate care packages to others. However, the previous point illustrates that many young carers are not identified as such by staff. A structured programme of awareness-raising and training within social services and in collaboration and cooperation with other statutory and voluntary agencies is

required. Such joint training will then enable professionals to work together to identify young carers and to arrange for assessment of their individual needs.

Provision of services

Broadly speaking young carers have needs which can be grouped under three headings. The need for information, the need for support and someone to talk to, and the need for practical services. Information can be provided by a range of agencies. For example, social services departments can provide information on how to access services, claim benefits etc. Health care professionals and voluntary organisations such as the MS Society and The Terrence Higgins Trust can offer information on specific illnesses, prognoses, care management etc. Voluntary organisations can offer more general advice and information services, advocacy etc. Information needs to be child-centred and must take into account language and literacy abilities.

The need for someone to talk to and for emotional support could be met by initiating befriending and support schemes, possibly from outside social services so as to be perceived in a less threatening light. Befriending may be better provided by youth and community workers or by trained and vetted counsellors/befrienders, monitored by voluntary agencies. The Young Carers Research Group has produced guidelines on how such befriending schemes might be set up, and the checks required to ensure child protection (Aldridge and Becker, 1994b). In addition to formal befriending services, any professional in contact with young carers can offer a sympathetic ear and acknowledge their worries and fears.

Many of the practical services required by young carers and their families can be provided or arranged by social services under the Community Care and Children Acts. For example, if young carers are deemed to be children in need, services can be provided to the family as well as the child under the Children Act. Services provided to an ill or disabled family member under community care legislation can improve the lives of young carers. Practical services can include home care, meals on wheels, day centre provision, equipment and adaptations in the home and respite care. Indeed respite care is acknowledged as being of major importance to carers.

Respite care can offer young carers the opportunity to go to school and give them a much-needed break from caring duties. A strategy for providing respite care for young carers should be seen as a priority. Ideally, it should be flexible enough to

accommodate the individual needs of young carers and their families. This would entail breaking with 'traditional' respite care models and making the new strategy child and family centred. The result would be a strategy offering them much more than just the opportunity to attend school, but also the chance to engage in leisure activities and other out-of-school activities.

Staff in social services should also familiarise themselves with other services available within the borough. There may be many services, such as youth counselling, welfare rights and legal advice (including specific advice regarding nationality and immigration issues), careers and educational advice and support networks, volunteer bureaux and many others which may be useful to young carers. A knowledge and awareness of what is available will enable staff to work with other agencies and with children and families to find acceptable services and support for them.

Charging creates problems both for the families of young carers - especially those on low incomes - and also for the continuity of services. A refusal of services due to charging policies can result in the young carers taking on even more responsibilities in the household. Charging policies need to be structured in such a way as to minimise the further poverty and exclusion of many young carers and their families. This will entail Southwark Social Services monitoring the impact of charging policies on young carers.

A designated project for young carers has been funded and will shortly begin meeting the needs of young carers in Southwark. Specific young carers projects such as this can be a valuable way of meeting young carers' needs. Ideally projects should be child-centred and the services provided tailored to suit the circumstances of individual young carers. However, by themselves such projects cannot deal with all the needs of young carers and their families and establishing a young carers project should not be seen as an opportunity to pass on all young carers' issues to such a project. Young carers need to be 'owned' by a number of departments and agencies, and seen as an important area of work for all professionals in the field. This may entail the introduction of effective mechanisms to ensure that the views of young carers are sought, listened to and taken into account. Feedback can then be sought through consultation and/or the establishment of user groups which will inform the development of the young carers project. The young carers need to be involved at every level if service provision is to meet their needs. The project should have a set of practice guidelines for work with young carers and should be

monitored and evaluated to ensure that it provides a service which is efficient and effective, targeted at meeting needs, and responsive to the need to change as new needs are identified.

When identifying young carers, assessing their needs and providing services to them, professionals must be sensitive to ethnicity and culture, gender and age. The specific cultural, religious and ethnic needs of young carers and their families must be identified and responded to in a sensitive and appropriate manner. Only those services which are culturally acceptable to the whole family should be offered. If the services are not culturally acceptable, the family will refuse them with the result that the costs of caring will fall on the young carer. Here it is important to remember that young carers are individuals with unique experiences and that what might be right for one may not be right for another. It is also important to note that those from black and ethnic communities may have specific needs which might be best met by groups explicitly geared to meeting needs in minority communities. Racial stereotyping can also affect young carers. There is an assumption that black and ethnic communities tend to 'look after their own' and this can be used as an excuse for not providing the proper services. Similarly, the existence of the extended family can be used as an excuse for ignoring the fact that children might be acting as carers. There may also be problems with communication. Young carers from black and ethnic cultures are often used as interpreters and translators within the family group, often as the link between their parents and the various agencies or services. All too often they have to interpret and translate information relating to official forms about which they have little knowledge or understanding. Young carers should not be taken advantage of in this way.

Traditional gender roles in many families can result in girls taking on caring responsibilities or boys manual work. Although gender is not the major factor in determining which children within specific families become carers, it can play a part in some families. Professionals too can subconsciously assign traditional gender roles. Care must be taken to ensure that assessment and service provision avoid and remedy such gender stereotyping.

Many young carers start caring at a very early age. This needs to be acknowledged when identifying, assessing and providing services to them. While needs are broadly similar, some will be age-specific. The age and level of understanding of the child must be considered at all time.

No study has yet been conducted in the UK on how the needs of young carers change throughout childhood and into adulthood, when many continue to care. There are approximately 1,000 adult carers in Southwark who started caring in childhood. The Social Services Department may wish to consider contracting further research - which will have national importance as it will be the first of its kind - to examine those adult carers in the Borough who started caring as children and how they perceive their needs have changed over time, and how their needs have, or have not been met. Further details can be provided by the Young Carers Research Group on request.

Conclusions

Southwark has shown its commitment to young carers by commissioning this research and by funding a designated young carers project. The policy issues raised by this research offer a way forward for work with young carers in Southwark. Working in partnership and sharing information is the best way of ensuring that the needs of young carers and their families are properly addressed. It also makes sense in economic terms as in the long run it will save on far more costly, and damaging, interventions. Two areas where substantial savings could be made are in the costs of residential care for adults and the costs of looking after children. In the early 1990s the average cost of residential care was £230 per week for all client groups (Harding, 1992). A report by the National Audit Commission into the cost of looking after children showed how expensive this can be (£30,000 per year, The Times, 10 June 1994). The provision of support to families may prevent the need for such interventions. The aim should be to break from the 'traditional' service boundaries and deal collectively with the needs of young carers and their families. Young carers need to be seen by both the social services and the other agencies as 'whole' persons - children and carers - requiring support from a wide range of sectors. Their needs must be considered in the context of the needs of the family as a whole. This would have the effect of minimising the possibility of young carers falling through the net of possible support services, and the feeling among parents that they are being devalued.

In the future the demand for children to take on caring roles is likely to increase rather than decrease. Family size and structure, an ageing population and other demographic changes in society are combining to make this almost inevitable. Better provision to meet the needs of young carers and their families needs to be given a high priority if young carers in Southwark, and their families, are to receive

sensitive and appropriate support and services. Prompt and continuing action is required to prevent young carers remaining the hidden face of community care in Southwark.

Appendix 1: Agencies and Organisations Contacted for this Study

All the Southwark-based voluntary and statutory organisations listed below were contacted by letter, fax and telephone on at least one occasion. Many received two or three follow-up calls and letters plus complimentary copies of some of our research reports. In total, more than 70 letters/faxes were sent and over 210 telephone calls made to identify and access the twelve young carers interviewed for this Report.

Voluntary Organisations

Black Elderly Group Southwark
Hillret Bradshaw

'Care Free' Youth Services

Charlie Chaplain Playground
Nick Weldon

Camberwell Advocacy Project
Vicky Lipscombe

Children's Rights and Participation
Project
Veronica Plowden and Bernie Baker

Charterhouse in Southwark
Clodagh O'Reilly and
Husenara Begum

Contact a Family
Lydia Yee

Cultural Unity Working Group
Robin Feka

Family Welfare Association
Bridget Lee

Fast Forward Youth Project

Independent Advocacy Service
Angela Stanworth

The Landmark
Maggie Woonton and Ros Peddlebury

Leat
Chris Van D'Arque

South London Family Services Unit
Nick Topliss

Southwark Carers
Sue Child and Julian Smith

Southwark Community Carers Forum
Tamara Essex and Diane King

Southwark Carers
Sue Ward

Southwark Disabled Association
Caroline Nelson

Southwark MS Society
Mrs J Edmonds

Southwark Muslim Women's
Association
Zarfar Igbal

Southwark Phoenix Women's Health
Dr Pat Adjinn-Tetty

Southwark Veit-Chinese Refugee
Community
Quang Duc Nguyen

Southwark Women's Aid, Disabled
Unit
Linda Graham

Southwark Women's Centre

St Gile's Trust
Pauline Mc Donald

NSPCC
Ron Bloomfield

Organisation for Blind African
Caribbeans
Chigor Chike and Marcia Green

Statutory Services

Education Welfare

Sue Baxter - Youth Service
John Guest EWO
Teresa Seale EWO

Equality Unit

Pat Reynolds

Otter Canoe Club
Dave Slack

Southwark Playschemes
Stan Langley

Somalia Women's Refugee Group
Abid Haid

South Asian Women's Association
Surinder Dhillon

St. Paul's Church
Rev Graham Shaw

Surrey Docks Play Association

Teenage Information Network
Monical Beddle

The Rain Trust
Fr. Peter O'Driscoll

Welcare
Patsy Pace

Young Carer's Project Lewisham
Gary Sparling

Schools

Cherry Gardens - Marion Trimbath
Keyworth Primary - Christine Albrecht
High Shore School - Yvonne Conlon
John Ruskin School - Liz Coleman
St Paul's - Don Prescott
Tuke School - Sue Osborne

Health

Brenda Cairns
Peter Eweje
Dr's Higgs and Harris
Simon Jones
Liam McClelland
Barbara Scott
Sue Mc Donald
Brenda McLoughlin
Dr Kevin Zilkha

Home Office Substance Misuse Unit

Hannah Rapport

Social Services

Clive Birkhamshaw
Jackie Blumler
William Chatterton
Vince Clarke
Christine Cocker
Dawn De Leon
Bill Earlie

Social Services

John Emery
Peter Facy
Steve Hall
Andrew Hannon
Nick Hervey
Tod Heyda
Christine Holleran
Joyce Kaye
Pat Lesson
Peter Murphy
Annette O'Callaghan
John O'Hagan
Vassila Paraskeva
Gillian Paul
Cathy Pilkington
Wesley Powley-Baker
Tony Roberts
Andrew Sullivan
Owen Vaughan
Beverly Willacy
George Wright

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