

**HE
CARES
DO
YOU?**



Carers Strategy

for Southwark

2005 - 2008

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Introduction

There are an estimated 25,000 - 26,000 carers in Southwark who provide regular unpaid care for a relative, friend or partner. Hundreds of these carers go unidentified or unsupported in Southwark every year. To ensure that effective support services can be offered to these carers, we have developed this multi-agency Carers Strategy for Southwark.

This Strategy and the accompanying Action Plan has been developed in response to the national strategy, in partnership with representatives from the voluntary and community sector, health and social care, representatives from all partnership boards within Southwark and carers themselves.

The Carers Strategy for Southwark is an overarching strategy, reflective of the current agenda of integration between health and social care services, and representing the provision of carers services across all service areas within Southwark. It is a means of ensuring integrated planning, delivery and evaluation of services.

Our strategic vision for Southwark's carers includes ensuring:

- The need for improved identification of and engagement with carers
- Better Patient and Public Involvement
- Access to quality information, advice and advocacy for carers
- All carers are informed of their right to an assessment
- Support for daily living
- Respite services are available, that recognise the need to give carers a break
- Carers are informed about choice and Direct Payments
- The health needs of carers are recognised
- Crisis services and interventions are available when needed
- That the housing needs of carers and the cared for person are considered
- Employment, training and leisure needs of carers are recognised

The aim of this strategy is to develop more targeted and co-ordinated services for carers, leading to a reduction in unmet need.

Our commitment is to develop services which provide real and effective support to carers, helping to improve their day to day experience of caring in Southwark.



Chris Bull,

Strategic Director of Social Services and Chief Executive of Southwark PCT.

Executive Summary

The Carers Strategy for Southwark provides a local response to the National Strategy, Caring about Carers (1999). The Carers Strategy for Southwark is a document that will plan for better, more integrated and locally responsive care services in Southwark. It also provides an opportunity to provide information on legislation relating to Carer Support.

Carers are the major providers of care and support to people in the community. Without such care many people are at risk, would have a reduced quality of life or might require care away from the home.

The Carers Strategy for Southwark will define what issues are important for carers and details how services will develop to have a positive impact on the quality of life for Carers.

The strategy aims to provide a framework to ensure that quality service and support is in place by improving current services and identifying priorities and objectives for developing services in the future.

It will also be the aid that determines how monies from the Carers Grant (DOH) are allocated annually.



Overview of the Carers Strategy for Southwark

Definition of Carer

The National Strategy for Carers (1999) defines a carer as being;

“A person who looks after someone who is ill, frail, disabled or unable to cope without whom they would need the support of the statutory services and might need to enter a residential or nursing home or go into hospital”.

The Carers Strategy Forum has devised a carers definition of its own;

“A carer is someone of any age who spends significant unpaid time providing care and support for a relative, partner, friend or neighbour who due to frailty, illness or disability would otherwise be unable to live independently”.

Mission Statement

Southwark will provide high quality services for carers that are flexible and person centred.

Southwark will achieve this by working in partnership, by recognising, respecting and supporting both adults and young carers in their own right and by training and supporting staff to fulfil the strategy's aims and objectives.

Aims for Service

- We will give carers a say in service planning and assessment
- We will have two carer representatives on each Partnership board to ensure views are put forward
- We will find out and address specific needs of carers from Black and Minority Ethnic communities
- We recognise the role that carers have in supporting the cared for person and consequently the practical and emotional needs that follow
- We will use qualified and well trained staff with good knowledge of carers issues
- Linking carers who use health and social care services to link with mainstream services
- Southwark wants to support carers to improve services
- We will ask carers what their priorities are annually and use this to inform the Carers Strategy for Southwark.
- We will offer person centred Carers Assessments that address practical and emotional support needs
- We will work with other services in Southwark to ensure that carers get the right support when needed

Aims for the future

- Continued working in partnership across all sectors
- Increased numbers of carers accessing Direct Payments to meet their own leisure, respite educational or training needs
- Increased number of Carers Assessments being completed across all sectors and once completed better coordination of services to ensure appropriate outcomes as a result of Carers Assessments
- Proposal to undertake a more thorough and inclusive mapping exercise throughout Southwark to ensure the needs of carers, both current and future, are met adequately
- Coordination of annual stakeholder events in Southwark for carers and/or those supporting carers to coincide with National Carers week

Carers Strategy Forum (CSF)

The Carers' Strategy Forum is a cross-cutting Forum within the Health & Social Care Partnership structure in Southwark. The purpose of the group is to set the strategic direction for carers services in Southwark and also to decide the spend of the Carers' Grant in Southwark.

All service area Partnership Boards, the voluntary sector and carers have representation on the Carers Strategy Forum (see membership list in Appendix 1) to ensure that the strategic direction developed by the Forum reflects all partners' priorities. The Carers Strategy Forum has developed a terms of reference to clarify the aims, responsibilities, membership and decision making arrangements of the forum group (Refer to Appendix 2).

The Carers' Grant is a grant from Department of Health (DoH) and forms part of the Government's Strategy for Carers published in 1999. The Grant is to facilitate provision of flexible services for carers and is granted to Southwark Council to decide the spend locally. The prioritisation of need and the methodology will be decided via the Carers Strategy Forum.

In order to assist with the development of the Carers Strategy for Southwark a number of sub-groups were developed to concentrate on particular aspects of the strategy. They included;

- Mapping/Consultation sub-group
- Communication sub-group
- Allocation methodology sub-group
- Launch and Publications sub-group

The strategy recognises the fact that effective partnerships between, Health, Social Services, the voluntary/community sector and other relevant partners is key to delivering outcomes that improve support for carers.

National and Local Context

National Policy Context

The Carers Strategy for Southwark is supported by a number of statutory and local plans. The key documents are listed below.

The National Carers Strategy, 1999

In 1999 the government launched its National Strategy "Caring about Carers". The National Strategy emphasises three strategic elements:

Information

- A long-term care charter (Better Care, Higher Standards) on what people can expect from long term care services
- Improving the consistency of charging for services
- Delivering good health information to carers
- NHS Direct Helpline for Carer Information
- Government information on the internet

Support

- Involving carers in planning and providing services
- Consulting local organisations supporting carers

Care

- Carers right to have their own health needs met
- New powers for local authorities to provide services for carers, as well as those being cared for
- Helping carers take a break
- Carers Grant to facilitate carers to take a break

Other National Policy relating to carers includes;

National Service Framework for Mental Health (1999)

The Government published a National Service Framework for Mental Health. Seven standards of expected good practice, addressing five integrated areas. They are;

- Mental Health Promotion
- Primary Care and access to services
- Effective services for people with severe mental illness

- Caring about Carers
- Preventing Suicide

The NHS Plan set additional targets for April 2004 to compliment earlier April 2001 targets as contained within the National Service Framework for Mental Health. Under the heading "Support for Carers", two targets are identified.

- 1 Increased carers breaks and
- 2 strengthen carer support networks

Valuing People (1999) Learning Disabilities concerning Older People specifically.

Valuing People: Moving Forward Together (2004), the government's annual report on Learning Disability, highlights what has been done to ensure that Parents and Carers of people with learning disabilities have adequate support and information available to them.

The priorities for Carers of People with Learning Disabilities were listed within **Family Matters – Counting Families (2001)**. They included;

- The need for **quality services** for those they care for was an important priority.
- **Time off** and the need for respite care was seen as a priority. The dual function of respite is that of providing a break for the carer as well as an opportunity for the service user in terms of their own needs to establish a broader range of relationships and opportunities.
- **Emotional support** – the emotional needs of all the members of the caring family need to be recognised and supported.
- **The need for training and support to care**
- **Financial security**
- **A voice**
- **Full information**
- **The need for carers health and well-being to be included in assessments**

A National Service Framework for Older People (2001)

A National Service Framework for Older People (2001)

The National Service Framework for Older People sets for the first time, clear national standards defining the care and treatment that older people can expect. It was introduced to ensure fair quality, integrated health and social care services for older people.

NATIONAL LEGISLATION CONTEXT

Other key pieces of national legislation relating to Carers include;

The NHS & Community Care Act 1990 – set the framework for the implementation of community care policies and procedures and established support for carers as a national priority.

The Health and Social Care Act (2001) stipulates the duty to involve and consult local people. Local Primary Care Trusts (PCT's) must seek to involve and consult with local people.

The Carers (Recognition & Services Act) 1995

Implemented in 1996 the Act gives carers who provide a substantial amount of care of a regular basis the right to an assessment of needs which should focus on their ability to care and continue to provide care.

The Carers and Disabled Children Act 2000

New freedoms for local authorities to decide what services to deliver that will best meet the needs of carers, helping them maintain their important caring roles and helping them to look after their own health and well being. The act also "enables local authorities to offer carers support services which, in their view, will support the carer in their caring role" (DoH, 2005, p.7).

The Carers and Disabled Children Act (2000) was a significant milestone for carers as it provided carers with a right to an independent assessment of need for the first time.

Community Care Direct Payments Act 1996

Carers Equal Opportunities Act, April 2005

The Carers (Equal Opportunities) Act 2004 seeks to give carers more choice and better opportunities to lead a more fulfilling life by ensuring that carers receive information about their rights under the Carers and Disabled Children Act 2000 (DoH, 2005, p.7).

"The 2004 Act makes three main changes to the existing law around carers services.

- Section 1 places a duty on councils to inform carers, in certain circumstances, of their right to an assessment of their needs
- Section 2 provides that when assessing a carer's needs, council must take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities
- Section 3 facilitates co-operation between authorities in relation to the provision of services that are relevant to carers" (DoH, 2005)

CHILDREN'S SPECIFIC LEGISLATION.

Children's Act 1989

Places the duty to ensure that welfare of children is safeguarded and promoted. Relevant to both young carers and parent carers of children with disabilities and special needs.

Carers and Disabled Children's Act (2000)

In the National Strategy for Carers (1999), the government indicated the need for legislation that enabled local councils to provide services direct to carers. The Act builds on the Carers (Recognition and Services) Act 1995 and gives councils the power to supply certain services following assessment.

The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 places a duty on local authorities, in certain circumstances, to make direct payments to enable people to obtain for themselves the services that they are assessed as needing.

LOCAL STRATEGIES AND PLANS FOR CARERS.

In addition to the Carers Strategy a number of other local strategies and plans have been developed which will improve services for carers directly or indirectly.

Southwark PCT Local Delivery Plan (2004)

The Local Delivery Plan reflects a coherent, integrated approach to planning for health improvement and well being, healthcare and treatment within the local health economy. The Local Delivery Plan covers the area of, and is produced by Southwark Primary Care Trust. (www.southwarkpct.nhs.uk) The Carers Strategy Forum will seek to monitor and advise where appropriate on the content of the LDP in relation to Carers issues in Southwark.

Southwark Alliance – A Community Strategy for Southwark 2003 – 2006

Following consultation with local people the strategy sets a number of priorities for Southwark. Most importantly for carers and cared for is the priority to improve the health of the borough. The Community Strategy aims to improve the health of the borough by;

- Tackling the causes of ill-health
- By improving the quality of service provision
- By focusing on vulnerable groups such as older people and children
- By improving experience for patients (Southwark Alliance, 2003, p.21)

Adults with Mental Health Problems – the Southwark Strategy (2001)

In the document Services for Adults with Mental Health Problems – the Southwark Strategy (2001) a number of priorities for carers are identified.

They include;

- Services which proactively involve carers in planning, service development, service delivery, recruitment of staff and commissioning of services
- Dedicated service – increased carers' breaks
- Strengthen carers' support networks
- Effective structures and systems for ensuring that a wide network of Carers are involved in the monitoring, planning and development of services
- Develop system for monitoring carers assessments through the CPA system
- Develop clearer guidance on confidentiality and sharing of information with carers (p.36)

Commissioning Strategy and Business Plan for Children's Services – 2004 – 2007

The Commissioning Strategy forms an important part of the Southwark Children's Strategic Plan which will drive services toward a fully integrated service and is a key organisational tool in the New Strategic planning framework to integrate health, education and social care services to meet the needs of children, young people and their families, including carers.

Single Assessment Process (SAP)

Implementation of a Single Assessment Process will to ensure a person-centred approach to assessment and care planning for service users. Full involvement of individuals and their carers in both assessment and care planning for service users. Full involvement of individuals and their carers in both assessment and care planning is recognised good practice.

PRIORITIES FOR LOCAL PARTNERSHIPS BOARDS.

The Carers Strategy Forum through consultation with those partnership boards represented have developed a list of overarching priorities for Carers Services in Southwark as well a list of service area specific priorities.

GENERAL PRIORITIES FOR CARERS SERVICES FOR SOUTHWARK ARE;

- Need for improved Identification of Carers
- The need for services that provide advice, advocacy and information for Carers
- Importance of Respite/ Breaks for carers
 - This priority acknowledges the implementation of the new Carers (Equal Opportunities) Act 2004 in England and Wales in April 2005
 - Acknowledging the importance of the opportunity for Carer and Cared for to have a break together

- Carer Support Groups – support and development of
- Training and Development around issues important to Carers that include; the importance of access to employment, moving and handling training, injury prevention etc.
- Carers consultation, involvement and participation
- Transition issues across all service areas
- Ensuring proportionality is reached with regards to BME carers and issues of access. (This in particular with regards to Asian Carers)
- The difficulties for carers of dealing with the behavioral issues of those they care for

Mental Health priorities:

- Looking to fund family support posts
- Carers Packs requires additional funding to continue
- Further funding for breaks for Mental Health carers
- Carers Support Groups are currently not spread evenly across the borough and Mental Health services would like the opportunity to expand into all geographic areas of Southwark

Children's Services priorities:

- Early Years
- Gaps in services for families of children under 5 with severe disabilities
- Parents with MH issues
- Adults/Children in family affected by HIV/AIDS
- Challenging Behaviour needs
- Broadening the reach of carers breaks e.g. evening out, sibling visits, shopping trips
- Educational Achievement in KS1
- Parents & Carers – strengthening role of parents, teaching parents relationship skills
- Transition issues
- Complex needs of carers – where more than one person/child is cared for
- Black and Minority Ethnic (BME) issues
- Young Carers Issues and support
- Parents Council
- Enhanced service for behaviour support services

Older People priorities, including Health Perspective:

- Make sure all carers get an assessment
- Home based respite
- Carers Employment Training (for carers of older people)
- Proper identification of all carers
- Support transition for carers as well as service users (stroke/falls/acute onset)
 - Transition issues should include benefits and welfare information and advice.
- Variety of respite provision (in home/out of home)
- End of Life support

Learning Disabilities Priorities:

- Valuing People Document – support for older carers with their end of life planning
- Identification of carers of people with Learning Disabilities who do not access services – BME carers in particular
- Support for carers through any change process e.g. externalisations
- General advice and information to help carers make appropriate choices
- Training for carers to build confidence and ability

Physical Disabilities Priorities:

- Need for intense information at point of becoming carer
- Breaks – specifically financial help for holidays, user and carer together
- Training for carers – lifting & transfer
- Transition issues are also key

Overview of the joint Strategy for Southwark

Introduction

The Carers Strategy is a local response to the National Strategy, Caring about Carers (1999) and provides an opportunity to provide information on legislation relating to Carer support. The joint strategy aims to provide the framework for developing and maintaining practice that supports carers in Southwark.

The purpose of the strategy is to outline Southwark's plan for carers over the next 3 years. It is planned that the implementation of the proposals outlined in this document will lead to improved services for carers and the people they care for, subject to review on an annual basis.

The strategy recognises the vital role that carers play in looking after those who are sick, disabled, vulnerable or frail in the community and seeks to ensure that provision is made for more and improved services that respond to their needs.

Some Facts about Southwark

Southwark is one of the most deprived local authority areas in England and Wales. "Levels of deprivation in Southwark are high. The index of Multiple Deprivation 2000 establishes Southwark as the 9th most deprived local authority in the country. A number of areas of high deprivation have been identified across the borough. This deprivation is apparent across a range of indicators including employment, income, health and education" (Southwark Alliance, 2003, p.25).

Southwark's People

- Southwark's population is around 250,000
- Nearly 40% are from black or ethnic minority groups, the largest of which is black African
- Over half of Southwark pupils in secondary schools are eligible for free school meals and just under half of those in primary school
- 10% of households in the borough are headed by lone parents

The number of older people in Southwark (about 5% of the population are over 60) is a lower percentage of the population than in many places in the UK. This reflects the relatively transient population, many younger people moving to other areas after a short time in Southwark.

Levels of unemployment are relatively low (about 3% of the adult population), but many Southwark residents work outside of the borough. Many jobs are in the service sector which generally has lower rates of pay than in other jobs.

Southwark's Health

- Residents of Southwark experience higher rates of premature death and greater ill health from hypertensive disease, lung cancer and chronic liver disease compared to the averages for England and Wales
- The major causes of death for both men and women are circulatory, cancers and respiratory diseases
- There are about 925 people with moderate, severe or profound learning disabilities in Southwark
- It is estimated that there are 9,700 adults with physical and sensory disabilities in Southwark
- Up to 2000 people each year are subject to the Care Programme Approach (CPA) undertaken by mental health services
- There is a much higher level of admittance to services specialising in forensic psychiatry than in other areas in Southwark
- Up to 220 people each year have a stroke

Approximately 26,000 carers reside in Southwark. This is an estimate based on national research, many of those who look after someone do not recognise themselves as carers. About 5,000 people are known to services supporting carers in the borough. These are of all ages and from all sections of the community. Many of these people, at some stage need some help or support. Of those over 7000 are likely to be providing over 20 hours of care per week, nearly 3,000 more than 50 hours per week.

The Carers Strategy Forum (CSF)

Background

The Carers Strategy Forum was formed in June 2004 to ensure an improved and transparent means of developing both a Carers Strategy for Southwark as well as a more consultative process in the development of Carers services.

Structure and Composition of the Carers Strategy Forum

The Carers' Strategy Forum is a cross-cutting Forum within the Health & Social Care Partnership structure in Southwark.

All service area Partnership Boards, the voluntary sector and carers have representation on the Carers Strategy Forum to ensure that the strategic direction developed by the Forum reflects all partners' priorities. The Carers Strategy Forum has developed a terms of reference to clarify the aims, responsibilities, membership and decision making arrangements of the forum group (Appendix 2).

Role and Function

The purpose of the group is to set the strategic direction for carers services in Southwark and also to decide the spend of the Carers' Grant in Southwark.

A Working Document

The Carers Strategy for Southwark sets out a primary programme for change that encourages the development of services that fully recognise the vital role played by carers in the welfare and quality of life of the people they care for.

The cross-sector nature of the Carers Strategy Forum (CSF) aims to be a good example of joint support networks and partnership working across Southwark.



What exists in Southwark for Carers?

As part of the development of a Carers Strategy for Southwark, the Carers Strategy Forum agreed that it would be helpful to establish a comprehensive digest of services that are available for carers in the borough.

A small working group was set up to coordinate the collation of information and to devise the format for the mapping approach. It was accepted that once established there would need to be on going work to ensure that the information collected is as up to date as possible.

The information for the mapping exercise was collected from a number of sources.

- Via the projects/services funded by the Carers Grant in Southwark
- From agencies represented on the Carers Strategy Forum. For example; Southwark Carers and Contact a Family
- Questionnaires were also distributed to member organisations of Southwark Community Care Forum (SCCF)

The questionnaires were divided up according to service area and target group. Then each service identified level and type of service provision available for carers.

Appendix 4 refers to the process and methodology for the mapping exercise.

Appendix 5 lists the services identified via the service mapping area. Services are divided up according to service area/target group. Each service then lists the level and type of service provision for carers.

Using the data and information gathered this strategy sets out to;

- Map the shape of current services
- Inform future investment in and shape of services
- Examine the interface between the range of services available

The mapping exercise determined that primary general support is relatively limited. The range of secondary providers is wider ranging but tend to be more general providers of service in Southwark and therefore have no particular focus on carers and carers needs.

It is anticipated planned that a more extensive service mapping and consultation process with carers will need to take place in the near future to look at the services and needs of Southwark's carers in greater detail.

Consultation and Needs Analysis**What are the current and future needs of Carers in Southwark?**

For all the carers known to access and use services for carers in Southwark there is still a large number who do not identify as carers and therefore remain excluded from services and the information that exists to assist them in their caring role.

It is recognised that better ways of engaging with carers and identifying hidden carers is needed. The involvement of carers in the development of an effective strategy is seen as critically important.

As part of the development of a Carers Strategy for Southwark a consultation exercise was undertaken during September and October 2004. A secondary consultation exercise also took place in late November and early December 2004 to get further more detailed information about the services that had been used by carers and to see what additional services they may benefit from. The exercise was coordinated by Southwark Social Services, working with Contact a Family and Southwark Carers.

Agreement was reached by a small sub-group mandated by the Carers Strategy Forum, that the most effective approach to undertaking such research was by use of a written questionnaire, distributed as widely as possible by the above mentioned agencies.

It was accepted that this would generally only obtain the views of carers known to agencies in the borough and would not gain views from individuals who do not engage with service providers. This has specific relevance in relation to carers from BME communities and those from other 'hard to reach' groups. Further work to engage with, and obtain the views of carers from these groups is suggested.

Three different versions of the questionnaire were designed. The first version was designed to find out what parent/carers feel, the second version was for adult carers and an appropriate approach for ascertaining the views of young carers was also developed in partnership with the Young Carers Project at Capital Carers.

In addition Southwark Carers staff conducted a number of interviews with carers, with whom they were already working. A total of 6,290 questionnaires were distributed in total. Across both Adult and Parent Carers a total of 367 forms were returned.

Experience has shown that the level of response in Southwark (and more widely) to survey approaches such as this, are generally low.

If it is accepted that the total number of carers, looking after a person or people resident in Southwark is of the order of 25,000 (interpolating national statistics), the total response rate (between parent and adult carers) of 367

gives a proportionate response rate of 1.4%. The response represents 5.8% of the total number of question forms distributed. This is above the average rate of response for this type of exercise.

Analysis of Responses

Given that the two distributed questionnaires contained differing questions for Parent Carers and Adult Carers the responses are analysed separately below. Issues for which common questions were posed are detailed towards the end of this report.

Parent Carer Responses.

Given the relatively random response achieved there is little correlation between the profile of the cared for child and that which would be expected from the known demographics in Southwark.

Only 32.5% of parent carers responding looked after a female child, which is significantly less than the ratio that would be expected. Half of the parents that responded cared for a child aged 5 to 10 years old, again a higher proportion than would be expected.

Key issues identified via the consultation included;

- Poor understanding of the role of carers and the range of services that could provide effective support
- Limitations on both the volume and quality of services that providers offered to carers
- An expectation of some workers (especially Social Workers) that carers would be prepared to 'fill gaps' where other services could not provide support
- Limited access to respite provision
- Poor linkage and coordination of support across agencies (a number of respondents noted case conferences where less than half of the professionals involved in the case attended)
- Lack of carer needs assessment and where delivered no additional provision of services. Where assessments had occurred there appears to be little attempt to review the need over a period of time
- Delays in achieving assessment of the cared for child
- Limited communication with carers about issues relating to the case

The relatively low level of requests for more funding for breaks and more specialist child care facilities appear to have some links with comments received about the quality and effectiveness of some existing services and the feeling amongst many parent carers that they are the best individuals to care for their children and fully understand each child's needs.

The relatively high number of respondents requesting improved counselling provision reflects the overall shortage of such services in the borough and to some extent the lack of specialist rather than generic counselling provision. The need for further support from education service providers also reflects the need to ensure that an appropriate cross-sectoral approach to service provision is achieved as part of strategic service development.

Access to Assessment

Further work is required to identify the ongoing impact of the assessment process and how assessment affected the range of services that were provided.

The low delivery of assessments for carers is worrying, with only 40% of respondents receiving an assessment of their needs. This obviously does not reflect the number of parents responding who accessed Social Services provision for their child, which will have an impact on the ability for a Carers Assessment to be delivered.

Adult Carer Responses

As with the response from parent carers the total number of questionnaires returned a small proportion of the total estimated number of adult carers in Southwark. This means that the responses cannot be considered, as fully definitive, but give an overview of the issues adult carers feel as most important. There are similarities between the responses from adult carers and parent carers, but also some key differences, especially in relation to the development of services.

The Cared For Person

The most significant proportion of carers look after a partner, although 16% of respondents care for another relative. Few carers in this survey look after someone who is not a member of the family

The majority of those caring for someone with a learning disability state that the person cared for is their son or daughter.

The high proportion of carers looking after someone who lives at their address (87%) is indicative of the level of support that these cared for people may require and to some extent may reflect the shortage of appropriate independent living options across the borough. Further research into this issue is required.

Unlike the situation with parent carers by far the greatest proportion of cared for people has a physical or sensory impairment (49%), with the other impairment types having a reasonably even distribution. This will have an impact on the type of support services that are required for the cared for person and also the support needs for the carer. A key issue that may arise is the need for carers who undertake lifting and handling of the cared for person

to receive appropriate training and the need to work with carers to risk assess the caring tasks.

Adult carers identified two key issues are being significant for them

- Provision of more advice and information
- Better access to help within the home

This issue is significant given the number of service providers who produce publicity materials relating to carers services in the borough.

Importantly few carers requested further funding for breaks. The reasons behind this relate to some carers feeling that it is difficult for them to take a break (with a direct link to respite quality and volume) and also reflects the view that many carers have that they can afford to fund breaks themselves. Many older carers also are reluctant to apply for money, fearing that some degree of means testing will apply.

Although the sample size is small, both in absolute terms and in proportion to the overall number of carers in Southwark the key issues raised are significant.

For both adult carers and parent carers, satisfaction with the range of services provided is less than would be hoped.

The consultation found there is a major issue with a low proportion of carers receiving assessments and for both parent carers and adults there are a range of services that need to be developed and improved.

The results of this work need to be considered in concert with the results needed to improve the response rate from carers in the future. The information gleaned from this work will provide a foundation measure to allow future service improvements to be gauged in terms of impact and effectiveness and plans need to be developed to ascertain how information of this sort can be robustly collected in the future.

Following the initial written consultation with carers completed in September and October 2004 it was agreed the further information would be needed about the services that had been used by the carers and to gain additional information about what other/extra services could help carers.

The secondary consultation involved those respondents who had participated in the first stage had made specific comments about services and potential service needs for the future. With only 38 interviews with Adult and Parent carers taking place the responses and outcomes were quite limited. However, similar themes were raised in the secondary consultation analysis but it raised the point again and again that further, more detailed research would be needed to investigate such issues in more depth.

Young Carers

19 Young Carers were also consulted to assist with the development of the strategy. All the young carers who took part in the study care for someone within their immediate family group. This reflects the general trend for young carers.

As with both adult and parent carers the spread of services that young carers access is wide and balanced.

The findings from the information gauged from the young carers suggests the need to ensure that the strategic approach to carers services moves towards wider engagement of all agencies and groups that come into contact with carers.

Young carers ranked 3 key services in need of further development. They include;

- Better respite facilities
- More funding for breaks
- Better support from GP's or health professionals

Although the sample size of young carers was relatively small the information gathered does give a clear indication of the key priorities for development of services for young carers.

Further research and consultation is needed to identify if the young carers who have assessed support via Social Services have received a detailed assessment of their needs or have been immediately referred to other services for support.

Market Research conducted by Closer to Customers (c2c)

Given the difficulties in engaging with a significant number of carers for the purpose of the development of the strategy it was decided that a Market Research approach be commissioned to endeavour getting a better idea of what carers attitudes are towards carers support offered in Southwark.

A sub group of the Carers Strategy Forum was formed with the mandate of the Carers Strategy Forum. It was felt that a more targeted strategy to engage with carers already using or aware of some of the carers service in Southwark would assist with the development of priorities for Carers Services as well as the Carers Strategy.

At the time of commissioning the research it was acknowledged that the information gathered and the outcomes would help to shape the focus of a more intensive and wide ranging piece of research for the financial year 2005/06.

Southwark Carers made its membership list available to C2C so that contact could be made and quotas set to ensure a reasonably representative coverage of ethnic groups. A telephone questionnaire was then designed by C2C with the assistance of the members of the sub-group.

The objectives of the research was;

- To understand the needs of carers
 - What types of help they would most value that would make their lives easier?
- To test awareness of the services offered by various organisations within the borough
- To assess their views in the effectiveness of services available in Southwark
- To understand the barriers that exist towards making greater use of those services

The research was conducted over a two month period from December 2004 to January 2005. The fieldwork was by telephone and saw a total of 270 interviews completed. As the names of carers involved were obtained via Southwark Carers all of those people interviewed had some experience of at least one type of carers support service in Southwark. Not all carers however, had received statutory services from Southwark Council.

Key characteristics of those 270 carers who participated in the research were that a large percentage of carers have cared for somebody for an extensive period of time (longer than 5 years) and that 96% of the respondents have been resident in Southwark for 3 years or more.

Participants were asked to consider how well they felt they coped in their caring role. 58% of carers interviewed find it difficult to cope on at least some days. It is the carers who are in receipt of Social Services support that feel they are struggling. It could be that those carers and the people they care for have more complex difficulties and needs and therefore are more likely to be eligible for services from the statutory organisations.

Of those involved in the research a significant number of carers had never sought assistance or assessment from Social Services (43%) before. A large number of carers expressed an interest to make contact with such services to discuss particular issues and the same people were happy to assist with any further research.

The research highlighted a lack of information, knowledge and lack of confidence in what services exist in the borough.

41% feel that they would probably qualify for service if they approached social services.

46% of those interviewed knew where to go for carers related support services. Only 24% felt that the resources available are sufficient.

It is important to remember that those interviewed are known to at least one non statutory service as the list of those to contact for the research was compiled from the Southwark carers membership database.

For all the carers who engage with services already, there is an even larger number of people who carers in Southwark yet remain hidden from service providers and do not access any type of information, service or support. The biggest challenge for the future is devising ways to identify and engage with such "hidden carers" in the borough. The aware raising campaign and launch of the Carers Strategy seeks to do just that.

It is important to remember that those interviewed are known to at least one voluntary/community service as the list of those to contact for the research was compiled from the Southwark Carers membership database.

For the carers who engage with services already there are an even larger numbers of people who are carers in Southwark yet remain hidden from service providers and do not access any type of information, service or support. The biggest challenge ahead is devising ways to identify and engage with "hidden carers" in the borough.

A significant majority of carers who took part in the research felt they knew what they needed to improve their quality of life as a carer. Opinion was evenly split however, between the need for support in the home, the provision of respite facilities and the need for more and better quality information.

The Carers Strategy Forum had already identified via the partnership boards one of the key strategy elements as being the need for improved access to quality information. Importantly the research found that of those carers interviewed 35% said that both the need for practical support to carers at home was equally important to the need for provision of information, advice and counselling. 23% of carers felt that the need for respite care and respite facilities would be most beneficial to their lives (C2C, 2005, p.29).

The research shows that once a carer has engaged with a statutory service their knowledge and need for information advice and counselling is less. 43% of carers not in receipt of assistance from social services stated that the support they sought the most was the provision of information, advice and counselling related to their caring role.

The research therefore supports the key strategy element that more carers require access to quality information and that efforts are needed to ensure that more hidden carers are engaged with and identified and once identified, assessed to ensure their needs are met.

The research showed that subtle differences do exist between different ethnic groups and different types of carers; for example parent carers and carers of people over the age of 18 years.

One such finding is that those caring for children, young adults 18 and under, seek more practical support in the home, while those caring for people over the age of eighteen have a greater wish for advice and counselling.

Spouses and partners were likely to have been a carer to their husband/wife/partner for greater than 5 years. A large number of those carers had also been resident in Southwark for more than 3 years. It is vital to engage with

such carers for such consultation exercises because as long term residents and long term carers their knowledge and experience of services for carers should be acknowledged and involvement encouraged/nurtured.

58% of carers consulted admitted to finding it difficult to cope on 'some days' or 'most days'. The research shows those carers looking after a person with multiple disabilities and those caring for a neighbour or friend have the most difficulties coping.

Significantly for carers of children with disabilities/parent carers the research showed that they are more likely to access more than one source of help and support. Carers of children with autism/ASD access a number of services but the findings suggest that there is a level of frustration in wanting more support to meet their needs. Comparatively it shows that carers of people with mental health problems access the least number of support services.

The research has helped to cement the opinions expressed via the various partnership boards that services and support most sought by carers across all sectors includes;

- The need for appropriate advice, information about services
- Assistance with respite services both in the home of the carer for person and respite opportunities away from the home
- And support for caring for the cared for person in the home

A more substantial amount of research and consultation has been agreed by the Carers Strategy Forum and phase two of the consultation process will ensure that these findings are explored further.

Carers Grant

Background

The Carers Grant forms part of the Government's strategy for carers, set out in Caring about Carers(1999). It is designed to stimulate diversity and flexibility in provision of breaks for carers or direct services to carers to support them in their caring role.

Via the Carers Grant the governments' objective is to encourage councils to:

- Further develop innovative and high quality carers services in response to local needs
- Develop pragmatic, outcome focused approaches to the carers assessment, integrated with the development of the Single Assessment Process by April 2004 and promotion of joint working with health services
- Focus on the needs of carers, which is often the most effective way to prevent loss of independence
- Provide breaks for carers who provide substantial and regular care to a 'relevant adult' who lives at home and has been assessed under the NHS and Community Care Act 1990
- Provide breaks services for disabled children and their families under Part 3 of the Childrens Act 1989
- Support children and young people (Young Carers) under 18 who are carers in having a break from caring
- Fund voluntary organisations to provide breaks directly on the basis of their assessments
- Fund administration relating to local carers strategies and consultation

When the Carers Grant was first introduced in 1999 the government had attached a number of criteria to suggest how the grant might be best spent.

Since 2004-2005 the grant is no longer ring-fenced and minimum guidance exists for the grant however, service provision and data collection on breaks for carers is monitored and will continue to be monitored via the CSCI-P Delivery and Improvement Statement (DIS).

In line with the governments commitment to bettering services for carers 2004/05 has seen the Carers Grant funding increase by 48% from £125 to £185 million pounds.

The Carers Grant is without conditions and is not ring-fenced. The Joint Carers Strategy for Southwark is therefore paramount to ensure that the needs of carers and the need for appropriate targeted Carers Services are identified clearly in the strategy document.

Highlighting the governments commitment to carers issues and the encouragement of innovative carers services the amount of Carers Grant has steadily risen over the last 5 years, both nationally and locally. This is reflected in the table below.

Carers Grant Allocation for Southwark

1999 – 2000	£148,424
2000 – 2001	£424,4000
2001 – 2002	£665,476
2002 – 2003	£810,262
2003 – 2004	£952,944
2004 – 2005	£1.195 million
2005 – 2006	£1.8 million

The development of the Carers Strategy Forum was to ensure that a more strategic means of prioritising and allocating the Carers Grant across all health and social care boundaries was developed.

The monitoring, administration and auditing of the grant is the responsibility of the Carers Strategy Officer.

Main objectives of the Carers Strategy Forum in relation to the allocation of the Carers Grant were;

- To establish over-arching and service area specific priorities via consultation with Partnership Boards
- To ensure the Carers Grant allocation process is agreed prior to the beginning of the financial year
- To ensure the Carers Grant allocation is decided prior to the conclusion of the financial year and that all projects are informed of outcomes the allocation process prior to the end of the financial year

The allocation process for Carers Grant funding for 2005/06.

The Carers' Grant from the Department of Health is part of the Government's Strategy for Carers published in 1999. The purpose of the grant is to facilitate the provision of flexible services for carers.

The budget for the Carers' Grant for Southwark in 2005/06 is £1.8 million. In order to ensure that the grant is decided and allocated in a fair and transparent way the Carers Strategy Forum group has assisted with the formulation of a number of Application Forms that state what information is required when applying for funding.

Southwark has made a commitment to improve the strategic direction and application of Carers Services in the borough. Part of this commitment has seen the development of the Carers' Strategy Forum (CSF). The Carers' Strategy Forum is a cross-cutting Forum within the Health & Social Care Partnership structure in Southwark. The purpose of the group is to set the strategic direction for carers services in Southwark and also to decide the spend of the Carers' Grant in Southwark. The Carers Strategy Forum group has helped to formulate a list of overarching priorities for Carers Services in Southwark as well as a list of priorities specific to each client group.

An application pack outlining a clear and transparent process was distributed via the membership database of Southwark Community Care Forum (SCCF), to any organisation who have requested funding previously but had been unsuccessful.

It was also decided that in line with the writing of the Carers Strategy for Southwark, together with the development of the key priorities for carers services that the entire grant for 2005/06 would be available for allocation. This is to demonstrate the transparent nature of the process and the commitment to ensuring that the allocation is as equitable as possible.

Carers Grant Allocation 2005/06 Timetable

Application Packs/Forms sent out	28th – 31st January 2005
Completed Application forms due	Friday 4th March 2005
Allocation of the Carers Grant decided by Carers Strategy Forum	Friday 18th March 2005
Successful applicants informed of funding	Between 21st – 25th March 2005

A wide variety of groups and organisations expressed an interest in bidding for Carer Grant funding and wherever possible groups were encouraged to bid collaboratively.

As not all groups have the capacity or experience with applying for grant funding, support via the Southwark Community Care Forum (SCCF), Southwark Carers and the Carers Service Development worker was offered to all interested parties.

11 Key Strategy Elements

The Carers Strategy Forum have identified the following as the key strategy elements for carers in Southwark. The Carers Strategy for Southwark sets out 11 key strategy elements together with the priority objectives for developing support that will assist Carers with their caring responsibilities.

11 Key Strategy Elements

- 1 **Need for improved identification of and engagement with carers**
- 2 **Patient and Public Involvement**
- 3 **Access to quality information** – the need for services that provide consistent advice, advocacy and information for carers.
- 4 **Assessment Services**
- 5 **Support for daily living**
- 6 **Respite Services – Giving Carers a Break**
- 7 **Choice and Direct Payments**
- 8 **Health needs**
- 9 **Crisis Services/Intervention?**
- 10 **Housing**
- 11 **Employment, Training and Education**

1. Need for improved identification of and engagement with carers

To undertake more extensive research and consultation throughout the borough as a means of identifying hidden carers and understanding better the experience of being carers in Southwark.

Update all policy within Health and Social Care to reflect the commencement of the Carers (Equal Opportunities) Act, 2004.

Establish consistent care management and assessment practices when engaging with carers, especially for the first time.

To liaise with Care First/NHS Direct and Performance teams to monitor and evaluate any improvement in;

- Completion of Carers Assessments
- Outcomes for carers
- The provision of relevant information that should flow from the launch of the Carers Campaign, the carers free-phone helpline and introduction of staff to the new Carers (Equal Opportunities) Act 2004
- To encourage carers to become involved in and contribute to the strategic planning and development process via membership of the Carers Strategy Process and as Carers' representatives on each partnership board

2. Patient and Public Involvement

To encourage carers to become involved in and contribute to the strategic planning and development process

- Via membership of the Carers Strategy Forum Process and as Carers' representatives on each partnership board
- Via the provision of appropriate support to ensure that this can happen.

Involve Carers in planning and evaluating services (including the Carers Grant) via the existence of the Carers Strategy Forum and through links with all Partnership Boards in Southwark

3. Access to Quality Information

There needs to be better coordination of the dissemination of up to date and relevant information for carers in Southwark.

The writing of the Carers Strategy and Action Plan, the development of the Carers Strategy Forum and the organisation of a Carers Conference for practitioners in Southwark who work with carers and a Carers Exhibition all seek to help raise awareness of the issues faced by carers and are aimed at improving the information made available for carers.

To ensure that carers and carers services are kept informed of any amendments to the strategy and any issues/ changes to legislation it is planned that an annual stakeholder event will be planned to coincide with National Carers Week.

The development of a Carers Telephone Helpline will ensure that carers have access to relevant and up to date information for Carers in Southwark.

2005 will see the development of a free carers help line telephone service for carers who are resident in the London Borough of Southwark.

The Carers Telephone Helpline will also ensure that both written material relevant to carers and access to interpreter services is also possible at the point of contact.

With the introduction of the strategy information leaflets will be updated to reflect the availability of new Carers Telephone Helpline and the commencement of the new Carers (Equal Opportunities) Act, 2004.

4. Assessment Services

Social Services Departments have a responsibility to consider the ability of a Carer to continue with their caring role and the Carers Assessment aims to establish the support needs of Carers to enable them to do this.

Carers Assessments are designed to identify the range of support carers need and to provide or signpost to services that may meet this need.

The Carers (Equal Opportunities) Act 2004 will ensure for the first time, that local authorities must when carrying out carers assessments, consider how service provision will impact on the carers' lives with regard to work, education, training and leisure (DoH, 2005, p.8).

Under Section 1 of the 2000 Act, carers aged 16 or over are eligible for an assessment of their ability to provide and continue to provide care where;

- The carer does not provide or intend to provide the care under a contract or as a volunteer for a voluntary organisation
- They provide or intend to provide a substantial amount of care on a regular basis for another individual aged 18 or over
- The local authority is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of Community Care Services
- The carer asks the local authority to conduct assessment (DoH, 2005, p.10)

As a result of amendments made by the 2004 Act, a carers assessment under the 2000 Act must now include a consideration of whether the carer works or wishes to work and whether or not the carer is undertaking, or wishes to undertake education, training or any leisure activity

Assessments need to be seen as the gateway for carers to access services and support (DoH, 2005, p.10).

Southwark's performance and completion of Carers Assessments to date has been poor but it is envisaged that with ongoing training of staff in the statutory sector that there will be an ongoing improvements in the number of Carers Assessments completed. It is hoped that Health and Social Services Carers Assessments will be better linked in the future. It is via the integration agenda that this will occur and through co-ordination across all sectors by the Carers Service Development Worker.

Following a carers assessment, the local authority has a duty to take into account the results of the assessment when deciding what services to provide to the cared for person (DoH, 2005, p.11).

Link Health assessments with Social Services Carers Assessments.

This is the endeavour of the Single Assessment Process (SAP).

Closer links between Acute Trusts and other services e.g. Hospital Discharge teams in particular with regards to Older People.

Social Workers and other practitioners do not have the full access to information about what services exist for carers. The Carers Strategy aims to assist this by identifying types of service available.

Staff training in new legislation (Carers and (Equal Opportunities) Act, 2005) to also coincide with the launch of the Carers Strategy for Southwark in mid 2005.

Carers Assessments for Young Carers

- Young carers require a significantly higher level of support from staff than adult carers would, to complete the assessment form to a standard which effectively conveys all the necessary information
- Ideally the assessment should be carried out face-to-face with the young carer, in a child-friendly manner, using age appropriate language. The comprehension level and literary skills of the young carer (and sometimes the parent) are important considerations. Similarly, if the parent has a sensory impairment, mental health issue or does not speak fluent English this can prevent them being able to support their child fully during the assessment process. The young carer should be given the option of completing the assessment without the person they care for being present. The young carer should be informed that they can choose to have someone besides SSD staff present. Staff from the Young Carers Project or another appropriate person can act in this supporting role. This person should not actually be carrying out the assessment (their role instead should be seen as one of an advocate).

5. Support for Daily Living

- Support for daily living is vital to ensure that carers are able to continue in their caring role while still looking after their own needs emotional and well-being
- A carers assessment is the best means to assess how a carer is affected by the role they play in the cared for persons' life
- There needs to be a willingness to look for better and more flexible ways to provide day care and transport options that can fit with a carers employment and other responsibilities
- At the time of the initial assessment where a need is identified there needs to be more proactive contingency planning

Via borough wide "Carer Awareness" training for front line workers to increase awareness and sensitivity to the support required for carers to maintain their own emotional health and well-being.

6. Respite Services – Giving Carers a Break

Involve Carers and organisations that support Carers in developing responsive services that provide a short break for carers. This will be achieved via the Carers Strategy Forum and consultation with service users and carers.

The Carers Strategy Forum has agreed to commission an extensive mapping exercise of the respite services that are commissioned for Carers in Southwark currently. A more extensive consultation process will be able to look at how carers prioritise the need for respite and break services.

Currently many of the respite and break services are funded via the Carers Grant and the demand, use and outcomes of such services will continue to be monitored.

7. Health Needs

Direct Payments for Carers

Under the provisions of the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003, Councils have a duty to make Direct Payments to every carer who is eligible for carers services and willing and able to manage Direct Payments, with or without assistance.

The purpose of Direct Payments for carers is to support them in their caring role and to maintain their own health and wellbeing.

Services & equipment which directly affect the Carer's role

Direct Payments can be made to carers for the purchase of equipment or services which directly affect their ability to fulfill their caring role.

With these types of services and equipment, there is a clear principle that a Direct Payment is an alternative to Council services which would otherwise be provided, such as transport, laundry services, respite or home care. Therefore the Direct Payment is not an additional burden on existing budgets, but may even be better value than alternative Council services.

Transport and Direct Payments

Where the carer is able to leave the house for respite, but has difficulty accessing other services or activities due to mobility or transport problems, Direct Payments can be made to the carer for transport costs.

Young Carers and Direct Payments

Young carers up to the age of 16 are not eligible for Direct Payments.

Children in transition (aged 16 or 17) may have Direct Payments to support them in their caring role, where the Council supports the decision to maintain their caring role.

The same rules apply to children in transition as they do to adult carers.

Encourage the use of Direct Payments for carers to support them in their caring role and maintaining own health and well-being.

8. Health Needs

- With the involvement of Carers and organisations that support carers, develop projects that promote safe practices that protect the health of carers. For example; Moving and Handling courses and First Aid
- Introduce Health Promotion Programmes for Carers
- Encourage the use of Direct Payments for carers to support them in their caring role and maintaining own health and well-being

9. Crisis Services/Intervention

- Ensure that crisis arrangements are discussed with carers and service users and incorporated into Care Plans and Carer support plans

10. Housing

Southwark has a high percentage of council owned housing (42%). This compares with 25% for inner London and 13% for England. There is a low proportion of owner-occupied dwellings (31%). This compares with 40% for inner London and 69% for England. The supply of affordable housing is decreasing and subject to increasing demand whilst house prices continue to rise at a rapid rate (Southwark Alliance, 2003, p.25).

There is a need to ensure that cared for people are able to remain at home for as long as possible which may mean that both a carer and cared for persons needs are assessed when looking at alternative housing options.

11. Employment/Training and Education

The Governments Strategy 'Caring about Carers' identifies that two thirds of working age Carers in the UK are in employment, with 20% caring for more than 20 hours per week.

The National Strategy (Caring about Carers) highlights that paid employment is important to Carers because it provides:

- Greater financial independence
- An external focus and another source of satisfaction
- Opportunities to maintain or develop informal support and social networks
- Improved self-esteem

Some carers wishing to return to work or training may find it difficult, because of loss of employment related skills or lack of confidence and this may be a barrier in successfully aiding Carers back to work. The difficulty of finding affordable replacement care for the cared-for person is also likely to become a significant issue that will require a long-term planning view.

A positive approach should be developed toward facilitating people who have caring responsibilities to stay in, or return to, employment if they chose to do so and support may be required in identifying:

- Providers of replacement care
- Information about training
- Information about work opportunities
- The provision of respite care whilst training or job seeking

The Carers Strategy for Southwark in relation to Carers and employment should seek to:

- Raise awareness of work and training issues for Carers
- Enable carers in making informed decisions by encouraging access to relevant information
- Sign posting to organisations who can provide training and/or support
- Development of flexible training opportunities that are provided at a time and place appropriate to the Carer
- Facilitating career and personal development through Adult Education opportunities
- Develop approaches within the statutory sector that are sensitive to the needs of working Carers
- Via the strategic planning process, encourage awareness of the needs of working carers (eg flexible working hours, sympathetic management responses to emergencies)
- Encouraging the development of flexible and affordable replacement care

Support to work or return to work needs to be given to carers. A need for increased resources is acknowledged. It is hoped that via a long term strategy more resources can be made available for such needs.



Carer Groups requiring specific support

This strategy acknowledges that all Carers require support that is appropriate to their own caring situation. However, there are groups of Carers whose needs in maintaining their caring role and looking after their own health and well-being require particular awareness and support.

- Young Carers
- Parent Carers
- Transition
- Black and Minority Ethnic (BME) Carers
- Older Carers

Young Carers

The strategy recognises that young carers are a particularly disadvantaged group whose specific needs require acknowledgement. The National Strategy, *Caring about Carers* (1999) clearly states that young carers have a right to the same life opportunities as other young people.

The number of young carers in Southwark is difficult to access due to the fact that some families are reluctant to draw attention to their situation and the intervention of statutory agencies. Statistics in the 2001 Census revealed that 760 children and young people provide unpaid care in Southwark. However, as the borough's estimated non-response rate to the Census was 18% (the 7th highest in the country) this figure is likely to be on the conservative side. Combining this with other factors (e.g. many young people and their families do not recognise their caring role) suggests that the real number of young carers in Southwark could be significantly higher than those reported.

Many factors in a family combine to influence whether a child will become a young carer including: family health, socio-economic status, network of support and the availability of effective services when needed. Young Carers generally care for members of their immediate family and young people in single parent families with a parent in need of support are particularly likely to spend a large part of their time providing care and take full responsibility for doing so.

Findings from the Young Carers Project, Capital Carers show that many young carers suffer from poverty and social exclusion. 89% of children are from lone parent families. Of the families known to the Young Carers Project 80% of two-parent families, both are dependent on their child to care for them. 98% of the families are without full-time work and 66% are from BME groups. The percentage of young carers in Southwark with educational problems is more than twice the national average. Of those young carers who live in lone parent families if the parent becomes ill and requires care the responsibility by default falls to children in the family in the absence of another adult.

The person cared for by the young carer may have any of the following health needs:

- Sensory impairments
- Physical disabilities
- Developmental disabilities
- Mental health issues
- Substance misuse issues
- Long term and terminal illnesses
- Or are elderly and frail

Many of those cared for have a dual diagnosis e.g. they may have a physical disability as well as depression. Some young carers look after more than one person.

The type of caring tasks young carers may be involved with include:

- Domestic housework and chores
- 'Emotional' caring (providing reassurance, cheering someone up etc.)
- Looking after siblings
- Running errands (withdrawing money, picking up prescriptions etc.)
- Helping someone move about the house
- Accompanying someone, pushing a wheelchair
- Reminding someone to take medicine
- Intimate care (helping someone wash, dress, go to the toilet etc.)
- Writing and reading letters
- Making phone calls, answering the phone or door
- Interpreting

Young carers may be primary or secondary carers. When a young carer has a primary caring responsibility it means they have taken on the main caring role for the 'cared for'. A young carer who supports the main carer in the family (e.g. a girl helping her mum care for a disabled sibling) has a secondary caring role.

Young carers with significant caring responsibilities should be defined as '**Children in Need**' under The Children Act.

Identifying Young Carers

Many children and young people with a caring role, find the term 'young carer' an alien one. They are simply doing what they have always done to help out at home. This may be especially so when the person cared for has less tangible health needs such as mental health or substance misuse issues. It can be much easier to see evidence of the caring that results from a physical disability (e.g. doing housework, shopping, personal care etc.) than aspects of emotional caring (e.g. trying to reassure, cheer up, prevent someone from harming themselves etc.). Even in these more obvious cases, identifying young carers can be a difficult task. Some families go to great lengths to conceal a child's caring role out of fear that their child may be removed from the home if the true extent of the situation was revealed. Other families are just unaware of the support they are entitled to, and do not know who to approach for help.

In order to identify young carers, professionals from a range of agencies need to approach families with the thought already in mind that there may be an unidentified young carer in that home. It can take careful observation, and sensitive (sometimes persistent) questioning to discover young carers. Families may not volunteer the information – professionals need to ask the right questions. It may take time to build up a trusting working relationship between the professional and family before they reveal the caring role their child undertakes.

Carers Assessments for young carers

It is a young carer's right to have their needs assessed as a carer. Ideally every young carer and their family should be informed of this when they are first identified. At present there are only a small number of young carers (both nationally and in Southwark) who have actually been assessed. Young carers who may not receive services as a 'child in need' (via The Children Act) should still be considered for support after having their needs assessed as carers. It is hoped that this can improve via the implementation of the Carers Strategy for Southwark.

Parent Carers of Children with a Disability

In common with all Carers, those caring for a child with a disability need access to adequate and appropriate respite services. Those providing a substantial amount of care for a disabled child must be supported to the same extent as carers providing care to those aged over 18 years.

In particular parent carers benefit greatly from access to services during school holiday periods, where the needs of siblings may also have to be considered and taken care of. Services and projects where siblings can attend activities with the child who is cared for are ideal.

Parent Carers of Children with a Disability

Whilst there are no precise figures on the numbers of parent/carers in Southwark, it is estimated that around 14% of the UK's 6.8 million carers are providing care for a disabled child or young adult. This number is only likely to increase with recent medical advances now ensuring the survival of many children with complex disabilities who require long-term, continual care, most of which is provided by their parents. This has a significant impact on services trying to meet the needs of carers as many disabled children are highly dependent not just upon their parents but all family members to meet their basic care and treatment needs, the majority of which do not diminish as the child grows older.

In the planning and provision of services, Southwark Carers Forum recognises that parents/carers of children with disability have significant support needs, some of which are common to all carers but many of which are unique to this group. The following factors shall be considerations in the planning and provision of services.

- Many children with disabilities and/or health conditions are diagnosed as having challenging behaviour. Whilst this varies widely in form and frequency, all its forms can act as unrelenting sources of stress and upset for the whole family. It may adversely affect a parent's social life; whilst general fatigue and difficulty in finding suitable sitters may prevent the parent from socialising outside the home, friends and even family members may no longer wish to visit the parent at home
- Many families are caring for more than one child with a disability and/or are caring for other family members in addition. Research has shown that these families have additional disadvantages compared to families caring for one disabled child including not working, and therefore being reliant on benefits as well as increased likelihood of lone parenthood and parental ill-health
- Caring for a child with a disability has been shown to cost at least three times more than the amount needed to bring up a child without a disability. Parents should therefore have good access to information on benefit entitlements i.e. Disability Living Allowance
- A high proportion of relationships break down as a result of the pressure of caring for a disabled child. There are a high number of lone parents caring for disabled children in Southwark

Transition

Transition is a process that affects service users and their carers across many different service areas. They include;

- Transition of a young person from children to adults – also a care leaver
- A young person with complex impairment moving into Adult Services

- A young person with moderate learning disabilities plus mental health issues
- A young person with challenging behaviour and learning disability
- Young Adults going from school to training/employment
- Adults with physical disabilities moving onto Older Persons services

The key issue for carers who care for people in transition is the way in which support is offered and transferred between sectors.

It is acknowledged that for many a period of transition involves many different agencies and it is the lack of clarity and coordination between such agencies that creates much stress with the risk of the cared for person falling through gaps in service.

Black and Minority Ethnic (BME) Carers

Southwark is a very ethnically diverse community and although the experience of caring is not different between the majority of carers it is the issue of access to services that proves the greatest difficulty for BME carers. Southwark needs to acknowledge the access issue and ensure that services that endeavour to break down the barriers to gaining information and services are encouraged.

Southwark's commitment to firstly; identifying those hidden carers in BME groups in Southwark and secondly building trusting and constructive working relationships with those carers is reflected by the fact that a BME Development worker has been funded via the Carers Grant for a number of years.

The objective of the BME Development Worker is to engage with isolated and minority ethnic groups via outreach work, information exchange and referral to mainstream services where appropriate. By developing closer relationships with such communities the communities themselves can then be encouraged to participate in consultation exercises and wider carer forum in the borough.

Older Carers

Older Carers is another group of carers requiring specific support. Many older carers in the community provide intensive support, often on low incomes, whilst suffering from a serious health condition or are frail themselves.

Older Carers often have issues that relate to their own age-related needs and also the needs of the person they care for.

Older Carers have specific issues relating to housing and property. The need for adaptations and maintenance to meet their own needs and that of the person they care for.

Assistance with end of life planning to ensure that provision of future care for the person they care is an issue specific to the older carers in the borough.

Monitoring the implementation of the Carers Strategy Action Plan.

The Carers Strategy Forum and Carers Strategy Officer will oversee the implementation of the Carers Strategy Action Plan.

Key tasks and targets will be regularly reviewed to ensure that they remain relevant and that objectives are being achieved and that the Action Plan is keeping pace with strategic developments.

Monitoring of the projects/services funded via the Carers Grant.

The Carers Strategy Officer together with other key practitioners across all service areas will ensure that all such projects are monitored appropriately ensuring that relevant contract/service level agreements are in place.

On a quarterly basis all services/projects will provide regular statistical information which will contribute to performance indicators such as the Delivery Improvement Statement (DIS) and also will help decipher if key targets within the Carers Strategy overall are being met.

Commissioning Strategy and Business Plan for Children's Services – 2004-2007

- Department of Health (1999) **Caring about Carers: A National Framework for Carers.**
- Department of Health (2000) **Quality Protects: Disabled Children, Numbers and Categories.**
- Department of Health (2001) **Family Matters – Counting Families in.**
- Department of Health (2001) **Valuing People: A new strategy for Learning Disability for the 21st Century – A white paper.**
- Department of Health (2001) **Valuing People: A new strategy for Learning Disability for the 21st Century – Implementation guidance.**
- Department of Health (2001) **National Framework for Older People.**
- Department of Health (2005) **Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004.** Carers and people with parental responsibility for disabled children. Combined Draft Guidance.
- HM Government (2004) **The Government's Annual Report on Learning Disability 2004. Valuing People: Moving Forward Together.**
- London Borough of Southwark/Southwark Primary Care Trust (2001) **Caring about Carers.**
- Lucas Sandberg Ltd (2004) **Mapping Voluntary perceptions of unmet needs of children and young people in Southwark.**
- Office of the Deputy Prime Minister (2004) **Mental Health and Social Exclusion – Social Exclusion Unit Report.**
- South London and Maudsley NHS Trust (SLAM) (2002) **Patient & Public Investment Policy, Guiding Principles and Resource Pack.**
- South London and Maudsley NHS Trust - SLAM (2003) **Southwark Action Plan Update.**
- Southwark Alliance (2003) **A Community Strategy for Southwark 2003-2006.**
- Southwark Alliance and Southwark Local Strategic Partnership (2004) **Choosing Health? A response to the Consultation on Action to improve people's health.**
- Southwark Social Services, Southwark PCT (North and South Southwark PCG's), the South London and Maudsley NHS Trust (SLAM), Lambeth Southwark and Lewisham Health Authority (LSLHA), service users, their carers, the voluntary sector and community groups (2001). **Services for Adults with Mental Health Problems – The Southwark Strategy.**
- Southwark Social Services Department and Lambeth, Southwark and Lewisham Health Authority (1999) **Carers Plan - 1999-2001.**
- Southwark Social Services Department and Lambeth, Southwark and Lewisham Health Authority (2000) **Revised Carers Plan – 2000-2002.**
- Southwark Children and Young People's Strategic Partnership Board (2003) **Supporting Southwark Children and Families: Next Steps. Local Preventative Strategy.**

Chair – Rod Craig, Head of Services: Older People and Physical Disability

Carers' Strategy Officer – Joanne Koen

Children's Commissioning Officer – Paulo Borges

2 representatives from:

Children & Young People's Strategic Partnership Board

Natalia Sali, Assistant Director, SCCF

Pat Foreman, Planning and Commissioning Manager

Children's Commissioning

Older Person's Partnership Board

Brenda Bond, Southwark Age Concern

Lesley Humber, Director of Operations and Locality Development

Physical, Sensory & Neuro Disability Partnership Board

David Stock, Director, Southwark Disablement Association

1 other

Mental Health Partnership Board

Nick Hervey, Head of Social Care, SLAM

Daniel Casey, Development Worker, Rethink

Learning Disabilities Partnership Board

Sarah Ford, Head of Learning Disabilities Services

1 other

Southwark Community Care Forum's Carers' Alliance

Stuart Read, Capital Carers

Camilla Ford, Project Manager, Contact a Family

Representing carers

Mark Gilbert, Chief Officer, Southwark Carers

**Stella Aber, BME Development Worker,
Taifa Community Care Project (BME carers)**

Yvonne Watkins-Knight, Partnership Officer, SCCF

Carers' Strategy Forum Terms of Reference

Introduction

The Carers' Strategy Forum is a cross-cutting Forum within the Health & Social Care Partnership structure in Southwark. The purpose of the group is to set the strategic direction for carers services in Southwark and also to decide the spend of the Carers' Grant in Southwark. The Carers' Grant is a grant from Central Government and forms part of the Government's Strategy for Carers published in 1999. The Grant is to facilitate provision of flexible services for carers and is allocated to Southwark Social Services to decide the spend locally.

All the client group Partnership Boards, the voluntary sector and carers have representation on the Forum to ensure that the strategic direction developed by the Forum reflects all partners' priorities.

The Carer's Strategy Forum will be reviewed on an annual basis and as part of this process the Terms of Reference will also be reviewed.

Aim

To set the strategic direction for carers' services in Southwark across all service areas.

Responsibilities

- To decide the priority areas for development of carers' services in Southwark with particular regard to those carers who do not easily access current services
- To develop the Southwark Carers' Strategy
- To decide the allocation of the Carers' Grant in Southwark
- To review the Carers Strategy for Southwark and Action Plan annually

Membership

Chair – Rod Craig, Head of Services: Older People and Physical Disability

Carers' Strategy Officer – Joanne Koen

Children's Commissioning Officer – Paulo Borges

2 representatives from:

- Children & Young People's Strategic Partnership Board
 - Natalia Sali
 - Pat Foreman
- Older Person's Partnership Board
 - Brenda Bond
 - Lesley Humber
- Physical, Sensory & Neuro Disability Partnership Board
 - David Stock
 - 1 other

- Mental Health Partnership Board
 - Nick Hervey
 - Daniel Casey
- Learning Disabilities Partnership Board
 - Sarah Ford
 - 1 other
- Southwark Community Care Forum's Carers' Alliance
 - Stuart Read
 - Camilla Ford
- Representing carers
 - Mark Gilbert
 - Stella Aber (BME carers)

(Pending direct carer representation when the 2 people named above will attend as officers supporting carers and not as members) Total = 17

All members of the Carers' Strategy Forum are responsible for reporting back to their constituent groups and bringing back issues to the Forum to inform the development of the strategy and priority areas.

Decision Making Arrangements

The allocation of the Carers' Grant will be made in the March meeting of each year. Decisions will be made within the context of the priorities identified by the Forum. Decisions regarding allocations of the Carers' Grant will be made by the whole of the group. The allocation meeting will be chaired by Rod Craig, in his role as Chair of the Carers' Strategy Forum and not as Chair of any other Partnership Board.

Any member of the group who has been involved in developing a bid will need to identify their conflict of interest in advance of the meeting. They will be required to leave the room whilst their bid is being discussed and decided upon.

Voting at Meetings

The Forum's decisions will be based on the principles of consensus and consultation. However, in the event of a vote, this will be decided upon by a show of hands and by a simple majority of those present.

For the Carers Strategy Forum to be quorate, 9 members will need to be present.

Please contact Joanne Koen, Carers Strategy Officer, Southwark Social Services /PCT on Phone: 0207 525 3603 or via email Joanne.Koen@southwark.gov.uk

If you would like to:

- Receive further copies of the Carers Strategy for Southwark
- Further copies of the Carers Strategy – Action Plan
- Participate in further carer consultations and events

Agencies and Projects that currently receive funding via the Carers Grant in Southwark for 2005 – 06:

Cambridge House

Capital Carers

Contact a Family, Southwark

Kids

Living Independence Networks

Making Spaces

Otter Canoe Group

Parents at Toucan (PAT)

Rethink

Repaying the Kindness

Southwark Carers

Southwark Social Services

Southwark NHS Principle Care Trust

Southwark Vietnamese Women Group

Taifa Community Care Project

The Federation of Voluntary Sector
Care Providers

Tideway Sailability