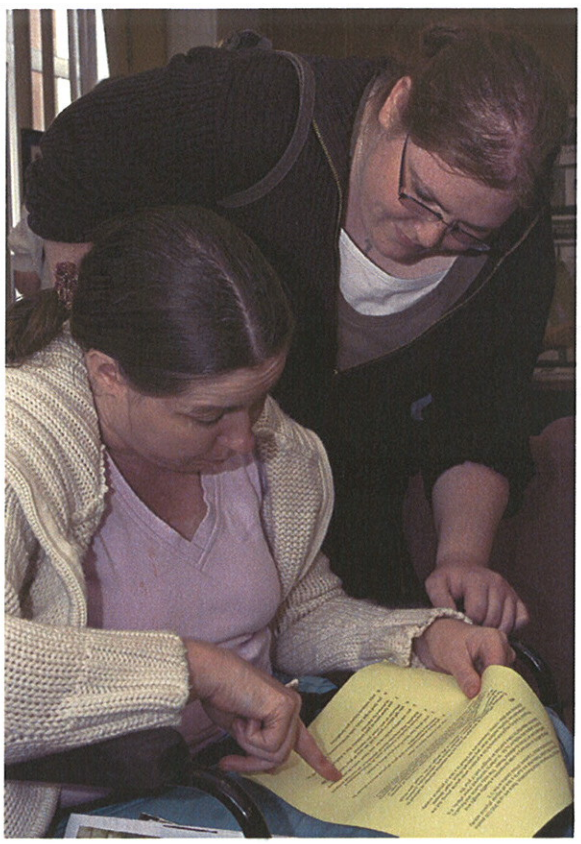
JSNA
Carers

National background

Carers look after family, partners or friends with long-term physical, mental or sensory disability. They are unpaid for the care they give and as a consequence may experience financial hardship. In England, almost five million people, 58 percent female, describe themselves as carers.[1] The 2000 *General Household Survey* reported that 38 percent of people looked after elderly and infirm parents and a fifth looked after a partner. Smaller, but significant categories in terms of need, are the parents who care for adult children with illnesses and disabilities until their own age means that they too need care and support; young carers who look after a parent; and carers who have their own health problems. The peak age for caring is 50 to 59 when more than a fifth of people provide some form of unpaid care, often for elderly parents.

Young carers needs are very different to those of adult carers. Issues around young carers are not considered here but discussed in detail in *Young Southwark: Children and Young People's Plan 2006-09*.[2]

The Office of National Statistics summarises some of the most significant features of informal carers:



Of those in paid work, part-time workers (15%) were more likely to provide care than full-time workers (11%). Self-employed people (13%) were slightly more likely to provide care than people who were employees (11%). People who were not in paid work and who looked after the home and/or family were the most likely to provide care (24%). This group also had the highest proportion (43%) of its carers providing 50 or more hours per week of care. Of the two remaining groups not in paid work, retired people (17%) were more likely than the average to be carers. There was also substantial provision of care among people who were themselves permanently sick or disabled (14%). [1]

The percentage of people aged 16 to 64 providing unpaid care does not vary greatly by social group. For both sexes the difference between those groups with the lowest and the highest proportion of carers was just 2 percentage points. However, there was a clear variation across the social groups in the number of hours of care provided. Over a fifth (22%) of carers in routine occupations and nearly two fifths (37%) of carers who had never worked or were long-term unemployed provided 50 or more hours of care per week. This compares with less than one in ten (8%) of carers in the higher managerial and professional group.[1]

Carers UK estimate that 3 in 5 people become a carer at some time in their lives, and that this will increase as people live longer and develop more complex health problems such as dementia and long-term conditions. By 2022, a fifth of the English population will be over 65. By 2027 the number of over 85's will have increased by 60 percent.[3]

A recent study *Valuing Carers* [4] calculates that the value of unpaid support that carers provide has now reached £87 billion a year. On this basis, the average carer would save the nation over £15,000 a year. This estimate is disputed by health economist, Julian Forder, who helped

produce last year's *Wanless Review* on the future funding of long-term care for older people. He estimates 'replacement' costs of the order £10bn.

Despite the important contribution that informal carers make to the wellbeing of the nation, the *Commission for Social Care Inspection* reports that the tightening of eligibility criteria meant that three-quarters of local authorities restricted services to people with 'substantial' needs (March 2008).

The government's *New Deal for Carers* includes additional funding for emergency support, a national helpline for carers and an expert carers programme. An extensive consultation on future support for carers was also undertaken in 2007 to update the 1999 *National Strategy for Carers.* The developing strategy will cover income, employment, health and social services and equalities. A *Standing Commission on Carers* is also established to oversee the development and implementation of both the New Deal and Strategy.

Physical and mental health of carers

Census 2001 reported on the self-assessed state of health of carers, Table 13.2. Carers who look after someone for more than 50 hours a week were twice as likely to report being in poor health than the general population. Large numbers of carers suffer an injury associated with lifting or handling the person they care for.[4]

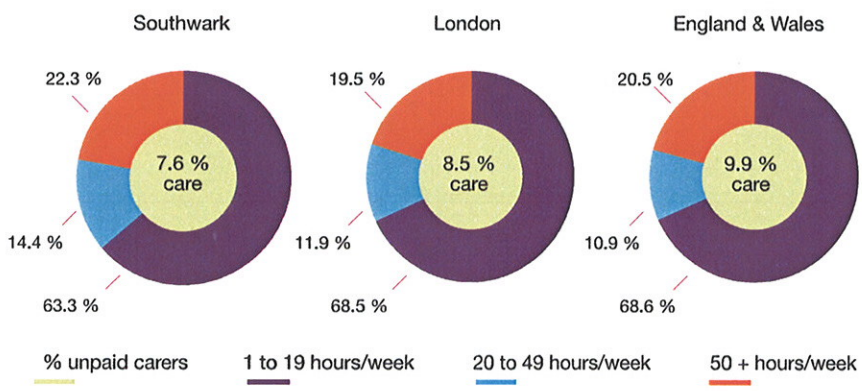
Carers are also more likely than non-carers to report psychological distress such as anxiety, depression, poor sleep, social dysfunction and loss of confidence/self-esteem.[6] Psychological distress is associated both with characteristics of the carer and with the intensity (amount) of caring. Women are more at risk than men, and carers reporting problems with their own physical health are more likely to experience neurotic symptoms. It is known too that long-term stress can exacerbate cardio-vascular disease and depress the immune system, making people vulnerable to a range of illnesses.

Southwark background

Demographics from Census 2001

In Southwark, 18,515 people (12% of adults) described themselves as carers, Figure 13.1. This may be an under estimate as informal carers often do not identify themselves in surveys. Forty percent of carers were from black and minority ethnic populations. Southwark has a slightly lower proportion of carers compared to London and England, perhaps explained by the comparatively young and transient population.

Figure 13.1 Unpaid care in the Census 2001



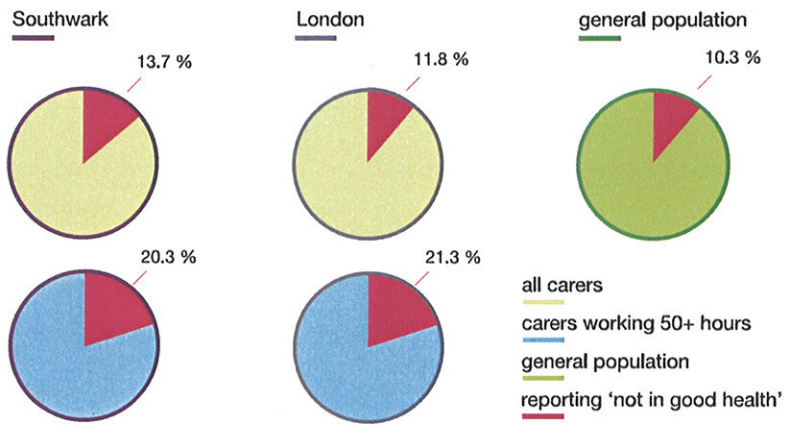
Source: Neighbourhood Statistics (ONS Crown Copyright Reserved)

It can be seen that a larger proportion of Southwark's carers provide more hours of care compared to London and England. This suggests that the needs in those cared for are greater, as is the potential for socio-economic disadvantage – because long hours of care are hard to

reconcile with paid work. Within Southwark, caring is particularly concentrated in areas of socio-economic deprivation, a quarter of local carers live in workless households.[7]

Figure 13.2 shows an association between self-reported poor health and higher numbers of hours of care. About 14 percent of Southwark carers reported their health was poor, the corresponding figure for non-carers was 10 percent. A fifth of carers providing more than 50 hours a week of care reported poor health. Research carried out on national longitudinal datasets shows that there is a dose-response effect and that ill health, particularly psychological distress, is more common in those providing more than 20 hours of care a week. [6,13]

Figure 13.2 Self-reported health of carers and hours worked, Census 2001



Source: Poor Health, 2004 (ONS Crown Copyright Reserved)

Future numbers of carers

Modelling the future numbers of carers in Southwark is complex (*see* chapter 2). We know that population numbers in Southwark are rising overall partly because of inward migration and also because of the comparatively high birth-rate – the seventh highest in London in 2005-6. As a result of improvements in medical care, more young people with complex disabilities are entering adult life with greater needs for continuing care. At the other end of the spectrum, the *Projecting Older People Population Information System* (POPPI) estimates that the numbers of people over the age of 65 will rise slightly from the 2008 figure of 24,500 people over 65 to 28,000 people by 2025, of whom 14,000 are estimated to have a limiting long term condition.

To project future numbers of carers (Table 13.1) the proportion of the population who care (7.6%, 2001 Census), has been applied to *Greater London Assembly* (GLA) *2007 Round Population Projections.*

Table 13.1 Estimated numbers of people providing unpaid care

Year	2008	2010	2015	2020	2020
Carers	20,800	21,600	23,700	25,500	27,200

Source: © GLA 2007 Round Population Projections

Note: unpaid carers rounded to nearest '00; using Census 2001 data and (higher) GLA 2007 RPP

In this estimate two points should be noted. The Census figure understates of the true proportion of carers, and the higher level GLA projected population (Figure 2.1) is used – since this better models the impact of inward migration in Southwark.

This work suggests that numbers of carers will increase steadily with some 27,000 providing informal care to family and friends by 2025. A more specific projection has recently been released by POPPI, which looks at the provision of care by people who are themselves over the age of 65, Table 13.2.

Table 13.2 People aged 65 and over providing unpaid care to a partner, family member or other person, by age projected to 2025

year	2008	2010	2015	2020	2025
age 65 to 74	1,493	1,470	1,517	1,657	1,867
75 to 84	648	618	625	595	633
85 and over	122	126	126	130	141
Total aged 65 and over	2,263	2,214	2,382	2,381	2,641

Source: Projecting Older People Population Information System (Crown copyright 2007)

These data suggest that in the future there will be substantial numbers of older carers some of whom may have unmet needs themselves because of old age, their own ill-health, or economic and social situation.

Department of Work and Pensions data (DWP)

A DWP longitudinal study data on Carers' Allowance (CA) provides information about numbers of carers, Table 13.3. The Allowance, worth up to £48.65 a week, is payable to adults spending at least 35 hours a week caring for a person who qualifies for either the 'middle' or 'high rate' care component of either Disability Living Allowance, or Attendance Allowance.

Receipt of CA can unlock other benefits, such as the preservation of national insurance contributions or increased entitlement to Income Support. However there are significant restrictions, it cannot be claimed by people in full time education or those earning more than £95 per week, and it is reduced by the amount received in certain other income-based benefits and the State Pension. In practice this means that many carers are disqualified.

Table 13.3 People receiving Carer's Allowance in Southwark, by age and gender, (to nearest 10), May 2007

Age	Male	Female
18 to 24	30	60
25 to 29	30	110
30 to 34	30	140
35 to 39	50	250
40 to 44	60	270
45 to 49	80	230
50 to 54	80	170
55 to 59	60	130
60 to 64	50	40
65 and over	20	60
Total	490	1,460

Source: Nomis on 6 December 2007 (ONS Crown Copyright Reserved)

Of 1,950 people who receiving CA in Southwark (May 2007) three-quarters were women. Many more people might be expected to be eligible in Southwark. We do not know whether this low uptake rate is due to restrictive conditions for eligability, a clash with other means-tested benefits and state pensions, or whether eligible people simply do not claim.

Carer's Allowance data do not identify who is being cared for. Gaining a better picture is important as carers' needs, to some extent, are generated by the needs of those that they care for. Some information about the older people who are cared for can be gleaned from looking at who is claiming Attendance Allowance (AA). This is a non means-tested benefit payable to people over the age of 64 who are so severely disabled, physically or mentally,

that they need help with personal care or supervision. Benefit of £44.85 is payable to people needing day time help, a higher rate of £67.00 is payable to people needing night care. People receiving AA are free to use it in any way they wish, although the level of disability required to qualify for the benefit means people receiving it are very likely to receive informal care. In Southwark (May 2007), 3,925 people over 64 were receiving the AA, of whom 2580 were women. Table 13.4 shows claimants by ward.

Table 13.4 Numbers of Attendance Allowance claimants by Southwark ward and rate, May 2007

Ward	claimants lower rate	claimants higher rate	total
Surrey Docks	65	60	125
South Camberwell	55	85	140
Brunswick Park	65	80	145
Peckham	65	80	145
Chaucer	50	100	150
College	80	85	165
Peckham Rye	75	90	165
Village	80	90	170
Grange	85	90	175
Cathedrals	85	100	185
East Dulwich	80	105	185
South Bermondsey	75	110	185
Faraday	85	105	190
East Walworth	110	85	195
Riverside	90	105	195
Camberwell Green	105	105	210
Livesey	115	110	225
Rotherhithe	115	120	235
Nunhead	115	125	240
Newington	105	140	245
The Lane	115	140	255
Total	1815	2110	3925

Source: DWP Information Directorate, 2007

Fifty three percent of those getting AA have it paid at the higher level indicating greater severity of need. This suggests that there is significant underclaiming by people who could qualify for lower rate support. It is possible that people only apply for AA when their condition deteriorates, at which point it is very likely that their carer is also of pensionable age. Gaining earlier access to AA, when the extra funding can play a preventive role, would greatly benefit this group of people and their carers.

Table 13.5 summarises the conditions experienced by people aged over 64 receiving AA at the national level. We do not have these data at local authority level, however for Southwark the picture is likely to be similar.

Table 13.5 Reasons for receiving Attendance Allowance in the UK, May 2007

Disabling condition	cases (000s)	%
Arthritis	481.17	31.9
Frailty	219.01	14.5
Heart disease	133.15	8.8
Mental health	123.08	8.2
Other	109.73	7.3
Stroke-related	102.72	6.8
Muscle / joint / bone disease	83.89	5.6
Chest disease	65.27	4.3
Blindness	54.82	3.6
Back ailments	31.77	2.1
Other conditions	102.88	6.8
Total	1507.5	99.9

Source: DWP Information Directorate, 2007

Voluntary organisations for carers in Southwark

Southwark Signpost lists 37 voluntary organisations as supporting carers http://www.southwarkpct.nhs.uk/signpost/.

Southwark Carers is the largest organisation offering a range of services such as advice, individual and group support, regular newsletters, respite breaks, social activities, relaxation, advocacy, and counselling services. It will have an active role in the updating of the *Local Carers' Strategy* as well as working to ensure that the new framework (from the National Carers' Strategy), leads to real improvements in the lives of carers.

Health and Social Care Services

Much of the current work within social care is supported by the Carers' Grant (and additional Emergency Cover money from 2008).[8] The new round of payments (2008-2011) will be a non-ringfenced general grant enabling local authorities to determine how to best deliver local and national priorities. Decisions as to how the money will be spent locally will be made through *Southwark Alliance*; although there is general guidance – 20 percent to support parent carers and to ensure young carers do not take on an inappropriate caring role; 24 percent targeted at adults, and the balance for older people. Any services to carers are to reflect the principles within *Putting People First*, and *The Carers (Equal Opportunities) Act* of 2004 which entitled carers to respite, access to leisure activities and employment.

The Carers' Strategy Forum meets every two months. Forum membership draws from a range of partnership boards, the voluntary sector and carers organisations. It provides consultation and expertise in the development of services to carers as well as overseeing Carers' Grant monies.

There are several pilots in Southwark around integrating telecare (assistive technology, alarms and monitors in the home and so on) into care plans. This technology has the potential to increase the independence and safety of the person being cared for, and thus enhance their quality of life. If technology can achieve this carers will also benefit by having more time for respite, leisure, or employment.

Multi-agency Carers' Strategy for Southwark (2005-2008)

This was developed in response to the 1999 *National Strategy*, in partnership with carers, the voluntary and community sector and health and social care. The priorities of the *Southwark 2005-8 Strategy* were:

- the need for improved identification of carers;
- the need for services that provide advice, advocacy and information for carers;
- the importance of respite/ breaks for carers including recognising the possible need for carer and cared for to have a break together;
- the need to ensure that the *Carers (Equal Opportunities) Act 2004* April 2005 is implemented;
- the support and development of Carer Support Groups;
- training and development around issues important to carers that include access to employment, moving and handling training, injury prevention and so on;
- carers' consultation, involvement and participation;
- transition issues across all service areas;
- improve access for Black and Minority Ethnic carers;
- assisting carers to deal with the mental health difficulties and behavioural issues of those they care for.

The *Southwark Health and Social Care Scrutiny* subcommittee considered carers' services for adults in 2006. An *Action Plan* was drawn up, which included:

- continuing work on the development of a new electronic case record system for recording carers' needs at assessment in order to ensure statutory requirements are met;
- the need for more strategic partnership working with the PCT and primary health care professionals through the creation of a project board to oversee development and delivery in 2008/9;
- the need to prioritise better support for carers;
- the need to ensure that the Carers Forum develops the capacity to respond to the planning of carers' services in a context of national and local policy change as well as changes to funding structures and cost pressures within adult social care.

Primary care

General practices have an important role in identifying carers in the wider population, as at present many carers have not yet had a Carers' Assessment. Without an assessment there can be no formal recognition of their role, or possibility of additional support. Carers' health is also an issue – as the Census showed, self-reported ill health is commoner in carers than the general population.

Carers presently known to the system are likely to be those who care for people with high levels of personal care needs. The majority of carers do not fall into this group and may not be identified until a crisis occurs in their own health, or that of the person they care for. This approach also precludes the possibility of the more low level preventive work, something identified as effective by *Partnerships for Older People Projects* (POPP).

The *GP Quality and Outcomes Framework* rewards practices for having a protocol for the identification of carers, and a mechanism for the referral of such carers for social services assessment. All practices in Southwark state that they have these arrangements in place. Because data is retained within the individual practice, nothing is known about the effectiveness of these schemes, and what the outcomes are for carers who are referred. If data were collected centrally, *via* a Contract Focus query, valuable information about Southwark's carers (for instance age, gender, ethnicity, postcode) would be captured and used to develop focused support services. RiO, the electronic case record system, could also be used to log carer details.

At practice level, a number of actions are possible where carers are identified. For instance offering a regular health check to pick up early on any health issues and providing flu jabs for carers who would not otherwise be eligible. Practices could be proactive in encouraging carers to approach the *Southwark Welfare Rights Unit*, to ensure that they, and the person they look after, receive any benefits for which they are eligible. The potential for developing this work in general practices has been recognized by the creation of a Carers' Health Liaison post based at Southwark Carers.

Local implementation of the NSF for Long Term Conditions

The *NSF for Long Term Conditions* (2005) is a ten-year strategy that specifies 11 quality requirements (QRs) underpinned by evidence-based markers of best practice. It aims to promote quality of life and independence via coordinated, person-centered care, easier access to information and support from diagnosis through to end of life. It emphasizes patient choice, rehabilitation, self-care and self-management, as well as case management for those with complex needs.

Locally QR 10 has been identified as an area requiring further work to ensure Southwark meet requirements (report presented to the PCT Board in mid 2006).

QR10 focuses on supporting family and carers and offers the following markers of best practice:

- carers are offered a health and social care assessment at diagnosis and all future interactions with information that addresses their needs and offered a written care plan agreed with them;
- carers can choose the extent of their caring role and the kinds of care they provide;
- carers have an allocated contact person;
- carers are treated as partners in care, they are helped to acquire skills to support their caring role and are given opportunity to work in partnership with specialist rehabilitation and care teams;
- a range of flexible, responsive and appropriate services is provided for all carers including emergency support, support for high dependency people at short notice, breaks for carers across a range of settings, culturally appropriate support for BME carers;
- carers who need help to adjust to changes have access to support based (where appropriate) on a whole family approach and delivered (where necessary) on a condition specific basis;
- carers awareness training for staff, education and training which involves carers in planning and delivery.

Assessments and services for carers of adults

Carers have a right to an assessment if they care for someone for '*a substantial amount of time on a regular basis*' (Carers (Recognition & Services) Act 1995 and the Carers & Disabled Children Act 2000). A carer's assessment aims to establish if the carer has unmet needs which, if supported and met, would help them to fulfill their role more comfortably and sustainably.

These might be:

- Help at home
- Day care
- Break services
- Aids and equipment
- Residential and nursing home care
- Direct payments
- Training to better meet the needs of the person they care for
- Palliative care
- Support to enable them to remain in employment
- Welfare benefits check and other financial advice
- Telecare and telehealth
- Home adaptations
- Carers' services available at a local level
- Help with medicines management
- Information about local organisations supporting carers

Carers also need to be informed about their rights and these rights need to be respected when drawing up of any package of care for the person they look after.

Although 2417 carer assessments/reviews were carried out in the year ending March 2007, Southwark Carers consistently report that two-thirds of carers are unassessed. To address this shortfall there are plans to streamline the process, develop an electronic client record, and undertake more outreach. Of all reviews only 43 were 'joint reviews' – where the review included an assessment of the person cared for. In all of these cases the carer's client had learning difficulties.

As a result of their assessment/review 43 percent of carers received a specific service, such as a respite break, and 57 percent received advice and information.

Figure 13.3 Characteristics of people cared for in Southwark, by age group, 2007

The RAP data does not permit us to know all the outcomes of the assessment however we know from other RAP returns that 932 of all carers (not just those assessed in 2006-7) received a service, such as a respite break.

Half the carers who had contact with social services only received advice and information. Again the structure of the data does not permit us to know any more about the content or outcome of this process.

There appears to be no easily available data on the ethnicity of carers who are assessed. Also the Care First database is incomplete, in that the total number of carers' assessments and outcomes is unknown. Such data would be helpful in planning and configuring services as they would act cumulatively as a carers' need assessment.

Different sources of data highlight inconsistencies in the recording of services for carers, further development of the electronic care record should help with this. Some of the inconsistencies noted should resolve as staff become more familiar with the recording system.

Patient and user concerns

Two attempts were made to consult with local carers during the drawing up of the *2005-8 Southwark Strategy for Carers*. However, response rates were low, we cannot be sure how representative the data collected was, and the information is now outdated. For these reasons, we consider two recent national datasets.

Carers UK Survey

In January 2006 the White Paper *Our Health, Our Care, Our Say*[10] promised to update and extend the 1999 National Strategy for Carers. To help inform this work Carers UK undertook a survey of 2,950 carers to establish what their priorities were, Table 13.6.

Table 13.6 Carers' top three priorities for change by percentages and actual number of responses

Carers' priorities	Frequency ranked first, second or third %	Total number of responses
Recognition from professionals	39	1142
Better services for disabled, older, and chronically ill people	35	1041
Carers' health	35	1030
Income in retirement for over 65s	32	959
Respite breaks	29	848
Income from benefits for under 65s	29	846
Long term care	21	605
Carers services	19	559
Employment	11	338
Leisure and training opportunities	10	293
Housing	9	263
Status	2	298

Source: Carers UK website

If the two income related questions are totalled, 1805 people rank finance as a priority issue, many more than rank either 'recognition' or 'carer's health'. These responses underline the need for good quality advice about money and access to sound benefits advice.

Although this questionnaire provides an indication of priorities, respondents are limited by the questions that they are asked. The next section looks at some of the themes that emerged in more open-ended face-to-face discussion sessions.

National consultation for New Deal for Carers

Major themes emerged from *New Deal for Carers* consultations undertaken with young and adult carers during 2007. Interim findings were:

- There is a lack of readily available, easily accessible, digestible information; carers find that the onus is on them to seek it out. There is a need for guidance to help carers navigate the information that is out there.
- There are inconsistencies in service provision and the quality of services available and provided depend upon where carers live. Carers call for greater standardisation across the board and minimum standards to reduce the stress and anxiety for the carer and the cared for person. There is also a perceived need to publicise the range of services available and their locations.
- There is a lack of service coordination centered around carers' needs. Carers are looking for greater personalisation of services brought about by greater cohesion between services.
- Delays in assessments, and waiting times for provision of services, limit carers' ability to provide the best possible care and reinforce perceptions that support for carers is insufficient.

- The level and extent of the bureaucracy in current systems frustrates and upsets carers. There is a perceived need to streamline process across the board.
- Carers feel there is lack of recognition, and widespread misunderstanding, and undervaluing of the role that carers provide. Carers want official recognition of their role in society.
- The perceived negative attitude of others to carers and caring, borne out in day-to-day experiences, impacts on the way carers are treated and the opportunities available to them. Carers want to see a change in current negative attitudes and behaviours.
- Carers' lives become increasingly synonymous with the person they care for and this limits the opportunities they have for a life outside caring. Carers want their lives to continue once they take on caring responsibilities.
- Many carers are financially worse off as a result of their caring role. Caring results in additional costs at the same time as carers' earning potential is reduced. Carers are looking for changes to benefits and allowances to minimise the financial impact of caring.
- Caring often impacts on the physical and emotional health of carers. Carers would like more support, and additional respite provision, to minimise the impact of caring on their personal health and additional respite provision. [5]

Met and unmet need

Using existing census and service use data to deduce needs

Based on Census data, at least 12 percent of Southwark's adult population are carers around half providing care for 20 or more hours a week. This suggests that there are many other carers also working either to supplement services offered to the person they care for, or to compensate for the absence of such services. Although better systems of data capture are being developed, the RAP return (Table 13.8) only provides a partial picture of activity, for instance these data show that the commonest outcome of a service approach was 'information or advice', making it very difficult to quantify the degree of any unmet need.

Carers may be referred to Southwark Carers, and the number of members, 3940, suggests that a good number may be benefiting from their support. The numbers involved however still fall far short of the actual numbers of carers in Southwark.

Many people who are assessed are not eligible for community care support, having needs classified as low or moderate, it is highly probable that many of these unsupported cases make use of informal care. It follows from this that there are a significant numbers of unrecognised carers, with unquantified health and social care needs, supporting people in Southwark.

Overall, the RAP return also showed that in 2006-7, just under 7000 adults with care needs received services in the community (such as meals on wheels, home care, day care or home shopping). Under ten percent (9.3%) received intensive home care of ten hours a week or more, Table 13.7.

Table 13.7 Number of people with intensive home care packages (18 years and above)

Condition	Total
Hearing impairment	<5
Learning disabilities	25
Mental health – dementia	<5
Mental health – other	11
Physical disability/ frailty / temporary Illness	589
Substance misuse	<5
Visual impairment	7
Vulnerable person	<5
Number receiving 10 or more hours/week of home care	638

Source: RAP , 2006-07

These figures suggest that the majority of the people who are actually receiving services in the community are likely to also need to supplement community services input with informal care. This highlights the importance of health and social care professionals configuring their work to be as supportive as possible of carers. A recurrent demand from carers (39%) is that practitioners and services recognise their input and work collaboratively with them (Table 13.6). Training for social and health care professionals to involve carers and strengthening existing good practice will help to reach out to the unmet need within the borough and empower carers in their role.

The data and other information sources surveyed here, as well as a considerable body of research[11] show that caring can be associated with socio-economic deprivation, poverty and ill-health. Socio-economic disadvantage, mental health problems and long-term conditions are already more prevalent in the Southwark population so it is highly likely that a substantial proportion of carers in the borough experience multiple disadvantage and deprivation in their own right, as well as in relation to their caring role.

Clear identification and stratification of need in carers is a priority, as is ensuring that they are recognised as important partners in the provision of services. People who are not eligible for community care services will still have needs.

Most carers receive advice and information from Social Services rather than a substantive service; what is offered must be as useful as possible so that carers can work effectively on their own behalf and that of the person they care for. This also needs to be born in mind in the planning of other council services such as leisure, recreation, transport and housing. New technologies also have the potential to make a difference, for instance via telecare, and the Internet and distance learning can help with this approach.

Resources One example of good practice is an interactive tool called *Care to Take a Look*, accessible at: http://caretotakealook.com/ [12] (also available as a CD). It has been designed by Carers UK with EU funding it enables policy makers, service providers and individual practitioners to explore the difference they can make when they begin to incorporate carers fully into their decision-making.

High quality benefits advice is available at: http://www.entitledto.co.uk/ and at: http://www. turn2us.org.uk/

Other resources include *Welfare Rights Unit*, or through self-help facilitated by health and social care services, and libraries.

Inequalities and inequity

Health

Health inequalities between carers and non-carers can be detected at the population level, however the adverse effects of caregiving on health and well-being are not uniform and do not affect all carers. Poor health in carers, especially raised levels of distress, is associated with particular care situations and caring relationships, and is more prevalent in women than men. This gender-related risk needs to be borne in mind as it is still easy to make assumptions about the appropriateness of a caring role for women, and to underestimate the need for support in what is seen as a natural function.

In general carers at increased risk of psychological distress are those who:

- care for a person with whom they have a particularly close relationship;
- give more than 20 hours of care a week;
- look after a person with mental illness or behavioural problems;
- provide a substantial amount of personal and physical care;
- do not receive regular breaks. [13]

Work and finances

The census showed that in Southwark 81 percent of carers in Southwark (14,778 people) were of working age; 43 percent are men. Three in five carers in the borough were aged 35 to 64, critical years when building a career or earnings. Table 13.8 shows that the majority of carers are in paid employment and are also putting in long hours of caring. Census data shows that people putting in the highest number of hours of care are most likely to be in routine and manual occupations. Unsurprisingly it is also this group whom are most vulnerable to losing contact with the work place, though many carers report that they give up work unwillingly because they feel there is no alternative.

Table 13.8 Carers of working age in Southwark by sex, employment status and weekly hours of care in the 2001 Census

	Males			Females		
Care hours a week	1-19	20-49	50+	1-19	20-49	50+
all carers	4422	930	1042	5330	1251	1803
carers in full-time work	2662	447	375	2303	389	288
carers in part-time work	380	74	33	1016	229	191
carers unemployed	373	94	73	265	51	61
carers permanently sick/disabled	229	82	155	228	85	165
carers at home/family FT	88	84	258	773	330	902
carers retired early	90	24	45	45	0	14

Source: 2001 Census Standard Tables, Crown Copyright 2003 (14)

The potentially adverse effect of caring on finances, and the limitations it imposes upon paid employment are well documented. Although we do not have data about the finances of carers in Southwark it is well recognised that people do not claim the benefits to which they are entitled.

1,950 carers received Carers Allowance in May 2007, under ten percent of the estimated caring work force in Southwark. This low number may be due to the very restrictive conditions around eligibility for this benefit, however carers may well be eligible for other means-tested benefits, and the person they care for may be eligible for some of the components of Disabled Living Allowance or Attendance Allowance as well as other means-tested benefits.

The *Southwark Welfare Rights Unit* works to ensure the maximisation of benefit uptake and takes referrals from Social Services. However it is likely that most people who are helped in this way are those assessed as having critical or substantial needs. They and their carers are helped to apply for the means tested and disability benefits they are entitled to in order to pay for their care packages. 365 people were helped in this way in 2006-2007. The unit also provides advice in 44 of the 48 general practices in Southwark. We do not know how actively practices signpost the carers they identify to benefits advice services.

Proactive benefits take up work has an important role in supporting carers by increasing household income for carers, and the people they care for. This work helps to reduce health inequalities as well as increase economic and social inclusion.

Carers summary

- census data indicates that there are 20,000 to 25,000 carers in Southwark making a substantial and unpaid contribution to the local health and social care workforce. In 2001, 37 percent of carers in Southwark provided care for more than 20 hours a week.
- being a carer may impact adversely upon health, especially those putting in long hours; caring for people with challenging behaviour, or who are themselves sick or disabled.
- census data for Southwark showed that 45 percent of carers of working age combine paid work with caring. Working carers are an important group but as research from Carers UK shows, many feel poorly supported, suffer impacts on their health and financial position, and would like more help from formal services.
- Other carers are unable to undertake as much paid work as they would wish because of the demands of their role. Caring for a relative or partner can leave people isolated and on a low income.

Recommendations for the JSNA process

- to ensure that the new electronic case record system for recording carers' needs at assessment is fit for purpose and embedded in practice
- to develop carers' assessments as a local resource so that carers' needs are better understood and services configured accordingly
- consider the role of primary care in the identification of carers in the community – at present information is only collected on the needs of carers when the person they care for is eligible for a community care package.

Service priorities

- broaden the identification of carers and develop high quality local intelligence about the carers 'workforce' so that it has higher visibility.
- ensure that all carers are aware of their rights and have access to benefits advice so that any extra financial support they, or the person they care for may be entitled to, is released in order to support them
- identify and support carers whose own health and well-being may be compromised
- increase awareness among health and social care staff of carers issues and the need to involve carers in decisions about the welfare of the person they care for
- ensure that all health and social care professionals work within the framework set out in Southwark's *Better Care Higher Standards Charter* and that all carers and the people they look after are provided with their own copies of the charter as part of their care plans.