King's Fund

Carers Impact Project in Southwark

The Picture Now

Feedback from Carers
July 1998

The Picture Now: Feedback from Carers

Contents

1 Improving outcomes for carers

Summary of feedback from carers

Issues raised by carers in 1997	A Positive Difference 1998	Issues to be Addressed
Improved access to social services: • more contact with social workers • back up in an emergency • access to review • improved access for black and ethnic minority carers	✓ Carer assisted by mother's admission to day care ✓ Carer received respite care	See 'Better assessments' - difficulties for carers trying to get help by phoning social services Little consistency - regular change of social workers Difficulty accessing occupational therapy Difficulties obtaining support in an emergency - professionals should recognise *'our emergencies <u>are</u> emergencies'* Very difficult to get through to main Southwark Council number
Develop links between carers and their GPs	✓ Good sympathetic response by GPs	Suggestions from carers: • surgeries should offer joint 'check ups' for carers and patients to check medication etc. • a 'fast track card' for appointments with GPs
A more outgoing approach to information: • professionals from the same ethnic group • keyworker or advocacy role		

Issues raised by carers in 1997	A Positive Difference 1998	Issues to be Addressed
A more consistent district nursing services	Very positive experiences: ✓ good and timely help ✓ regular, punctual and flexible visits ✓ excellent continuity ✓ reliable and thorough ✓ adequate time to accomplish tasks ✓ increased visits in response to condition of person cared for ✓ sympathetic response and 'listen more'; good communication with carer	Some concern raised about monitoring by district nurses where carer is not living in the same house as the person cared for Transfer of information between individuals within the team appeared erratic Concern about the ruling that nurses could not come out during the night (after 12:00) if a catheter becomes blocked Nurses not calling at a regular time which was a difficulty for the carer Nurses do not always read messages left by carer or respond to information from the carer
Better access to speech therapy services		Carers wanted more freedom to access speech therapy as the needs of the person cared for changes
More active listening by professionals	✓ District nurses listen more (see above)	Refusal by hospital to alter appointment to assist carer Ambulance service did not listen to carer about the need for a tail-lift
Better, more reliable transport	✓ School transport excellent	Very limited services - lack of transport at weekend for disabled people Dial-a-Ride too limited Substantial transport costs where carer lives at distance from cared-for

Issues raised by carers in 1997	**A Positive Difference 1998**	**Issues to be Addressed**
Reliable equipment		
Better quality home care	✓ Some improvement in quality ✓ More able to fit with needs of carer ✓ Staff of Southwark Homecare were 'exceptional' - well supervised and trained ✓ Regular checks on quality by Southwark Homecare	Concerns about standards offered by private agencies: • staff appear poorly trained • high turnover of workers • erratic timekeeping Frustration about boundaries on role of homecare staff Difficulties speaking to managers in social services or the homecare agency Unexplained reduction in hours offered Costs creating difficulties for carers None of the carers (except one) had had their views sought about the quality of the service provided
Respite care for children	✓ Reliable allocation of 7 weeks respite a year - 'wonderful' ✓ Social worker encouraged carer to take a break and tried to facilitate respite care ✓ Southwark Carers help to promote the importance of respite care	Carer had not received any respite and felt she needed some, but noone had discussed it with her Cost is a problem

Issues raised by carers in 1997	A Positive Difference 1998	Issues to be Addressed
Better assessments: • improved access • stronger identification of carers' needs	✓ Half the assessments were initiated by Social Services staff to focus on needs of carer ✓ Most assessments took place without long delay ✓ Carers were satisfied with the manner in which assessments were conducted and felt properly listened to ✓ The needs of the carer featured strongly or were the main focus ✓ All carers said there had been a written record of the meeting and 4 had a copy ✓ Positive outcomes: –extra help to 4 carers –recognition of their needs –access to people who had some authority	Difficult for carers initiating the process themselves - more than 4 attempts to get help over the telephone –but in one situation there was a 4 month delay –but one carer had 3 different social workers over the past year and had to repeat his story over and over again –2 carers would like to have been more prepared for the assessment meeting Carers had not known about the Act before the assessment Carers would like details about <u>what</u> is to be done as a result of the assessment and <u>who</u> will do it
Improved liaison between services		Closer co-ordination of health and social services needed when devising care plans Professionals need to think more laterally More clarity about who facilitates liaison

2 Follow-up interviews with carers in Southwark

2i) Recent experiences of Assessment by Social Services

Face-to-face interviews were carried out with six carers who had recently taken part in a community care assessment procedure. They were identified for us by Social Services. None had been interviewed during the preliminary stage of Carers Impact's work in Southwark. A before-and-after comparison of individual experiences is not therefore possible; nonetheless, the new material does offer an opportunity to compare the general patterns emerging at the two stages.

➨ *The carers and who they cared for*

The interview group contained three men and three women. Five were more than 55 years old, and three were over 70. The younger carer was in his early thirties. Three were spouse carers, two were looking after elderly parents, and one was caring for his brother. All but one lived in the same household as the person cared for. The periods spent caring ranged from 12 years to just over one year. All considered themselves the main or only carer for the person concerned, although most said that members of the family helped with household tasks and lifting. Four of the people cared for were wheelchair or bed-bound; one had learning disabilities with some associated physical impairments; and one had mental health problems.

➨ *Setting up the assessments*

An encouraging feature of the current round of interviews was that half the assessments had been initiated by Social Services staff with the explicit intention of focusing attention upon the carer. For example, a man who was providing 24 hour support for his wife with mental health problems did not recognise himself as a carer until his wife's social worker identified this role for him, urging him to register as a carer so that he could obtain a proper assessment of his own needs. Social workers suggested assessments for two other carers who were already receiving services but who required additional support because of a change in their circumstances. This provides tentative evidence that Social Services staff are beginning to use carer-centred assessments more purposefully as a means of providing extra support to relieve the emotional and physical strains of caring.

Setting up assessments proved more difficult for two carers who had initiated the process themselves. This echoes findings from the earlier research. One man had resumed the care of his brother with learning and physical disabilities a year ago on the latter's return from many years in Bangladesh. He telephoned Social Services four or five times to enquire about help, with very little idea of what might be available. The response was unproductive and unhelpful until he was finally put through to the social worker who arranged an assessment. He pointed out that many carers would have given up before they reached that point. The second carer had had a meeting with Social Services in the past but had had no social work contact for over a year. She wanted to get in touch in order to discuss a holiday for her husband but lacked the confidence to do so. Eventually her daughter rang on her behalf and the assessment took place; for her, however, access would have been easier if there had been an automatic follow-up of the previous contact.

Once the need for an assessment was identified and agreed, the meeting mostly followed quite quickly - between one week and one month later. One person did report a frustrating wait. In this case, the carer's support needs had arisen at her mother's regular review meeting and a carer assessment was suggested as a way forward. However, a further four months elapsed before this took place and a further month before the much-needed services were in place. This delay reduced the value of the assessment in her eyes.

➡ *How the assessments were carried out*

Four of the six assessments were carried out at the carer's home, one in the home of the person cared for and one at a Social Services unit. In the latter case, the carer, whose wife had mental health problems, considered that his own needs could not be properly discussed in a meeting at which she was present since she would accept neither the interpretation of her condition nor his need for support in coping with it. Otherwise the assessments were carried out in the joint presence of carer and cared for. The consequent lack of privacy in discussing their needs was not an issue for the carers, either because their views were thought to coincide with those of those they cared for or because the latter were felt to be unable comprehend the process.

The assessments were co-ordinated by just one professional, except in one case where a colleague also took part. Most were mentioned by name and most were said to be social workers (although not all the carers were clear on this point). In one case, the professional involved had identified herself as an assessment officer.

Without exception, the carers were satisfied with the manner in which the assessments were conducted. The meetings were small, informal and (mostly) in the familiar setting of home. The professionals concerned had been sympathetic and easy to talk to. One carer noted his surprise at receiving such an understanding response after battling unsuccessfully with other social services staff on the telephone. The carers felt properly listened to and able to discuss the issues important to them. Slightly qualifying this point, one mentioned that he had had a succession of three social workers in the past year, all of whom had undertaken an assessment; while all three had been good listeners, it had nonetheless been irritating to have to repeat his story over and over again. Two carers said that they would have been able to contribute more fully to the meeting if they had had a clearer understanding of what was to be covered and a chance to prepare themselves accordingly.

The needs of the carer featured strongly in the discussions and in three cases provided the main focus of the meeting. Only one carer felt that there had not been a specific discussion of her needs but, even so, remembered that the social worker had asked about her own health. Particular topics linked to the carer's well-being included benefits, practical support in the home and outside and the condition of the person cared for.

The recording of the assessment meetings appeared more consistent than a year earlier. All the carers said that there had been a written record of the meeting, and four had received a copy. One of the carers who had <u>not</u> received a copy recalled that the social worker had rung to tell her what was being done to follow up the assessment; the other, whose wife had mental health problems, had asked not to be sent a copy (although one was available) in case his wife found it and demanded a detailed explanation. Four of the carers were confident that the written record reflected their own needs; one was not convinced that all his points had been taken fully on board; and the remaining carer felt that the report was more focused upon her husband, although she did not see this as a problem.

When asked if there was anything that could be improved about the assessment process, none wanted to see changes in the conduct of the meetings themselves. However, there were some suggestions about steps which could be taken to improve outcomes:

- speedier implementation of agreed actions;
- closer co-ordination of Health and Social Services when devising care plans;
- more preparation for carers who have no previous experience of the assessment procedure and who have little idea of what to expect;
- linked to this, detailed explanations, verbally as well as in writing, of <u>what</u> is to be done as a result of the assessment and <u>who</u> will do it.

➡ *Were the assessments useful?*

For the carers, the usefulness of the assessments depended primarily upon whether they resulted in additional support and whether this support was found to be appropriate. These positive outcomes were identified by four people . The extra help obtained included aids and adaptations in the home, respite care, home care and a day centre place for the person cared for. Most felt that the help offered was adequate to meet their needs at the time but one carer was disappointed at being granted night-time care for just two nights when her mother (who lived separately from her) needed this service continuously. The

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only solution for the carer was to continue with a private arrangement which was a source of financial strain.

The need for emotional support for the carer was explicitly recognised in two cases where arrangements were made for attendance at a stress clinic and for a course of counselling via Southwark Carers. Although the carers concerned were pleased that their problems in coping had been recognised, neither service proved entirely appropriate. The carer who was referred to the stress clinic attended for 6 weeks and enjoyed it but then stopped because of the difficulties of fitting a regular commitment into her schedule. The second carer appreciated the sympathetic listening which the counsellor offered but felt that he needed more directive advice about strategies for coping with stress.

Two carers were reserving judgements about the value of their assessments because they had not yet been able to make use of the services discussed. A man who was caring for his wife with mental health problems had been offered a holiday plus support in the home for her while he was away; however, her volatile condition had made it difficult for him to plan the break. In another case, a holiday facility had been identified for the person cared for but, three months later, the social worker had not got in touch about the possibilities of transport and a grant for new clothes for the holiday which she had promised to investigate.

While tangible support was the most valued outcome of assessment, the carers also appreciated the recognition of their needs and views which the process conferred. Access to people in Social Services who had some authority and could make recommendations on their behalf was another benefit mentioned by a carer who had repeatedly been frustrated by his inability to speak to anyone with `clout' when he rang up the Council. In two cases, the assessment offered an opportunity to draw attention to faulty adaptations carried out by Social Services (both involving access ramps) which the carers had previously complained about to no effect.

➡ *Awareness of the Carers (Recognition & Services) Act 1995*

As a postscript to the interview, the carers were asked whether they had known about the Act before the assessment took place. Five said that they were completely unaware; the remaining carer remembered something being mentioned at a support group meeting but said that there were no forms to fill in and that she would not have known how to go about obtaining an assessment on her own.

Conclusions

Comparing the experiences of these carers with those interviewed a year ago is fraught with difficulty because of the uneven sizes of the interview groups and the differing recruitment methods. That said, the current interviews do provide some encouraging, if tentative, indications that Social Services staff are more aware of carer assessments as a mechanism for boosting the quality and quantity of support for carers and that they are generally more attuned to the carer dimension when undertaking assessments. The standards of recording also appear to have improved, with written records being more consistently made available to carers and more explicitly incorporating carers' needs. With regard to the assessment meetings themselves, the good practice recorded a year ago has been maintained, giving carers a high level of confidence in the process. Outcomes in terms of additional services are rather better for this year's interviewees.

Two areas for further improvement can be highlighted. These are closely linked. One is the need for stronger promotion of the Carers Act among carers, allied to practical advice about how to go about obtaining an assessment. The other is ensure that office staff within Social Services are better trained to respond to carers' enquiries and are aware of the possible need for an assessment. It seems that unless carers have a very specific enquiry, they are too often fobbed off when approaching Social Services by telephone; consequently, access to assessment may be blocked at the first point of contact.

2ii) Recent experiences of homecare and district nursing services

Telephone interviews were conducted with a small number of carers in order to gain some current feed-back about homecare and district nursing services. Both had been identified as areas of concern for carers during the earlier round of interviews and focus groups at the outset of the Carers Impact project in Southwark. Recruitment for the telephone interviews was disappointing, with only three carers being identified for each service. This tiny base must be taken into account when reviewing the points raised.

➡ *Homecare*

The three carers contacted had been interviewed during the preliminary research undertaken a year ago. All were receiving homecare from private agencies under contract to Social Services and all had experienced a change in agency during the year. One carer was also receiving some homecare direct from Social Services. At the time of the second interviews, their experiences were as follows:

Carer A
This carer was dissatisfied with the boundaries imposed upon the role of homecare staff. In her view, these were arbitrary and resulted in a poor match between the service offered and what was actually needed. Specifically, she wanted help around the home as well as personal care for her husband and was frustrated when told that this was not available. She was further irritated when the care assistants refused to use the hoist which she was able to manage on her own. Their solution was to prop her husband up in bed with pillows when she was out, but the carer had found that he suffered from eating problems when he spent too much time in bed.

She had some concerns about the quality of personal care provided. Her husband suffered from bed sores and she felt that these had been inexpertly treated. At the same time, the homecare staff seemed to resent being offered advice, regarding it as interference. Frequent turnover of staff exacerbated the problems, with each new worker having to be briefed by the carer. This ate into her time off and she suggested that new workers should be sent to discuss things with her the day before they started. The lack of continuity also meant that the workers were slow at noticing changes in the cared-for person's condition unless the carer told them.

Erratic time-keeping by the homecare workers was another issue raised by the carer. She complained that they rarely spent the full hour allotted and, indeed, on the morning of the interview had been in the house for only half an hour. This made her anxious about whether they were completing the agreed routine of personal care. Mistakes were also made quite regularly in the change-over between workers around days off.

The carer had made many complaints to Social Services in the past and was now in touch with an advocate who assisted her in putting her case across. She had discovered, however, that it was difficult to get hold of the relevant managers in Social Services or the homecare agency, either by telephone or face-to-face. No-one had been in touch within the past year to find out her views.

The cost of homecare had created difficulties for this carer. She had run up substantial arrears in her payments which she was now having to repay at the rate of £10 per week, making serious inroads into her income which was solely derived from benefits.

Despite this generally negative picture, the carer was able to identify some glimmers of improvement over the past year. She considered that the quality of work had improved a little, and she had been able to renegotiate the schedule so that her own day off occurred at the week-end rather than during the week. At her request, the workers were also coming in at a more convenient time in the weekday evenings, although there were still some difficulties at the week-ends.

Carer B

In comparison, this carer had a satisfactory experience of homecare. However, his needs were more straightforward since he required help with domestic tasks rather than with the personal care of his partner, which he managed himself. The workers assisted with ironing, hoovering and cleaning for four hours per week. Help with shopping had been offered but he rejected this because he liked to get out of the house regularly. He was generally pleased with the quality of the work done, saying that he did not expect the place to be spotless in the time allowed. The same carer came in each day and stayed for the full time allocated. There had been problems in the past though, and some of the workers coming in had been `unbelievable' in their sloppiness. His partner had run a cleaning service before she had become disabled and had commented that some of the workers seemed to be entirely untrained.

The only change identified by this carer over the past year was a reduction in the number of homecare hours from six to four. This was a source of dissatisfaction since he considered that the amount of work to be done justified the extra time. Someone had visited him from Social Services to inform him about the reduction but he was not clear why it had been imposed. No-one had sought his views about the quality of the service provided.

Like the first carer, this man was struggling with the cost of homecare. Until recently he had been paying £2.30 per week and claimed never to have missed a payment. He was therefore shocked to be told that he had accumulated arrears of more than £300 which he was also paying off at a rate of £10 per week. He felt that he could not afford this amount and was seriously considering whether he was able to continue with the service.

Carer C

This carer was heavily reliant upon homecare for his wife who was suffering from advanced dementia and who had associated physical disabilities. A complex package of care had been put together, involving Southwark Homecare (the Social Services direct provider) and a private homecare agency, plus Crossroads for night-time sitting.

On the whole, the homecare arrangements blended well and were reliable but the carer considered that the service provided by Southwark Homecare was unquestionably superior to that offered by the private agency. The staff of the former were `exceptional' - well-supervised and trained, and reliably spending the full time allotted, plus extra if it were needed to accomplish time-consuming tasks such as taking his wife to the commode. In comparison, the private agency staff were thought to be adequate but tending to rush through their schedule, often not staying for the full hour. While the regular workers seemed well-trained, there were occasional lapses in quality when temporary replacements came in. Continuity of workers was, however, considered good for both services.

Checks on quality were regularly carried out by Southwark Homecare through visits to the carer from supervisors approximately every three months. The private agency had rung up once or twice in the past but not recently.

When asked whether the homecare service had changed for better or for worse over the past year, this carer said that it was about the same and certainly no worse. But, like the other carers, this man was anxious about the cost of homecare. He had been paying £2.30 per week for some time and, although he felt an increase was due, was concerned about how he would manage if this were substantial.

Points arising

The three case studies suggest that the following issues are likely to be important in the future planning of homecare services in Southwark:

- Quality of service and time-keeping by private homecare agency staff;
- Levels of training and supervision offered by private agencies;
- Amount of feed-back sought from carers by private agencies;
- Ease of access by carers to the managers of private homecare agencies and Social Services homecare managers;
- Costs of homecare to carers and the possibility of substantial arrears being accumulated without early warnings being given;

- Inflexible boundaries around the role of homecare staff;
- Arrangements for the carer to brief new homecare workers about detailed personal care arrangements when worker turnover is high.
- Dissatisfaction caused by unexplained reductions in hours of service offered.

➧ *District Nursing*

The three carers interviewed had not been involved in the earlier phase of the research. They were identified for us by Optimum Health Services in Southwark. All were receiving support from the district nursing service at the time of interview and had been doing so for some time.

Carer D
This carer was very satisfied with the amount and quality of district nursing support which he was receiving in order to help him care for his wife. A nurse came in twice a week to dress bed sores. His wife was catheterised and the nurse changed the catheter whenever it needed doing, every month or two months. The carer valued the regularity and punctuality of the nurse's visits but also said that they were flexible and that she would be prepared to come at a specific time if required. He was satisfied that she spent enough time at each visit to perform the required tasks thoroughly.

Continuity was excellent - the same nurse had been coming for 7 or 8 years and, if she was off for any reason, the back-up nurse was also well-known. Communication with the carer was good. The nurse made an entry in the record book each time and was forthcoming with information if the carer asked.

The only issue of concern for the carer over the past year had been the ruling that the nurses could not come out during the night (after 12.00 midnight) if the catheter became blocked. The only option would be to ring the ambulance and take his wife into hospital. This had not yet arisen but the carer pointed out the difficulties and distress that would be caused by having to transport his wife (who could not walk) from an upstairs flat in the middle of the night in order to accomplish a simple procedure. Otherwise, the carer considered that the service had remained consistent over the year and was unable to identify any further improvements needed.

Carer E
The carer lived separately from her mother who was wheelchair- bound. Following a recent assessment, the district nurses were now visiting her mother three times per week , as compared to once a week or fortnight previously. The service had been stepped up because of the need for increased attention to her mother's dressings.

This carer was also pleased with the quality and amount of support provided. The service had been responsive in adjusting the level of support in line with her mother's increased needs. The nurses were described as reliable and thorough. They were always prepared to make a special visit if needed and were willing to fit in with the carer's schedule. This was important since the carer was with her mother for set hours each day. Advice was readily available for the carer whenever it was required, for example about any changes in the dressings. Continuity was described as good; there were three regular nurses, one of them coming more frequently than the others. They spent enough time in the home to accomplish the necessary tasks; the carer could remember only one occasion when a nurse had rushed in and out, and this individual had not been part of the regular team.

No significant changes in the service were identified by the carer over the past year, other than the increased number of weekly visits necessitated by her mother's condition.

Carer F
The carer, who was herself disabled, was living separately from her elderly parents but spent each day and evening with them. Her father was suffering from dementia, while her mother was frail and chronically sick.

The district nurses used to visit twice a day but were now coming just once. The carer seemed unclear about the reasons for the reduction in the level of service but regretted it. In her view, it was linked to a less responsive approach by her GP over the last 10 years, manifested in a greater reluctance to visit.

The nurses' main function was to monitor and administer her parents' medication. At one stage, her father had been able to use a dispensing box for tablets but could no longer cope with this. Now the nurses gave both parents their medication in the morning and the carer took care of it at night. The arrangement was said to work quite well but there had been difficulties when the carer was on holiday and the nurses had given her father medication (laxatives) which she considered unsuitable. These had subsequently been stopped.

The nurses did not call at a regular time and this caused the carer some inconvenience. They might visit at any point between 9:00 am 1:00 pm. The carer would have preferred a consistently early visit so that her mind was at rest about the medication; if the nurses had failed to call by 1:00 pm, the carer felt that she had to chase them. Another problem was that the nurses would not order medication when it ran out but would inform the carer so that she could do it. Since the carer was not always there when the nurses called, this sometimes resulted in delays in obtaining the supplies.

The nurses were quite good at keeping the carer informed, recording information in her parents' folder. They were less good, however, at reading any messages which the carer had left. A little while ago, this had resulted in a panic when they called and her father was not there; they had failed to read the message that he was in hospital.

Continuity was described as reasonably good. Although several different nurses were involved, they were all from the same practice team. The carer did not consider that different individuals calling was a problem for herself or her parents. The nurses did, however, have a tendency to be `in and out like a shot' and the carer did wonder if they always spent enough time over her father's medication. Sometimes he was reluctant to take it and they then left it for the carer to administer.

When asked whether she could identify any improvements in the district nursing service, the carer mentioned the unresolved difficulties she had in obtaining incontinence pads for her parents. She had rung a central number to enquire but had then been referred back to her own surgery for an assessment. This was carried out by telephone rather than through a visit and resulted in the wrong sort of pads being delivered. The carer was still waiting to obtain the right ones.

Points arising

The three case studies illustrate differing carer experiences of the district nursing service. Two carers were extremely satisfied while the third found the support adequate but hedged about with minor problems. Their combined accounts suggest that the following are key attributes of a successful district nursing service from the perspective of a carer:

- reliability and punctuality, combined with a willingness to be flexible about visits when required;
- continuity - preferably of specific nurses but otherwise of several recognised individuals within a team;
- sufficient time taken to accomplish the tasks in a thorough, unhurried way and to inform the carer of changes in the nursing regime;
- two-way communication with the carer, the nurses noting the carer's messages as well as recording their own;
- levels of support adjusted in line with patient need;
- readily available advice for the carer when required;
- sensible arrangements for out-of-hours emergencies, avoiding any unnecessary disruption to the patient;
- clearer arrangements for the supply of incontinence pads.

3 Carers Review of Progress

Feedback from follow-up focus group

A focus group was convened to help Carers Impact assess Southwark's progress in implementing its carers action plan. Six carers attended, all of whom had participated in a focus group during the preliminary research. This was useful in giving a `before and after' perspective on developments in Southwark.

The carers were invited to concentrate on those areas of the action plan of which they had recent experience (i.e. during the past year).
This produced 10 discussion topics. In practice, it was not always possible to confine the discussion to a specific time-frame, and some of the points made were general observations rather than reports of recent changes.

Access to services

- There were mixed experiences of obtaining new services during the previous year. One carer reported that her mother's admission to day care for three days per week had lightened her load. Another had received respite care for the first time, although the problems encountered in trying to transport her son down from their fifth-floor flat had apparently almost counteracted the benefits of the subsequent holiday. Someone said that counselling had been withdrawn for the person with mental health problems whom she cared for and that, despite being offered counselling for herself, she had felt `abandoned' by this loss of service.

- A particular problem was identified in gaining access to the Occupational Therapy Service. A carer who was experiencing mobility problems of his own had been waiting for weeks for a response to his request for help.

- The carers felt strongly about the need for support in an emergency. They believed that local services continued to be deficient in this area. One reported that when her mother's oxygen machine had failed in the night, the service at the given night-time number had been unable to respond, necessitating a wait until 7 am. The mother of a severely disabled teenage girl had been unable to obtain help for herself when she was ill and had had to rely on her 16 year old son. The carers felt that they should be treated with respect when they got anxious during a crisis, and that professionals should recognise that `our emergencies are emergencies'.

- A central emergency telephone number was requested, manned by someone who is familiar with services and who can direct carers appropriately. The main Southwark Council number was dismissed as useless because it was so difficult to get through.

- One carer valued the consistent support which she gained from her fieldworker from the Association for Spina Bifida and Hydrocephalus who had been in touch since her daughter's birth fifteen years before. Better access to services had been a key benefit, along with emotional support. Those looking for mainstream social work support, however, found that social workers changed regularly and that there was little consistency.

Links between carers and their GPs

- The carers' recent experiences were generally positive. One said that she could not fault her GP or the staff at the health centre who were quick to respond when she needed them, for example by fitting in appointments. Others commented on their GPs' sympathetic attitudes to carers.

- One carer had encountered a problem in arranging a surgery appointment for her mother which she could also attend. When the doctor saw her mother at home without the carer being there, she felt that he was likely to miss those problems which her mother was reluctant to raise or perhaps unable to identify.

- A suggestion was made that surgeries should offer joint check-ups for carers and patients, for checking medication and other routine matters. The carers felt that they received no monitoring and that it would give them confidence to be part of a team.

District nursing services

- Once again there were positive experiences to report. For example, one carer had received good and timely help from the District Nurses in coping with her mother's severe constipation, and was impressed that they had returned later in order to check that she was comfortable. Someone else said that the District Nurses did listen more now and respond more sympathetically.

- While District Nurses were efficient in dealing with `one-off' problems, they were found to be less effective in monitoring situations and picking up alarm signals, such as slurred speech on the part of the person cared for. This was particularly an issue where the carer lived separately and needed the various professionals going into the home to be alert to changes in the situation. Confidence in the District Nurses' monitoring skills and in their capacity to respond to information from the carer remained low. An example was a failure to empty a commode for a whole week when the carer was away, despite a specific request that they should do so. Changes in the personnel coming into the home were seen to be at the core of the problem; although the District Nurses worked in consistent teams, the transfer of information between individuals within the team appeared erratic.

Active listening by professionals

- The carers recounted recent experiences of services failing to adapt to meet their needs. A recent example was a refusal to change a hospital appointment to later in the day even though the earlier time was difficult for the carer to manage. Another was an ambulance turning up without a tail-lift for a wheelchair user, despite prior warning by the carer that this would be necessary. There was a strong feeling that services should be more prepared to listen to the carer's analysis of the problem; costs would thereby be saved and frustration reduced for both carers and users.

- The carers did not necessarily want to be given priority in the delivery of services - sensitive recognition of their particular circumstances was more the issue. On the other hand, they felt there were occasions -such as setting up appointments with GPs - where a `fast track card' would be useful.

- A National Helpline for carers - possibly funded through the Lottery - was suggested as a useful means of dispensing general information about access to services and benefits.

Transport

- School transport was said to be excellent but otherwise Southwark was once again depicted as offering severely limited services compared to other areas. The lack of transport at the week-end for people with disabilities was highlighted. Dial-a Ride remained impossible to access because of the limited service that could be offered with just two buses.

- A suggestion was made that the carer should be entitled to use the cared-for person's transport pass (this entitlement already existing for the orange badge parking scheme). The costs of transport could be substantial when the carer and cared-for lived at a distance from each other.

Quality of homecare

- Concerns about the standards of homecare offered by private agencies surfaced once again. Staff were said to be sometimes too poorly trained to perform even straightforward tasks. Horror stories included workers failing to distinguish between soiled and unsoiled laundry when making up washloads; ironing a pile of laundry which had already been ironed by someone else the previous time; having to be told to turn the dial on the iron in order to adjust the temperature; and hanging up items of wet clothing on top of each other so that they failed to dry. Constant monitoring by the carer was considered necessary.

- Because of changes in lifting and handling regulations, homecare staff were said to have become less flexible in the tasks they were prepared to undertake.

- High turnover among workers was seen as a critical issue. One carer had had 14 different workers in the previous 6 months. He had expressed his concerns to Social Services who sympathised but did little else. Constant turnover was believed to undermine quality and increase the load on the carer who had to brief each new worker. A heartfelt plea was made yet again for properly trained and consistent workers who could become known and trusted.

- The carers believed that older people in particular were reluctant to complain about a substandard service because of a reluctance to upset anyone and fears of losing the help they were getting.

- None of the carers had experienced additional monitoring of homecare by Social Services during the previous year.

Respite care

- There was considerable variation in the carers' access to respite. The carer with a teenage daughter was receiving a reliable allocation of 7 weeks respite a year, which she described as `wonderful'. She was also extremely enthusiastic about the unit providing the care; an extra bonus was that her daughter could continue to be cared for there when she became an adult. At the other extreme was a carer who had not received any respite at all and who felt that she needed some. However, no-one had discussed it with her and she was uncertain about whether she would be entitled to it given that her caring was mainly mental rather than physical. Her husband was reluctant to go out and there was no-one to relieve her in the home.

- The cost of respite was an issue for a carer with a severely disabled adult son. At £400-500 per week, with the cost of her own holiday on top, it was difficult to manage more than a short spell away.

- Weekly respite care which ran from Saturday to Saturday made it difficult for carers to arrange a full week's holiday for themselves. It would be better if respite was offered from the previous Thursday so that the carer could have a breathing space to get ready.

- The carers felt strongly that there should be a recognised entitlement to respite care. One said that older carers need compulsory, regular respite 5/6 times per year. Another said that an 8/9 day break twice a year would be ideal.

- A carer reported strong encouragement from Social Services to use respite care in order to take a holiday. The social worker had tried to reassure her mother who was reluctant to accept the idea. He had then suggested an alternative approach of supplying additional care in the home when the carer was away.

- The role of Southwark Carers in promoting the importance of respite care was also mentioned.

Liaison between services

- It was agreed that professionals needed to develop their lateral thinking when viewing a caring situation and deciding what information needed to be passed on. Too often they analysed things too narrowly in relation to their own professional concerns.
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- Responsibility for facilitating liaison needed to be more clearly assigned between professionals.

Speech therapy

- The carers wanted more freedom to access speech therapy as the needs of the cared-for person changed.

Top priorities for Southwark

Out of the preceding discussion, the carers felt that the following should feature at the top of the agenda for change:

- A central emergency number for carers;
- Greater readiness by professionals to see carers as a priority;
- Passes to prove that one is a carer;
- Carer training and awareness-raising for all employees;
- Better transport, especially at week-ends.