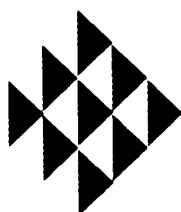


King's Fund



Carers Impact Project in Southwark

Where have we got to?

Final report based on a workshop
held on 22 July 1998 to evaluate the
Carers Impact Project in Southwark

QBAN (Kin)

KING'S FUND LIBRARY
11-13 Cavendish Square
London W1G 0AN

Class mark Q3A2	Extensions Kin
Date of Receipt 10/8/05	Price Donation

Contents

Introduction	2
Executive Summary	3
Report of the workshop	5
1 Background to the project.....	5
2 The Picture Before.....	6
3 The Picture Now	8
4 Making Progress.....	17
5 Looking ahead - keeping the work on course and monitoring progress	18

Appendix 1: Workshop Participants

Appendix 2: The Carers Impact Process - what has helped / not helped

Appendix 3: Carers Impact reports and publications

Introduction

Members of the Joint Community Care Planning Group for Carers and other people representing the partner agencies met to evaluate the Carers Impact Project in Southwark and to:

- ◆ review the changes which have taken place during the course of the project and the impact on carers' lives
- ◆ identify what had helped and hindered progress
- ◆ identify how the work would continue
- ◆ evaluate the Carers Impact process

The workshop was facilitated by Penny Banks from Carers Impact at the King's Fund.

Executive Summary

The evaluation meeting identified the following progress achieved since the beginning of the Carers Impact Project in 1997 and issues to be addressed in future joint work to support carers living in Southwark.

1 Steps forward to meet the outcomes carers want

There has been action by all the agencies on the wide range of issues raised by carers at the start of the Carers Impact Project in 1997. Some of this action has been initiated through the direct work of Carers Impact, for example, following the assessment workshop and other work has been part of different ongoing agendas in Southwark.

The action is detailed in section 3 of this report alongside feedback from carers of their experiences which indicate current strengths and weaknesses. Whilst there are some difficulties in making a direct comparison between the experiences of the carers interviewed a year ago and those more recently, there are signs of improvements in some key areas, notably in assessments of carers' needs.

There is also positive feedback from carers about their experiences of the district nursing and homecare services, although some carers continue to express concerns about the quality and, in the case of homecare, the costs of the service.

2 Areas for action

The following areas for action are indicated by the feedback from carers and from the discussions at the workshop:

- carer access to services - particularly for carers trying to access help from social services over the telephone and trying to get help at times of emergency
- recognition by *all* staff from *every* agency so that hidden carers are identified and carers are not just seen as a resource but are treated as partners and their needs are taken into account. This is particularly important for Primary Health Care.
- support to carers from black and ethnic minority communities and to address the key issues raised by the research of the Cultural Unity Working Group
- opportunities for a break, particularly for carers whose first language is not English
- transport, particularly at the weekends

3 Partnership working

Whilst there is evidence of joint working at all levels to improve support to carers, for example, at a practice level in developing shared care records, the need to continue to develop a joint approach across all sectors and agencies was identified. This includes more lateral thinking and solutions to care planning at a case level.

There also appears to be potential in further developing the dialogue between all the partner agencies at the Joint Community Care Planning Group for Carers to share good practice and develop each agency's response to carers.

4 Taking carers into the mainstream

There are clear examples of addressing carers issues within core mainstream services such as homecare and district nursing, but there appears to be some way to go in ensuring all services, particularly health services, are responsive to the needs of carers and that responsibility for carer support does not just lie with specialist and voluntary sector organisations. A balance between specialist services to carers and carer responsive mainstream services, which are often directed at the user/patient, does appear to be critical given the feedback from carers, both locally and nationally.

The JCCPG may be interested in initiating a survey of managers and staff to find out their knowledge of local carer policies and strategies which other Carers Impact sites have piloted.

5 Engagement with carers

Individual carers have been involved in different activities such as in a number of different local research projects and in the workshop on assessments. Managers have also gone out to consult and speak with carers, for example over the learning disability services. However individual carers are not taking part in the JCCPG and there appears to be scope for further direct engagement with carers to develop services and practices in all the partner agencies.

6 Keeping carers on the agenda and monitoring progress

Outside pressures on statutory agencies, a lack of management time for development work, organisational changes and staff turnover have not made it easy to progress the issues raised by carers. Effective monitoring and mainstream ownership will be vital in ensuring the work continues and policies to support carers are put into practice and not sidelined as new health and social care arrangements are put into place.

There are important monitoring systems which have been set up, for example to monitor homecare and equipment services and to identify carer assessments and unmet needs. These could be usefully developed for all services which impact on carers and for other reviews, such as on hospital discharges, to ensure the outcomes for carers are specifically addressed.

Report of the Workshop

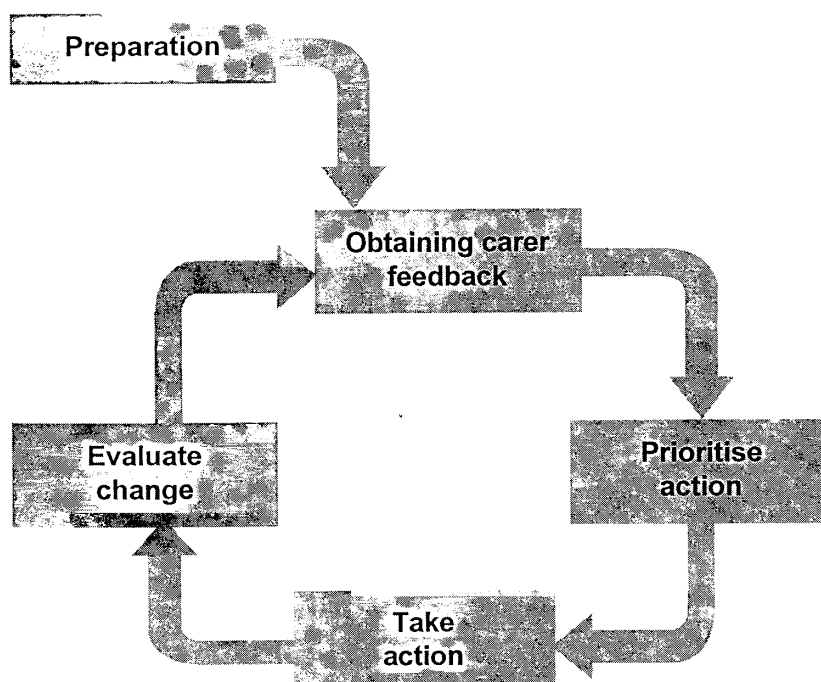
1 Background

The Carers Impact Project in Southwark was one of six demonstration projects taking part in the national development programme which aimed to show how health and community care services could work together to make a positive difference in carers' lives.

The project in Southwark aimed to:

- ♦ build on the substantial work already undertaken by the site
- ♦ involve all the key agencies
- ♦ involve carers throughout

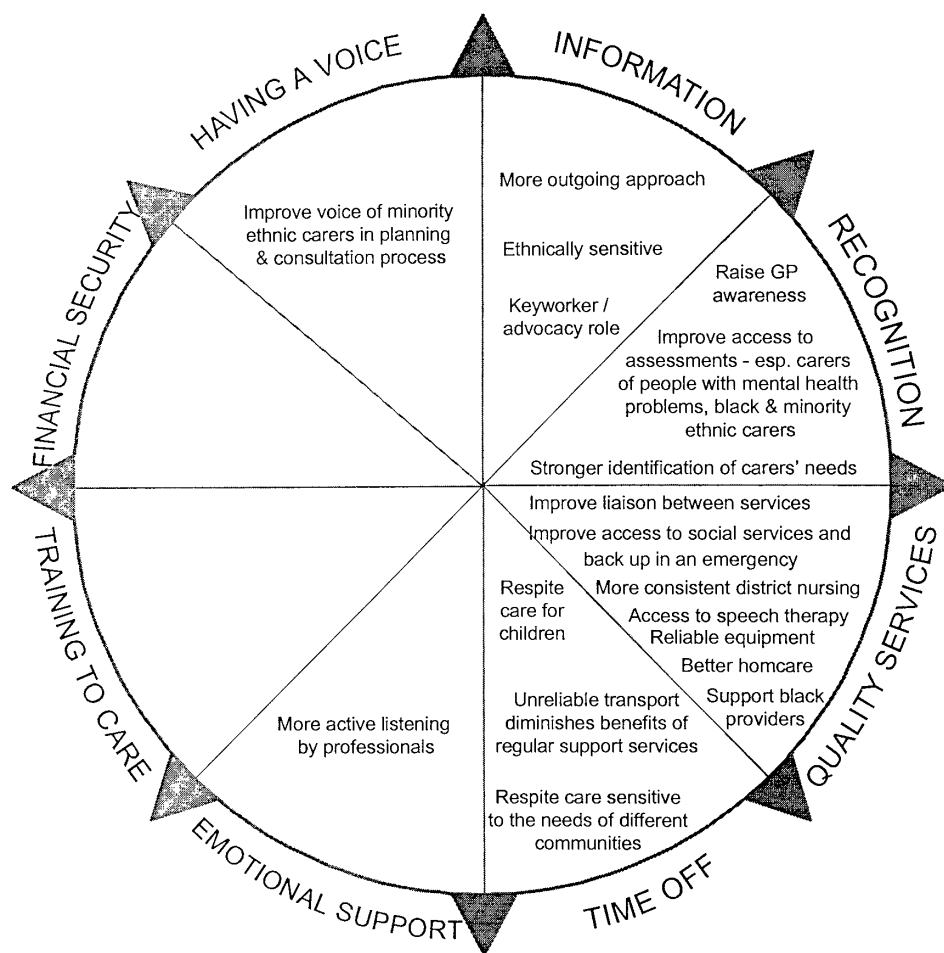
The project method



2 The Picture Before

a) Feedback from carers January 1997

Carers gave the following key messages^{*} about their experiences of services in Southwark and what was needed to achieve the outcomes they wanted (as detailed around the 'Compass').



^{*} 'Report of the focus groups and interviews conducted with carers in April-June 1997'. H Bagshaw, J. Unell, King's Fund.

See also - Feasibility Research of Black and Minority Ethnic Carers - Cultural Unity Working Group

2 The Picture Before *cont.*

b) Structures and work in progress

- ◆ Southwark Joint Community Care Planning Group for Carers leading on carer issues
- ◆ Three year strategy agreed
- ◆ A range of research projects, including Young Carers
- ◆ Cultural Unity Working Group to undertake research with carers from black and minority ethnic communities
- ◆ An established carer organisation - Southwark Carers
- ◆ Social Services interest in reviewing carer assessments

c) Local issues

- ◆ An ageing population; increasing numbers of elderly people caring
- ◆ A high incidence of mental health problems
- ◆ Moves towards joint commissioning of services to people with learning difficulties and concerns about ageing carers
- ◆ A diversity of local health providers

3 The picture now

The Carers JCCPG has steered and progressed the work during the course of the Carers Impact Project and has produced a number of different strategic and implementation plans which have addressed the feedback from carers and other ongoing carer issues.

The following chart identifies the **action taken** by all the partner agencies to improve services in response to the feedback from carers obtained in June 1997.

Feedback from carers is summarised in the third section of the chart identifying carers positive experiences as well as their messages about 'issues to be addressed'. This feedback is more fully described in the report '*the Picture Now: feedback from carers July 1998*' which was presented by Carers Impact at the workshop.

This feedback from carers was obtained from:

- ◆ A focus group attended by six carers who had participated in the first focus group in 1997. This was useful in giving a 'before and after' perspective on developments. Carers were invited to concentrate on their experiences of services over the last year relating to the original key messages from carers.
- ◆ Face-to-face interviews with six carers who had recently taken part in a community care assessment procedure. None had been interviewed during the preliminary stage, but the new material does offer an opportunity to compare the general patterns emerging at the two stages.
- ◆ Telephone interviews with six carers to obtain feedback about homecare and district nursing services. This small number of carers needs to be taken into account when reviewing the points raised.

1

Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998*	
		A Positive Difference	Issues to be Addressed
<p>Improved access to social services:</p> <ul style="list-style-type: none"> • more contact with social workers • back up in an emergency • access to review • improved access for black and ethnic minority carers 	<ul style="list-style-type: none"> ➤ Carers Impact workshop on assessments resulting in higher profile on carers and more regular reviews involving carers ➤ Social services training on Young Carers ➤ Reorganisation within social services disability teams into specialisms - physical disability and learning disability - emphasising carers in group and individual supervision ➤ Care Programme Approach for mental health developed and broadened to include carers 	<ul style="list-style-type: none"> ✓ Carer assisted by mother's admission to day care ✓ Carer received respite care 	<p>See 'Better assessments' - difficulties for carers trying to get help by phoning social services</p> <p>Little consistency - regular change of social workers</p> <p>Difficulty accessing occupational therapy</p> <p>Difficulties obtaining support in an emergency - professionals should recognise '<i>our emergencies <u>are</u> emergencies</i>'</p> <p>Very difficult to get through to main Southwark Council number</p>

* The Picture Now: feedback from carers J Unell and P Banks, Carers Impact 1998

	Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998	
			A Positive Difference	Issues to be Addressed
2	Develop links between carers and their GPs	<ul style="list-style-type: none"> ➤ Southwark Carers work with Primary Health Care Teams - intensive work with three practices; training for 14 practices ➤ Health meetings with GPs ➤ More open referral system (mental health) giving better access to carers ➤ Voluntary sector advocacy with PHCT ➤ Health Visitor training provided for Chinese carers 	✓ Good sympathetic response by GPs	<p>Suggestions from carers:</p> <ul style="list-style-type: none"> • surgeries should offer joint 'check ups' for carers and patients to check medication etc. • a 'fast track card' for appointments with GPs
3	<p>A more outgoing approach to information:</p> <ul style="list-style-type: none"> • professionals from the same ethnic group • keyworker or advocacy role 	<ul style="list-style-type: none"> ➤ Social services leaflet for carers produced ➤ Asian social worker recruited in elderly teams (Social Services) ➤ Southwark Carers translation project ➤ Information stands - Elephant and Castle shopping centre ➤ Information day for black and minority ethnic carers 		

	Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998*	
			A Positive Difference	Issues to be Addressed
4	More consistent district nursing services	<ul style="list-style-type: none"> ➤ New work on shared care records ➤ Monitoring care plans for work with carers ➤ Promoting carer assessments 	<p>Very positive experiences:</p> <ul style="list-style-type: none"> ✓ 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 	<p>Some concern raised about monitoring by district nurses where carer is not living in the same house as the person cared for</p> <p>Transfer of information between individuals within the team appeared erratic</p> <p>Concern about the ruling that nurses could not come out during the night (after 12:00) if a catheter becomes blocked</p> <p>Nurses not calling at a regular time which was a difficulty for the carer</p> <p>Nurses do not always read messages left by carer or respond to information from the carer</p>
5	Better access to speech therapy services	<ul style="list-style-type: none"> ➤ Established community therapy teams (for adults) aiming for better identification of appropriate therapy to meet needs of person cared for 		<p>Carers wanted more freedom to access speech therapy as the needs of the person cared for changes</p>

	Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998 ¹	
			A Positive Difference	Issues to be Addressed
6	More active listening by professionals	<ul style="list-style-type: none"> ➤ Social services care management refresher course involves carers ➤ Southwark Carers training sessions with CPNs at the Maudesley Hospital ➤ Lewisham and Guy's Mental Health Trust Carers Strategy 	✓ District nurses listen more (see above)	<p>Refusal by hospital to alter appointment to assist carer</p> <p>Ambulance service did not listen to carer about the need for a tail-lift</p>
7	Better, more reliable transport	<ul style="list-style-type: none"> ➤ Day centre review looking at transport issues ➤ Review carried out of Dial-a-Ride 	✓ School transport excellent	<p>Very limited services - lack of transport at weekend for disabled people</p> <p>Dial-a-Ride too limited</p> <p>Substantial transport costs where carer lives at distance from cared-for</p>
8	Reliable equipment	<ul style="list-style-type: none"> ➤ Social services contract for OT equipment: <ul style="list-style-type: none"> -waiting list reduced -ongoing monitoring - improvements indicated -health service OTs can access the service 		

9

Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998*	
		A Positive Difference	Issues to be Addressed
Better quality home care and community respite care	<ul style="list-style-type: none"> ➤ Three new contracts with new homecare specification which includes informing carers; linked to bonus system ➤ Ongoing monitoring and review ➤ Market research by MORI ➤ Care management guidance established ➤ Quality measures by Capital Carers: <ul style="list-style-type: none"> – formal quality system based on what carers/clients say – care folders in the home to share information between carer and care workers – supervisors introduced to monitor quality – carers can specify characteristics of care worker 	<ul style="list-style-type: none"> ✓ 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 	<p>Concerns about standards offered by private agencies:</p> <ul style="list-style-type: none"> • staff appear poorly trained • high turnover of workers • erratic timekeeping <p>Frustration about boundaries on role of homecare staff</p> <p>Difficulties speaking to managers in social services or the homecare agency</p> <p>Unexplained reduction in hours for one carer</p> <p>Costs creating difficulties for carers</p> <p>None of the carers (except one) had had their views sought about the quality of the service provided</p>

	Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998*	
			A Positive Difference	Issues to be Addressed
10	Respite care	<ul style="list-style-type: none"> ➤ Reorganisation of social services - specialist children's disability teams ➤ Capital Carers - respite care service to parent carers - seminars for parent carers ➤ Contact a Family established in Southwark ➤ Day care review is planning for 24 hour respite care 	<ul style="list-style-type: none"> ✓ 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 	<p>Carer had not received any respite and felt she needed some, but no one had discussed it with her</p> <p>Cost is a problem</p>

11

Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998*	
		A Positive Difference	Issues to be Addressed
<p>Better assessments:</p> <ul style="list-style-type: none"> • improved access • stronger identification of carers' needs 	<ul style="list-style-type: none"> ➤ Carers Impact workshop on good practice in carer assessment ➤ Assessment form revised ➤ Better data collection from September 1998 ➤ Mental health social workers more proactive in addressing carers issues in course of assessment ➤ Higher number of joint assessments ➤ District nurses prompting carers to identify themselves to social services to have an assessment ➤ HIV clinical nurse specialists prompting awareness of dual needs of user and carer ➤ Carer assessments a priority for CHC ➤ Research by Cultural Unity Working Group ➤ Young Carers research and Young Carers Project ➤ Health Education Authority - special programmes on carers health 	<ul style="list-style-type: none"> ✓ Half the assessments were initiated by Social Services staff with explicit intention of focusing on the needs of the 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 two thirds of carers interviewed had a copy ✓ Positive outcomes: <ul style="list-style-type: none"> –extra help to carers –recognition of their needs –access to people who had some authority 	<p>Difficult for carers initiating the process themselves - a number of attempts to get help over the telephone</p> <p>–but in one situation there was a 4 month delay</p> <p>–but one carer had 3 different social workers over the past year and had to repeat his story over and over again</p> <p>–two of the carers interviewed would like to have been more prepared for the assessment meeting</p> <p>Carers had not known about the Act before the assessment</p> <p>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</p>

	Issues raised by carers in 1997	Action Taken as at July 1998	Carer Feedback, July 1998	
			A Positive Difference	Issues to be Addressed
12	Improved liaison between services	<ul style="list-style-type: none"> ➤ Work in progress on health and social services shared care records ➤ Regular health meetings with GPs and meetings with social services teams (older people) ➤ Development of the three borough group for physical disability ➤ In mental health services, winter pressures funding and encouragement to take a whole systems approach ➤ Southwark Carers - better links with Health Authority ➤ Capital Carers - more links with Social Services, Adults & Children, Education Welfare, Schools 		<p>Closer co-ordination of health and social services needed when devising care plans</p> <p>Professionals need to think more laterally</p> <p>More clarity about who facilitates liaison</p>

4 Making Progress

The meeting identified what had helped and hindered progress in taking action



What has helped

- New government agenda:
 - promoting health and social services working together
 - positive agenda, especially as it includes rehabilitation
- Primary Care Groups offer key opportunities
- Minister for carers
- Amalgamation of Trusts
- Huge agenda faced by all the organisations - but it can be a positive chance to review practice
- Carers Impact project has given a focus and independent facilitation
- Carers National Association report on carers experiences of the NHS
- Health Action Zone →
- Health services now looking at needs of whole person
- Recognition of cost effectiveness of supporting carers - £150 m contribution picked up by local press and now the mayor's theme for the year
- Development of early intervention strategy (older people)
- *Joint* Community Mental Health Teams
- Southwark Carers to join with Princess Royal Trust for Carers



What has not helped

- Very heavy government agenda for statutory sector- little time to consolidate
- Joint review by SSI and Audit Commission has diverted social services attention
- Government health agenda - rapid response, supported discharge - dangers if are carers not properly involved
- Perception by some that carers are seen as an 'appendage' and not having own needs
- Can be divisive to categorise carers into groups/by the condition of the person cared for
- Carers experiences vary according to the GP they see, or worker
- Many carers are still 'invisible'
- but many different 'zones' with their own rules and boundaries which are not coterminous
- Withdrawal of HIV counselling services
- Staff turnover- membership of JCCPG / Carers Impact Steering Group has changed
- Voluntary sector funding may be affected if carers are seen as the sole responsibility of the statutory sector
- Cuts in budgets, and tightened eligibility criteria BUT this has led to an emphasis on early intervention and concentration on the quality of services to try to square the circle
- Tight resources have also led to cuts in management and development capacity curtailed

5 Looking ahead: keeping the work on course and monitoring progress

Monitoring the overall strategy

- ◆ The Joint Community Care Planning Group for carers will continue to co-ordinate and monitor the work on carers
- ◆ Changes in planning structures with the creation of the new Primary Care Groups could offer better involvement of GP s

Carer Involvement

- ◆ Individual carers do not currently take part in the JCCPG. Carers organisations are represented on the JCCPG.
- ◆ Carers were involved in the workshop on carer assessments. It is not clear how far carers are engaged in developing other policies and practices within all the partner agencies.

Current Monitoring

The meeting identified the following ongoing monitoring and examples of evaluating the impact on carers:

◆ Homecare

- ⇒ Monitoring of homecare contracts with bonus system to encourage good practice
- ⇒ MORI market research on homecare
- ⇒ Monitoring availability of homecare staff who speak a range of languages

◆ Equipment

- ⇒ Monitoring contract for equipment - random phone checks and annual reports
- ⇒ Quality system introduced by Capital Carers

◆ District Nursing

- ⇒ Professional supervision of district nurses and reviews of records
- ⇒ Practice Development Groups to support nurses in implementing quality of service

♦ **Hospital discharge**

- ⇒ Monitoring / liaison teams at some hospitals to review discharge (but not always carer specific)

♦ **Assessment and Care Management**

- ⇒ SSD Assessment and Care Management Business Plan identifies audits of assessments
- ⇒ Management monitoring of assessments through supervision

♦ **Carers Counselling Services**

- ⇒ Recent evaluation of Southwark Carers counselling service

♦ **Carers voice**

- ⇒ SSD carer database established from the recruitment of carers taking part in the Carers Impact Project
- ⇒ Different research with carers to identify the issues
- ⇒ New recording of assessments will provide information on unmet needs for planning

Suggestions for new monitoring activities

- ♦ Monitoring to check services are culturally sensitive
- ♦ Use information on the take up of Attendance Allowance across the London Boroughs
- ♦ Promote standard over 75 check and standard registration to use as a monitoring opportunity

Issues identified by the meeting to take forward

- ◆ Respite care - especially for people without English as their first language
- ◆ Recognition of carers as part of the Primary Health Care Team
- ◆ Identify hidden carers
- ◆ Joint working front line - address care planning, generic workers and working across agencies

Priority issues identified by carers taking part in the focus group

- ◆ 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 weekends

Appendix 1: Participants List

John Bland	Southwark Carers
Rachel Carter	Southwark Social Services
Vivienne Cencora	Optimum NHS Trust
Peter Eweje	The Maudesley NHS Trust
Peter Facey	Southwark Social Services
Billy Govinden	Lewisham and Guys Mental Health NHS Trust
Joan Harding	Southwark Social Services
Stephanie Jeffrey	Lambeth, Southwark and Lewisham Health Authority
Angela Johnson	Cultural Unity Working Group
John Keidan	Southwark Social Services
Paula McCabe	Lambeth, Southwark and Lewisham Health Authority
Trevor Precious	Southwark CHC
Sally Robert	City University / King's Healthcare
Barbara Scott	Optimum NHS Trust
Julian Smith	Southwark Carers
Sue Ward	Southwark Community Care Forum
Debbie Wood	Southwark Social Services

Appendix 2: The Carers Impact process

The following are the views of the workshop participants:



What has helped

- Given focus and direction
- Provided impartiality
- Independent facilitation by an external organisation releases statutory agencies to participate more fully
- Excellent facilitation and tools you can use
- Raised carers issues up the agenda of all the agencies, especially health
- Boosted carers involvement, for example in the assessment workshop
- Clear reports on workshops
- Made us look critically at ourselves - carer feedback was very helpful



What has not helped

- Would have welcomed more knowledge of other sites
- Lack of black and minority ethnic researchers
- Health would have welcomed greater clarity of extent of remit (i.e. project did not include parent carers) and more intensive involvement from Carers Impact

General Points

The Carers Impact process was grafted onto the ongoing work of the planning group and community care planning. The same issues were being addressed but the processes were different and needed to be clarified at some stages.

Appendix 3: Reports produced by the Carers Impact Project in Southwark

1. Report on the focus groups and interviews conducted with carers in April-June 1997. H Bagshaw, J Unell
2. Moving Forward on Carer Assessments: Report of a workshop held on 22 January 1998 to develop measurable indicators of good practice in carer assessment
3. The Picture Now: feedback from carers July 1998

General reports and publications

1. Putting the Carers Act into Practice. Report of a workshop held on 26 September 1997 at the King's Fund
2. Carers Impact: How do we know when we have got there? Improving support to carers: Report of the first year's work of Carers Impact October 1997
3. The Carers Compass: Directions for improving support to carers. King's Fund publishing June 1998



King's Fund



54001001323503

