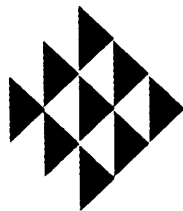




King's Fund



Carers Impact Project in East Sussex

Where have we got to?

Final report based on a workshop
held on 15 December 1998 to
evaluate the Carers Impact Project
in East Sussex

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Appendix 1: Workshop Participants and Members of the Steering Group

Appendix 2: Carers Impact Process: what has helped / hindered

Appendix 3: Carers Impact Reports and publications

Introduction

Members of the East Sussex Carers Impact Steering Group (see Appendix 1) met to evaluate the Carers Impact Project in East Sussex 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 East Sussex.

1 Partnership working

The project's multi-agency steering group, with carer involvement, has proved valuable in developing a partnership approach to supporting carers, sharing good practice and co-ordinating the work of the different agencies. It is proposed that this group, with added representation from the hospital trusts, continues to take the lead on developing and monitoring East Sussex's joint strategy and action plan. Two-way links between the steering group and the Carers Community Care Planning Group, the Primary Care Groups and work on the Joint Investment Plans and the Health Improvement Programme are seen as essential in ensuring there is a coherent strategic approach to carers' issues.

2 Steps forward to meet the outcomes carers want

There has been action by all the partner agencies to address a number of issues highlighted by carers at the start of the Carers Impact Project in 1997 (detailed in section 3). Raising awareness of the needs of carers has been a priority and important work has been undertaken with GP s, primary care and hospital and community staff. Carer awareness and good practice in carer assessments has also been a key focus for social services. This has demonstrated some of the difficulties for staff who are unclear about local policy and the priority to give to carer assessments where budgets are under pressure.

There has been positive feedback from carers using a GP practice with a carers support worker attached, although carers continue to report very varied experiences of the carer awareness of GPs and the need for better information from primary care. Inconsistency of practice is also evident in carer assessments. Although some carers have identified very positive outcomes from assessments there is still evidence of little explicit focus upon the needs of the carer within the process.

3 Ensuring carers are part of mainstream activity

Whilst there has been important work to ensure mainstream services recognise and respond to carers a great deal of innovative work has been initiated and carried out by the specialist voluntary sector (see audit of services illustrated by the Carers Compass on page 8). Much of this work has relied upon short-term funding, often out of necessity on a project basis, which has inevitably meant developments have been precarious and under considerable pressure as more

needs have been recognised yet there has been no corresponding growth in budgets.

The steering group will want to ensure carer support is seen as the business of all mainstream services and there is a strategic, rather than piecemeal approach to carer support which does not rely on one-off projects and where the voluntary sector is properly supported in its partnership role with the statutory agencies.

The results of the staff surveys, asking about their awareness of the work on carers, may provide a useful pointer to the extent of the ownership of the carer agenda by staff at all levels within the partner agencies. This feedback will also be able to inform the joint training programme which will help to raise the awareness of staff. Clarifying management responsibilities to monitor frontline work with carers will also be important in ensuring the system reinforces the good practice promoted through joint training.

4 Engaging with carers

The steering group is keen to ensure carers are genuinely and effectively involved in all the new arrangements for health and social care, building on the already established networks and avoiding token representation. There is a need to find more systematic ways of obtaining feedback, rather than repeating research exercises, and this has been identified as a priority task for the next stage of work.

5 Continuing the work and monitoring progress

Given the feedback from carers about the inconsistency of their experiences, monitoring the quality of services and practice has been identified as another priority in continuing the work and a task for all the agencies involved.

Co-ordination of the action taken by all the agencies and monitoring the overall progress on the strategy is seen as a key role for the steering group. An ongoing dialogue with carers on the steps taken as well as hearing their experiences and views will be an essential part of this work.

The work with primary care, on assessments and on carer- friendly employment policies; the joint agency approach and the engagement with carers should provide a good base and headstart for addressing the agenda which is likely to emerge from the government's National Carers' Strategy due out for consultation at the beginning of 1999.

Report of the Workshop

1) Background

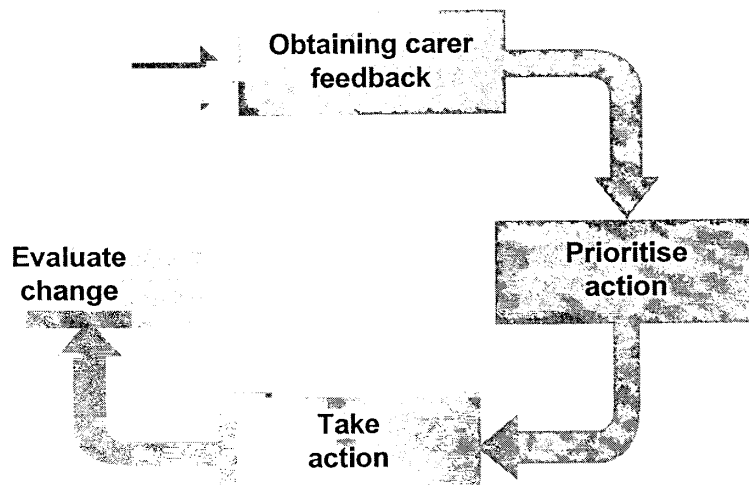
The Carers Impact Project in East Sussex was one of six demonstration projects taking part in the national development programme which aimed to show how health and community care services could work together to make a positive difference in carers' lives.

The project in East Sussex aimed to:

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

The project method

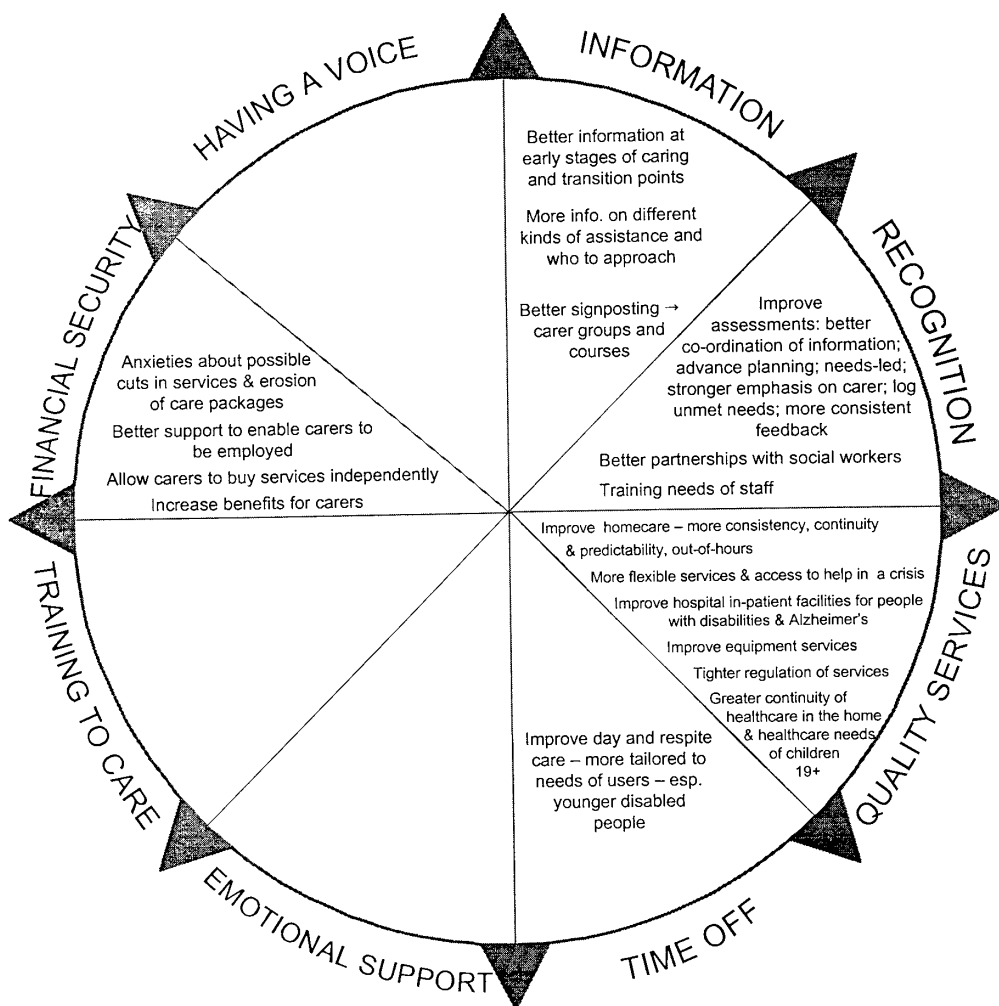
Preparation



2) The Picture Before

a) Feedback from carers October/November 1997

Carers gave the following key messages* about their experiences of services in East Sussex 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 October/November 1997'. H Bagshaw, J. Unell, King's Fund.

2 The Picture Before *cont.*

b) Processes in place

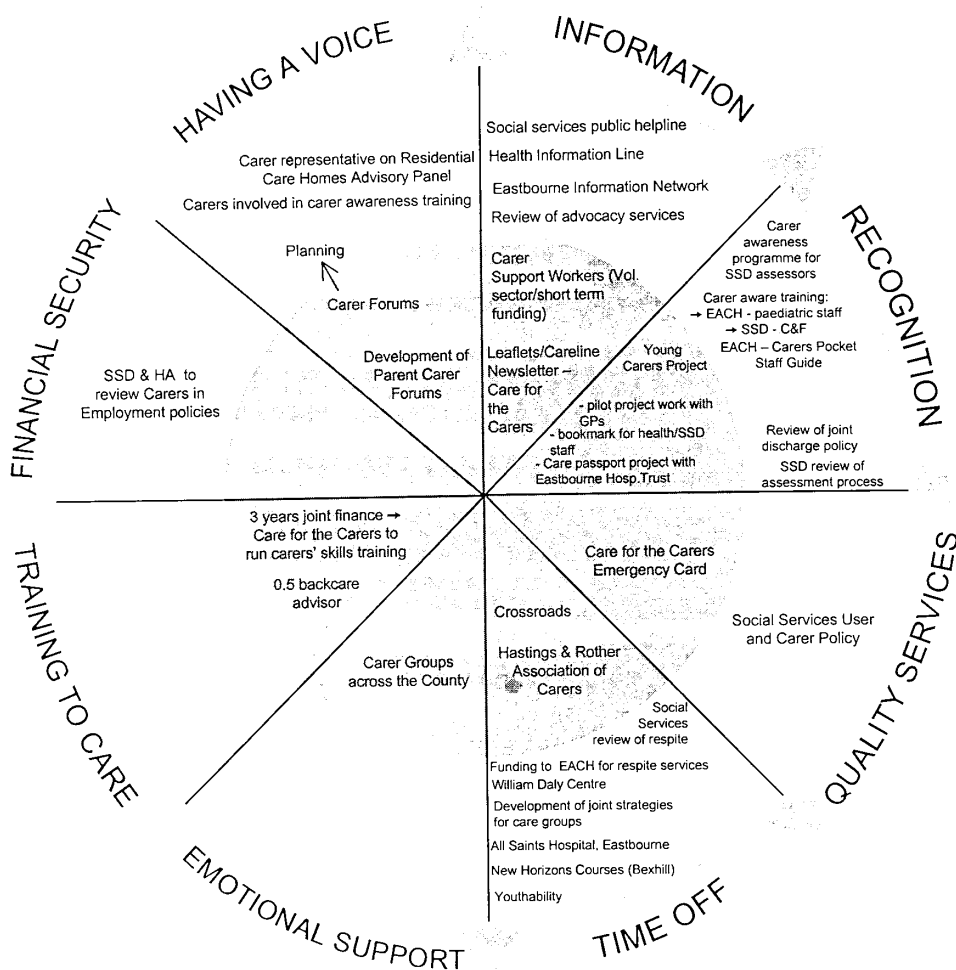
- Multi-agency Carers Executive Planning Group
- Annual review of joint strategy
- Network of carers forums, supported by Care for the Carers Council

Key Issues

- ♦ Changes in personnel due to local government review and social services and health authority restructuring

3) The picture now

The multi-agency East Sussex Carers Impact Steering Group has led the work during the course of the project. As part of its work to address the feedback from carers it reviewed the services and support to carers in the county in August 1998 using the 'Carers Compass' (ref. Appendix 3). The shaded circle shows the specialist carer services in place and the white outer circle shows the work in progress within mainstream health and social services.



What have we got in place to support carers?

The Picture in August 1998

3) The picture now (cont.)

In September 1998 East Sussex, Brighton & Hove Health Authority, East Sussex Social Services and East Sussex Care for the Carers signed up to a Joint Strategy and Action Plan which highlighted the key issues which all the partner agencies had agreed to focus on to improve the outcomes for carers.

The following chart identifies the **action taken** by all the partner agencies to address these issues since obtaining the first carer feedback in November 1997.

The third section of the chart summarises the most recent feedback from carers and identifies 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, December 1998' which was presented by Carers Impact at the workshop.

This feedback was obtained from:

- i) Telephone interviews with 11 carers to ask about their experiences of GPs and Primary Care over the past year, with particular reference to whether they were offered support and recognition and how far their needs were accommodated. Five of these carers belonged to GP practices with an attached carers support worker; the others were with practices which did not have this resource.
- ii) Face-to-face interviews with 5 carers about their experience of assessment.
- iii) A focus group attended by 3 carers, each of whom had participated in a focus group during the preliminary research.

East Sussex Joint action plan	Action Taken as at December 1998	Carer Feedback, December 1998*	
		A Positive Difference	Issues to be Addressed
<p>To ensure carers are fully informed at the first point of contact</p> <ul style="list-style-type: none"> • to identify carers through primary health care teams • to identify carers through assessment process • to offer information to carers at the point of identification 	<ul style="list-style-type: none"> ➤ Joint finance for Carers Support Workers for GP Practices ➤ Copies of the report "Carers: Partners in Primary Care" distributed to GPs/PCGs ➤ Information provided for carers on the Primary Care arrangements ➤ Carer forums informing PCGs of these networks ➤ Eastbourne Downs Primary Care Group will make carers a priority ➤ Health Promotion to produce a laminated noticeboard leaflet for GP practices ➤ East Sussex Medical Audit and Advice Group are considering a carers audit ➤ Currently evaluating Carers Pocket Staff Guide ➤ Evaluation of Eastbourne 'Care Passport' ➤ Further joint finance for Young Carers Project ➤ Need to Know Carers Card given to staff at induction by EACH ➤ New Hospital Discharge Process agreed – includes carers issues 	<ul style="list-style-type: none"> ✓ Some carers found GPs ready to interpret symptoms, anticipate developments and give full explanations of medication regimes ✓ Efficient and speedy response to emergency calls praised by carers ✓ 4 out of 5 carers in the GP practice with an attached carers support worker felt the practice was progressing and trying to improve things ✓ Carers support worker effective in reaching out to carers ✓ Most GPs willing to make home visits ✓ Experience of carers using the practice with a carers support worker attached was consistently more positive than those using the practice without a worker 	<ul style="list-style-type: none"> • GPs and primary care staff are often reluctant or unable to offer information • Potential problems with medication need to be flagged up more clearly by GPs and hospital specialists • Difficulties raised by 2 carers about their GPs knowledge of the cared-for person's condition; GP refused to diagnose her child during the first year; concerns about inappropriate pain-killing medication • <u>But</u> 2 carers experienced difficulties in calling out their GP • <u>But</u> little to distinguish between the two groups interviewed in the extent to which GPs offered explicit recognition and support. <i>(NB difficult to interpret findings – see full report p.9)</i> <p>Carers need more information about:</p> <ul style="list-style-type: none"> • home care agencies and help in identifying the 'right' criteria against which to assess home care agencies

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

	East Sussex Joint action plan	Action Taken as at December 1998	Carer Feedback, December 1998	
			A Positive Difference	Issues to be Addressed
1	To ensure carers are fully informed at the first point of contact (Cont.)	<ul style="list-style-type: none"> ➤ HART to start a group with local carers to look at introducing care passport / training of staff, including inductions. Regular meetings between carers and Trust staff planned on current issues <p>BUT</p> <ul style="list-style-type: none"> ➤ <i>Loss of carers support worker in Peacehaven</i> ➤ <i>No new funding available for backcare advisor, although increasing demand for the service, nor for other services such as equipment</i> 		<ul style="list-style-type: none"> • insurance cover when staff come into their homes <p>Carers would like a 'central' information point</p> <ul style="list-style-type: none"> • Proactive information and advice about incontinence is needed
2	<p>To ensure carers needs are taken into account alongside users</p> <ul style="list-style-type: none"> • to provide staff with carer awareness training • to improve carer assessments 	<ul style="list-style-type: none"> ➤ Questionnaire distributed to survey staff carer awareness within the Health Authority, Trusts and Social Services and to disseminate joint strategy, report on Primary Care and Joint Priorities Guidance ➤ Rolling programme of staff training in Social Services ➤ Carer awareness training for staff working with children with complex needs and their families. Progress review planned Dec/Jan (EACH) ➤ User and carer involvement policy (SSD lead with health involved) to be consulted on next Spring ➤ Advocacy review also taking place 	<ul style="list-style-type: none"> ✓ 2 carers reported their GP has a positive attitude to carer support and asked how <u>they</u> were ✓ Good level of awareness of the community care assessment process 	<ul style="list-style-type: none"> • Carer awareness among GPs and primary care staff remains patchy and variable • Rotation of cases between hospital specialists inhibits awareness • But carers unaware of an explicit focus upon their own needs • Little differentiation between the needs of the carers and the person cared-for within the assessment process • Only one carer, out of 5 interviewed, was told about the Carers Act and the right to a separate assessment

East Sussex Joint action plan	Action Taken as at December 1998	Carer Feedback, December 1998*	
		A Positive Difference	Issues to be Addressed
To ensure carers needs are taken into account alongside users (Cont.)	<ul style="list-style-type: none"> ➤ Audit of discharge policy; Care for the Carers involved in methodology. Hastings & Rother NHS Trust ➤ Audit of hospital admission and discharge policies – Uckfield and Crowborough – to include carers needs. ➤ Consultation on East Sussex joint discharge policy ➤ Carers awareness training sessions for Health Visitors ➤ Plans to discuss carers awareness training with PCGs ➤ SSI Inspection on rural issues included views of carers ➤ Care for the Carers to produce carer checklist / information pack for PCGs and GP practices ➤ Challenges for senior managers and politicians to shadow a Carer for the day during National Carers Week (14-18 June 1999) ➤ East Sussex Chair to hold a 'Carers Party' ➤ Mori survey by Social Services of users and carers views on services 	<ul style="list-style-type: none"> ✓ Assessments conducted in a sensitive and relaxed manner ✓ Positive outcomes identified by carers from assessment: <ul style="list-style-type: none"> –bringing problems to the fore and clarifying them –knowing someone else would share the care on a regular basis –someone taking an interest –learning about the different services available ✓ All the carers interviewed had gained additional practical support 	<ul style="list-style-type: none"> • Only 2 out of 5 carers said they received a written record; no evidence these records adequately highlighted the carer's situation • But one carer felt there was little space to raise issues which were not on the assessor's agenda • None of the carers was offered an opportunity to speak separately to the assessor • Assessors varied in the extent to which different options and ideas were explored • Need for assessments to be reviewed so support can be adjusted. • But some carers felt they could have done with more

	East Sussex Joint action plan	Action Taken as at December 1998	Carer Feedback, December 1998	
			A Positive Difference	Issues to be Addressed
2	To ensure carers needs are taken into account alongside users (Cont.)	<ul style="list-style-type: none"> ➤ Carers Impact workshop on carers assessments (Carers, SSD, HA) - action plan agreed by all the participants; new eligibility criteria for carers under consideration ➤ Reviews underway: <ul style="list-style-type: none"> - assessments - joint assessments - self assessments for OT services ➤ EACH – Wealden – record keeping training, including training on recording carers' needs in assessments <p>BUT</p> <ul style="list-style-type: none"> ➤ <i>Examples of situations where funding disputes have delayed the provision of a service/equipment</i> 		<ul style="list-style-type: none"> • Two carers were very anxious about the cost of services and felt they would have benefited from a more rigorous financial assessment. • Negative experiences of assessment by carers in the focus group – no additional services offered as a result.
3	<p>To recognise carers in the workplace</p> <ul style="list-style-type: none"> • to review personnel policies to be carer aware 	<ul style="list-style-type: none"> ➤ Draft Social Services carer friendly employment policy to go to Personnel Sub-Committee ➤ Collation of current employment policies within HA & Trusts – discussions re: content and training 		

East Sussex Joint action plan	Action Taken as at December 1998	Carer Feedback, December 1998*	
		A Positive Difference	Issues to be Addressed
<p>To provide more responsive and flexible respite care</p> <p>To investigate a scheme for carers, using the experience of the Direct Payments Act, where carers are allocated a cash budget from which they arrange their own flexible respite care</p>	<ul style="list-style-type: none"> ➤ Social Services review of respite care with health; recommendations to Social Services Committee March 1999. Informed by Care for the Carers forums to discover carers needs (end of Jan) ➤ Piloting independent budget holding scheme – Care for the Carers / Social Services. Review early 1999 ➤ Introduction of 2 District Nurse led beds at Crowborough and Uckfield Hospitals available for respite care ➤ 1 year local sitting service – Polegate – joint finances ➤ Newhaven Downs House – 4 respite beds ➤ Final year of lottery funding for working with children with disabilities – Hastings <p>BUT</p> <ul style="list-style-type: none"> ➤ <i>Many schemes have short term funding</i> ➤ <i>More carers identified and needs being addressed within no growth funding</i> ➤ <i>Small provider organisations also have no more funding yet have to cope with increased service specifications and growing waiting lists</i> 	<ul style="list-style-type: none"> ✓ Regular respite in the home – a valued resource where the right person is providing the care 	<ul style="list-style-type: none"> • Respite and day care facilities remain scarce and often inappropriate for younger disabled people • Appropriate options are restricted for older people with specialised needs • Better planning of respite care is needed and more flexibility in the provision

4 Making Progress

The meeting identified what had helped and hindered progress in taking action to improve support to carers



What has helped

- Improved joint working:
 - closer relationships with other agencies
 - a good mix of people on the steering group
 - able to share good practice
 - review and work together culminated in joint strategy and action plan
- Outside facilitation
- Independent researchers who ask 'the right questions'
- Senior commitment – Chair of Health Authority and senior board of Social Services
- Being part of a national programme – able to compare and contrast with other areas
- Good standard of reports which could be disseminated and helped to raise credibility
- Definite process for the project and timescale ensured focus and commitment
- Partner agencies able to see the 'whole picture and your own part in it'



What has not helped

- Changing programme and absentees – breaks continuity of work
- Uncertainty about 'anyone's survival'
- People taken off the work by the constant need to react to the Government's agenda, often within short timescales
- Constant internal reviews (but hopefully these will eventually bear fruit!)
- Would have been helpful to spend longer getting to know the role and responsibilities of other steering group members
- Gaps in membership – e.g. South Downs NHS Trust
- Community Care Planning Group never fully integrated with Carers Impact Steering Group
- Small sample of carers consulted (but debate whether the information obtained was any the less useful for this)

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

The meeting proposed the multi-agency work of the Carers Impact Steering Group should continue.

The role of the Carers Impact Steering Group would be:

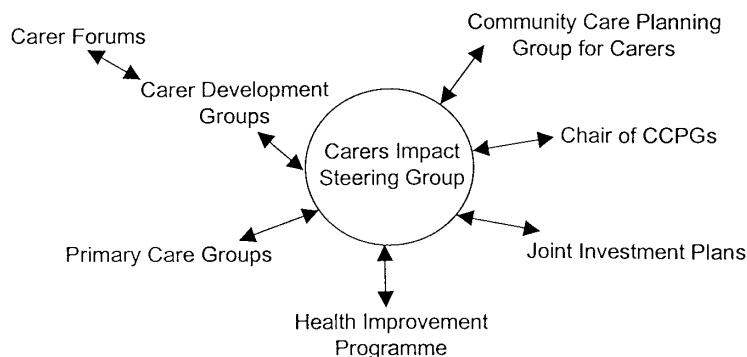
- to progress and champion issues for carers
- to take the lead in developing, co-ordinating and monitoring the joint strategy
- to ensure carers are fully involved in the work

Progressing the work

In order to carry out these tasks the Carers Impact Steering Group would need :

- **authority** from the senior boards of all the participating agencies to take the lead
- **two way links** with:
 - Community Care Planning Group for Carers
 - Chairs of the CCPGs
 - Carer Forums
 - Carer Development Groups
 - Primary Care Groups
 - Working groups on the Health Improvement Programme and the Joint Investment Plans

The Carers Impact Steering Group would thus be the focal point as illustrated in the following diagram:



- **to review the membership of the group** so that all the NHS Trusts are involved, including South Downs and Eastbourne Hospital Trust
- **to establish links with the Primary Care Groups** and discuss whether each Primary Care Group should nominate a representative for carers who would attend or receive notes of the meetings of the Steering Group
- **to clarify support to the working of the group** and agree who/which agency would chair the meetings (to be held 6 monthly), take minutes and progress chase outside the meetings.

Priority tasks for the next stage of work

It was agreed the group would need to progress the following:

1 Monitoring

- ♦ to revisit the earlier more detailed action plans so that all the partner agencies are clear:
 - *what* tasks are needed to address the key issues within the joint strategy
 - *who* would carry these out and by *when*
 - *how* these actions would be *monitored* and by *whom*
- ♦ to produce regular reports for the Community Care Planning Group on the work and its outcomes

2 Joint Training

- ♦ to analyse the results of the staff surveys and feed these into the plans for joint training

3 Carer feedback on the impact of services

- ♦ to review good practice in properly involving carers and to avoid tokenism
- ♦ to find ways of obtaining carer feedback on a regular systematic basis, rather than conducting full research, (for example by managers having responsibilities to visit a small number of carers on a regular basis to ensure they have been involved by staff going in to their home)
- ♦ to provide progress reports for Careline to keep carers informed and to ensure they can influence the work

Appendix 1: Workshop participants

Penny Banks	Carers Impact
Mary Colato	Care for the Carers
Paula Ellis	East Sussex, Brighton & Hove Health Authority
Sue Gross	Care for the Carers
Yvonne Hartnell	Association of Carers
Guy Pearman	Carer
Diane Pluckrose	Hastings & Rother NHS Trust (HART)
Jane Simmons	East Sussex Social Services Department
Jennie Starr	Eastbourne & County Healthcare NHS Trust (EACH)
Hilary Storm	East Sussex, Brighton & Hove Health Authority
Ken Wilson	Carer

Other members of the Carers Impact Steering Group

Graeme Barnell	Hastings & Rother Crossroads
Pat Buesnel	Sussex Rural Community Council
Jan Cackett	Hastings & Rother Crossroads
Sally Morran	Service Manager, Development (Children & Families)
Sarah Piper	Quality Manager, South Downs NHS Trust

Appendix 2: The Carers Impact process

The following are the views of the workshop participants:



What has helped

- Helpful facilitation
- Insight from other areas / groups
- Tight timetable helped to focus work and keep it going
- 'Think carer' is now on most people's agenda
- Link to national initiative helped to engage local politicians and MPs
- Impact of King's Fund / Carers Impact on government legislation
- Carers Impact focus groups linked to ongoing consultation
- Speedy production of reports helped to keep up the momentum



What has not helped

- Too short a period for developments to show an impact
- Some people not clear about the project at the beginning
- Dangers of 'over consulting' carers – must ensure they see positive results

Appendix 3: Reports produced by the Carers Impact Project in East Sussex

1. Report on the focus groups and interviews conducted with carers in October / November 1997. H Bagshaw, J Unell
2. Taking Action on Carer Assessments: report of a workshop held on 26 June 1998
3. The Picture Now: feedback from carers November 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
4. Carer Support: Time for a change of direction. A policy discussion paper. King's Fund publishing (Due Jan 1999)

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