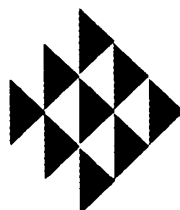


King's Fund



Carers Impact Project in Co Durham

Where have we got to?

Final report based on a workshop held on 13 October to evaluate the Carers Impact Project in Co Durham

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Introduction

Members of the Carers Impact Steering Group (Appendix 1) met to evaluate the Carers Impact Project 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 the issues to be addressed in future work to support carers living in Co Durham.

1. Joint working between health and social services

The project has resulted in a jointly agreed strategic direction for support to carers between the health authority and social services. This strategy and the accompanying action plans should assist in informing the Joint Investment Plans and Health Improvement Programme and help to ensure the carer agenda is not marginalised. However, there is still some way to go before carers issues are embedded within the policy and practice of all the partner organisations so progress in implementing the strategy will need to be kept under regular review.

2. Delivering the strategy

After considerable negotiation a new structure has been agreed to co-ordinate and monitor the strategy at a county level and to implement plans locally. It has not been easy to manage and co-ordinate the wide agenda and effectively involve a large group of players from different agencies, some from localities and some with a county-wide brief. It was agreed there needs to be careful consideration of future membership of the group, a clear brief for its work, clarity about its powers and decision making and effective leadership (*please see section 5*).

3. Carers as partners

Carers have not always felt they are equal partners in the joint work and have been frustrated, as have other members of the group, by the time it has taken to agree and implement any actions. Nonetheless, the carers have continued to give their time, commitment and energy to progressing the work. It was agreed that in any future work there should be regular checks to ensure information, plans and proposals are being properly shared and that everyone is clear about their roles and has an equal opportunity to participate in the process.

4. Steps forward to meet the outcomes carers want

A number of actions have taken place, both at a local and county level which are detailed in section 3. They include action on training, work with GPs and primary healthcare teams, assessments and telephone responses. The feedback from

carers, who were revisited by Carers Impact, indicates some progress; for example carers valued better responses to their telephone calls and sensitive assessment meetings. However, the feedback continues to indicate good practice is not consistent, for example in the response of GPs to carers and carers being informed about assessments. The full feedback from carers is described within the report produced by Carers Impact – “The Picture Now: feedback from carers October 1998”.

5. Monitoring progress and the impact of services

The inconsistency of practice has highlighted the importance of more systematic monitoring both of assessment practice and the quality of services. Carers have underlined their understandable reluctance to make complaints and it was agreed qualitative feedback needs to be obtained in ways which give carers and users opportunities to speak freely.

6. Taking carers ‘into the mainstream’

There are plans for ensuring every locality has a carer support project and worker to progress local joint initiatives involving health, housing, community and social services. Whilst this is an important part of the strategy to raise carer awareness and further partnership working at a local level, there are some dangers that support workers could be left to carry forward the work alone. Short term funding for projects can also present problems. The joint strategy is clear that all mainstream services should take responsibility for progressing the work to ensure all services are responsive to carers. It does appear from the feedback from the health and social services staff surveys that there needs to be further work to embed carers issues within the core work of all the partner organisations so that there is a clear responsibility for all staff to ‘think carer’.

Report of the Workshop

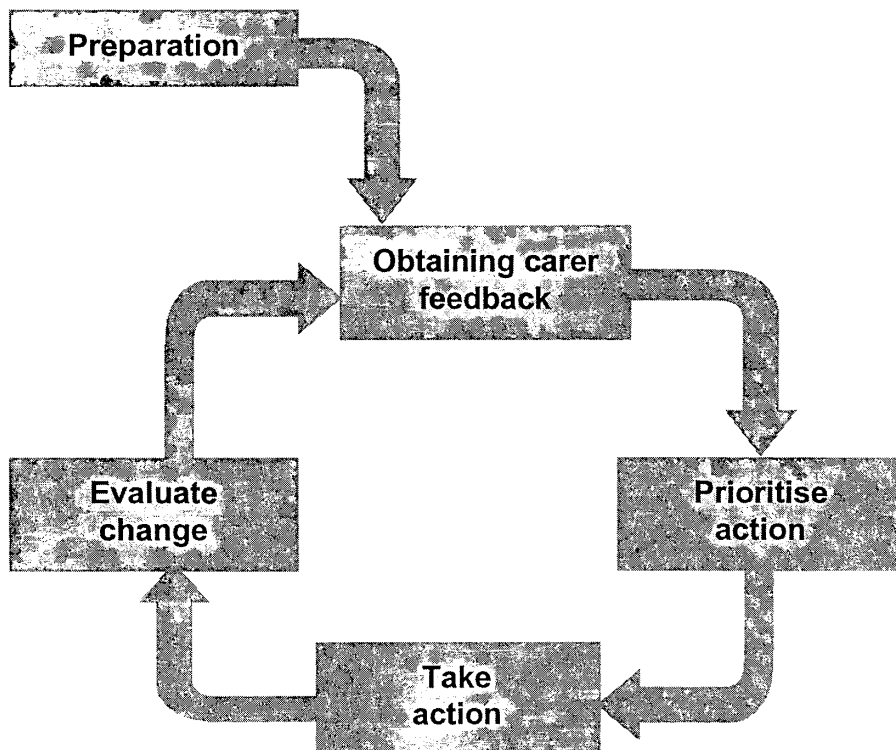
1 Background

The Carers Impact Project in Co Durham 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 aimed to:

- ◆ build on the work in Co Durham
- ◆ involve all the key agencies
- ◆ involve carers throughout

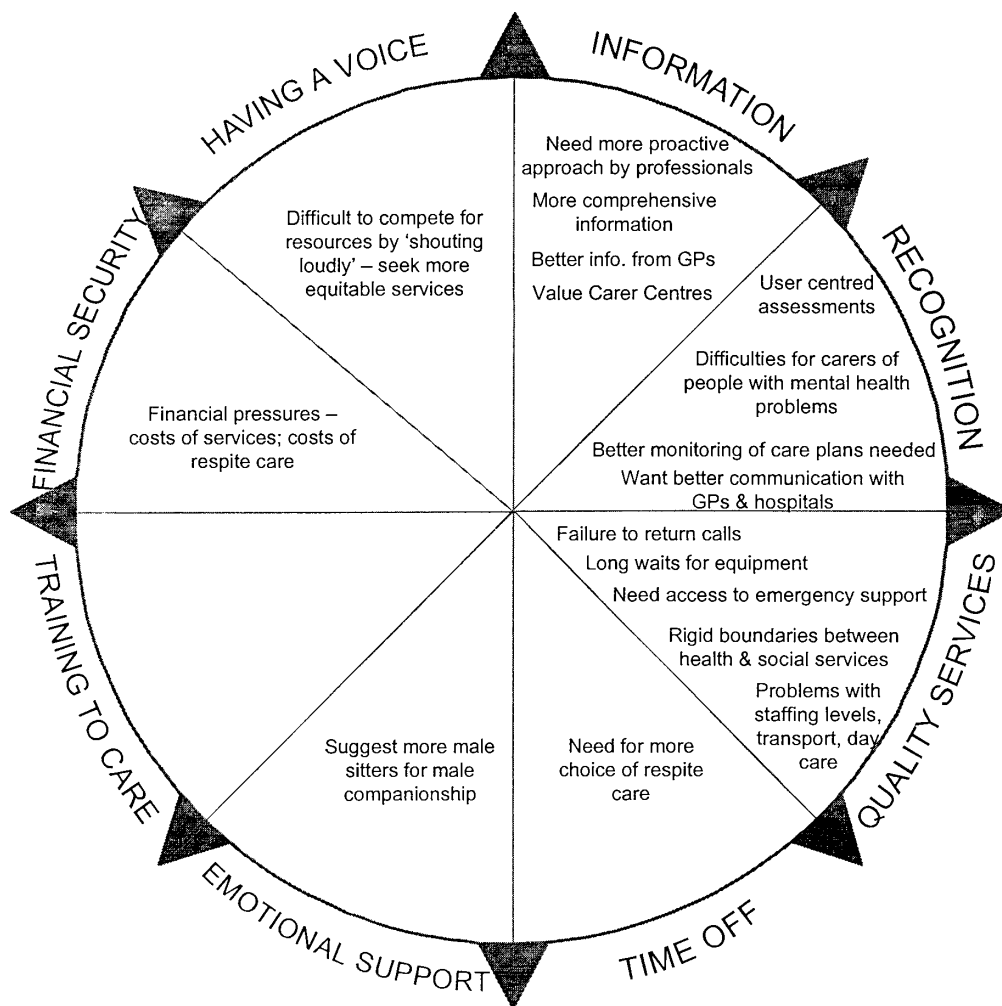
The project method



2 The Picture Before

a) Feedback from carers September 1997

Carers gave the following key messages* about their experiences of services in Co Durham 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 September 1997'. H Bagshaw, J. Unell, King's Fund .

2 The Picture Before *cont.*

b) Structures and work in progress

- ◆ A County Carers Development Group with no health authority representative and no locality representation
- ◆ A social services policy
- ◆ County and local carer support projects
- ◆ Carers Centres in some localities
- ◆ Some health input to address the needs of carers at a local level – eg South Durham NHS Trust funded courses for carers and training for nurses on carers' issues

c) Key issues for the Carers Impact Project

- ➔ to involve health partners more fully in the work to support carers
- ➔ to progress joint working on carer support

3 The picture now

The following chart summarises:

- The **Joint Action Plan** which was agreed by all the partner agencies in response to the feedback from carers at the first stage of the project
- The **action taken** to implement the plan both individually by agencies and in some instances jointly between agencies
- **Feedback from carers** which notes positive experiences and issues to be addressed. This feedback is more fully described in the report '*The Picture Now: feedback from carers October 1998*' which was presented to the workshop.

This feedback from carers was obtained through:

- i) Telephone interviews with four carers about their experiences of telephone responses from social services, all of whom had taken part in the first round of interviews.
- ii) Telephone interviews with three carers about their experience of GP / primary care services.
- iii) Face-to-face interviews with seven carers about their experiences of assessment.
- iv) A focus group attended by three carers, each of whom had participated in a focus group during the preliminary research.

Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998*	
		A Positive Difference	Issues to be Addressed
1 To ensure all staff are carer aware and carers are better informed	<ul style="list-style-type: none"> ➤ Joint strategic direction agreed between Durham County Council Social Services Department (DCCSSD) and Co Durham Health Authority (CDHA) (carers and young carers) ➤ DCCSSD and the CDHA joint funded Carers Impact Project ➤ CDHA surveyed ward managers and district nurse managers (See appendix 2ii) ➤ CDHA employed staff training co-ordinator – carers issues on pre- and post-education training ➤ DCCSSD: <ul style="list-style-type: none"> – revised care management process and integrated carer assessments – carried out staff survey (see Appendix 2i) – further developed the Carers Register to keep carers informed – revised information leaflets – planned staff development and contract with Services Users and Carers as Trainers (SUCAT) to train managers 	<ul style="list-style-type: none"> ✓ Receptive attitudes to training needs among younger managers (Durham County Care) 	<ul style="list-style-type: none"> • No noticeable improvement in GP awareness (see 4) • No compulsion for staff to attend SUCAT (Service Users & Carers as Trainers) training • Information still hard to come by; mostly comes from other carers or specialist organisations

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

Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998	
		A Positive Difference	Issues to be Addressed
1 To ensure all staff are carer aware and carers are better informed (cont.)	Derwentside <ul style="list-style-type: none"> ➤ Locality Group working on information pack with Stanley Carers' Project to give to carers on discharge from hospital ➤ Locality Group submitting bid to JCMG (November) to facilitate a multi-agency conference to 'change attitudes' ➤ Stanley Carers' Project raising carer awareness with professional and voluntary agencies ➤ Teesdale: GP liaison work started ➤ Easington: funding secured for appointment of local carer project/development work ➤ Wear Valley Carers Impact: support groups launched ➤ 11 week training course run for carers ➤ Age Concern: Countywide ReAct Project ➤ Carers handbooks supplied 		

	Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998	
			A Positive Difference	Issues to be Addressed
2	To ensure all community care assessments take carers needs into account	<ul style="list-style-type: none"> ➤ DCCSSD: Care management audit ➤ Staff Survey ➤ Derwentside: New user/carer forum run by CVS in Stanley lobbying social services on assessments, community care charter etc. 	<ul style="list-style-type: none"> ✓ Most carers interviewed had positive experiences of the assessment process/meeting ✓ 5/7 carers interviewed considered their needs had been taken into account 	<ul style="list-style-type: none"> • Carers unclear whether an assessment has taken place • <i>BUT</i> 2/7 carers felt they had been <i>sidelined or ignored during assessment meetings</i> • Staff do not always seem aware of the importance of assessments and are reluctant to assess where carers / users are paying for services • Carers are poorly informed of their rights under the Carers Act • <u>Most</u> carers did not receive a copy or written records of assessments • Some delays in obtaining an assessment • One carer was distressed by the assessment meeting where representatives from health and social services argued about funding responsibilities

Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998	
		A Positive Difference	Issues to be Addressed
<p>To actively involve carers and ensure they are listened to</p>	<ul style="list-style-type: none"> ➤ Consultation using Carers Register – DCCSSD ➤ User/carer forum – DCCSSD ➤ Joint Strategy agreed for user/carer participation ➤ Consultation on day care charges ➤ <i>BUT</i> lack of consultation on changes in respite care provision for people with learning disabilities ➤ Teesdale Carers Centre runs Carers Forum ➤ Carer involvement in developing locality Carers Impact Action Plans: Easington and Teesdale ➤ Stanley Carers Project is starting a support group – carers views will lead the project work ➤ Wear Valley Carers Initiative launch – two part-time development workers ➤ Carer involvement in steering group for carers network project in Easington ➤ Carers conference held in Chester le Street on housing for people with learning disabilities ➤ SUCAT – partners with DCCSSD training team in delivering training on user and carer issues ➤ SUCAT – request for funding from health and social services to raise status ➤ Action to improve telephone system and standards issued about use of voicemail etc. 	<ul style="list-style-type: none"> ✓ Carers welcome resources for local carer consultation and support through carers development workers ✓ Some good experiences of prompt and courteous responses from social services and health staff ✓ Once carers get through to social services, there is a generally helpful response from the first contact 	<ul style="list-style-type: none"> • <i>BUT</i> same level of resources not made available to users - fear this could prove divisive • Concerns that 3 or 4 carers in the Development Group could be seen as a substitute for proper consultation • Problems in getting through to social services - telephone frequently engaged or rang without being answered • Variable experience of having messages returned • Some dissatisfaction with the quality of the overall response. Staff did not signal they understood the urgency of the call

	Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998	
			A Positive Difference	Issues to be Addressed
4	To ensure services are responsive to carers	<ul style="list-style-type: none"> ➤ Teesdale Red Cross Resource Centre opened in Barnard Castle ➤ Questionnaire sent out (Durham & Chester le Street) to highlight parent carers' problems when people with learning disabilities are admitted to hospital ➤ Age Concern Durham County input from project workers to carer support groups etc. ➤ Stanley Carers Project is talking to DCCSSD about carers' needs ➤ <i>BUT wheelchair clinic in Teesdale closed due to staffing changes</i> 	<ul style="list-style-type: none"> ✓ Bathroom alteration completed ✓ Rapid and effective response by social services when carer collapsed <p>GP/Primary Care</p> <ul style="list-style-type: none"> ✓ Good support from GP where: <ul style="list-style-type: none"> - GP took a personal interest - readiness to provide home based care when needed - an explicit recognition of the strain experiences by the carer - information provided especially to access other support services - prompt access to GP of choice through surgery appointments system 	<ul style="list-style-type: none"> • <i>BUT it took 2 years from original request</i> • <i>BUT regulations do not permit carer to share caring with paid staff</i> • Inconsistent response to carers between practices - ranging from outstanding support from GP and community nursing team to an indifferent response • Insufficient support to carer whose own health broke down • Lack of understanding of pressures on carers • Lack of information • Difficulties getting an appointment
5	To provide accessible, co-ordinated services	<ul style="list-style-type: none"> ➤ Carers issues to be included in agenda of Joint Investment Plans and Health Improvement Programme ➤ Locality action plans being developed 		<ul style="list-style-type: none"> • Inconsistencies between districts and between adjacent authorities with regard to social services charges • Carers in Easington particularly affected by inconsistencies between health/social services boundaries

	Co Durham Joint action plan	Action Taken as at October 1998	Carer Feedback, October 1998	
			A Positive Difference	Issues to be Addressed
6	To provide appropriate quality services	➤ Durham & Chester le Street steering group is planning a local carers project		<ul style="list-style-type: none"> • Worries about loss of quality of homecare where direct provision is replacing existing contracts with private providers • Carers remain fearful of complaining in case services are withdrawn or the person cared for suffers

3 The Picture Now (Cont.)

Wider ownership of carers issues

The Health Authority and Social Services surveyed staff about awareness of their organisations' work on carers, the Carers (Recognition & Services) Act 1995, local carers resources and the joint strategy.

A survey of ward managers and district nurse managers of the acute and community trusts revealed a fairly low level of awareness of the issues but a willingness to learn more and a clear acceptance that recognition of carers was part of their core role.

The Social Services survey highlighted an apparent gap between theory and practice; for example, 100% of staff responding to the survey said that carers were fully involved in the care management process. There are plans to repeat this survey.

Further details of these surveys are in Appendix 2.

Training needs

It was agreed that the results of these surveys underlined the importance of training for staff.

It was hoped that a contract could be agreed with SUCAT (Service Users and Carers as Trainers) to provide training for all staff who were involved in care management and attendance would be compulsory.

4 Making Progress

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



What has helped

- Working jointly has given more clout within individual agencies
- Health and social services getting together
- Involvement of local players
- Having carers in the group
- Up-to-date report from Carers Impact on carers feedback provided evidence, validity to the work and reinforced previous messages
- The development of an explicit joint strategic direction
- Social Services identified £300,000 for carer support



What has not helped

- • **but** some confusion with different messages received locally and difficulties with the changing membership of the group
- • **but** carers role not strong enough; a lack of balance with statutory agencies
- • Carers sometimes felt intimidated
- • **but** concerns that the previous Red Cross report had already given the same messages and carers were being consulted yet again
- • **but** dangers in getting 'hung up on strategy and not action'
- Lack of clarity about:
 - who is making the decision – not everyone had felt engaged in changed thinking about county/locality responsibilities
 - the roles and responsibilities of each member of the group
 - the role and 'power' of the group
- • **but** concerns about short term funding of carer projects – uncertainties for carers and workers

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

It was agreed that in order to co-ordinate the work and keep the work on target, that:

- 1 The **Joint Performance Review Group** would monitor the overall implementation of the strategy
- 2 The **County Carers Development Group** would monitor the overall action plan.
- 3 The **JCMGs** would be responsible for the implementation and monitoring of action plans at a locality level
- 4 **Membership of the County Carers Development Group:**
 - each JCMG would be represented on the county group
 - carers from each locality network/support group would be on the county group

Issues to be clarified and agreed

1. Membership of the county group

To consider:

- *who needs to be on the group (too large a group may be counter productive)*
- *who can make things happen*
- *who might block action if they are not involved*

2. **Chair:** his/her responsibilities for progress chasing, co-ordinating actions, reporting back, ensuring the agenda identifies all the ongoing issues, keeping meetings to agreed times

3. The brief for the group, which would include:

- ➔ to finalise the joint action plan
- ➔ to monitor its implementation
- ➔ to identify how each action would be monitored – to check it had taken place and to evaluate its impact on carers
- ➔ *to ensure the county group is not a 'talking shop' by agreeing a clear timetable and responsibilities for the action plans*

4. The workplan and priorities for the next year

which would include

- ➔ ensuring the carer agenda is addressed within the Joint Investment Plans, the Health Improvement Programme, and the work of the Primary Care Groups
- ➔ revisiting the monitoring of the number of carer assessments and good practice
- ➔ finding other ways than complaints procedures to obtain feedback from carers who are reluctant to complain for fear of reprisal and loss of services
- ➔ keeping staff, carer networks and others updated on the progress of the work
- ➔ reviewing the funding of carer support to include the distribution between localities and the problems of short term funding for projects

5. The roles and responsibilities of each member of the group

6. Decision making – who/where decisions would be made to address the action plans

7. Support to the carers involved – possibly through the locality networks or some kind of reference group?

8. Consider a preparatory workshop for all members of the county group to share information on how the systems work.

Appendix 1: Workshop participants

Steve Bamlett	Carers Worker for the Easington Area
Bill Beaumont	Principal Officer (Partnerships) Durham County Council Social Services
Linda Brown	Development Officer, Red Cross Carers Project
Susan Forster	JCMG Development Officer, Durham County Council
Sydney French	Carer
Debbie Glenn	Assistant Director (Primary & Community Strategy) Co Durham Health Authority
Rob Goffee	Carers Support Derwentside
Sheila Grant	Carer
David Harvey	The Princess Royal Trust for Carers Teesdale Carers Centre
Ken Ibbotson	Carer
Mary McHale	Crossroads, Easington Area
Sue Orton	Carers Support Worker (Learning Difficulties) DISC
Julia Plinston	Partners in Care
Nigel Porter	Assistant Director, Durham County Council Social Services
Ann Richards	Wear Valley Carers Initiative Support Worker
John Smith	Wear Valley Carers Initiative Steering Committee / Carer
Audrey Wells	Community Services Manager, British Red Cross Society
Kathleen Young	Age Concern

Other members of the County Carers Development Group

Ursula Altmann- Hoyle	JCMG Development Officer (Durham & Chester le Street) Durham County Council
Louise Carlton	Sedgefield Carers Centre
Rebecca Habergham	Partners in Care
Brian Key	Locality Manager (North Durham), Durham County Council Social Services
Donna Thorne	DISC Young Carers Support, South West Durham

Appendix 2: Staff surveys

i) Durham County Council Social Services

220 forms were circulated to social services staff and 67 returned. The responses were as follows.

	Yes	No
1. Did you know that it is estimated nationally that 1 in 7 adults is a carer?	49%	51%
2. Are you aware of the Carers (Recognition & Services) Act 1995?	97%	3%
3. Have you been informed about the Department's procedures for carer assessments, in response to the Act?	85%	15%
4. Do you think the Department gives appropriate acknowledgement and recognition to carers?	46%	54%
5. Where appropriate, do you involve the carer(s) directly in the care management/assessment process?	100%	0
6. Do you know about the current county-wide Carers Project in partnership with the Department and the British Red Cross?	46%	54%
7. Did you know the Department has a policy for carers?	88%	12%
8. Did you know the Department is developing a Joint Strategy/Action Plan for carers?	16%	84%
9. Did you know that there is an inter-agency Young Carers Group to address the needs of children who are carer?	55%	45%

Appendix 3: The Carers Impact process

The following are the views of the workshop participants:



What has helped

- Acted as a catalyst
- Pushed carers up the agenda
- Focussed the work and helped look at key areas
- Gave carers more recognition
- Useful process
- External agency gave credibility to the work and messages
- Raised carer awareness of a larger group of people
- Highlighted the issues with health
- Helpful to have joint work between health and social services
- Shared information at a county level
- National work helped to raise profile
- Highlighted importance of monitoring (e.g. self assessments being monitored)
- Produced action / some results



What has not helped

- Time for project too short
- Individual players need more time to progress the work
- **but** quite painful at times! Localities did not feel involved / had no ownership
- Would have been helpful to spend more time ensuring everyone had a shared understanding of how the systems work

Appendix 4: Reports produced by the Carers Impact Project in Co Durham

1. Report on the focus groups and interviews conducted with carers in September 1997. H Bagshaw, J Unell
2. The Picture Now: feedback from carers October 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

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