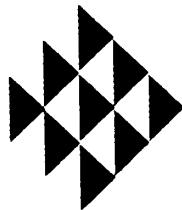




King's Fund



Carers Impact Project in Hertfordshire

Where have we got to?

Final report based on a workshop
held on 1 October 1998 to evaluate
the Carers Impact Project in
Hertfordshire

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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 workshop shared different perspectives of the progress made since the beginning of the Carers Impact project in 1997 and identified the following key points.

1 Development of joint working on carer support

It was agreed there had been progress on one of the aims of the project to bring together all the key agencies to improve support to carers, and for the first time all the NHS Trusts became involved alongside the Health Authorities and County Council. These new partnerships were then able to initiate a range of actions to improve awareness, recognition and support to carers.

However, it was acknowledged that this joint working was still at a relatively early stage and there was more to do in solving some of the boundary and co-ordination problems. Partnerships between housing and health and social services and the wider voluntary sector were still relatively underdeveloped. Carers on the steering group felt opportunities had been lost to significantly progress the joint work.

2 The scope of the work

A broad joint action plan was agreed in response to the initial feedback from carers who took part in focus groups and semi-structured interviews. The action plan attempted to co-ordinate new work with work already planned or underway.

The resulting actions by the partner agencies reflected the different stages they had reached in their work to support carers; some, for example, have written carers issues into their business plans and strategies for the first time, whilst other agencies forwarded direct practical work, such as information to signpost carers within care plans (*please see section 3 for details*).

However, there are concerns that the scope of this agenda was too wide and in danger of becoming unfocused. Carers on the steering group felt that the tensions between addressing the needs of carers, whatever their caring situation and meeting the wishes of carers looking after people with specific needs, were never properly resolved within the steering group.

The management and co-ordination of such a broad plan was not easy and some explicit prioritisation was needed to facilitate progress.

3 The impact on the lives of carers

There was some positive feedback from carers interviewed one year on about their experiences of assessment and home care services and some examples of increasing awareness by GPs and hospital staff (see section 3 and the report "*The Picture Now: feedback from carers September 1998*"). But in contrast to this feedback from carers who had 'got into the system' there was evidence from the voluntary sector of significant difficulties for increasing numbers of carers in accessing services and assessments. Staff feedback (see appendix 2) also indicated their real concerns about the difficulties and reality of delivering the policy to support carers at the front line.

4 Joint working with carers

Carers expressed serious concerns about their engagement in the steering group and as a result felt the agenda had moved away from the core issues important to them. The group agreed that in future work it would be essential to clarify, and review regularly, everyone's roles and responsibilities. Better ways to involve carers need to be considered, possibly having some kind of carer reference group which links to wider carer networks.

5 Next Steps

Although there had been difficulties in making it work, the group agreed that the joint approach needed to continue and that important work was beginning. It was agreed that a joint group should continue to forward the work with consistent membership and chair; a clear brief; a timetable; and agreed roles and responsibilities of members of the group. The group also must have explicit links to other key commissioning and planning groups and processes at both county and locality levels, and particularly Primary Care Groups and the Health Improvement Programme.

6 Monitoring progress

As a priority the group would need to identify in more detail how it would co-ordinate and review the action planned and how it would obtain feedback on the impact of each initiative

Report of the Workshop

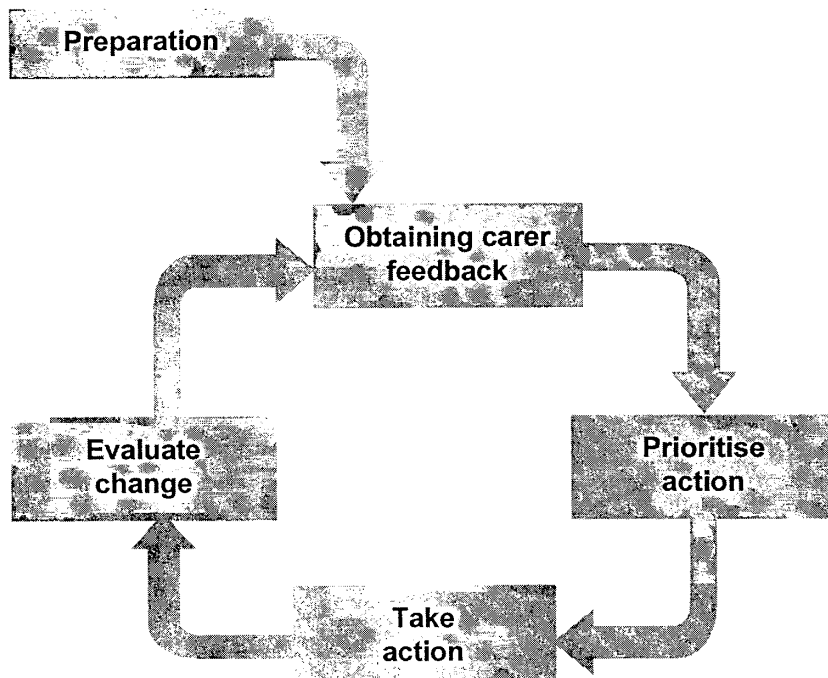
1 Background

The Carers Impact Project in Hertfordshire 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 Hertfordshire aimed to:

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

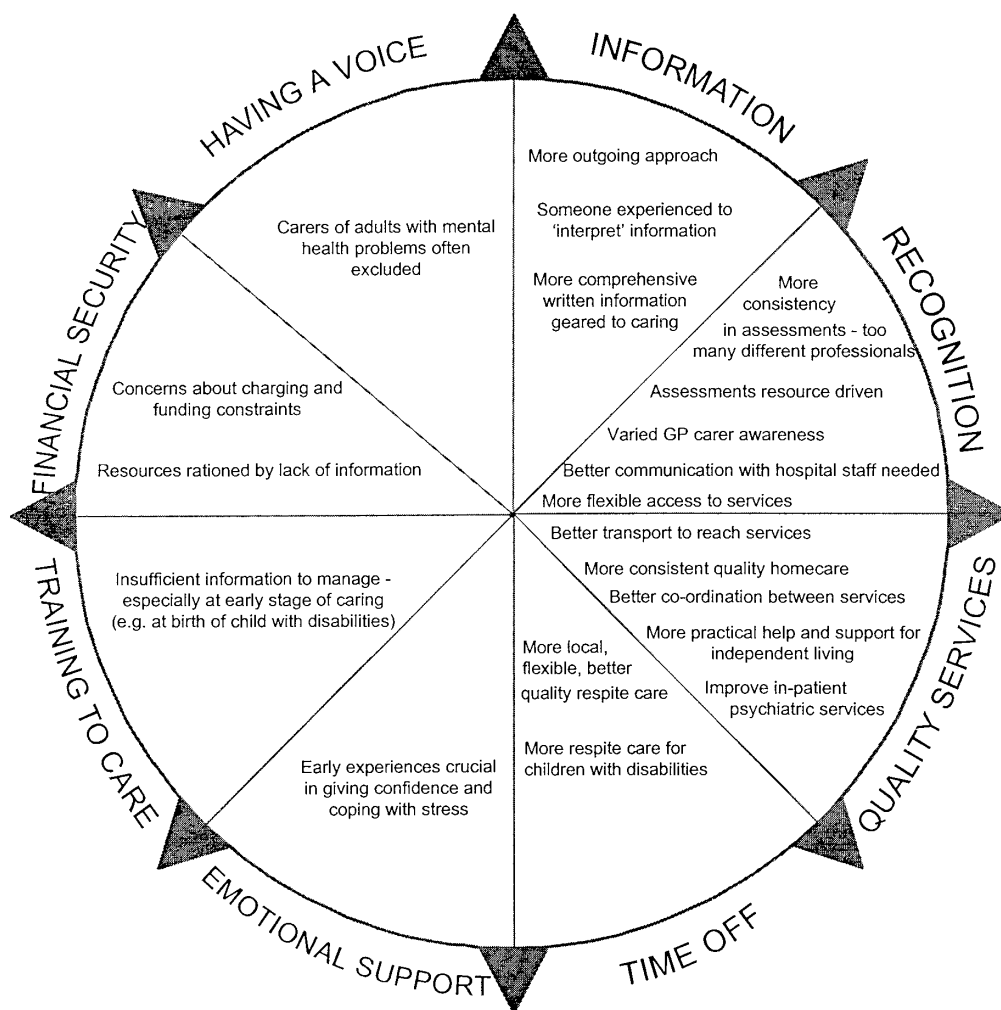
The project method



2 The Picture Before

a) Feedback from carers June-July 1997

Carers gave the following key messages* about their experiences of services in Hertfordshire 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 June-July 1997'. H Bagshaw, J. Unell, King's Fund .

2 The Picture Before *cont.*

b) Processes in place for progressing carers' issues

- No joint planning / action group on carers
- Policy Officer, Users & Carers, Social Services
- Young Carers multi-agency group
- Carers involved in locality planning
- Support to the voluntary organisation, Carers in Hertfordshire
- Health and Social Services commitment to the Carers Code

c) Key local priorities

- to progress **joint** working and involve health partners
- to work with GPs / primary care

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 September 1998*' which was presented to the workshop.

This feedback was obtained from:

- i) Face to face interviews with six carers who had recent experience of assessment. One had been interviewed during the first stage of the Carers Impact project in Hertfordshire; the others were new contacts.
- ii) Telephone interviews with seven carers using home care services, all of whom had taken part in interviews or focus groups during the preliminary research which had identified home care as an area of concern.
- iii) Telephone interviews with six carers about their experience of GPs / primary care over the last year, a second area of concern.
- iv) A focus group attended by three carers who had participated in the first focus group a year ago.

Please note:

In addition to the action and feedback summarised in the following tables, the workshop identified the difficulties for carers of tightened eligibility criteria (please see page 17)

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
		A Positive Difference	Issues to be Addressed
1 Recognition Carer awareness raising	<ul style="list-style-type: none"> ➤ Primary Health Care Pack launched and disseminated by Carers in Hertfordshire ➤ Staff survey by Social Services, West Hertfordshire Health Authority, and East Hertfordshire NHS Trust (See Appendix 2) ➤ Both health authorities contracted with Health Promotion to address carer issues. Joint work in Hertfordshire to progress this ➤ Joint Young Carer Strategy launched ➤ Dissemination of Young Carer Video Pack ✗ <i>BUT funding for the Youth Service sessional work is no longer available</i> ➤ East Hertfordshire District Council Housing Strategy has separate heading on 'carers' ➤ In-service training on carers - East Hertfordshire NHS Trust provided 150 community staff ➤ West Hertfordshire Community Health Trust is working with Carers in Herts to work with the elderly care services to recognise carers needs ➤ West Hertfordshire Health Authority has disseminated information on carers through its staff newsletter, annual report and GP bulletins ➤ Joint finance identified for carers issues 		Little consistency between general practices in terms of carer awareness

2

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
		A Positive Difference	Issues to be Addressed
<p>Choice</p> <ul style="list-style-type: none"> • Carer-friendly response at first contact • Carers know what help is available • Improve carer assessments 	<ul style="list-style-type: none"> ➤ Reception staff induction training (East Hertfordshire NHS Trust) includes carers needs ➤ Eligibility criteria workshop held in May 1998 between carers, county councillors and Social Services staff ➤ Training session held with client services managers ➤ Carers in Hertfordshire Contact Card promoted through East Hertfordshire NHS Trust and piloted - Borehamwood ➤ New Social Services guidance on carer assessment ➤ Young carers assessment guidance ➤ Young carers included in eligibility criteria for children's' services including triggers for adult services ➤ New leaflet for carers on assessment ➤ User and carer satisfaction strategy ➤ All districts have protocols around joint work between mental health and children's services ➤ District training includes slot on young carers ➤ Joint assessment of patient and carer in nursing home at home scheme - East Hertfordshire NHS Trust and Social Services 	<ul style="list-style-type: none"> ✓ First contact with Social Services had been initiated by a hospital doctor or GP ✓ Assessments had taken place promptly ✓ Social Services staff are helpful, open and sympathetic ✓ Carers felt they were properly listened to and account taken of their separate needs ✓ Carers valued Social Services staff who understood their needs and the tensions between the carer and user ✓ Assessment resulted in extra practical support and gave reassurance 	<p>Carer had repeated difficulties in contacting social services because her mother's name was 'lost' on the computer</p> <p>No-one discussed the future with carers and anticipated what would happen when caring stopped</p> <p>Carers unclear whether an assessment had taken place</p> <p>Carers poorly informed of their rights under the Carers Act</p> <p>None of the carers interviewed had received a written copy of the assessment</p> <p>One negative example given of an OT assessment</p> <p>2/6 carers identified the need for better co-ordination of services</p>

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
		A Positive Difference	Issues to be Addressed
3 Equity <ul style="list-style-type: none"> • Needs of carers from all communities are addressed • Equal access to support across the county 	<ul style="list-style-type: none"> ➤ Action by Carers in Hertfordshire : <ul style="list-style-type: none"> - awareness raising with 11 Health Advisors going into peoples homes - Links with Watford Racial Equality Council to produce information for carers from ethnic communities, linked to Primary Healthcare Resource Pack - Meeting with Asian Users Management Group to 'spread the word' - Contacts with other UK initiatives to find other information already produced ➤ Watford Care Link translated information into different languages, plus on tape ➤ Minority Ethnic Young Carers Sub Group is being set up ➤ Parents Reference Group facilitated by Carers in Hertfordshire to liaise with planners, cross county 		

4

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
		A Positive Difference	Issues to be Addressed
<p>Consultation / Involvement</p> <ul style="list-style-type: none"> • Carers involved in every relevant activity of health and social services 	<ul style="list-style-type: none"> ➤ West Hertfordshire Health Authority choosing right direction - active locality involvement ➤ East Hertfordshire NHS Trust involving carers in user groups ➤ Carers looking at Hertfordshire Connect ➤ User / carer satisfaction strategy for district quality systems ➤ Users and carers home care panel ➤ Districts providing Carers Days ➤ Carers involved in workshops with County Councillors on eligibility criteria ➤ Parent carers video presented to members ➤ Social Services produced 'toolkit' - best practice booklet for involving users and carers ➤ Carers involved in training nurses ➤ Carers involved in every activity of Carers in Hertfordshire - for example: <ul style="list-style-type: none"> - in production and monitoring of Primary Health Care Pack - working party to establish standards for carer friendly surgeries 		

	Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
			A Positive Difference	Issues to be Addressed
5	Information All staff give information / signpost carers	<ul style="list-style-type: none"> ➤ Carer Contact leaflets now with Patient Care Plans and distributed to all clinics (East Hertfordshire NHS Trust) ➤ West Hertfordshire Community Health Trust has set up group to look at Carer Contact leaflet in Care Plans ➤ Health provision training co-ordinated with Carers Week; displays in clinics ➤ Sharing community information databases 		Parent carer would have welcomed more information from her GP Carers would like more specialist expertise within general practice on specific conditions
6	Practical Help <ul style="list-style-type: none"> • Improve opportunities for a break • Improve care at home 	<ul style="list-style-type: none"> ➤ Multi-agency respite care group set up ➤ Conference to involve users and carers in home care standards ➤ Overnight nursing service offering carers contact for support ➤ Nurse availability to prevent admissions - Nursing Home at Home - East Hertfordshire NHS Trust ✗ <i>BUT new eligibility criteria excludes some people from the homecare service</i> 	<ul style="list-style-type: none"> ✓ 5/7 carers enjoyed greater continuity of workers over the year ✓ Carers receiving 'in house' home care more confident about quality of training ✓ Charges withdrawn following reassessment (5/7 carers) ✓ Most carers very satisfied with overall quality of service ✓ Service reliable and delivered at convenient time (in the mornings) 	Concerns about adequacy of staff training <u>but</u> no clear explanation of the charges, nor assurance whether service would continue to be free of charge One carer's payment increased over 3 times for the same level of service <u>but</u> some reports of unsatisfactory individual workers Convenient timing in the evening more difficult to arrange Unmet needs for home care support when emergencies arise

	Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
			A Positive Difference	Issues to be Addressed
6	Practical Help <ul style="list-style-type: none"> • Improve care at home (cont.) • Other practical help 		<ul style="list-style-type: none"> ✓ Excellent voluntary sector day centre where staff are very supportive to carer 	<p>Carers concerned about changes of provider - particular worries about losing in-house homecare</p> <p>Taxi transport replaced following re-tendering of contracts - carer lost continuity of service</p>
7	Emotional Support Ensure carers' feelings are respected and responded to	<ul style="list-style-type: none"> ➤ Carers in Hertfordshire are holding a seminar for carers and people who provide emotional support services; liaising with University of Hertfordshire ➤ Carers in Hertfordshire negotiated funding for Bishop Stortford support group to record experiences of caring and document emotional needs of carers X BUT staff feel constrained by funding pressures to provide effective support 		<p>Lack of follow up support from some professionals as carer adjusted to life without his wife</p> <p>More help needed to manage transitions</p>
8	Minimise the cost of caring Ensure carers are fully informed of benefits	<ul style="list-style-type: none"> ➤ Benefits leaflet updated ➤ Benefits training for District Council ➤ Community staff training unit ➤ Money Advice Unit in East Hertfordshire NHS Trust 		<p>Carer not informed of benefits until her mother was offered respite care</p> <p>Benefits system fails to recognise caring responsibilities as a legitimate reason for not seeking paid work</p>

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998		
		A Positive Difference	Issues to be Addressed	
9	<p>Co-ordinated services</p> <ul style="list-style-type: none">joint work with primary care <p>support carers at hospital discharge</p> <p>carers input into joint commissioning</p>	<ul style="list-style-type: none">Health Authorities and Social Services jointly facilitated a workshop for all trusts across Hertfordshire to share good practice. Resulted in new initiatives such as the Carer Contact Cards in Patient Care PlansAction within St Albans and Hemel Hempstead NHS Trust:<ul style="list-style-type: none">Primary Care Pack circulated to managers and consultantsPresentations to link nurses and other staffCarer communication sheet introducedMonitoring impact of Primary Health Care PackCarers in Hertfordshire piloting Contact Card in Borehamwood which has encouraged co-ordination between agenciesSeminar to be held in October on confidentiality issues, carers and mental healthReport produced by mental health project, at Carers in Hertfordshire, identifying need for national action and to clarify local misunderstandings	<ul style="list-style-type: none">4/6 carers were able to obtain prompt appointments with GPNurses' helpline set up in one practice	<p>Inconsistency between practices in terms of carer awareness</p> <p>but helpline of variable usefulness</p> <p>Carers identified the need for:</p> <ul style="list-style-type: none">More home visits for patients with chronic illness and limited mobilityMore active monitoring of the condition of the person cared forMore flexible arrangements for children with special needs (e.g. extra hours available outside normal surgery hours)Better systems for identifying carers on medical records

Hertfordshire Joint action plan	Action Taken as at September 1998	Carer Feedback, September 1998	
		A Positive Difference	Issues to be Addressed
Co-ordinated services (cont.) <ul style="list-style-type: none"> • improved communication between services to support parent carers 			One carer considered poor liaison between health and social services, and between his wife's and his own GPs, resulted in a breakdown in his health

The Picture Now (Cont.)

Feedback from workshop participants

- Carers have not experienced any positive change over the last year in terms of new or increased services
- More carers are approaching Carers in Hertfordshire with problems
- There are indications from work with some carers that tightened eligibility criteria are not only meaning more people do not get a service but people who are eligible are suffering from a long wait to get assessments, often in very difficult situations
- A number of home care reassessments which have been challenged have seen the original decision reversed; there are concerns that carers are unnecessarily suffering distress because of poor assessments
- Carers who do get a service are generally very satisfied

Comments from staff survey (social services)

- "...there seems little point in pursuing carers' needs when we are in the position of finding the basic provision / services for the person needing the care under threat of withdrawal"
- "Since the introduction of eligibility criteria, it is very difficult to take into account carers' needs"

(See appendix 2 for further details)

4 Making Progress

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



What has helped

- Health and Social Services working together
- Talking together and sharing good practice
- Recognition that carers are not just a social services issue
- Multi-agency approach has helped Carers in Hertfordshire who find agencies more aware / receptive
- In some areas, locality planning has engaged well with carers
- Carers pack has been very useful to raise awareness
- Primary Care Groups have potential to forward carers issues
- Ability to move small amounts of resources around



What has not helped

- Insufficient dialogue between Housing, Health and Social Services. Difficulties now that District Councils are not direct providers - need to raise awareness of housing trusts and involve housing managers who are in key position to identify carers needs
- Health authorities are facing a huge government agenda - difficulties prioritising work
- Lack of clarity about the direct role of the health authority in tackling carers issues
- Tightening eligibility criteria are affecting carers and the response from staff from health and social services (fear people may be discharged into a 'black hole')
- Boundary between health and social services even less clear now
- Constrained resources
- Lack of ability to influence GPs and to some extent, consultants
- Span of work is huge - (both scope of the issues and the size of the county) difficult to manage and to co-ordinate all the activity

Carers' views on 'making progress' and the process and substance of the project.

Carers on the steering group and Carers in Hertfordshire presented a report (*Appendix 2*) on their view:

- Some progress on primary health care - steering group enhanced the impact of the resource pack
- Lack of consistent chairing and no continuity of leadership of the group
- Insufficient effort to understand from carers and a gradual shift away from their central issues and concerns



What has helped



What has not helped

- Lack of clarity about roles and responsibilities of members of the steering group
- The 'specialist' and 'generic' debate was never resolved satisfactorily
- Lack of focus to the analysis and to the strategy subsequently developed - it would have been better to concentrate on one or two issues
- Meetings outside the group did not include carers
- Very little is perceived to have been achieved - concentration on initiatives already underway
- Missed opportunity to resolve problems between health and social services
- Need to identify lack of resources and tackle management of resources and practices

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

Learning the lessons and taking the work forward

The meeting agreed that there was considerable work still to progress and that the multi-agency working was at a very early stage.

It was agreed that a **joint working group** needed to continue to:

- ➔ keep up the focus of the work and continue to share good practice
- ➔ monitor the action taking place
- ➔ develop more systematic monitoring of the impact of the work on carers
- ➔ address the cross agency, interface, problems
- ➔ find the best way of ensuring locality initiatives as well as county wide consistency
- ➔ link to and engage with other key planning and commissioning arrangements, particularly the Health Improvement Programme and Primary Care Groups
- ➔ involve other networks such as the wider voluntary sector (via Carers in Hertfordshire)

Issues to be addressed include

- Identify how actions will be monitored
- Develop ways to monitor the impact of action on carers
- Follow up the staff surveys

From the feedback from carers it was agreed that **it was essential to review how carers are involved**. The joint group would need to work together to:

- clarify everyone's expectations
- ensure continuity of membership and chairing
- clarify roles and responsibilities of members of the group
- consider the balance of the group
- consistently review progress
- keep a clear focus to the work, with time limits

Appendix 1: Workshop participants

Tim Anfilogoff	Policy Officer, Users and Carers, Hertfordshire Social Services
Fatima Clarke	Sister, St Albans & Hemel Hempstead Hospitals NHS Trust
Gerard Green	Assistant General Manager - Primary Care, West Hertfordshire Community Health Trust
Will O'Neill	Housing Development Officer, East Hertfordshire District Council
Shari Payne	Commissioning Manager, West Hertfordshire Health Authority
Sue Reeve	Director, Carers in Hertfordshire
Pieter Shipster	Commissioning Manager, East & North Hertfordshire Health Authority
Caroline Tapster	Assistant Director Commissioning, Hertfordshire Social Services
Jane Thompson	Clinical Director, East Hertfordshire NHS Trust
Betty Warren	Carer
Jenny Young	Carer

Other members of the steering group

Jane Calnan	Carer
Sally Hickman	District Manager, Hertfordshire Social Services
Valma James	Watford Racial Equality Council
Headley Parkins	Equal Voice
David Quigley	Family Services, North Hertfordshire NHS Trust
Rupinder Sandhu	Equal Voice
Linda Small	Community Care Development Worker, Community Development Agency in Hertfordshire
Peter Thomas	St Albans Afro-Caribbean Association
Glyn Trollop	Carer

Appendix 2: Wider ownership of the work - staff surveys

- 1 Hertfordshire Social Services** - summary of responses
- 2 East Hertfordshire NHS Trust Community Service Directorate** - Survey results, part 1 (Part 2 to be completed following a training programme)

3 West Hertfordshire Health Authority

The survey indicated low awareness of carers issues:

- 80% were not aware of the Carers (Recognition & Services) Act 1995
- 50% knew about Carers in Hertfordshire
- 30% knew about the Joint Action Plan

**SUMMARY OF RESPONSES TO STAFF SURVEY ON CARERS' AWARENESS
AS AT 21 SEPTEMBER 1998**

Notes:

- staff described themselves
- *managers* includes assistant and deputy managers
- *epd/other* are District team staff who have described themselves as epd or not described themselves
- *admin* includes services and teams admin
- the high percentage of *don't know/no answers* on questions 6,7,8 relates to some respondents having lost the second page on email

1. Do you think the Department encourages staff to give appropriate recognition to the needs of carers?

	Services			Teams							Other			No Job	
	Manager	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(43%) 3	(50%) 11	(17%) 1	(90%) 9	(71%) 5	(60%) 3	(58%) 7	(80%) 4	(67%) 2	(64%) 16	(83%) 5	(13%) 1	(44%) 4	(43%) 20	(53%) 91
No	(43%) 3	(50%) 11	(83%) 5	(10%) 1	(29%) 2	(40%) 2	(33%) 4	(20%) 1	(33%) 1	(36%) 9	(17%) 1	(38%) 3	(44%) 4	(49%) 23	(42%) 70
Don't know	(14%) 1	-	-	-	-	-	(8%) 1	-	-	-	-	(50%) 4	(12%) 1	(9%) 4	(5%) 11
Total	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

Note: this is a subjective question. A high no percentage may indicate not a lack of awareness but a feeling the Department should do more (see Comments Section below)

2. Are you aware of the Carers (Recognition and Services) Act of 1995?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(71%) 5	(14%) 3	(17%) 1	(90%) 9	(43%) 3	(100%) 5	(58%) 7	(40%) 2	(100%) 3	(80%) 20	0	(38%) 3	(100%) 9	(53%) 25	(55%) 95
No	(29%) 2	(86%) 19	(83%) 5	(10%) 1	(57%) 4	0	(42%) 5	(60%) 3	0	(20%) 5	(100%) 6	(63%) 5	0	(47%) 22	(45%) 77
Don't know	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

3. Has the Department informed you adequately about the provisions of the act?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(29%) 2	(9%) 2	(17%) 1	(70%) 7	(14%) 1	(40%) 2	(17%) 2	(20%) 1	(33%) 1	(20%) 5	0	(13%) 1	(44%) 4	(6%) 3	(19%) 32
No	(57%) 4	(91%) 20	(83%) 5	(30%) 3	(86%) 6	(60%) 3	(83%) 10	(80%) 4	(67%) 2	(76%) 19	(100%) 6	(88%) 7	(55%) 5	(89%) 42	(79%) 136
Don't know	(14%) 1	0	0	0	0	0	0	0	0	(4%) 1	0	0	0	(4%) 2	(23%) 4
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

4. Do you know about the county wide voluntary organisation Carers in Herts?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(100%) 7	(27%) 6	(50%) 3	(80%) 8	(14%) 1	(100%) 5	(58%) 7	(80%) 4	(33%) 1	(64%) 16	(33%) 2	(38%) 3	(100%) 9	(49%) 23	(55%) 95

No	0	(73%) 16	(50%) 3	(20%) 2	(71%) 5	0	(42%) 5	(20%) 1	(67%) 2	(36%) 9	(67%) 4	(63%) 5	0	(51%) 24	(44%) 76
Don't know	0	0	0	0	(14%) 1	0	0	0	0	0	0	0	0	0	(0%) 1
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

5. Did you know the Department is signed up to a Joint Action Plan for carers with Health and other agencies?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(57%) 4	(23%) 5	0	(30%) 3	(29%) 2	(60%) 3	(8%) 1	0	0	(8%) 2	(33%) 2	(25%) 2	(67%) 6	(15%) 7	(22%) 37
No	(43%) 3	(77%) 17	(100%) 6	(70%) 7	(71%) 5	(40%) 2	(92%) 11	(100%) 5	(100%) 3	(92%) 23	(67%) 4	(75%) 6	(33%) 3	(85%) 40	(78%) 135
Don't know	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

6. Did you know the Department has a Policy Officer (Users and Carers)?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(57%) 4	(9%) 2	(17%) 1	(60%) 6	(43%) 3	(100%) 5	0	(40%) 2	0	(32%) 8	(33%) 2	(63%) 5	(100%) 9	(30%) 14	(35%) 61
No	(43%) 3	(91%) 20	(83%) 5	(40%) 4	(57%) 4	0	(83%) 10	(60%) 3	(100%) 3	(68%) 17	(50%) 3	(37%) 3	0	(64%) 30	(61%) 105
Don't know	0	0	0	0	0	0	(17%) 2	0	0	0	(17%) 1	0	0	(6%) 3	(3%) 6
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

7. Did you know there was a multi-agency Young Carers' strategy to address the needs of children who are carers?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(43%) 3	(14%) 3	(33%) 2	(80%) 8	(43%) 3	(100%) 5	(50%) 6	(60%) 3	(33%) 1	(72%) 18	(33%) 2	(63%) 5	(67%) 6	(11%) 5	(41%) 70
No	(57%) 4	(77%) 17	(67%) 4	(20%) 2	(43%) 3	0	(50%) 6	(40%) 2	(67%) 2	(28%) 7	(67%) 4	(38%) 3	(33%) 3	(28%) 13	(41%) 70
Don't know	0	(9%) 2	0	0	(14%) 1	0	0	0	0	0	0	0	0	(62%) 29	(18%) 32
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

8. Did you know about the County Council's guidance for managers (and staff) about ways of supporting carers who are employed by HCC?

	Services			Teams							Other			No Job	
	Managers	RSWs	Homecare	Managers	Client Ser	Dev Wkrs	c and f	ld	mh	epd/other	Admin	Training	Centre	Details	All
Yes	(29%) 2	(23%) 5	(17%) 1	(30%) 3	29%	0	(17%) 2	0	0	(20%) 5	(67%) 4	(38%) 3	(44%) 4	(4%) 2	(19%) 33
No	(71%) 5	(77%) 17	(83%) 5	(70%) 7	(71%) 5	(100%) 5	(83%) 10	(100%) 5	(100%) 3	(80%) 20	(33%) 2	(63%) 5	(56%) 5	(34%) 16	(64%) 110
Don't know	0	0	0	0	0	0	0	0	0	0	0	0	0	(62%) 29	(17%) 29
	7	22	6	10	7	5	12	5	3	25	6	8	9	47	172

2 East Hertfordshire NHS Trust

RESULTS - Part 1

Number of questionnaires sent out: 442

Number of questionnaires returned:

Completed	181	
Staff left	18	
Queries to be sorted out	6	205

Response rate:	Total number of forms	46%
	Completed forms	41%

1. Have you attended a presentation about the needs of carers?

Yes 5 (3%) No 174 (96%) Blank 2 (1%)

If Yes, did you learn all you needed to know about the subject?

Yes 4 (80%) No 1 (20%)

2. Have you attended a session run by Diana Dewberry or Morny Drury on Customer Care?

Yes 1 (.5%) No 162 (89.5%) Blank 18 (10%)

If Yes did you learn all you needed to know about how to deal with carers?

No 1

3. Have you watched the Young Carers' video "Make use they're alright"?

Yes 2 (1%) No 178 (98.5%) Blank 1 (.5%)

If Yes, did it help you understand the problems faced by young carers?

Yes 2

4. Have you watched the Young Carers' video "I care, do you?"?

Yes 1 (.5%) No 179 (99%) Blank 1 (.5%)

If Yes, did it help you understand the problems faced by young carers?

Yes 1

5. a) *Have you seen a copy of 'The Key for Carers' - primary health care resource pack?*

Yes 51 (28%) No 129 (71.5%) Blank 1 (.5%)

b) *How useful do you think it is?*

Very useful	11	(21%)
Useful	33	(65%)
Not very useful	1	(2%)
No use at all	0	
Blank	6	(12%)

6. *Do you know where to access a 'Key to Carers' pack?*

Yes 60 (33%) No 116 (64%) Blank 5 (3%)

7. *In order to be able to assist carers do you feel you need more information on any of the following:* (multiple choice)

Support groups	104	(57%)
Respite care provision	96	(53%)
Day/residential care availability	81	(45%)
Benefits	80	(44%)
Provision of equipment	78	(43%)
Sources of practical help	109	(60%)
Blank	43	(24%)

8. *In addition to those areas highlighted above, are there any other topics on which you would like further information?*

Yes 18 (10%) No 117 (65%) Blank 46 (25%)

9. *Have you heard of the 'Carers in Hertfordshire' organisation?*

Yes 79 (43.5%) No 97 (54%) Blank 5 (2.5%)

If Yes, have you put anyone in touch with them?

Yes 8 (10%) No 64 (81%) Blank 7 (9%)

10. *Are you aware that there is a multi-agency Young Carers strategy to address the needs of young people who are carers?*

Yes 38 (21%) No 135 (75%) Blank 8 (4%)

11. Have you seen the Carers Contact Card?

Yes 7 (4%) No 170 (94%) Blank 4 (2%)

If Yes have you ever given a carer one of these Cards?

No 7

**12. If you are based in a clinic or GP practice are any of the following on display?
(multiple choice)**

Carers notice board	18	(10%)
Telephone nos. for Carers' support	22	(12%)
Leaflets for carers	43	(24%)
'Key for Carers' resource pack	14	(8%)
Blank	125	(69%)

13. Do you consider it to be part of your job to take carers' needs into account?

Yes 156 (86%) No 19 (10.5%) Blank 6 (3.5%)

14. Are there any occasions when you consider carers should be specifically excluded from discussion/assessments of a patient's needs?

Yes 65 (36%) No 87 (48%) Blank 29 (16%)

15. Which of the following best represents the proportion of adults in the UK who are carers?

1 in 4	6	(3%)
1 in 8	35	(19%)
1 in 12	24	(13%)
1 in 16	10	(6%)
1 in 20	13	(7%)
Don't know	81	(45%)
Blank	12	(7%)

16. Are you aware of the Carers (Recognition and Services) Act 1995?

Yes 45 (25%) No 126 (70%) Blank 10 (5%)

17. *The above Act defines a carer in a specific way. Please indicate whether each of the following statements would be TRUE or FALSE according to the Act.*

	True	False	Don't know	Blank
Carers do not have to live at the same address as the person cared for.	118 (65%)	14 (8%)	33 (18%)	16 (9%)
Carers must be related to the person cared for.	4 (2.5%)	136 (75%)	26 (14.5%)	15 (8%)
A carer must have responsibilities for the person cared for on a regular basis.	106 (59%)	19 (10%)	39 (22%)	17 (9%)
Volunteers providing care through a voluntary organisation are included.	56 (31%)	31 (17%)	74 (41%)	20 (11%)
Paid carers are not included.	21 (12%)	74 (41%)	69 (38%)	17 (9%)
Only carers who do not have other paid employment are included.	4 (2.5%)	112 (62%)	49 (27%)	16 (8.5%)
Carers must be aged 18 years or older.	27 (15%)	93 (51.5%)	45 (25%)	16 (8.5%)
Carers can look after more than one person.	110 (61%)	6 (3%)	48 (27%)	17 (9%)

18. *Does the Act entitle carers to an assessment of their own needs as a carer?*

Yes 62 (34%) No 111 (61%) Blank 8 (5%)

19. *Do you consider carers should be involved in assessments of patients' needs?*

Yes 173 (96%) No 1 (.5%) Blank 7 (3.5%)

20. *Are you aware that the Trust has signed up to a Joint Action Plan for Carers?*

Yes 35 (19%) No 128 (71%) Blank 18 (10%)

21. *Do you feel the Community Services Directorate encourages staff to give appropriate recognition to the needs of carers?*

Yes 62 (34%) No 52 (29%) Blank 67 (37%)

22. *Is there anything else the Community Services Directorate could do to help you help carers?*

Yes 60 (33%) No 26 (14.5%) Blank 95 (52.5%)

23. Please indicate which of the following staff groups you belong to:

Admin/Clerical	15	(8%)
Chiropodist	4	(2%)
Dentist	3	(2%)
Dietitian	5	(3%)
District Nurse	25	(14%)
Health Visitor	34	(19%)
Manager	1	(0.5%)
Nursing Auxiliary	6	(3%)
OT	9	(5%)
Physio	21	(12%)
Receptionist	2	(1%)
School Nurse	11	(6%)
SLT	12	(7%)
Total Care Team	1	(0.5%)
Nursing Auxiliary/TCT	2	(1%)
District Nurse/Twilight	1	(0.5%)
District Nurse/TCT	2	(1%)
District Nurse/School Nurse	2	(1%)
District Nurse/Nursing Auxiliary	1	(0.5%)
Admin/Receptionist/School Nurse	1	(0.5%)
Admin/Health Visitor/School Nurse	1	(0.5%)
Other*	7	(4%)
Blank	15	(8%)

*Nurse Advisor - Elderly Care

Dental Nurse

Domestic

Specialist Nurse (Continence Advisor) x 2

HVA

Blank

*Carers In Hertfordshire***Carers Impact Project 1997-1998: Carers Report**

Introduction

The four carers who had been involved in a multi-agency group have met with Carers in Hertfordshire to produce this report. We have commented about the *process* and *substance* of the project in Hertfordshire, i.e. our views of the benefits and progress achieved for Carers and also of the experience of being involved.

Process

The advice from the Kings Fund consultants was to ensure that the project had consistent chairing. Regrettably, this did not happen. Initially, as carers we felt valued and respected, but after the retirement of the original Chair, there was no continuity of leadership of the steering group.

Subsequently, the group experienced frequent changes of Chair, lateness, lack of preparation, attention and commitment to the work of the group. This showed insensitivity and a lack of understanding of carers and of the seriousness of the work. As a group, there wasn't sufficient effort to understand from carers what its all about. In our view, there was a gradual shift in the agenda away from the central issues and concerns. The minutes did not accurately reflect carers concerns and events of meetings.

There seemed to be many different ideas amongst professionals about what it meant to be a member of the steering group and why people were there. So for example, some people saw it as an individual responsibility; others saw themselves as substituting for someone else and others didn't turn up.

These factors exacerbated the lack of continuity.

As carers, we saw our own role as not necessarily giving a personal opinion, but conveying the views of other carers at the receiving end of statutory services. We believe that "agency defensiveness" continued and our contribution was viewed as unconstructive. This can be encapsulated in the comment that, "agencies would have been glad if carers hadn't participated".

It would have easier for us to work in the group if roles and responsibilities regarding the Carers Impact project had been clarified, to bring expectations in line and to fill any gaps in the process.

There was no clear thought from the outset about the respective value of a specialist or generic approach to the analysis. The pragmatic decision to arrange for the researchers to interview one specialist support group, as distinct from the other individual carers, and subsequently to report major specialist concerns, gave rise to a debate about the best approach to use, which was never resolved satisfactorily. It seemed that agencies found specifics too difficult to handle.

Carers In Hertfordshire

In one carer's view, the attempt to generalise caring issues was a major flaw in the process and contributed to the poor outcome. In the absence of a clear direction, carers continued to debate the specialist v. generic issue to no avail.

Carers thought there was a lack of focus to the analysis and to the strategy subsequently developed. The action plan is dominated by relatively inconsequential issues, of concern to agencies, but not reflecting the central concerns of carers. The plan reflects things that the steering group thought they could do, and not the central concerns of carers. The action plan has too many objectives, with loose targets and monitoring, and is likely therefore to produce a superficial result.

It would be more effective and of more benefit to carers, to select one or two fundamental issues and work in detail on objectives, monitoring and review.

Progress

We discussed the action plan to think about progress achieved. At the time of this report, carers had no information or evidence of progress about many of the objectives. The establishment of sub-group structure and health meetings have excluded carers. In checking the action points, very little is perceived to have been achieved, especially if account is taken of pre-existing initiatives now included under the Carers Impact umbrella. The Carers Impact project was an opportunity to analyse why some of the earlier initiatives were necessary and address fundamental cross-agency issues. Instead there has a concentration on initiatives already completed or underway.

Based on the knowledge available to us, 30% of the objectives in the action plan have resulted in progress or benefit to carers. Of the 46 objectives in the plan, 43% relate to work that was already underway or achieved before Carers Impact.

We are aware of some progress made on primary health care, and think that the steering group has enhanced the impact the resource pack would otherwise have had.

Conclusion

We recognise that there are positive aspects of caring through Health and Social Services but there are too many unresolved problems. Carers Impact, so far, has missed the opportunity to identify and help remedy these. We emphasise that if there is a serious intention to take on board comments and more forward, there is an urgent requirement for carers' major concerns to be discussed with agencies; to be understood and monitored at the highest level.

Some of the problems reflect lack of resources ; these need to be identified so that carers know where they stand and can consider appropriate lobbying initiatives.

However, there are many issues which could be resolved through improved management of resources and practices. If these are not tackled, carers will speak of this project as a wasted exercise. If these needs receive proper response, some good can still come out of Carers Impact.

Appendix 4: The Carers Impact process

The following are the views of the workshop participants:



What has helped

- Helped to get senior management involved
- Given credibility to the work
- Kept 'the wheels turning'
- Assisted in raising carers issues with professionals
- Brought together people from different backgrounds and agencies
- Helpful in seeing the points of view of all who took part
- "A lot of good has come out of this which should help all parties in the future"
- Brought health more into the picture and jointly with social services



What has not helped

- See Appendix 3: Report from carers and Carers in Hertfordshire on the Carers Impact Project
- Too much was attempted in too short a time
- Would have liked clearer advice about models attempted in other parts of the UK
- **But** unhelpful when others too focused on one issue
-

Appendix 5: Reports produced by the Carers Impact Project in Hertfordshire

1. Report on the focus groups and interviews conducted with carers in June-July 1997. H Bagshaw, J Unell
2. Carers and the New Eligibility Criteria: Report of a workshop held on 21 May 1998 to consider carers' experience of the new eligibility criteria
3. The Picture Now: feedback from carers September 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



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