





Carers Impact Project in Bolton

Where have we got to?

Final report based on a workshop held on 17 November 1998 to evaluate the Carers Impact Project in Bolton

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Introduction

Members of the Bolton Carers Impact Steering Group (see Appendix 1) and other people representing the partner agencies met to evaluate the Carers Impact Project in Bolton 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 Bolton

1 Partnership working

The establishment of a multi-agency steering group with carer involvement has proved valuable in raising the profile of carer issues and co-ordinating and monitoring progress to improve support to carers. It is proposed that this group. which includes representatives from the health authority, NHS Trusts, housing and social services, the Carers Support Project and voluntary organisations, continues to lead the work which is beginning to show positive results for carers.

2 Steps forward to meet the outcomes carers want

There has been action by all the agencies on a wide range of issues raised by carers at the start of the Carers Impact Project in 1997 (detailed in section 3). Some of this action has been initiated through the direct work of Carers Impact, for example, following the joint workshop on assessment. Other ongoing work has been identified as having an important benefit to carers, such as the Rapid Response Teams. Other important initiatives include improvements in information to carers, continence services, support to black and minority ethnic communities and the time stroke patients wait for rehabilitation services.

There has been some positive feedback from carers on their experiences of assessments, obtaining help in an emergency, involvement in hospital discharge, support from GPs and co-ordinated health and social services. The challenge remains to address the lack of consistency in this good practice which carers have highlighted in all their feedback.

3 Ensuring carers are part of mainstream activity

There are good examples of action to ensure carers are recognised and supported by mainstream services - such as building carers issues into the service level agreements with home care providers; the monitoring of good carer aware practice by nurses; reviewing carers involvement in hospital discharge. Whilst there are some concerns that a special multi-agency group devoted to carers issues could 'let others off the hook', the workshop agreed that the group's role in monitoring the progress of other strategic groups should help to keep carers issues on everyone's agenda.

The group would also ensure that there continues to be a good balance between the highly regarded work of the specialist carer support project and the response of mainstream health and local authority services.

The results of the different staff surveys (p.15 and Appendix 2) suggest there is still work to be done in raising carer awareness with a number of staff from all the partner agencies.

4 Engaging with carers

The commitment to involve and engage with carers has been evident throughout the project. There also appears to be a genuine concern to find more ways of hearing carers feedback so that carers do not feel compromised in speaking about services. More work is indicated in engaging with and hearing the voice of carers from the minority ethnic communities.

5 Continuing the work and monitoring progress

Given the feedback from carers about the inconsistency of their experiences, monitoring the quality of services and front line practice appears to be a priority for the next essential stage of work.

It will also be important to carry out the commitment to regularly evaluate progress on the joint action plan and where necessary clarify priorities for action.

The work to date, the joint agency approach and the involvement of carers should provide a good base and headstart for addressing the agenda which is likely to emerge from the Governments' National Carers Strategy due out in January next year.

Report of the Workshop

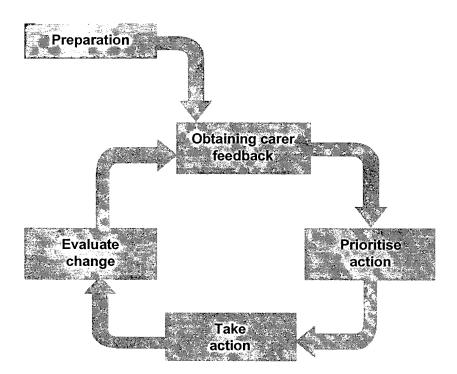
Background 1

The Carers Impact Project in Bolton 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 Bolton aimed to:

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

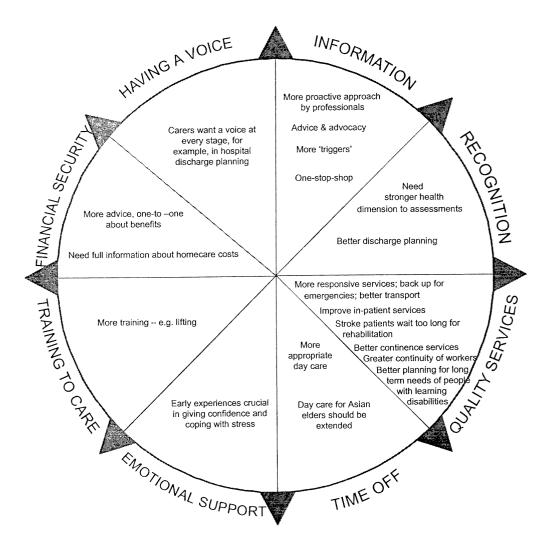
The project method



2 The Picture Before

a) Feedback from carers October 1997

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



^{* &#}x27;Report of the focus groups and interviews conducted with carers in October 1997'. H Bagshaw, J. Unell, King's Fund .

2 The Picture Before cont.

b) Work in progress in 1997

- Social Services and voluntary sector took the lead on carer support
- Social Services policy was to 'mainstream' carer issues. No specific planning group was devoted to carers and every Joint Strategy Team for each care group was expected to address carers needs

3 The picture now

The multi-agency Bolton Carers Impact Steering Group has led the work during the course of the project and is monitoring the implementation of the action plan produced in response to the feedback from carers.

The following chart identifies the **action taken** by all the partner agencies to improve services since obtaining the carer feedback in October 1997.

Feedback from carers is summarised in the third section of the chart 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, November 1998' which was presented by Carers Impact at the workshop.

This feedback was obtained from:

- Telephone interviews with 10 carers; five of whom has taken part in the first round of interviews at the start of the project and who were asked about their experiences of accessing information and advice; a further five carers who had not been interviewed in the preliminary research were asked about their experiences of hospital discharge.
- Face-to-face interviews with 7 carers about their experience of assessment. This work was undertaken by the Social Policy Research Unit, University of York, who provided these preliminary findings.
- A focus group attended by 7 carers who had participated in the first focus group held in 1997. This was useful in giving a 'before and after' perspective on development. Carers were invited to concentrate on their experiences of services over the last year related to the issues covered by the Bolton Action Plan.

	Bolton Joint action plan	Action Taken as at November 1998	Carer Feedback, A Positive Difference	September 1998 Issues to be Addressed
1	To ensure carers have good access to information, advice and advocacy improve quality and availability of information raise staff awareness	 ➤ Strategy adopted for production of joint public information — evaluation of effectiveness of information ➤ Successful bid: NHS Direct — telephone helpline from April 1999 ➤ Carer checklist produced and distributed ➤ Emergency card for carers reprinted ➤ Comprehensive booklet on loan equipment produced for patients and carers by Community Trust ➤ Staff awareness bulletin "1 in 8" ➤ Carers linkworker and support worker posts funded by joint finance ➤ Staff surveys — Social Services, Community Trust and Bolton Hospital NHS Trust 	 ✓ Sympathetic responses from professionals to carers requests for reassurance and/or practical suggestions ✓ 4/5 carers interviewed received information routinely through mailing lists, carer groups etc. ✓ Good supply of information via Bolton Carers Support Project ✓ Specialist deaf-blind worker helpful 	 <u>But</u> effectiveness of advice varies 2/5 carers felt let down when professionals failed to follow up first contact Professionals do not always refer on to more appropriate information sources Search for information often 'hit and miss' Carers would like a highly visible and accessible central carers information resource Advice given by GPs and nurses not always attuned to the emotional perspective of the carers Carers want all professionals to be more pro-active in information giving
			✓ Some positive experiences of being kept informed when cared- for person in hospital	<u>But</u> other experiences where hospital staff were not pro-active in giving out information, nor about discussing the implications of the illness

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

Bolton Joint	Action Taken	Carer Feedback,	
action plan	as at November 1998	A Positive Difference	Issues to be Addressed
To improve the assessment process for carers	 Workshop facilitated by Carers Impact on carers assessments – for health and social services; carers involved. Resulting Action Plan being monitored by steering group 	✓ Involvement of named and known workers who maintain contact, especially where there has been an absence or delay in tangible services	 <u>but</u> personalised link not always there "I wasn't aware what services where available. No one kept in touch" Access to assessment is
	 Community Trust – piloting patient held records. Includes 'triggers' to improve 	✓ Carers relieved to have their own needs recognised and 'legitimised'	sometimes rather arbitrary or accidental
	assessment process and to highlight all carers, including young carers		Social Workers sometimes fail to respond to requests for an
	 SSD – statement of need within care management process now includes carers 		assessment
	needs		On occasions carers have not been conscious of making an
	 All new clients for Crossroads must have a carer's assessment 		informed choice about the format of the assessment
			There appears to be a low number of 'carer assessments'.
		✓ Reviews and assessments are	but varied practice
		sympathetic and provide opportunities to raise issues ✓ 2/5 carers involved in multi-agency assessment meetings in hospital	It is not always clear whether a formal assessment is taking place and whether its focus is the carer or the person cared-for
		where future support needs were discussed	Some workers leave carers assessment forms for carers to complete, others jointly complete forms with carers
			Carers uncertain about what has happened and what will happen next

	Bolton Joint	Action Taken as at November 1998	Carer Feedback	September 1998
3	To ensure services are co-ordinated and responsive to the needs of carers	 Community Trust and Social Services have made progress on joint working on home care and district nursing – shared care Carers link worker with GPs Carer Support Project co-ordinates 3 carers projects – Linkworker, Making Space and Thickford Centre Carers Support Worker Co-ordination within Social Services – training for all staff – Firwood Day Service 	 ✓ Good experiences of the coordination of health services post hospital discharge (Physio, OT, District Nurse, Elderly Liaison Officer) ✓ Elderly liaison Officer linking with Social Services ✓ Carers either directly involved in discharge planning or kept informed ✓ Most of the carers interviewed felt they had been offered an appropriate level of practical support following discharge ✓ Generally satisfied with level of coordination between services 	 Difficulties cancelling services when cared-for person goes to respite care Difficulties re-installing 'cancelled' services But one carer was concerned about intervals between out-patient appointments and needed more specialist information and advice about the management of the illness of the person cared-for
4	To ensure there is back- up support in an emergency	 ➤ Reprint and wide distribution of emergency card for carers ➤ Mental health – established out of hours team for carers ➤ Careline – expanded service – a mobile service which can respond to an emergency 	✓ Good experience of emergency domiciliary support provided by Social Services	

	Bolton Joint action plan	Action Taken as at November 1998	Carer Feedback,	September 1998 Issues to be Addressed
5	To ensure carers receive emotional support and counselling	 Audit system checks if District Nurses provide emotional support to carers Continence Team had developed training sessions for carers Carer support workers – 2 projects – one for older people and one supporting people with mental health problems Support for minority ethnic carers – new support group at Lilian Hamer Community Care Centre 	 ✓ Elderly Liaison Officer a valuable source of emotional support ✓ Carers Support Worker listens and gives access to counselling 	 Advice by GPs and nurses not always attuned to emotional perspective of carer Carers group for those caring for people with visual problems has been closed
6	To ensure quality of health services	 Hospital Discharge Audit reviewing involvement of carers in discharge arrangements Reviewing all policies and the carer agenda as part of Health Authority Accreditation Carers invited to multi-disciplinary team meetings Information produced for carers by community healthcare and hospital – includes directory of services – hospital services, information packs on how to access services and how services link (dissemination plan to be considered) Open access audiology at Royal Bolton Hospital Rapid Response Team Stroke Unit – partial implementation – listened to carers: people now waiting less time for rehabilitation services 	 ✓ Excellent GP care – easy to contact; good signposting; sympathetic; offering help rather than waiting for you to ask for it ✓ The carers who were interviewed were generally satisfied with the quality of care in hospital 	But some negative unhelpful experiences – depends on individuals rather than on any common standards of care But dissatisfactions expressed by focus group carers in hospital care for older people on some wards of Bolton Hospital – experiences of dirty ward; mother looking neglected Length of waits in out-patient clinics Anomalies about who pays for incontinence supplies when caredfor person in residential care (for respite) or hospital

	Bolton Joint action plan	Action Taken as at November 1998	Carer Feedback	September 1998
6	To ensure quality of health services	 Continence service developments PACE project big reduction in waiting lists for products Reviewing accessibility of hospice − e.g. for minority ethnic communities − specialist social worker in post Improving take up of cervical cytology − carers to take care of themselves Access to palliative care drugs out of hours − Landmark House Carers involved with patient held records and the formation of care plans and decision making. Records are audited every 3 months and back up visits made 		
7	To ensure appropriate quality of community care services	 ➤ Social Services Department – extension of home care service to overnight and weekends ➤ Carers – sitting service in adult placement ➤ Opening at Lilian Hamer Community Care Centre ➤ Service agreements with independent providers includes carers issues ➤ Jubilee Centre – sensory impairment team fully established 	 ✓ Good experiences of day care ✓ Positive experiences of residential care ✓ Skilled social workers who assist carers and help cared-for person to accept services which they feel anxious about 	Lack of transport to take person to Age Concern day centre Carers feel vulnerable when caredfor person is frail and likely to fall. One example: Social Services threatened to call police and investigate abuse But standards vary widely between individual workers

Bolton Joint action plan	- Action Taken as at November 1998	Carer Feedback, A Positive Difference	September 1998 Issues to be Addressed
To ensure services are	➤ Minority ethnic worker for diabetes in post		
sensitive to the needs of people from the minority ethnic communities	➤ Social Services has employed extra staff from minority ethnic communities to improve assessments		
	➤ Also specialist home care team for minority ethnic communities		
	➤ Cultural awareness training by the MATG		
	➤ Information from stroke unit for minority ethnic communities (including carers)		
	➤ Accessible information for minority ethnic communities (including carers) — Macmillan Nurses		
	➤ Opening of Lilian Hamer Community Care Centre		

The Picture Now (Cont.)

Wider ownership of the carer agenda

Bolton MBC Social Services, Bolton Community Healthcare NHS Trust and the Royal Bolton Hospital Trust reported back on their surveys to ask staff about their awareness of the Carers Act, the local Carer Support Project and the Joint Action Plan. This exercise was partly to get a snapshot of the 'ownership' of carers issues, beyond the steering group, and to help raise awareness.

Of the 17% who responded to the Social Services Survey, 90% were aware of the Carers Act and 93% aware of the Bolton Carers Support Project. Less than half knew there was a Carers Strategy and Action Plan and a Carers Impact Steering Group. Please see appendix 2 for further details,

The Bolton NHS Trust has piloted a similar survey with 30 qualified nurses. Whilst the vast majority said they positively seek to involve carers the returns indicated nearly half of the staff who gave feedback are not aware of the Carers Act, nor of the work of the Carers Impact group.

The Community Healthcare NHS Trust has surveyed more than 600 staff. The results are not yet available.

Making Progress 4

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



What has helped

- Priority has been given to carers for → joint finance - resulted in three new pieces of work
- The different perspectives within the group - both multi-agency and different carer viewpoints
- Able to build on history of joint working
- King's Fund involvement
- Research helped to give a clear focus for the action plan
- Carer feedback helped Royal Bolton Hospitals NHS Trust take action
- Independent facilitator/researcher helped carers to express their views one focus group was an 'explosion of pent up feeling'
- Commitment of people on the steering group and a strong desire to progress work. Individuals willing to pick up the work despite other heavy commitments
- Good and consistent chairing of the steering group
- · Carer champions at different levels in the partner agencies
- Willingness of agencies to listen and ensure carers could speak up
- Carers are a current political 'fad' –



◀ What has not helped

- Joint finance is not mainstream danger of getting cut
- Carers scarcely mentioned in national quidance
- Plan was very broad prioritisation might help
- A challenge to co-ordinate all the strands, keep everyone on board and ensure each agency was kept engaged and aware
- More work required to take carers issues into the mainstream
- Need to review how to progress work with black and minority ethnic carers cannot just rely on one person to carry the agenda
- Difficult to measure outcomes
- Need to reach out to a large number of carers
- Need to consider whether parent carers should be involved in future work
- Relatively short timescale to achieve results (but stopped drift)

will this continue?

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

Work to take forward

♦ More consistency in practice

It was agreed the feedback from carers and staff highlight the need to continue the work to ensure more consistency in good practice and quality services. Different forms of monitoring need to be developed and ways of getting systematic feedback from carers about services in which carers do not feel compromised and are able to speak freely about their experiences.

A commitment to review progress

The feedback showed the progress that could be made in taking a joint approach and the importance of a regular review with carers fully involved.

A joint group to progress the work

It was agreed that a joint multi-agency group was needed to continue to take the work forward, to assist in meeting national health and social care priorities guidance and to co-ordinate action. The danger of mainstream services seeing this group as taking responsibility alone for carer issues had to be avoided. Instead the group would monitor activity by all the mainstream services to ensure carers issues were embedded within their systems.

The **role of the group** would thus include:

- to monitor all planning documents of all the partner agencies to ensure these address carers issues and connect to the Joint Action Plan for carers;
- to ensure carers issues are integrated into all the services of all the different care groups at an operational level;
- to ensure the Primary Care Groups address the carer agenda;
- to co-ordinate and monitor the implementation of the Joint Action Plan on carers and update and prioritise the plan annually;
- to assist in developing ways of monitoring each of the actions and finding ways of assessing the impact on carers;
- to ensure the voice of carers influences the work at all levels strategic, operational and at a practice level and that their voice is 'a roar'.

Preparatory tasks for the next stage of work

It was agreed the group would need to review:

- the scope of its brief: would <u>all</u> carers parent carers and young carers be included?
- the membership of the group should the independent/private sector be involved?
- the spread of the work across care groups and communities, for example, are carers of people with mental health problems and carers from black and minority ethnic communities able to access the same support as other carers?
- the carers 'representation' are there other ways to involve carers in the work to widen the 'base' of carers?

Appendix 1: Workshop participants

Michelle Clarke Carers Support Worker, Carers Support Project

Mike Cooney Assistant Director, Adult Services, Bolton Social Services

Department

Eve Crabtree Assistant Director, Commissioning, Wigan & Bolton Health Authority

Mary Cummings Carer and Vice-chair, Crossroads

Peter Elton Director, Public Health, Wigan & Bolton Health Authority

Ann Gillespie Locality Manager, Community Healthcare Bolton NHS Trust

Jan Hough Manager, Crossroads

Cath King Bolton Social Services Department

Joan Leonard Assistant Director, Corporate Planning Services, Wigan & Bolton

Health Authority

Ann Parr Deputy Director, Public Health, Wigan & Bolton Health Authority

Albert Pope Ex-carer, Alzheimer's Disease Society

Margaret Ranyard Research Officer, Bolton Social Services Department

Lisa Smith Carers Link Worker, Carers Support Project

John Walters Medical & Elderly Directorate, Royal Bolton Hospitals NHS Trust

Joyce Young Locality Manager, Community Healthcare Bolton NHS Trust

Other members of the Carers Impact Steering Group

Kath Dakin District Nurse Team Leader, Bolton Community Healthcare NHS

Trust

Jane Harrison Chair, Commissioning Project

Anis Haroon Ethnic Minorities Health Forum

Ron Howard Head of Nursing Services, Royal Bolton Hospital NHS Trust

Enid Rostron Carers & Making Space

Katy Scivyer Housing Manager, Bolton MBC Housing Department

BOLTON SOCIAL SERVICES STAFF SURVEY Appendix 2

1. Carers (Recognition and Services) Act 1995

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

YES (37) 90%

NO (4) 10%

COMMENTS:

2. Carers Support Project

(a) Are you aware of the Bolton Carers Support Project?

YES (38) 93%

NO (3) 7%

(b) Do you know how to access the project?

YES (26) 63%

NO (15) 37%

(c) Can you suggest 3 services that it provides?

YES (22) 54%

NO (19) 46%

COMMENTS:

3. Bolton Council's Caring Strategy

(a) Are you aware that Bolton Council has a Carers Strategy and Action Plan?

YES (17) 41%

NO (24) 59%

(b) Do you know what it sets out to do?

YES (9) 22%

NO (32) 78%

COMMENTS:

4. Bolton Carers Impact Project

(a) Are you aware of the Carers Impact Steering Group?

YES (20) 49%

NO (21) 51%

(b) Can you say what it is trying achieve?

YES (12) 29%

NO (29) 71%

COMMENTS:

(c) Do you know who to contact, in the Department, for information about the Project?

YES (16) 39%

NO (25) 61%

COMMENTS:

5. Can you estimate the number of percentage of adults in Bolton who have caring responsibilities.

The estimates ranged from 5-99%

15% did not estimate the answer.

COMMENTS FROM QUESTIONNAIRE

Are you Aware of the Carers (Recognition and Services) Act 1995?

Aims to provide greater recognition of carer role and to provide assessments where required

Acknowledging the right of carers to have their own needs recognised Vaguely understand the gist of it.

Obliges local authorities to make Carers aware of their right to assessment of their needs - not statutory responsibility to meet an identified need. Although Carers have a right to an assessment not always resources to meet their needs or those of service users - can lead to further frustration.

Can you suggest 3 services that it provides

Sitting, Newsletter, Counselling
Raising Awareness, giving information, linking with other projects
Offers support to carers, to provide information re services
To provide a forum for discussion
Michele Clark - Carers Development Worker, Newsletter, Carers Forum, Advice
and information, practical help, counselling support.

Can you say what it is trying to achieve?

Lobby organisations in support of carers - provide apt information/training for Carers

A better service for carers and implementation

Kings Fund Project - workshops aimed to raise awareness

Finding best practice to share across agencies, teams etc. to improve service delivery and customer satisfaction

I do not know what this is trying to achieve - but would appreciate more information (Children with Disabilities Team)

Do you know who to contact, in the Department, for information about the Project?

Embarrassed not to know, but neither do any of my colleagues.

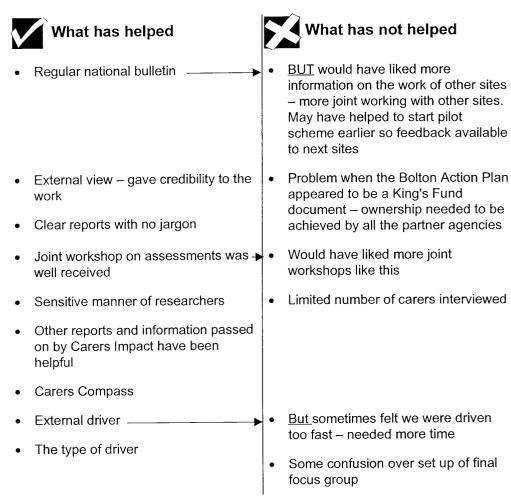
No - but please let me know - especially if there are any Childrens Reps on this panel (Children with Disabilities Team)

I have a caseload which involves a lot of contact with carers, but I have never been asked by the Department to give information on them (Children with Disabilities Team)

CK/BT

Appendix 3: The Carers Impact process

The following are the views of the workshop participants:





Appendix 4: Reports produced by the Carers Impact Project in Bolton

- 1. Report on the focus groups and interviews conducted with carers in October 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

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