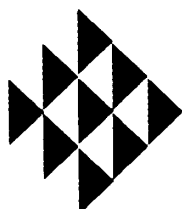


King's Fund



Carers Impact Project in Tameside

Where have we got to?

Final report based on a workshop
held on 3 June 1998 to evaluate the
Carers Impact Project in Tameside

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Contents

Introduction	2
Executive Summary	3
Report of the workshop	5
1 Background to the project	5
2 The Picture Before	6
3 The Picture Now	8
4 Making Progress	15
5 Looking ahead - keeping the work on course and monitoring progress	16
 Appendix 1: Membership of the Joint Strategy Sub-Group on Carers and the Carers Council	
Appendix 2: Staff Awareness Survey - summary of results	
Appendix 3: The Carers Impact process - what has helped / not helped	
Appendix 4: Reports produced by the Carers Impact Project in Tameside	

Introduction

Members of the Joint Strategy Sub Group on Carers and the Carers Council met to evaluate the Carers Impact Project in Tameside 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 made since the beginning of the Carers Impact Project in 1997 and issues to be addressed in the future joint work to support carers in Tameside:

1. Key structures established to progress carer support

As a result of the project, two key structures have been established:

- ♦ **Joint Strategy Sub Group on Carers** which:
 - co-ordinates and monitors the multi-agency action
 - links into planning processes (although it was questioned how effectively it links with other joint strategy groups)
 - acts as a focus for carer issues
 - includes carer representation from the Carers Council
- ♦ **Carers Council** which has two-way communication with carers involved in local support groups and a direct voice in the Joint Strategy Group

2. Engagement of carers and taking carers seriously

There is evidence of action by all the different agencies to increase the involvement of carers in activities other than planning and to build on the excellent work of the Carers Centre to increase the voice of carers. For example, carers are being invited to participate in the Quality Standards work of the Health Authority, they are involved in auditing discharge procedures and they are being consulted in the homecare survey.

Including carers from all communities and minority groups has been taken seriously; there has been successful outreach work with Asian carers and the participation of carers with sensory disabilities has been sensitively facilitated.

3. Development of joint working on carer support

The meeting affirmed that working relationships across the agencies have strengthened and there is a readiness to usefully share ideas and practices which have resulted in a range of direct action to support carers (detailed within this report - section 3 pp8-15).

Involving GPs remains an issue but there has been some limited success in engaging with them, particularly where health and social services have worked together.

4. Steps forward to meet the outcomes carer want

There has been considerable action by all the agencies on a wide range of issues which were raised by carers at the beginning of the project. The evaluation of the impact of this action has taken place in a relatively short timescale and the feedback from carers is not a systematic analysis. However, although this feedback is limited, it does give some useful impressions of current strengths and weaknesses and indicates a number of key areas for action; these include:

- ♦ improving carer assessments
- ♦ increasing GP awareness
- ♦ improving continence services

5. The need for more monitoring and a focus on quality

Further work to co-ordinate and review current monitoring systems has been identified. In addition, more systematic feedback and monitoring systems could usefully be developed, for example, in monitoring good practice in carer assessments and in obtaining regular carer feedback on the continence service and primary healthcare services.

6. Beginning to take carers issues into the mainstream

There are some concerns that carers issues are still seen as specialist and somewhat marginalised. A social services survey to assess staff awareness of carers issues indicated there is still some work to do to achieve wider ownership. There are examples of achieving mainstream ownership through, for example, staff induction training on carers, unit agreements which identify actions to engage carers and carer involvement in discharge planning audits. These could be usefully extended so that action on carers issues is not seen as the sole responsibility of the specialist carers team or left to committed individual staff.

7. Keeping up the momentum

Improved monitoring and mainstream ownership will be vital in ensuring the work continues to move forward, particularly when the catalyst of a national development project ends; individual champions move on and when other pressures compete with staff time.

Report of the Workshop

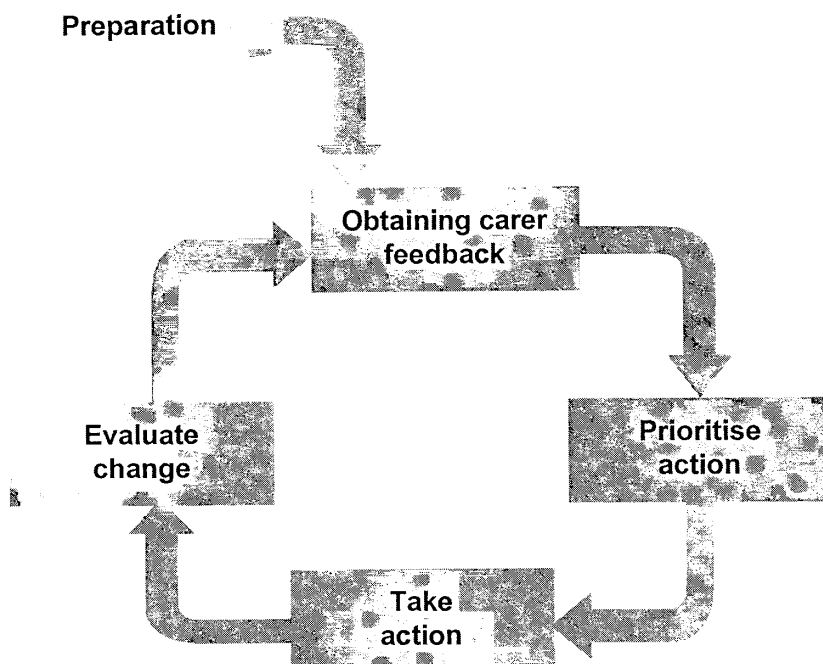
1 Background

The Carers Impact Project in Tameside was the first 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 Tameside aimed to:

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

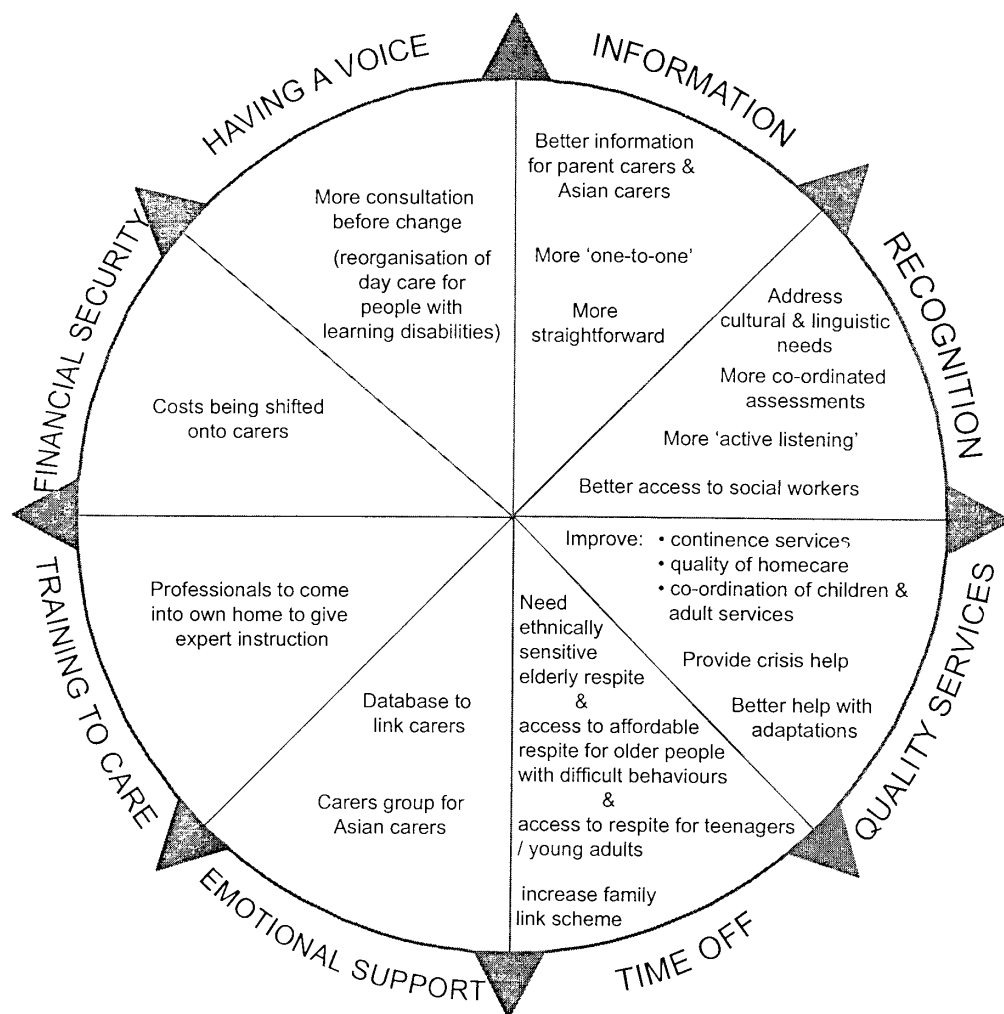
The project method



2 The Picture Before

a) Feedback from carers February 1997

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

2 The Picture Before *cont.*

b) Process in place in 1997 for progressing carers issues

- ♦ Strategy Steering Group
 - majority of members were carers
 - no formal links into planning process
- ♦ Officer Partnership Group had ceased to exist

c) Key issues identified at the beginning of the project

- ♦ the need for a more co-ordinated approach between the agencies
- ♦ better monitoring of the carer support strategy
- ♦ work to achieve mainstream ownership

3 The picture now

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998*	
		A Positive Difference	Issues to be Addressed
To ensure carers are better informed (which requires staff to be carer aware)	<ul style="list-style-type: none"> ➤ Information on Carers Centre disseminated to hospital ward based staff. 3 wards now have leaflets at bedside (in information book). Dissemination of information has raised staff awareness. ➤ Carers Council, Carers Forum, Carers Week, Newsletter and local carer meetings have informed carers. ➤ Special information sessions held for Asian carers. ➤ Information officer post now advertised (social services) ➤ Staff awareness audit ➤ Training audit ➤ Awareness raising sessions with mental health team ➤ Awareness raising sessions held with independent providers 	<ul style="list-style-type: none"> ✓ Homecare workers more carer aware - but room for improvement! ✓ Carers Centre ✓ Social Events, Carers Week etc. ✓ Charter Days 	<p>Professionals do not always see carers as the experts and do not fit with carers routines</p> <p>Need more advertising for the Carers Centre</p> <p>Problems finding hidden carers</p> <p>Assumptions made about young carers</p> <p>Carer is forgotten when the caring role ends</p>

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

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998*	
		A Positive Difference	Issues to be Addressed
<p>To ensure good practice in assessments and care co-ordination</p>	<ul style="list-style-type: none"> ➤ Carers Impact workshop on good practice and monitoring. Report disseminated - work in progress ➤ SPRU research - raises awareness among staff. Research in progress ➤ Nursing assessment on admission to hospital now highlights carers ➤ Assessment form (learning disabilities) for respite care has added 3 new questions on carers ➤ Carers Centre has worked with social services staff to raise awareness about carers assessments ➤ Development of joint assessments - discussions about young people / adults interface ➤ Young carers project has now started ➤ Carers assessment forms and information leaflet 	<ul style="list-style-type: none"> ✓ More involvement in daughter's care plan ✓ Young carer offered assessment with educational psychologist ✓ Carer asked about the help she needed 	<p>Need more involvement of carers in assessment.</p> <p>But only when at the 'end of her tether'</p> <p>But carer filled in assessment form and never saw or heard of it again!</p> <p>More self recognition by carers needed</p> <p>People do not know about carers' rights to an assessment</p> <p>Lack of acknowledgement within private sector of the importance of needs assessment for people with learning disabilities</p>

Tameside Action Plan Agreed June 1997	Action Taken	Carer Feedback, May 1998	
	As at June 1998	A Positive Difference	Issues to be Addressed
To involve primary healthcare teams and GPs	<ul style="list-style-type: none"> ➤ Award scheme for GP practices investing in carers ➤ Funding for GP awareness raising session.. 6 practices agreed to get involved as a result of the session ➤ Bid for health funding for project with GPs ➤ Carers have been identified as priority for Ashton Renewal Area Management Group 		<p>Problems of access and communication for deaf carer and deafblind husband at GPs</p> <p>Insufficient information from GP and lack of recognition by GP</p> <p>Greater clarity needed about who will co-ordinate routine health checks for person with learning disabilities.</p>
To strengthen the carers voice within joint planning	<ul style="list-style-type: none"> ➤ Joint Strategy Sub Group on carers established ➤ Carers Council established ➤ Asian carers represented on Carers Council ➤ Carers represented on Joint Strategy Group 	<ul style="list-style-type: none"> ✓ Carers Council ✓ Joint Strategy Group 	

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998	
		A Positive Difference	Issues to be Addressed
To improve continence services	<ul style="list-style-type: none"> ➤ Leaflet on continence services explaining criteria, altered with carer input 	<ul style="list-style-type: none"> ✓ More discussion with carers ✓ 'open door policy' - anyone can ring in 	<p>but not yet sorted: -</p> <p>Inadequate and inflexible supplies</p> <p>Lack of expert advice</p> <p>Costs of meeting the shortfall</p> <p>Difficult to get information about continence services</p> <p>No laundry service to deal with acute continence problem</p>
To inform carers of training available	<ul style="list-style-type: none"> ➤ Mapping exercise completed. JSG Sub Group on carers to review ➤ More training courses available for carers - provided by Acute Trust 		<p>Carers need training at home</p> <p>Carers need specific training in handling people with behavioural problems</p>
To inform carers of all available counselling services	<ul style="list-style-type: none"> ➤ List of counsellors compiled. Vetting taking place. Final list to be published within the next 2 months 	<ul style="list-style-type: none"> ✓ Hospital referred carer for counselling ✓ Carer support groups 	<p>but after insensitive diagnosis giving</p> <p>Very little choice of counselling mainly private</p>

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998	
		A Positive Difference	Issues to be Addressed
To support Asian carers	<p>Action taken as part of the Black Communities Initiative</p> <ul style="list-style-type: none"> ➤ About 80 carers now in contact ➤ Meetings held to raise awareness ➤ Asian carers are members of Carers Council ➤ Information sessions held for Asian carers ➤ Outreach work with Asian carers ➤ Bi-lingual contact points for one-to-one services 		Respite unit unable to cook Asian meals

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998*	
		A Positive Difference	Issues to be Addressed
To continue work to progress respite care	<ul style="list-style-type: none"> ➤ Sub group now reviewing respite care (learning disabilities) ➤ Some work on respite care for parent carers 	<ul style="list-style-type: none"> ✓ Carers of people with learning disabilities have confidence in respite care and regard it as an essential support ✓ Better quality of care for people with learning difficulties ✓ Good dialogue with social services about the needs of person being cared for 	<p>One carer considered there was inadequate space for wheelchairs at respite facility</p> <p>Unit had no adapted transport for taking son on extended trips during his stay</p> <p>No back-up to ensure quality of day care when staff absent</p> <p>Cutbacks in respite allowance</p> <p>Rising costs of respite care</p>
To improve homecare services	<ul style="list-style-type: none"> ➤ Best Value project is obtaining feedback from carers and working to obtain ongoing feedback ➤ Funding transferred to children's services - homecare services for parent carers 	<ul style="list-style-type: none"> ✓ Good support for carers of people with Alzheimer's disease 	<p>Inconsistency of homecare for older people</p> <p>Expensive service</p>

Tameside Action Plan Agreed June 1997	Action Taken As at June 1998	Carer Feedback, May 1998	
		A Positive Difference	Issues to be Addressed
To ensure carers have access to help in a crisis	➤ Review of respite services will include how parents can access respite in a crisis	✓ Examples given of how services have responded in a crisis	
To progress work on housing needs of carers	➤ Housing representatives now on JSG Sub Group on carers (housing issues to be reviewed)		
To meet the commitments of the Carers Team	➤ Ongoing work on hospital discharge, carers awareness training, support to Carers Forum, Carers Council, support groups; direct work with carers, newsletter, GP practice pilot	✓ Well planned discharge with home visits to check facilities	

4 Making Progress

The meeting identified what had helped and hindered the process in taking action



What has helped

- ✓ A local 'history' of carers support
- ✓ King's Fund initiative - Carers Impact
- ✓ Formation of Joint Strategy Sub Group on carers
- ✓ Establishment of Carers Council
- ✓ Champions at senior level - commitment and involvement
- ✓ Joint work across agency boundaries
 - networking between agencies
 - interlinking groups and cross membership
- ✓ Consistent membership of JSSG →
- ✓ Staff commitment
- ✓ Carers Act →
 - staff training on assessments
- ✓ Government lead on participation and emphasis on patient and carers consultation
- ✓ Carers have been helped by:
 - being taken seriously
 - recognition of their needs for training
 - Carer Centre support groups
 - clearer information and more widely available

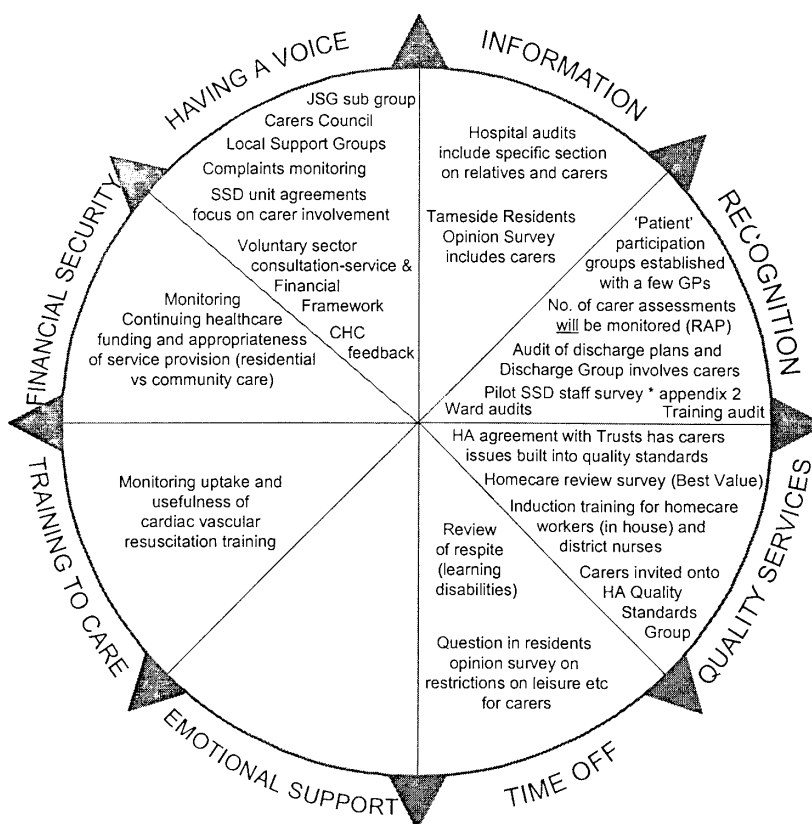


What has not helped

- ✗ Lack of funding for community care
- ✗ Waiting lists
- ✗ Difficult to involve GPs
 - hide behind confidentiality
- ✗ Lack of connection between JSG sub groups
- ✗ Services division between children / adults
- ✗ But large bureaucracies with different agendas
- ✗ emphasis on clinical effectiveness at expense of quality of life issues
- ✗ But lack of ownership in the mainstream
- ✗ Low recording of unmet need
- ✗ But no resources with the Act
- ✗ But still the emphasis is on patients
- ✗ Low level of monitoring
- ✗ Low level of 'quality' awareness / quality principles
- ✗ Carers frustrated and angry at lack of recognition and:
 - abuse of the term 'consultation'
 - communication problems for deaf carers and Asian carers

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

- ◆ The JSG Sub Group on carers will continue to co-ordinate and monitor the overall action plan
- ◆ The Carers Council will ensure the voice of carers is represented in the discussions
- ◆ Other JSG sub groups have been asked to take carers issues into account and to identify how their plans will be monitored
- ◆ The meeting identified a range of current monitoring activities which are summarised in the following diagram:



- ◆ It was agreed there was a **need to develop all aspects of monitoring**, both to co-ordinate and learn from the different monitoring exercises already in place in the different agencies and to work on establishing new (realistic and achievable) ways of assessing progress

Appendix 1

Members of JSG Sub Group on Carers

Ann Barlow	Carer
Sue Bennett	Community Dementia Team
Shela Beswick	Co-carer
Wendy Bickerstaff	Practice Director, Windmill Practice
Bridget Bradbury	Carer
Steph Butterworth	Unit Business Manager - Learning Disabilities
Eddie Francis	Team Leader - Provider Unit
Dave Griffiths	Tameside & Glossop Community & Priority Services NHS Trust
Martin Higgins	Corporate Services
Alison Johnson	Tameside and Glossop Acute Trust
David Jones	Unit Business Manager - Customer Services Unit
Pam Jones	Assistant Director Social Services
Hilary McGee	West Pennine Health Authority
Lina Patel	Black Communities Initiative - Customer Services
Cherry Platt	Education Department
Tony Powell	Housing Department
Althea Rankin	Team Leader - Reception & Initial Assessment Unit Team
Ray Slamon	Carers Officer - Carers Centre
Phil Spence	Planning & Commissioning - Social Services
Tracy Wilson	Practice Director - Richmond Group Practice
<i>Former member:</i>	
Charles Barker	Assistant Director - Social Services (until May 1998)

Members of Carers Council

Fatima Atchia
Ann Barlow
Shela Beswick
Bridget Bradbury
Annie Burns
Wendy Cooke
Hilda Holme
Sarwar Ibrahim
Christine Jones
Keith Martin
Albert Midgley
Zoe Nightingale
Margaret O'Connor
Lillian Renshaw
Pamela Spilsbury
Charles Walker

Appendix 2: Staff awareness survey

Summary of results

A questionnaire was circulated throughout the social services department which asked staff nine questions relating to their awareness of carers issues. The following is a breakdown of their responses.

A total of ninety questionnaires were returned. Most were returned anonymously which makes it difficult to identify areas where some awareness training is required.

	Yes	No
1 Do you think that the department has encouraged staff to give appropriate recognition to the needs of informal carers?	68	22
2 Are you aware of the Carers Recognition Act?	67	23
3 Do you feel informed about the provisions within the Act?	51	39
4 Are you aware of the Joint Strategy Sub Group (for carers)?	58	31
5 Are you aware of the Tameside Carers Centre?	87	3
6 Are you aware of the Black Carers Network in Tameside? (This links informal carers from the ethnic minority communities)	42	48
7 Are you aware of the Young Carers Development Project? (This is a two year Joint Finance project)	23	67
8 Do you know about the formation of a Carers Council in Tameside for carers to represent the issues of carers?	32	58
9 Are you aware of the Staff Carers Support Group which meets monthly?	48	42

Appendix 3: The Carers Impact process



What has helped

- ✓ Raised the profile / awareness
- ✓ Acted as a catalyst
- ✓ Helped establish cross agency involvement / ownership / JSG sub group
- ✓ Structured approach
- ✓ Credibility of national reputation / given strength
- ✓ Recognition and credibility of carers input helped validate work already done
- ✓ Hasn't felt 'fixed'
- ✓ Objectivity
- ✓ Links across the country
- ✓ 'we learnt a lot'
- ✓ 'Penny is a good model'



What has not helped

- ✗ Initial claim to 'scientific' process leading to the measurement of outcomes
- ✗ Short timescale to achieve change
- ✗ So evaluation felt like a 'hoop' to go through
- ✗ Not enough contact!
- ✗ Problems fitting extra work into existing workloads / may have been done at the expense of other work?



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

1. Report on the focus groups and interviews conducted with carers in February 1997. H Bagshaw, J Unell
2. Taking Action: report of a workshop held on 18 June 1997
3. Taking Action on Assessments: A workshop held on 29 January 1998 to develop measurable indicators of quality, from the carers' perspective, of assessment and care planning.
4. The Picture Now: feedback from carers 1998
5. Where have we got to?: final report based on a workshop held on 3 June 1998 to evaluate the Carers Impact Project in Tameside

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