King's Fund

Carers Impact Project in Tameside

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.

Feb 1998

Taking action on carer assessments

Introduction

This report summarises the material produced by a workshop which was set up in response to feedback from local carers who took part in the first stage of the Carers Impact, Kings Fund project. The JSG Carers Sub Group is taking forward a range of carer issues in Tameside, one of which is carer assessments.

The workshop included carers, health and social services representatives, both assessors and providers, staff from the Customer Services Unit and the Carers Centre.

Penny Banks and Mike Hatch from the Carers Impact project at the Kings Fund facilitated the meeting.

Charles Barker, Chair of the Carers Sub Group and Assistant Director, Social Services introduced the day. The workshop aimed to review the progress made in implementing the Carers Act and undertaking carer assessments and to propose measures and ways of monitoring good practice. This work would not only assist Tameside in ensuring consistent good practice in carer assessments, but would also help the national Carers Impact programme in developing ways of monitoring assessment practice.

Contents of this report

1 The National Picture (presentation)

The Carers Act is the first piece of legislation to recognise fully the role of carers within community care law. There are two key elements:

- the **carers right** to ask for an assessment of their ability to care
- the **local authority's duty** to take into account the results of this assessment when looking at what support to provide to the person cared for

The following evidence comes from the Carers Impact projects across the country and other research listed in Appendix 2.

The local authority perspective

The Carers Act has had a positive impact and acted as a "motivator for change". For example, the Carers Act has generated:

- work on policy guidance and procedures (46% of authorities responding to the Carers National Association/Association of Directors of Social Services survey say they have new procedures)
- consultation with carers on assessments (91%)
- increased information for carers (76%)

The Act has also promoted better practice

- 87% of local authorities <u>claim</u> it is routine to inform carers of their rights when carrying out an assessment of the user
- 98% say it is their policy to give carers a copy of the care plan or results

But....there are underlying policy tensions between the rhetoric of needs-led approaches as against the imperative to stay within budget.

Resource difficulties

The Carers National Association research found:

- 1 in 6 authorities planning to reduce initiatives for carers because of cuts
- 1 in 3 authorities said charges for services had increased significantly since April 1996. Charges have shown to be a deterrent for carers asking for and having an assessment

Differing interpretations of assessment

- Many authorities have a **'procedural model' of assessment** where the goal of assessment is to gather information to see if the client meets a set of eligibility criteria. (See *"Access to Assessment"* - A.Davis et al). Often the screening and initial assessment is not so much about identifying need as testing peoples eligibility for further assessment and/or services. Access to assessment is then limited at the earliest possible stage and often takes place with no direct contact with either the user or carer.

  'Access to assessment' showed how different teams in the same authority approached the task of determining assessment eligibility differently. Specialist disability teams were more likely to acknowledge people's legal entitlement to a comprehensive assessment of their needs, rather than an assessment of their eligibility for a service.

- Fewer people receive **comprehensive assessments which address all their needs** and lead to a care package designed to meet their needs.
- **Many people have a 'low level' / simple assessment -** often by an occupational therapist leading to a supply of equipment
- **There may be difficulties in defining 'carer' assessments,** particularly as caring is a two-way relationship and in many situations it is not easy to decide who is doing the caring and who is being cared-for.

Differing definitions of 'regular and substantial care'

Under the legislation carers are eligible for an assessment if they offer a *"substantial amount of care on a regular basis"*. This has been left to local authorities to define. In some authorities all carers are offered an assessment whilst in others only carers caring for a certain number of hours are eligible.

Difficulties in monitoring assessments - both numbers and practice

The Carers National Association survey showed only 14% of authorities had collected statistics on the numbers of carers offered an assessment since April 1996. The figures ranged from 2-6,000!

The Carers experience of assessments

Few carers appear to be getting an assessment - in the CNA survey 21 % had an assessment of some kind.

Where they do, many have positive experiences of assessment

- Over half said services increased as a result of assessment
- Carers praise helpful staff and report increased confidence to take up services and support. Many say they feel valued and recognised and have 'peace of mind' (some carers say this is even when no immediate services are offered).

But for a number of carers nationally

- there is evidence of some difficulties for carers getting into the system for the first time
- carers are unclear of the status of meetings - is it an assessment or not?
- carers were unclear how assessment could help them to manage their situation
- carers are not informed of their rights even though their relative was assessed (53% - CNA)
- few carers are given information about the Carers Act at hospital discharge (awareness raising with health professionals is an ongoing issue)
- there is a lack of information at the time of assessment to consider options
- many carers are notgiven written results (56% of those assessed - CNA)
- for the most part assessment concentrated on the person cared for and both workers and carers may have little understanding of the value of an assessment of the carers' needs
- assessments between health and social services are not co-ordinated - carers have to repeat the same information time and time again
- carers do not feel they are allowed to talk about what is important to them
- assessments often do not build on the support and frameworks which disabled people and carers have established for themselves (see *"Access to Assessment"*)
- carers experience baffling jargon and poor communication, and often a focus on completing forms
- carers may be disillusioned where there are no tangible outcomes
- concerns about charges prevent carers from asking for or having assessments
- there is a great diversity in experience:

  - *within the same authority and between authorities; carers' experience may vary according to the type of team carrying out the assessment*
  - *between carers of people with different needs - particular problems of carers of people with mental health problems (confidentiality issues); different procedures within learning disability teams; young carers are often not recognised.*

Carers from black and minority ethnic communities have particular difficulties in addition to those listed above:

- lack of information, including how to access services
- communication and language barriers

Carers feedback on their experience in Tameside

Some of these points were raised by carers in their **feedback to Tameside** (see Appendix 2 Carers Impact report on the focus groups and interviews conducted with carers)

Assessment worked well for many carers, but:

- some had difficulty in getting into the system and finding out about services
- there are particular difficulties for Asian carers knowing how to access services and assessments
- carers often have to repeat the same information and want more co-ordinated assessments
- some carers wanted an opportunity to talk about more than an item of equipment
- many wanted better listening and no assumptions made
- some carers were uncertain about the status of their meeting - none had received a copy of the assessment of their needs
- assessments were often strongly focused on the user - many carers too have little understanding of the value of a separate assessment of their needs

Conclusion

Nationally we have not got there - comprehensive needs led assessments which address both user and carer needs in an integrated way are not yet the norm.

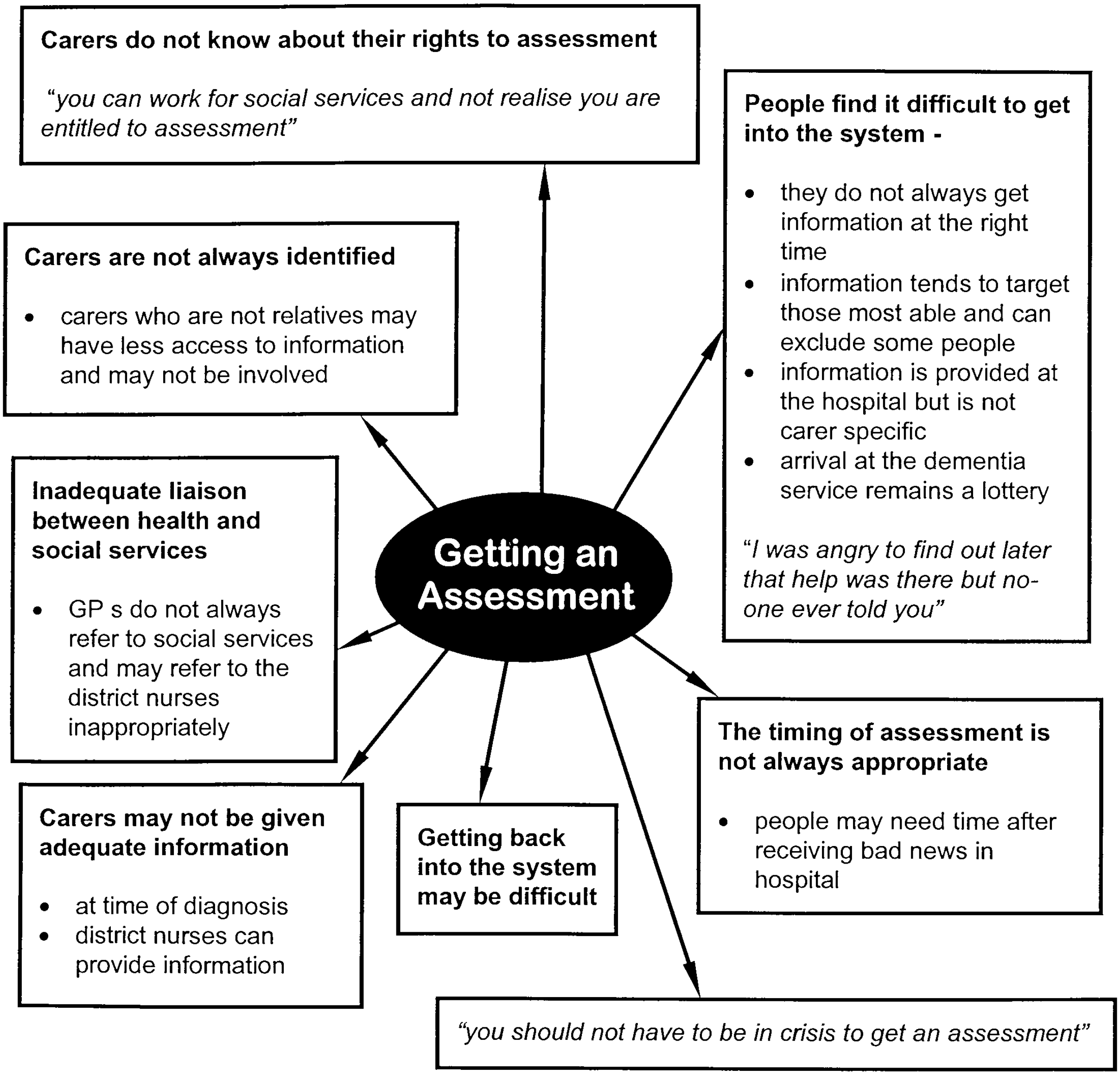
There are a range of pressures working against this -in particular the financial constraints and tightening eligibility criteria. This can mean carers are simply viewed as a resource, for example a quick answer to releasing a bed, rather than people with needs in their own right.

It is very difficult to generalise as there are many examples of excellent practice and satisfied carers. The Act has helped to raise awareness.

The challenge is to build on the good practice already evident and to work towards more consistent practice. Hence monitoring good practice is the subject of this workshop.

2 Local experience of carer assessments

The following issues were raised by the workshop participants :



Getting an Assessment

Carers do not know about their rights to assessment

"you can work for social services and not realise you are entitled to assessment"

People find it difficult to get into the system -

- they do not always get information at the right time
- information tends to target those most able and can exclude some people
- information is provided at the hospital but is not carer specific
- arrival at the dementia service remains a lottery

"I was angry to find out later that help was there but no-one ever told you"

Carers are not always identified

- carers who are not relatives may have less access to information and may not be involved

Inadequate liaison between health and social services

- GP s do not always refer to social services and may refer to the district nurses inappropriately

The timing of assessment is not always appropriate

- people may need time after receiving bad news in hospital

Carers may not be given adequate information

- at time of diagnosis
- district nurses can provide information

Getting back into the system may be difficult

"you should not have to be in crisis to get an assessment"

Local experience of carer assessments *continued....*

Assessments

What do we mean by integrated assessments?

"If the assessment takes into account the needs of users and carers, whose assessment is it? Whose care plan is it?"

Are we doing any carer assessments?

- how do we inform carers of their rights and the benefits of an assessment?
- district nurses do a holistic assessment but not with a specific carer focus
- carers perspective is included, not their needs
- the in patient experience focuses on the patient not carer
- in hospital 'rotation beds' the consultants assessment has more weight
- premature discharge scuppers assessment

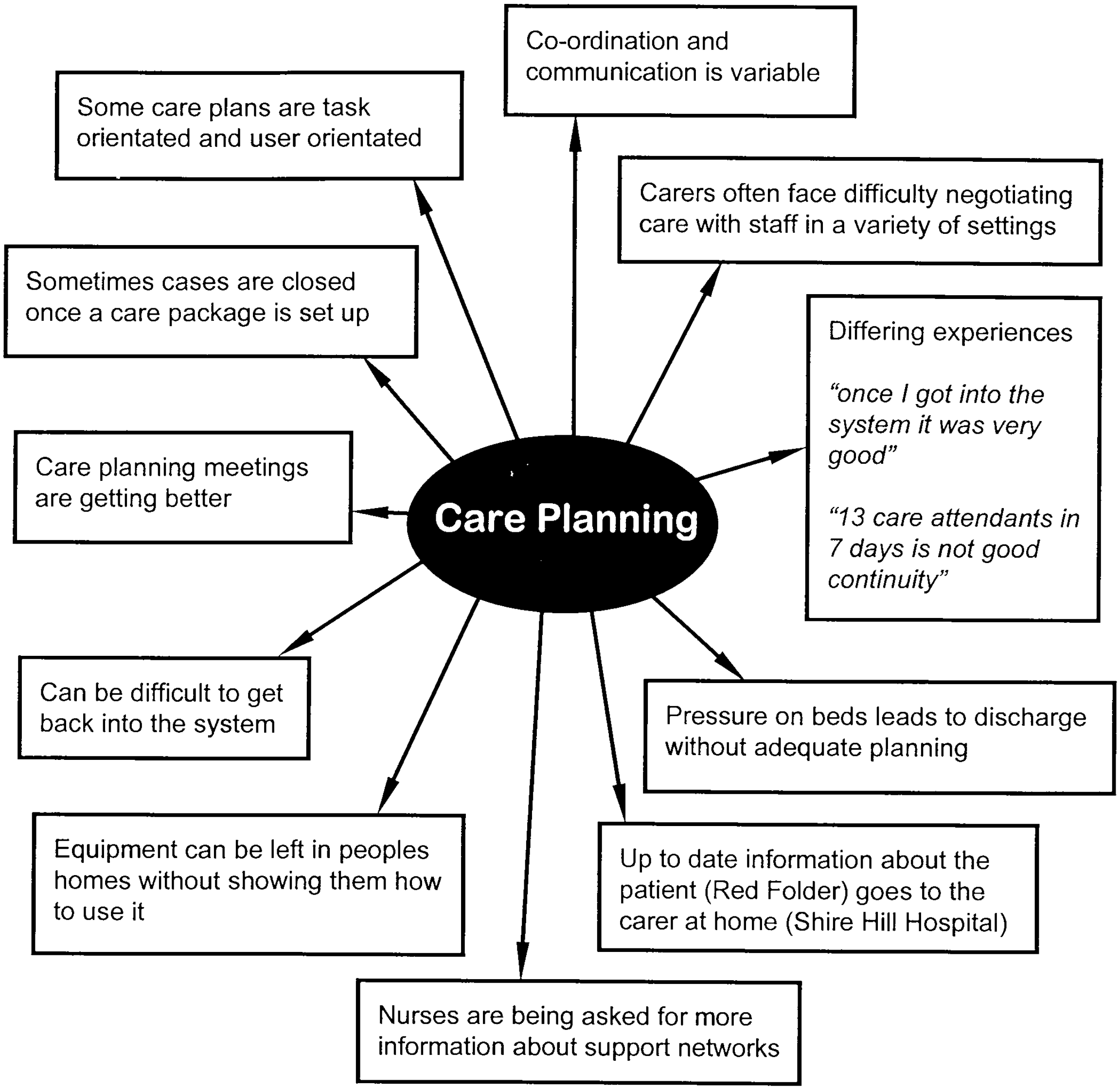
Carers may be assessed but this may not be made explicit

"I don't know if I was assessed"

- Social Services level 2 forms require carers views
- Carers respite - review/assessment form (learning disability)
- 2/3 of the work on dementia is focused on carers
- assessment pack is given out with each assessment (adults and learning disability, social services)

How good are the assessments?

- Carers are offered the chance to complete their own assessments - we (learning disabilities) do not get many back
- *"I was so wrapped up in caring, tiredness stopped me from saying what all my needs are"*
- Is it a one-off event to be offered a carer assessment?
- *"assumptions are made because of my culture and expectations that I had to give up work"*



Care Planning

Co-ordination and communication is variable

Carers often face difficulty negotiating care with staff in a variety of settings

Differing experiences

"once I got into the system it was very good"

"13 care attendants in 7 days is not good continuity"

Pressure on beds leads to discharge without adequate planning

Up to date information about the patient (Red Folder) goes to the carer at home (Shire Hill Hospital)

Nurses are being asked for more information about support networks

Equipment can be left in peoples homes without showing them how to use it

Can be difficult to get back into the system

Care planning meetings are getting better

Sometimes cases are closed once a care package is set up

Some care plans are task orientated and user orientated

3 Good Practice in carer assessments

The workshop identified key good practice points:

Getting an assessment

1. **There is a single point of contact and carers are not passed around**
2. **Carers should not have to keep repeating the same information**
3. **All staff in all agencies - especially GP s - know their responsibility to give, or to signpost, clear information**
4. **Requests for information may only be a first step - always check if further support is needed**

Other good practice points raised:

- *Carers should be involved both at admission and at discharge from hospital.*
- *Do not make assumptions about who is the carer. For example " Next of kin" is not necessarily the carer*
- *Staff need to be clear about their role in assessing the needs of both the user and the carer*
- *Reach out to hidden carers; for example provide information for carers when people take up benefits*
- *Recognise the needs of carers even when the person cared for has died or is in residential care*
- *People with less complex needs do not get the small amount of help which could prevent a crisis or breakdown in care (NB People are worried about the quality of private care)*
- *All statutory services should have easy to read information packs, including GP s, primary health care teams and hospital. These should be jointly produced, with carer involvement. These should also be available at other key locations in the community.*

Assessment

1 **All carers are given clear, accessible information about the meaning and purpose of assessment**

2 **It is always made explicit when an assessment is taking place**

3 **Assessments are not a test but a shared process with honesty and respect (for example appointments are punctual and kept) on all sides**

4 **Everyone should be treated as an unique individual and no assumptions made**

5 **Carers have the right to challenge assessments and should know who and how to make contact if their circumstances change**

Other good practice points;

- *All carers should have a copy of their assessment*
- *Assessments should be undertaken in a relaxed atmosphere, using everyday language*
- *Carers should be given the space and privacy to talk and assessments conducted on their terms*
- *Friends or an advocate can provide support*

Care Planning

1 **There is shared (between health, social services and the user and carer) agreement and understanding about the purpose and content of a care plan**

2 **Everybody has a copy of the care plan which is :**
    - **clear and concise**
    - **provides key contact names and numbers , including emergency contacts**

3 **Carers and users are fully involved in developing the care plan, as equal partners in the process**

4 **Carers should not have to keep repeating the same information**

Other good practice points:

- *care plans need to be multi disciplinary so that all the needs of the user and carer are addressed*
- *it needs to be clear how the care plan will be monitored*

4 Good Practice, Key indicators and monitoring

1 **There is a single point of contact to services and carers are not passed around**

Target	Monitoring
• All agencies/services have a recognisable access point where: – it is clear who responds to calls and how – no call is left 'uncompleted' • All staff give their name, position and contact number • x % staff complete customer care training • No carers are passed around	• Check staff knowledge of the policy through supervision • Spot check calls • Teams (RIAT) monitoring of Community Care Charter standards and monitoring of Patients Charter • Each access point samples the experience of a small number of carers on a regular basis

2 **All staff in all agencies , especially GP s, know their responsibility to give, or to signpost, clear information**

Target	Monitoring
• All staff have received carer awareness training • All staff receive carer awareness training as part of their induction • All customer care training includes reference to carers and is explicit about local policy and the definition of carer	• Audit numbers of staff who have taken part in recent carer awareness training or workshops • Use supervision to check staff understanding of policy on information giving • Code jointly produced information for carers to identify where it has been obtained (e.g. from which GP s)

3 **Requests for information may only be a first step - always check if further support is needed**

Target	Monitoring
All carers have an opportunity to talk further when a request for information is made	Supervision Obtain feedback from carers on their experience
All enquiries are logged to see what happens to them	Regular review of data
All enquiries receive a follow up letter	File check
All staff give their name and a contact number at the point of request	Spot checks

4 **All carers are given clear, accessible information about the meaning and purpose of assessment**

Target	Monitoring
All carers and users are given explanatory information which is clear, relevant and in an appropriate format for them	Checklist for assessors to include sending out information in advance of the assessment meeting/s.
All carers know in advance when, at what time and where the assessment will take place	File check of appointment letters Obtain feedback from carers about suitability of arrangements and if they were kept

5 **It should always be made explicit to both the users and carers that an assessment is taking place**

Target	Monitoring
All assessment forms have a prompt/checklist to ask if it has been made clear that an assessment is taking place	Audit completion of checklists
All carers sign and receive a copy of the assessment	Check files for signed copy
x % staff take part in refresher courses on carer issues, have ongoing dialogue with carer groups and take part in joint work with carers	Supervision

6 **Assessments are not a test but a shared process with honesty and respect on all sides**

Target	Monitoring
• All carers feel their views are valued and *their* priorities are recognised	• Post assessment survey [*] with carers
• All carers are offered privacy	• File check carers are offered privacy[**]

7 **Everyone should be treated as an unique individual and no assumptions made**

Target	Monitoring
• If there is more than one carer there should be an assessment for each	• File check to ensure the correct number of completed assessment forms
• The outcome of assessment should be based on a genuine interpretation of the facts	• Audit number of refused assessments • Supervision checks that information collected matches assessment outcome
• The outcome of assessment should be presented in a form the carer can understand and use	• Check carers received copy of assessment and care plan
• All unmet needs are recorded	• Examine care plans and check unmet needs are recorded. Identify how this data will be collated and used

8 **Carers have the right to challenge assessments and know who and how to make contact if their circumstances change**

Target	Monitoring
• All carers have contact names and numbers for everyone involved	• File check on information left with carer
• All carers are aware of the complaints procedure and have information about it	• Checklist includes information on complaints

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[*] NB Surveys: the workshop discussed some of the difficulties in getting good information from questionnaires or by people who are not seen to be independent

[**] 'confidentiality' can present problems in fully sharing information

9 **Every body has a copy of the care plan which is clear and concise and provides key contact names and numbers , including those for emergencies**

Target	Monitoring
• All carers gets a copy of the care plan which include all contact numbers	• Audit files - carers sign copy of care plan

10 **There is shared agreement about the purpose and content of a care plan**

Target	Monitoring
• All carers have only one care plan, or at least information about services **in one place only** (e.g. Communications Book / Sheet)	• Audit joint assessments

11 **Carers and users are fully involved in developing the care plan , as equal partners in the process**

Target	Monitoring
	• At review check on user and carer views of their involvement

12 **Carers should not have to keep repeating the same information**

Target	Monitoring
• All carers have an explicit, detailed care plan • All agencies agree the care plan should confirm there is a 'communications book' which should be left with the user and carer and to which everyone contributes • All communications should be sensitive to the needs of people who are blind or deaf • Services, not carers, are responsible for coordinating the care package (unless the carer wants to take on this role) • Hospital assessments and care plans follow the patient out (The Red Book)	• Audit office copies of care plan and copies left with carer • Telephone survey asking carers about the quality of information on the care plan • Audit organisations and ask carers about the use of the communications book • Assessor completes checklist which indicates communications book has been left (and other good practice - see following points) - regular check on this via supervision, spot checks etc.,

Good ideas to take forward

The workshop suggested the following ideas were particularly useful to take forward:

- **Develop a checklist** to be used in working with carers for use by both staff and carers. This checklist would identify the above key good practice steps and could be used for monitoring purposes.
- **Automatic copy of letters to carers**
- **Develop a joint** (health and social services) **care plan**
- Ensure a **communications book** is left with all users and carers

Appendix 1: Workshop Participants to be completed

Hazel North	Adult Placement Scheme
Sam Littlewood	Assessment Team - Learning Disability Service
Tania Ward	Assessment Team - Learning Disability Service
Mike Webb	Children's Services
Sue Webster	Tameside & Glossop Community & Priority Services NHS Trust
Margaret Hardwick	Tameside & Glossop Community & Priority Services NHS Trust
Neville Hanselle	Tameside & Glossop Community & Priority Services NHS Trust
David Hackney	Tameside & Glossop Community & Priority Services NHS Trust
Sue Bennett	Community Dementia Service C& PS Trust
Amanda Howarth	Community Dementia Service C& PS Trust
Steve Blezard	RIAT (Referral & Initial Assessment Team)
Caroline Eaton	RIAT (Referral & Initial Assessment Team)
Joyce Ratican	Assessment Team, Adult Services
Eddie Francis	Provider Team, Adult Services
John Dunne	Customer Services Unit - Quality Assurance
Teresa Jackson	Customer Services Unit - Advocacy - Older People
Fatima Atchia	Customer Services Unit - Black Communities Initiative
Ray Slamon	Customer Services Unit - Carers Centre
Dave Jones	Customer Services Unit
Karen Robinson	Assessment Team, Adult Services
Jude Quigley	Mental Health C&PS Trust
Louise Burgess	Mental Health C&PS Trust
Geoffrey Hamer	Carer
Norma Hulme	Carer
Stanley Mascarenhas	Carer
Lynn Ferguson	Carer
Margaret Brindley	Carer
Christine Boote	Carer
Annie Burns	Carer
Brenda Bradshaw	Carer
Margaret Bolger	Carer
Sheila Beswick	Carer

Facilitators:

Penny Banks	Carers Impact
Mike Hatch	Carers Impact

Appendix 2: References

1. **In on the Act? Social Services' experience of the first year of the Carers Act**
   Carers National Association / ADSS October 1997

2. **Still Battling? The Carers Act one year on**
   Carers National Association June 1997

3. **Carers Impact Project in Southwark: Report on the focus groups and interviews conducted with Carers April - June 1997**
   J Unell & H Bagshaw Carers Impact, King's Fund 1997

4. **Carers Impact: How do we know when we've got there? Improving support to carers. Report of the first year's work of Carers Impact**
   P Banks Carers Impact, King's Fund 1997

5. **Putting the Carers Act into Practice: Report of a workshop held on 26 September at the King's Fund**
   Carers Impact, King's Fund 1997 (includes references to current research)

6. **Access to Assessment. Perspectives of practitioners, disabled people and carers.**
   A Davis, K Ellis, K Rummery. Community Care / Joseph Rowntree, Policy Press 1997