

CARERS Northern Ireland

Involving and consulting carers

A guide to giving carers an effective voice

Why this guide?

What is carer involvement?

It is active participation by carers as equal partners in the planning, monitoring and development of the public services that affect their lives. Carers, like users of services, need to be involved at all levels, from individual assessments and care planning to reviews of government policy on community care.

The journey so far

The idea for this short guide came out of the process of drawing together a Carers Manifesto for Northern Ireland. With backing from the Prudential Carers Awareness Fund, Carers Northern Ireland consulted with a wide range of individuals and groups during 1999 to produce a Manifesto setting out carers' policy priorities.

The last stage of the process was a series of workshops at a conference in November called '*Giving Carers an Effective Voice*'. These explored how carers could get more effectively involved with professionals and institutions in order to influence public policies and services. So much valuable experience and advice came out of the day that we felt that the key suggestions should be written up and shared with a wider audience.

The guide starts by offering an insight for both carers and professionals on how to improve communication on a one-to-one basis. It highlights carers' views and experiences of consultation by and with statutory organisations, and explores what carers and carers groups can do to support the processes. Everything in this booklet is based on the ideas and words used by local carers and other participants on the day.

Who is this guide for?

- For **professionals** who want to improve their practice by being more open to carers' needs and to their expertise.
- For **carers** who want to be more confident and proactive in their interactions with health and social services.
- For **carers groups and other voluntary organisations** that want to support and empower carers.
- For **planners** who want to make sure that they develop the services people really need and target those services most effectively.
- It will be particularly useful for **GPs and others in primary care teams** and commissioning groups who are dipping their toes into the unfamiliar waters of carer involvement for the first time.

Ways to involve carers

1. Patient participation groups
2. Satisfaction surveys
3. Questionnaires – to the general public, or to specific interest groups
4. Focus groups
5. ‘Citizens Juries’
6. Public meetings
7. Invite carers to speak at staff meetings or training sessions
8. Involve a range of carer and user representatives on planning groups
9. Regular ‘forum’ with voluntary and carer group representatives
10. Go out to existing groups to seek their views

A whole range of publications exist that describe these and other mechanisms for carers and user involvement, and that discuss the benefits of using them. For details of further reading and advice, contact the Carers Northern Ireland office.

Communicating with Carers

What helps?

‘Knowledge is power’. Carers need to know who to talk to, and what their rights are. They should prepare well, be well informed, be clear and concise in putting their points forward and know what outcome they want to achieve.

Support and encouragement makes a difference. This can come from simply meeting other carers and sharing experiences. For some carers, having a supportive companion along to a meeting can help them communicate with more confidence. Others need to be directed towards an independent advocate who can guide them through the system, or even speak for them.

There are three key areas where carers feel professionals can help:

- By being open with information, and honest about the restrictions on them
- Through demonstrating an open, empathic attitude which values the carer. Carers want to be able to communicate on an equal basis with someone who listens, and is committed to responding in some way to what they hear.
- Through working to develop mutual trust and respect

There are personal qualities that carers should try to cultivate also: patience and perseverance, good listening skills, honesty, self-esteem and assertiveness.

Good structures allow two-way communication. Carers should be able to get all the information they need to be active partners. They should have access to the people who actually make the decisions concerned, with face-to-face meetings where necessary. There must be clear ‘rights to redress’ if carers feel they have not been listened to properly.

What hinders?

The day-to-day pressures of caring. Lack of time is a factor, and some carers report that tiredness, depression, loss of confidence and lack of self-esteem lead to feeling helpless, and a tendency to give up if communication problems arise.

Previous bad experience of not being listened to or taken seriously is very off-putting. Some carers will need to be persuaded that their views really do count.

Getting the right information at the right time is hard, from getting answers to specific medical problems to finding out who has responsibility for a particular decision. Carers of people with mental health problems experience particular problems because of difficulties and caution around confidentiality.

A big problem is use of jargon – it's hard to communicate with someone if they don't speak the same language as you!

Carers are put off if they encounter unsympathetic or patronising attitudes. It is particularly frustrating if a professional does not acknowledge or value the role of carer. Sometimes carers concerns do not match professionals' own priorities.

There is an imbalance of power in carer/professional relationships. Carers feel very vulnerable, particularly if making complaints. Fear of being labelled 'trouble-maker' and of victimisation or retaliation (eg withdrawal of services) discourages many carers from raising issues of concern. Disturbingly, carers describe a number of examples where these fears turned out to be well founded.

Carers experience a range of emotions that can impact on communication, such as anger, guilt, frustration, inferiority, fear and despair. As a coping mechanism, and in order to have some sense of control, carers try to detach themselves, if possible, from the rawness of their emotions. However, for some, anger is a very powerful motivator. It can give carers the determination to persevere until a proper resolution is reached.

How carers defined 'consultation'

"Real consultation is...

" . . . seeking my opinion and involvement in the decision-making process."

" . . . a two-way process with follow-up and feedback within a short timeframe."

" . . . not just lipservice."

" . . . people coming together to discuss and give thought to future practice."

" . . . about achieving mutual understanding and an acceptable outcome. For this process to succeed, it must be equal, timely and genuine."

The key words for professionals are information, sensitivity and mutual respect.

The key message for carers is 'Get organised, get involved and expect to be respected!'

Essential elements of quality consultation

Before you start

- Don't bother consulting unless it will genuinely influence outcome.
- Inform and educate people about why they should get involved.
- Try to make all information clear and jargon-free

Systems and structures

- Set limits to participation. People may be scared off by having to make open-ended commitments.
- Have clear boundaries and terms of reference, with clear expectations of all participants
- Set up good systems for communication, with a named contact person.
- Ensure the public knows how to contact lay representatives outside of meetings.
- Use more than one mechanism for seeking views.
- Support user and carers groups in the community and go out to seek their views
- Start early enough to allow maximum participation – it will probably take longer than you think!

Involving carer representatives

- Have a range of carers involved, not just one token representative. This offers a range of perspectives, and also means your process will survive if individuals' caring responsibilities occasionally have to take precedence.
- Use widespread advertising to encourage people to come forward, don't just call on the people who have been involved before.
- Think about transport arrangements, timing and venue for meeting – will they be equally accessible to all?
- Avoid a 'top-down' approach. Everyone with an interest needs to be represented right from the start.
- Equal status for all participants is essential.

Supporting lay involvement

- Create opportunities to learn "the system" and relevant procedures.
- Provide all the information lay people need to participate on an equal footing.
- Offer training if required. Consider what training carers can offer the professionals, as well as the training carers may need.
- Encourage a genuine exchange of views and respect all contributions.
- Cover the costs of involvement eg travel costs, expenses for wider consultation by representatives. Offer to provide or pay for respite so carers can attend.

Not just a talking shop

- Share a realistic analysis of limitations (eg finance).
- Decision-makers should be involved directly in the process.
- There should be in-built review and monitoring, and clear lines of accountability.
- Feedback on results of the consultation needs to be widely disseminated.

Supporting Carer Involvement

Voluntary organisations and carers groups checklist;

Increase public knowledge and use of existing services

- do more awareness-raising exercises
- encourage carer involvement in your activities by offering transport, respite, training

Form partnerships with other voluntary and statutory organisations

- share information and resources for a common purpose
- promote advocacy services in other organisations
- speak with one voice through forums such as the Carers Network NI and working in partnership with organisations like Carers Northern Ireland

Empower carers through training and other events – build up their self confidence

Carers checklist

Speak up about how you feel without feeling guilty or afraid

- be prepared to put thoughts, ideas, suggestions and complaints in writing
- find out about assertiveness training if you think it may help you
- be well informed and well prepared (Carers UK and other groups can help)

Get together to have an effective voice

- encourage others to recognise themselves as carers
- join Carers UK or a local carers group - flex your collective muscle!
- it may be a little late to help you, but your involvement today will improve things for the carers of tomorrow

Be proactive rather than reactive. Be creative - look for solutions, not just problems.

Why wait to be asked? Strategies for carers

Getting/spreading information

1. Attend relevant conferences and seminars
2. Feed back informally/directly to health professionals
3. Feed comments through Carers Groups
4. Do some local research

Putting your case/lobbying

1. Individual & group lobbying through letter writing, petitions etc.
2. Talk to your District Councillor
3. Talk to your MP
4. Talk to your Assembly Member
5. Invite professionals and politicians to join you and listen
6. Demonstration/march
7. Attend or hold public meetings to express your views
8. Use local newspapers & other media

Contacts with other organisations

- Share experiences through Carers Groups
- Involve professionals/politicians who are carers

Organisations

- Join Carers Northern Ireland and other organisations representing carers
- Take part in Patient Participation Groups or Focus Groups
- Join your Health & Social Services Council
- Ensure community groups represent carers' interests
- Two way communication with voluntary organisations (e.g. CAB)

Procedures

- Use the complaints procedures if you have a problem with standards of service
- Check your Board's commissioning plan to see what they are doing for carers
- Have leaders who can represent your group (but don't leave it all up to one person!)
- Legal challenge – often resolves one situation, but may create a precedent
- Become a Lay Assessor
- Find out about primary care commissioning in your area.

Want to find out more?

There are a growing number of good practice guides, findings from pilot projects and reports on research into user and carer involvement. Three documents that Carers Northern Ireland has found particularly helpful are:

'Quality Standards: Consumer Involvement in Community Care Services'. Available from the Social Services Inspectorate, Castle Buildings, Upper Newtownards Road, Belfast BT4.

'User Involvement: A guide to developing effective user involvement strategies in the NHS'. Available (price £4) from the College of Health, 21 Old Ford Road, London E2 9PL.

'Consultation with carers in the North West of England.' Copies available from Carers Northern Ireland (cost £2).

A more detailed reading list is available from Carers Northern Ireland.

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