

CARERS Northern Ireland

Involving and consulting carers

A guide to giving carers an effective voice

About Carers Northern Ireland

Carers Northern Ireland is the voice of carers. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers Northern Ireland is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Why this guide?

This updated guide looks at how carers can get more effectively involved with

public service workers and organisations in order to influence public policies and services. It also offers advice for both carers and professionals on the best way of communicating with each other.

Changes have taken place in Northern Ireland since this guide was first produced in 2000. These include more emphasis on equality, a requirement that public bodies' policies should not have a negative impact on certain groups, including carers, and changes in how public services are to be delivered.

What is carer involvement?

It is carers taking part actively as equal partners at all levels. Carers, like users of services, need to be involved in the planning, monitoring, development and evaluation

of the public services that affect their lives. Full carers involvement should be about power sharing.

Who is this guide for?

For public service workers, in health, social services, housing, education, social security, and politicians, 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 dealings with the people who make decisions or provide 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.

Ways to involve carers

- Involve a range of carer and user representatives on planning groups
- Satisfaction surveys
- Questionnaires – to the general public, or to specific interest groups
- Focus Groups / Patient participation groups
- Hold carers open days, during Carers Rights Day or Carers Rights Week to promote your services to carers and talk to them informally
- Public meetings in places where carers are most likely to be, e.g. day centres, health centres, hospitals
- Invite carers to speak at staff meetings or training sessions
- Regular 'forum' with voluntary and carer group representatives
- Go out to existing groups to seek their views
- Consultation using the internet or email

Contact Carers Northern Ireland for further advice or for details of publications that describe these methods and the benefits of using them.

Communicating with carers

- What helps?

Action Points For Carers

“Knowledge is power”

Know who to talk to, and what your rights are. Prepare well, be well informed, be clear and concise in putting your points forward and know what outcome you want to achieve.

Get as much support and encouragement as you can. Meet with other carers and share experiences. Taking a supportive companion along to a meeting may help you communicate with more confidence. Get an independent advocate who can guide you through the system, or even speak for you.

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

Action Points For Professionals

- Be open with information, and honest about any restrictions on involvement
- Show an open, empathetic 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.
- Work to develop mutual trust and respect

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.

Communicating with carers

- 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.

Be aware that some carers may be socially excluded in other ways, they may have a dual role i.e. although carers, they may themselves have a disability, or come from a black minority ethnic background and may experience additional barriers, such as language or access to services.

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”

“... open, inclusive and informed”

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

“ . . . not just lip service”

“... meeting a need to feel I am being listened to, valued and appreciated”

“ . . . 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!”

Professionals: 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.
Make sure 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 views, and also means your process will survive if individuals' caring responsibilities occasionally have to take priority.

- 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.
- Travel expenses/alternative care costs to be paid promptly.
- Take into account opening and closing times of the day centres and paid care worker arrangements.
- Engage with specialist voluntary agencies, such as Disability Action, NICEM, CoSo or statutory Equality/Good Relations Officers.

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 e.g. 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.
Ensure feedback and report back on any action taken to those consulted.

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 local forums or working in partnership with organisations like Carers Northern Ireland. Carers who are involved with local consultations and campaigns can get additional support and help by joining Carers UK Equal Partners project. For more information see www.carersuk.org/equalpartners.

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/ communication training if you think it may help you
- be well informed and well prepared Carers Northern Ireland and other groups can help

Get together to have an effective voice

- encourage others to recognise themselves as carers
- join Carers Northern Ireland or a local carers group - flex your collective muscle!
- 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

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

Putting Your Case/Lobbying

Individual & group lobbying through letter writing, petitions etc.

Talk to your district councillor

Talk to your MP

Talk to your Assembly Member

Invite professionals and politicians to join you and listen

Demonstration / march

Attend or hold public meetings to express your views

Use local newspapers & other media

Use your local community planning process to get your voice heard

Contact With Other Carers

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

Use the Patient and Client Council

Ensure community groups represent carers' interests

Set up two way information sharing 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.

Where can I 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 have found particularly helpful are:

'Making user involvement work: supporting service user networking and knowledge'

Joseph Rowntree Foundation,

tel 01904 615905

email info@jrf.org.uk

'Working together: Carer participation in

England, Wales and Northern Ireland' Social Care Institute for Excellence, Goldings House, 2 Hay's Lane, London SE1 2HB,

tel 020 7089 6840

fax 020 7089 6841

textphone 020 7089 6893

email www.scie.org.uk

'Quality Standards: Consumer Involvement in Community Care Services'

Available from the Social Services Inspectorate, Castle Buildings, Upper Newtownards Road, Belfast BT4 3

For further information, contact:

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