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Consultation with Carers Good Practice Guide

Executive Summary

We hope it is now widely accepted that carers have a right to be consulted about the services and decisions which affect them. We believe that such consultation is likely to lead to better decision-making by service providers, planners and commissioners.

The Government's intentions for consultation and involvement of carers were laid out clearly in the National Strategy for Carers¹:

“carers should be involved in planning and providing services”

So, consultation with carers should be seen as a 'MUST DO', within the expanded levels of public and user consultation now expected of public sector service providers.

The amount of consultation with carers has been increasing but we found many concerns about the quality of consultation with carers. Carers Centres told us that some of the carers they were in contact with have grown ambivalent and even cynical about consultation and

involvement processes with statutory service providers. The reason given for this was that those carers who had experienced consultation and involvement with statutory service providers too often found the experience to be a negative one.

Recent research in Scotland asked carers whether the agencies consulting them followed the Government's recommended good practice principles. What emerged in many areas was a picture of “weak or indifferent practice” where adherence and commitment to good consultation principles “were the exception rather than the rule”².

Poor or indifferent practices in consultation include such things as not taking account of the pressures and strains typical in carers lives when setting the times and dates of meetings. The principle of giving prompt feedback to carers after consulting with them is also widely disregarded by service providers, despite many carers feeling that this is the most important principle of good practice in consultation.

Background to the project

The good practice points in this guide come mainly from the *Carers Speak Out* Project, supported by Barclays, which was undertaken by The Princess Royal Trust for Carers in the first half of 2002.

The project included running one national and eleven regional consultation events. These events attracted an audience of over 1,400 carers, professionals and decision-makers. In planning their events, PRTC Carers Centres were asked to identify issues and good practice in consultation and to try out different or creative ideas in consultation. The results of that work have informed this guide.

The *Carers Speak Out* project has demonstrated that it is possible to do consultation well and that when it is done well, carers appreciate this and are only too willing to remain involved. We hope that this guide can make a positive and practical contribution to others 'doing it well'.

¹ Caring about Carers – A National Strategy for Carers, HM Government, February 1999.

² Joint Futures for Carers: Making Local Partnerships Work, Coalition of Carers in Scotland, 2002

Checklist for planning and running a consultation event

Planning an event

- Leave plenty of time to plan and advertise the event. If possible give 12 weeks notice of the date. Carers will then need at least 6 weeks notice to make arrangements for alternative care and transport.
- Involve carers in planning the event or talk to carers about what issues to include in the programme.
- Start later and finish earlier to fit in with the needs and difficulties of carers
- Planning the timetable is important. Do not overfill it. Make sure carers get the chance to participate and make their input. Leave plenty of time for questions and contributions from carers. If needed, cut down the time taken for presentations or talks by the principal speakers.
- Build in extra minutes between sessions in the timetable to give people time to move between rooms. Aim for an informal and relaxed atmosphere.
- If a carer's representative is involved in planning the event, consider including a personal message from them in the invitation.

- Think about contacting carers who may not normally attend events or who do not think of themselves as carers. Advertise the consultation widely to attract these 'hidden' carers. Use local press and radio.
- Provide quality information to carers, in the formats or languages they need.
- Send information well in advance of the event (at least one and preferably three weeks in advance). This should include directions, a timetable, what results you want from the consultation, background reading or questions/facts to help carers focus on the issues to be discussed.
- Plan a run-through of the event with all those involved.
- Ensure that the venue staff understand the aims of the event and the importance of making sure that carers feel valued and well looked after.

Picking a suitable venue

- Choose a central location, convenient for public transport.
- Ensure the venue has wheelchair access, hearing loops and clear signs in large print.
- Rooms should be spacious and

welcoming, with good acoustics. Check that all rooms used for discussions in large and small groups will be suitable. Check that the layout of the room will not intimidate carers.

- In rural areas, consider taking the consultation out to local places that carers can get to more easily and lay on transport for them.
- Be sensitive to cultural differences which may affect food and other activities.

Supporting carers to attend

- You must offer to provide or pay for alternative care for the person cared for by the carer. You must offer to reimburse expenses for other costs incurred by carers attending e.g. childcare costs.
- You could pay for fares or lay on transport such as taxis or minibuses, direct to the venue, for all those carers who need it. Laying on transport will save carers time.
- When meeting carers' expenses consider ordering tickets needed for train or other transport, paying for taxis, meeting care costs directly or offering vouchers. This will ensure that carers do not run into problems

- with benefits.
- Plan support for carers who use community languages. Have event materials available in appropriate languages. Before the event, have staff that speak community languages and have knowledge about local communities contact carers to explain the event and deal with any questions.
 - If needed by carers, offer translation services and run workshops in community languages.

The consultation event and feedback afterwards

- Start the consultation by reporting on how any past consultations have had an effect on services for carers.
- Have relevant professionals around throughout the day to listen to carers.
- Get decision-making managers or politicians there to listen to carers and to answer questions on policy or strategy. Meeting carers face to face is more likely to influence their thinking.
- Involve managers from any new health and social care structures and have them explain their new structures and any changes to services. Get them to listen to carers input.

- Run workshops and discussion groups effectively by allowing sufficient time and being clear about the focus and structure. Give carers enough information and time before the session to consider what they want to say. Have a handout with the information and questions.
- Allow enough time in the discussion sessions for carers to express views. Don't let other sessions overrun and eat into the discussion time.
- In discussion groups, plan seating to allow all carers the same chance to talk and be listened to, for example, at round tables. Plan how to record points made by carers and conclusions reached. Focus on ideas for solutions as well as problems.
- Build in ways for carers to add to the discussion by writing a thought or idea on a note or card, in case they missed a chance to speak.
- If feedback is to be made after the discussion, have a carer or carers do this, with support from event organisers.
- Stick to the timetable. Have the

event chaired by someone who makes sure that sessions finish on time.

- Getting feedback is a key concern of carers. Provide feedback promptly after the consultation event. Make links between carers views and local/national policy.

Additional ideas to make a consultation event enjoyable for carers

- Carers are giving up precious free time to attend your consultation event. You can recognise this by finding ways to make the event enjoyable for carers as well as productive for you.
- If offering lunch have a good standard of food in attractive surroundings. Have music in the lunch break.
- Allow carers time to socialise.
- If time allows, consider putting on extra sessions with fun or informative activities, allowing carers to enjoy experiences such as alternative therapies or to gain new skills.
- Consider using a drama performance to get a message across as an alternative to presentations or speeches.

General principles for successful consultation

Successful agencies will:

- **Be committed to the process**

Your organisation should be genuinely committed to the consultation process. You should be undertaking the consultation because you believe that carers have a right to be consulted, and that consulting them will contribute positively to decisions about the development of services. You must also be able and prepared to undertake the consultation properly and thoroughly. If your organisation is not genuinely committed to the consultation, if there is no real opportunity for affecting outcomes, or if there are insufficient resources to do it well, it is better not to consult at all.

- **Recognise the distinctive circumstances of carers**

You have to recognise that carers have particular difficulties in attending anything, precisely because they are carers. Consulting with carers requires a different approach.

It will be more of an effort for a carer to participate in the consultation than it is for those organising their participation. Carers deserve to be treated with respect and to have some recognition of the fact that they are giving up free time which is already precious to them.

- **Be clear what the consultation is about (and what it is not about)**

You need to be clear so that you choose the best method and approach and so that carers can understand what you are consulting about. Check also that carers have not been consulted locally before about that issue or service development.

Don't ask general questions about carers' views on particular services unless you want their views on all aspects of those services and the gaps in services as well. You can either be specific about the proposal you are consulting on or you can ask

for carers' own ideas about what types of service or support would help them.

- **Always provide prompt feedback, and be clear about outcomes and timescales**

Be as prompt as possible with feedback about the consultation. Inform participants about the process and the timescales for change. Also inform carers when the changes actually happen on the ground. Only give a timescale for change on which you can actually deliver.

- **Avoid jargon and don't assume carers have specialist knowledge**

Don't use jargon or abbreviations in your consultation – get someone from outside to check your material beforehand. If you assume carers have specialist knowledge, you may make them feel excluded and reduce the effectiveness of the consultation.



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