

Exploring ways for staff to consult people with dementia about services

Previous research has demonstrated that, given the right support, individuals with dementia can express opinions about services. However, staff need help with identifying and using opportunities for meaningful consultation. This study by Kate Allan explored how staff can encourage people with dementia to express their views and preferences in the course of day-to-day practice. The focus was on the process of undertaking service user consultation with people with dementia. The study found that:

- f** A range of consultation approaches was effective for some individuals at some times. These took both verbal and non-verbal forms. Individual people responded variably to particular approaches at different times and in different circumstances.
- f** Identifying starting points for consultation required careful consideration of the person's strengths and needs regarding communication, their background and interests, and apparent feelings about aspects of the service. The kind of relationship they had with members of staff was another important factor.
- f** Resources such as pictures, word cards and objects proved helpful for stimulating conversation and interaction for some people. These needed to be carefully chosen, again with the person's background and current interests in mind.
- f** Providing opportunities for people to talk about services in an indirect way, for example speculating on what another person's opinions might be, usually worked better than asking people direct questions.
- f** It was important to help staff to recognise their existing skills and knowledge and to enhance their confidence. This was achieved by encouraging them to talk about their experiences, ideas and feelings regarding communication. This pointed to the need to incorporate more time for reflection and discussion within the daily routine.
- f** The researcher concludes that service settings are complex environments in which it is often difficult for staff to find opportunities to undertake communication and consultation work, and to follow through on plans. It is necessary both to address aspects of the organisation which act as barriers to communication, and also to support staff in utilising opportunities which present themselves spontaneously.

Background

Over the past decade there have been major changes in the way dementia as a condition is understood. It is now widely accepted that communication is fundamental to good care, and it is seen as essential that service providers consult people with dementia about their experiences and preferences regarding their care.

This study set out to explore how staff can encourage people with dementia to express their view of services within the constraints and complexities of normal care settings. The focus was on the process of undertaking service user consultation work, rather than attempting to gather people's opinions about care.

Thinking about these issues is at an early stage. This work was speculative and exploratory. The findings should be interpreted in that light.

Embracing individuality

Dementia affects different people in different ways and does not obscure the individual character of the person affected. Given this variability, the diversity of situations in which individuals find themselves, and the range and complexity of services, efforts to consult users about their preferences and needs had to be developed on an individual basis.

This meant taking the background, personality and current interests of the person into account. Consideration had to be given to individuals' strengths, needs and preferences regarding ways of communicating, and what circumstances would be most favourable to these.

Developing approaches to consultation also meant considering the particular character of the person's relationship with the services they were using. The kind of relationships service users had with individual care practitioners was also an issue.

As well as being an important aspect of research, the issue of consent is central to the practice of involving the person in their care. A novel consent procedure, which attempted to keep the individual at the centre, was used in the study.

Approaches tried by staff

Consultation work can be approached in many ways. For some it took the form of a verbal exchange in the course of intimate care, or during other activities such as trips out of the service setting or recreational pursuits such as singing, dancing and watching television. Other staff used pictures or other visual stimuli as a focus for more extended conversations or

interaction. Staff were often surprised by how much was expressed at these times.

Some practitioners focused on non-verbal approaches to consultation. They often started by observing non-verbal reactions and modifying an activity or routine accordingly. Given the subtlety and largely unconscious nature of much non-verbal communication, this proved challenging. However, once they started thinking about these aspects of expression and interaction, staff became fascinated with what they noticed and learned.

The responses of the participants with dementia to the approaches tried varied, reflecting individuals' differences as people and their different experiences of living with dementia. However, as a general observation, indirect approaches which allowed the service user the maximum degree of control over what was spoken about, and in what way, seemed to be the most effective, for example, rather than asking direct questions about someone's opinions, showing them a picture of another person with whom they might identify, and inviting them to speculate on what they might think or feel about aspects of a service.

Whatever was done, it was crucial that the emphasis was on providing opportunities for the person to express themselves, rather than adhering to a specific procedure or technique.

Practitioners' perceptions of their own role

Many of the staff who participated in the project initially expressed apprehension or doubt about their ability to contribute. They were not sure if they had the right knowledge or skills, even when it was evident that they were able to communicate successfully with service users. One practitioner said:

"I was very nervous and unsure about where to start and about my own capabilities."

Throughout the work, attention was given to helping staff to identify the things they did which were special and important, and boosting their confidence to try out new things.

The role of reflection and documentation

The project highlighted the importance of providing opportunities for staff to reflect on and talk about their experiences. It was often only once a practitioner had tried something out and then had

the chance to talk about what had happened that new insights and ideas for developing the work emerged.

The pivotal role of reflection time was particularly evident when small groups of staff were able to come together to talk about what they were doing. There were many occasions when the researcher observed staff sharing stories about incidents, ideas about the meaning of words and actions, and feelings about individuals and relationships. Staff enjoyed and valued these times, which helped them to develop their understanding of the work and their own part in it, and to learn more about their colleagues and how they functioned as a team. One member of staff said about these sessions:

"Often you remembered things when we were all together in discussion."

Many staff kept written notes about their work over and above any usual requirements. Although this was always an effort, many of those who managed it commented on how helpful it was. It seemed to serve several functions:

- writing was another way of reflecting on work undertaken;
- the act of writing about initiatives probably helped to fix details and reflections in the practitioners' minds;
- it was a reminder to staff and promoted continuity, especially if there had been a break in time between initiatives;
- where other staff had access to notes, they served as a form of communication and sometimes a stimulus to the sharing of experiences and insights.

In addition, many staff made audio recordings of their conversations with participants. Almost all of the practitioners initially found the prospect of recording themselves speaking to other people daunting, but after discussing their feelings and the potential benefits and learning about others' experiences, they were willing to try it out. Having overcome their apprehension, most found this practice extremely helpful. It highlighted both the complexity and depth of what was talked about. They also learned a great deal about their own communication style and that of the other person. One practitioner said:

"I think it is an excellent way to communicate on a one-to-one basis, and you do actually forget the tape recorder is on and relax very easily."

Facing the challenges

There were often difficulties in keeping to planned arrangements for communication and consultation due to a range of factors which characterise care settings, particularly residential services. These included day-to-day changes in staffing arrangements, fluctuations in the well-being and needs of service users, whether or not participants wished to undertake work for the project at any one time, variations in the energy of staff, and so on.

Attention to the practical constraints of undertaking planned work revealed that even in residential services the amount of time that staff have to spend with an individual over the course of, say, a week is very restricted. This is particularly the case for part-time staff.

Working closely with people who are experiencing such profound changes in their lives as those with dementia is personally extremely demanding. For staff to provide high quality care they needed appropriate support, such as regular opportunities to talk about what was happening and how they felt about it. More specifically, exploring ways of consulting service users about their needs is a complex activity, and again staff need to be supported both in generating ideas and in reflecting on their efforts. The potential for consultation work to touch on personal issues for staff should also be borne in mind.

The place of consultation within care

The multi-faceted and variable situations in which people with dementia find themselves mean that consultation needs to become an integral and ongoing part of what happens from day to day and week to week if it is to be effective.

Embracing this could seem a daunting objective. However, although it did in some senses constitute more work for staff, when a 'breakthrough' was made - perhaps an occasion when a new idea was communicated or when familiar words or actions were understood in a new way - practitioners found this exciting and rewarding. It seemed to reinforce their sense of meaning in the importance of what they do. One member of staff said:

"You have a better understanding with the client and now have built a better relationship with them."

Conclusions for policy and practice

This study demonstrated that it is possible for staff in busy service settings to undertake meaningful consultation work with people with dementia, even those who have significant difficulties in expressing their ideas, needs and preferences.

Staff had a natural interest in the subject of communication. Finding ways to support them in enhancing and deepening communication with service users has the potential to transform their understanding of their role, the people for whom they care and the nature of dementia as a condition.

However, tendencies on the part of staff to underestimate their own skills and knowledge, and some features of the ways that services are organised, readily combined to constrain the potential for communication and consultation to take its proper place.

The researcher suggests that ways forward include:

- Reinforcing services' commitment to the centrality of communication throughout care practice;
- Helping staff to become more aware of the skills and knowledge they already have, and through enhanced self-esteem and confidence encouraging them to develop their resources further;
- Making a greater commitment to supporting staff in reflecting on their experience of working and communicating with people with dementia;
- Subjecting a range of organisational features of services to scrutiny in terms of how they affect communication and consultation practice.

About the study

The researcher worked with 40 practitioners (most of whom were unqualified) in 10 services (day, residential and long-term nursing care, and also a counselling service) in Scotland and England. A total of 31 people with dementia took part in the study. A wide range of communication issues were represented within this group. The fieldwork phase in some of the services lasted 10 months. In others, it was as short as 6 weeks. Work took an individualised and developmental form, and attention was paid to the range of factors which affected the course and progression of the work.

How to get further information

The full report, **Communication and consultation: Exploring ways for staff to involve people with dementia in developing services** by Kate Allan, is published for the Foundation by The Policy Press (ISBN 1 86134 318 3, price £16.95).