

User involvement and the seriously ill

User involvement has become an important part of the aims of health policy. But how realistic is the concept and do all users want to be involved? This research brings the voices of people with serious illness, and those caring for them, into the debate about how far health and social care services can reflect their views. Interviews revealed:

f People tended to take 'each day at a time' and were reluctant to anticipate or talk about possible future needs.

f The seriously ill will be few in number in any locality. But their needs may be great. This may leave them at a disadvantage: their wishes about the distribution of health and social care resources may be very different from those of the broader local population.

f Many people did not want to associate themselves publicly with their illness and or join national or local groups or associations. This level of 'invisibility' within the community could allow policy-makers and planners to sideline those who are most ill. Low levels of involvement also raise questions about how representative organisations are when 'speaking for' people with a certain illness.

f The needs of ill people and their carers may often conflict. Carers were often more keen to meet others for support and to find out information; this could mean organisations being dominated by carers' agendas.

f People with serious or terminal illnesses need services from a range of agencies. Different agencies have their own approaches and perspectives on both the need to consult and the means of consultation. From the point of view of service users, there is no clear route for consultation. There is also a potential for conflict between public participation and user involvement.

f The researchers conclude that practical, emotional and conceptual barriers to involvement should act as a spur to imaginative thinking rather than an excuse for inaction. However, it needs to be recognised that people living with serious illness or approaching the end of their lives may have other agendas and more pressing concerns and therefore may actively choose not to take part in user involvement.

Background

This study sought to understand the scope for user involvement for people with a serious illness. The researchers considered how user involvement might be seen from the bottom up, and its possible place in an individual's life, rather than from the top down, as a policy initiative.

The research addresses three principal areas:

- experiences of illness
- the meaning of user involvement
- the policy context

It is based on interviews with people with multiple sclerosis (MS), motor neurone disease (MND) or cystic fibrosis (CF), and with their service providers and carers.

The experience of illness

Living with uncertainty

Uncertainty is one of the most difficult aspects of illness to cope with for all three groups.

"Being well with cystic fibrosis can be almost as damaging mentally as being very ill with cystic fibrosis. You are told about this horrendous disease. I used to grow up thinking I probably wouldn't be here by the age of twenty. Yet, you might be really well with it and you think, 'Well, why am I not ill?' You think, 'Well, maybe it can happen tomorrow' or 'When is something going to happen?'. It plays on your mind almost as much if you are very well as if you are very ill because, if you are very ill, you know." (Person with CF)

If things are uncertain, room for hope remains, although the grounds for hope vary between different illnesses. People gave vivid accounts of the stress of living with alternating hope and disappointment - improvements in health followed by relapses, over-optimistic reports of new drugs/treatments, symptoms recurring despite treatment and so on.

Uncertainty, hope and the experience of disappointment do not necessarily preclude user involvement. But they do frame the experience of the ill person and their carers. Not least, they make many demands on a person's time and emotional energy, with a consequent impact on the space for other things.

Living 'a day at a time'

People tended to take 'each day at a time' and were reluctant to anticipate or talk about possible future needs.

"I didn't really want to know to what extent the disease could develop. I needed to be able to cope with it as it developed and not be worrying about what might or might not happen two years down the road." (Person with MND)

"You have to take each day at a time because you can't look too far ahead because it would just frighten you to death." (Mother of daughter with CF who had decided against an organ transplant)

"I used to (look ahead) but now I don't. I haven't done that in a long time. Now I try things day by day. I don't think you can plan for the future, not now I'm at this stage of things. It's very hard work keeping going day by day at times." (Person with MS)

Social invisibility and exclusion

There are many reasons why people with serious and potentially life-limiting illness become socially 'invisible':

- People who are ill tend to live outside the conventional structures, but some also choose not to meet with others in the same situation.

"I have got to the stage now where I don't want to go to the (MS) Society because I am the worst... ." (Person with MS)

"When he was well he didn't like seeing people who were worse than him. Then, when he got worse, he got worse quickly and was not able to meet. He didn't get help really from others; he couldn't take part in anything. It was a huge effort in the end." (Carer of person with MS)

- It is not surprising that people attempt to maintain a 'normal' lifestyle for as long as possible.

"My advice: plan a normal life. Normal people die at all ages every day. Yes, as CF individuals, we are at a disadvantage but let's not handicap ourselves with an attitude to boot." (Person with CF)

- Many people do not want to associate themselves publicly with their illness and do not join national or local groups or associations.

"If their children are not ill, both parents and children want to get on with living a normal life and to dissociate themselves from anything to do with cystic fibrosis." (Specialist Nurse)

User involvement

Information and organisation

One cannot assume that information will be generally welcome, let alone sought after. Individuals develop their own strategies for managing the flow of information: at times they may seek it out; at other times they might avoid it or bracket it off in a discrete and contained area. There are different needs for information at different stages of illness and the needs of people with the illness and their carers can conflict.

People expressed a wide range of fears: of confrontation with one's own mortality, a fear of the illness worsening, of losing friends, of forming relationships with people who might die, of being seen as unwelcome and unhelpful by those with the same diagnosis but less developed symptoms, and so on. These fears varied according to the individual's circumstances, particularly the stage of illness. However, they were less significant for carers. Carers were often more keen to meet others for support and to find out information; this could mean organisations were dominated by carers' agendas.

Organisations for people with MS, MND and CF have a relatively low level of active membership, both nationally and in local branches. This is a characteristic they share with many groups. Low levels of involvement raise questions about the representativeness, and hence the legitimacy, of organisations when they seek to act as proxy voices for the needs of people with a certain condition.

The relationships with professionals

There is a danger that user involvement simply ties people into systems that remain essentially unaffected:

- Professionals may only welcome user involvement when it conforms to what they want to hear.

"I've been to a 'User Network' meeting and a counsellor gets up and says how they are going to bear in mind the feelings of the people they are looking after. But there is actually no difference." (Person with MS)

- Many people experience the community in which they live as hostile and dangerous. It is not the place they would choose to look for support. The

relationship with the professional is sometimes more comfortable.

"I find socially that my old mates won't say hello to me, and not talk to me any more, either because they don't know what to say or that they are shocked at seeing me, how I am." (Person with MND)

- Trends towards shifting responsibility from the state to the individual may distract attention away from the social context of illness, and exclude the socially disadvantaged from adequate care.

Minority needs

Planning and policy-making based on needs assessment across populations may disadvantage people with less common illnesses. A level of invisibility within the community can allow policy-makers and planners to sideline those who are most ill.

Official consultation

A range of different agencies - including health and social services, independent and voluntary providers - provide the services which people with serious or terminal illnesses are likely to need. These services may not be identified as specifically for people with a particular illness or for people in the terminal stage of illness.

Consultations with users of social service agencies may be dominated by the largest or best-organised groups and, in the main, will reflect the needs of those with a largely stable physical condition.

By contrast, health services for people who are terminally ill are usually separately identified. Palliative care services tend to be seen by health service providers as exclusive to people who are in the late stages of terminal illness, and such services are dominated by provision for people with cancer.

Different agencies have their own approaches and perspectives on both the need to consult and the means of consultation. From the point of view of service users or potential users, there is no clear route for consultation. This leaves room for confusion, duplication of effort and wasting the time and energy of people who may have little of both left.

"A social worker's help was offered at the time [the neurologist] was telling me this. I thought: 'Well, does he mean a counsellor or someone who is going to give me some encouragement?' But when it worked out, it seemed the social worker was coming to tell me all the benefits a disabled person could get." (Person with MND)

Conclusions for policy and practice

By retaining some degree of control over their dying and deaths, people are able to influence the legacies and memories they leave behind. The concept of user involvement, as interpreted for this study, includes giving people not only the opportunity to take control over the ends of their lives but also to extend this legacy by influencing services for others after they have died.

Problems arise where opportunity turns into obligation and user involvement comes to be seen as a condition of receipt of services and, more widely, of responsible citizenship. An expectation that people will co-operate in a programme of user involvement may then move from an agenda of empowerment to one of moral coercion. However, the difficulties of involvement can act as a spur to imaginative thinking, rather than an excuse for inaction.

A reluctance to talk about future needs may be an authentic choice; if so, it should be respected as such. Alternatively, such reluctance may stem from the fact that people are not currently given appropriate opportunities or because the issues are raised in ways which inhibit discussion. It may also be a consequence of unsatisfactory encounters with service providers in the past.

A major problem is how to engage people in discussion when:

- There is a general reluctance or inability to anticipate future needs for services;
- The numbers of people in any local population with a specific illness or condition is very low;
- Many people do not wish to associate with others who have the same diagnosis;
- There are differences in the agendas of people with an illness and with their carers.

Ways forward include:

- Encouraging a recognition that even when there is no cure there is still much that can be done;
- Recognising that there are communities of interest as well as geographic communities and that both need access to decision-makers and service providers;
- Generating discussion in a wider arena than single condition groups, through alliances or disability organisations;

- Recognising that the issues which concern this group straddle agency boundaries;
- Visiting people in their own homes or establishing some form of technological link-up through telephone or computer networks. The potential of the Internet here is considerable.

About the study

The researchers interviewed 23 seriously ill people and 22 carers. In addition, specialist workers and members of voluntary and self-help groups were interviewed, facilities visited and meetings and conferences attended.

The three illnesses encompassed by the study embrace chronic, progressive and terminal disease. They affect predominantly different age groups: CF is most common in youth, MS in adulthood and MND in older age. Overall, they affect men and women in similar numbers. They include a spread between the optimism about finding a cure associated with CF, a continuing sense of uncertainty about the course of illness progression of MS and the predominate, but not universal, remorseless decline with MND.

How to get further information

The full report, *Too ill to talk? User involvement and palliative care* by Neil Small and Penny Rhodes, is published by Routledge (price £15.99, ISBN 0 415 23317 8).