

How much do service users want to be involved in planning local mental health services?

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Most initiatives in the health service now include reference to user participation. This study found that a significant number of users of a Community Mental Health Team wanted to be more involved in planning services.

Service users are increasingly being encouraged to contribute to the planning of mental health services. The National Service Framework for Mental Health refers specifically to involvement of service users in planning and delivery of services, also the need to "develop effective mechanisms for service user and carer involvement to occur regularly" (DoH, 1999). Rose et al., (1998) demonstrated that people with "severe and enduring mental illness" could have a voice in decisions about the mental health services they receive. Viv Lindow has gone further in suggesting that service users design and run their own services (Lindow, 1999).

Our local services have involved service users for a number of years in planning new mental health developments and now have a policy of paying service users for their expertise and time. The Shropshire Primary Care Trust has appointed a user development worker tasked with training and encouraging service users to act as user consultants in a variety of areas including service planning. The development worker sits on the Directorate Management Team in addition to supporting the patients' council and running a regular focus group on the in-patient wards. This initiative has already succeeded in raising the profile of service users in contributing to the Trust's aims. Service user consultants also sit on the locality management groups, the Shropshire Partnership Board and the Telford and Wrekin Operational Management Group. In addition, the Department of Psychological Therapies in Shropshire has also begun to fund and support service users in carrying out their own research, and has for several years employed them as planning consultants and as consultants on interview panels (Long et al., 2000). The Department has worked alongside the Shelton Patients' Council in publishing research into the views of service users. (Goodwin et al., 1999).

We are a group of mental health workers and two service users from an urban Community Mental Health Team. Our aim with this survey was to ask service users whether they wanted to be more involved in planning mental health services in the area (North Shrewsbury) and, if so, in what ways.

Method

A questionnaire was sent to everybody receiving a service from North Shrewsbury Community Mental Health Team (172 people) and 12 members of the Shrewsbury System Survivors group. There were two questions:

1. Are you involved in the planning of the mental health services you receive? If no, please say why you think you are not.

2. Would you like to be more involved? If so, how would you like to do this? If no, please tell us why not.

The responses from service users were categorised using a content analysis. An independent researcher then used the suggested categories to reclassify the statements. There was an 80% agreement between the researchers on how the responses should be categorised.

Results

Fifty-seven people replied; a response rate of 36%.

Involvement in planning

Twenty-three respondents indicated they were involved in planning mental health services, 19 were not. The yes answers predominantly reflected the point of view of the individual's own particular care (22 replies), for example;

"Yes, my social worker and I discuss my next move - to get me outside more."

"Yes, in as much that I phone for a visit rather than prearranged."

Only one person answering "yes" looked more broadly at planning services in general;

"Yes, through the adult subgroup of the joint collaborative team".

Reasons for non-involvement

A range of reasons were given for non-involvement; some gave as their reason for not being involved their lack of knowledge, or lack of information made available to them as to how to do this (7 responses):

"No! Never asked."

"No. I have never been approached to be so."

"No - don't know how to be"

Others saw it as due to a personal deficiency in themselves, or because they didn't believe their role as a patient allowed it (5 responses):

"no, not sufficiently qualified or confident enough."

"no, because I am a patient."

or as due to a deficiency in the service, in not encouraging users to be involved (3 responses):

"Lack of interest by service providers."

"To a certain extent, but mostly no. I feel quite powerless and vulnerable (I am currently "stuck" on an acute ward in Shelton). It is very hard to 'stand up for yourself' when caught up in the mental health system."

"No - I think you are told who to see and it is a case of, take the treatment that's offered or go away."

One respondent said they did not want to be involved, and there were three answers that could not be clearly categorised.

Wanting more involvement in planning

Thirty-one respondents wanted to be more involved, compared to 14 who did not. Most of the positive responses were accompanied by direct suggestions for the service to change in some way, or ways in which the service could encourage user feedback (23 responses):

"Yes, I wish existing groups and services paid more attention to social/communication skills and friendship/relationship skills. Courses I have attended have been woefully brief. I have learned a lot through books, but I feel that others who have not made the effort are severely emotionally and socially impoverished. Also I have met other users with speech impediments who are not getting speech therapy. One of the people was recently sectioned after a crime they committed. I am convinced that with adequate social skills and speech therapy they would never have got into this appalling mess."

" Yes I would like to be able to choose my psychiatrist."

" Yes. Outside the hours of 9 - 5 very little support is available in the

community.

Even a phone-in support organisation would aid the services and be complementary. Illness is a 24 hour scene and when it strikes at night, is despairing."

" Yes. Mental health providers deal too much in practical activities and not enough with mind stimulation."

Some respondents requested more information from the service (5 responses):

"Yes. I think it is of paramount importance to give as much choice/control to the patient as possible, especially with respect to therapy/treatment."

"Yes. I would like to make a point concerning newly 'diagnosed' patients in that if GPs issued them with leaflets, etc. a lot of stigma could be eliminated at source and at an earlier point in time."

"Yes I would like to have things explained more before you start treatment - like what it can do for you and what it can't."

Others requested to be consulted more about what they wanted (4 responses):

"Yes - provided this did not involve attending meetings. Responding to written or telephone surveys or giving views via these media would be acceptable."

"Yes I would want to give feedback about how I feel there should be improvements to existing programmes and groups."

"Notification of events and possibly a group meeting for suggestions."

"By telling people about my experiences."

Two people specifically said they wanted to understand the nature of the problems and diagnosis that had brought them into contact with the services in the first place, and the remainder gave no specific suggestion but felt they would like to be more involved, for example,

"Yes - however I can be."

(Some people's answers fitted into more than one category.)

Reasons for not wanting more involvement

The reasons given for not wishing to be more involved were that the respondent thought things were all right as they were (9 responses):

“No. Because that is the only contact I wish to have and the way I want to keep it.”

“No. I am quite happy at the moment.”

That the person felt unable to cope with more involvement (4 replies):

“No I don't think I would be able to manage any more involvement at the moment.”

I'm finding it hard enough to cope with what I'm doing now.”

That there was no point in being more involved (1 response):

“No. The reason that I would not like to be more involved is that to do so would be continuing a pretence that national and local health authorities are actually sincere in improving standards and functioning, when in reality it is, as always, doing more with less.”

Discussion

In talking about whether they were involved in planning the mental health services they were currently in receipt of, most people referred to their own particular care. In contrast, when considering whether they would like to be more involved than they were, the majority seemed to be referring to ways of being involved more broadly. About half of the sample felt involved, and half said they would like to be more involved in planning mental health services, and gave various suggestions for how this might happen, including giving written feedback about their views and experiences, attending management meetings or running a seminar on psychosis. In addition there were a number of suggestions about how the services could be improved, for example, more information at GP surgeries and availability of telephone support out of hours.

There are a number of possible reasons for the response rate of only 36%. The majority of people may not after all have been interested in being involved in planning; people may not have expected their responses to be taken seriously, or perhaps some mental health difficulties or medication make it harder to concentrate or to feel motivated to fill in questionnaires. People may have felt disinclined to participate in the survey, having started to move on and away from services. Our study would nevertheless indicate that

there are a number of people who use the mental health services in the north of Shrewsbury who would like to be more involved in planning these services, on a variety of levels, and who, moreover, have their own ideas how to do this. This suggests that Community Mental Health Teams would benefit from welcoming this enthusiasm and develop ways of listening to and acting on users' suggestions and feedback in a variety of more regular ways, for example by meeting regularly with interested user representatives, by actively seeking their opinions and making it easy for users to give feedback. The Trust should explore the provision of literature in GP surgeries and should advertise the availability of telephone advice.

The lack of involvement some users experience in relation to their direct care is concerning as the Care Programme Approach is supposed to support such involvement. As one aspect of the Trust's ongoing audit of the CPA, service users need to be routinely asked about the degree to which they feel involved in care plans.

As noted above, the Trust already employs user consultants in a variety of ways. To date there has been no specific budget for these activities. At CMHT level there is little flexibility within budgets. Any organization taking the payment of user consultants seriously needs to budget for this. One of the authors, an ex-service user, is particularly concerned that users should not be involved in a tokenistic way, as has often been her experience in the past, but that their contributions should be given real value. This is sometimes very hard for professionals to do, however good their intentions. Organizations wishing to signal that these activities are not optional extras need to fund them.

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