Adult mental health services

Focusing on the views of users and carers

Mental health is one of three national priorities for the NHS in Scotland. The Scottish Office has recently published a Framework for mental health services[1] which emphasises the need for local agencies to involve people who use mental health services and their carers in:

- the development of mental health strategies
- service planning
- quality monitoring.

The Accounts Commission is undertaking a study of the planning and provision of adult mental health services. In the summer of 1997, we commissioned a number of user and carer focus groups in different locations in Scotland, and some meetings and individual interviews with people from minority ethnic groups. The aim of these groups and interviews was to help in developing an appropriate methodology for our wider consultation with users and carers which is planned for the coming year.

The Commission is grateful to all the people who participated in, and helped arrange, the groups and interviews. We believe the findings of this work are of relevance to all people working in the field of mental health, and usefully complement other work by national bodies such as the Scottish Needs Assessment Programme.[2] The key findings of the focus groups are summarised below and are expanded on in the main body of this bulletin.

- 'Consultation fatigue' is beginning to be felt by some service users and carers. Increasingly, there is a danger that they will be reluctant to take part in consultation exercises unless they see their involvement having an impact on services.

- There is a marked similarity between the priorities for attention highlighted by users and carers.

- Some of their major concerns have little or no resource implications. These include:
  - a more positive approach to involving and empowering users and carers
  - being treated with respect and as equal partners in their care
  - improving the availability of information about services, medications and their side effects, and mental illness itself.

- Users would like to see a further development of:
  - crisis services, including early interventions to prevent crises occurring
  - out of hours services
  - community services which are accessible and of high quality.

- Carers endorsed these views, and added the following priorities:
  - stronger emphasis on multi-disciplinary care
  - better support and information for carers.

These issues have been raised before. Whilst the principle of user and carer involvement in mental health services is accepted widely it is still not always observed in practice.[3] Over the coming year the Commission's auditors will be examining the extent to which statutory agencies are actively involving users and carers in service planning and delivery.

Introduction

Legislation, primarily the NHS and Community Care Act 1990 and, more recently, the Carers (Recognition and Services) Act 1995 has encouraged the active involvement of the public in all aspects of commissioning, delivering and evaluating health services. More specifically, the Framework for mental health services in Scotland emphasises the importance of involving people who use mental health services and their carers in the planning, evaluation and delivery of services.

The Accounts Commission is undertaking a study of the planning and provision of adult mental health services by NHS trusts, health boards and local authorities.

We commissioned the Consultation and Involvement Trust Scotland to facilitate four focus groups with users and carers, and hold meetings and individual interviews with people from minority ethnic groups for whom English is not their first language. The groups were held in different locations in Scotland to ensure that urban and rural perspectives were covered. Participants were given a list of issues compiled from a detailed literature review, and asked to:

• validate the issues as being of relevance to them

• add any others which they felt had been omitted

• prioritise them.

The views of the groups and individuals are presented in this bulletin, and will be used by local auditors in structuring their own consultation meetings with users and carers.

This is the second in a series of bulletins on adult mental health services. The first bulletin covered the distribution of NHS resources allocated to adult mental health services, and provided comparative information on staffing and bed numbers between NHS trusts.[4] The next bulletin will give the findings of the Commission's research into indicative costs of different mental health service models.

Service priorities for users

People who use mental health services have clear priorities. Some of these have limited resource implications, such as improvements in the way in which they are treated by professionals, and more widespread availability of information. Issues which will require either further investment in mental health services, or a redistribution of current resources, include the provision of more out-of-hours and crisis services; and a higher priority given to the development of accessible community services.

Users have been saying for some time that they *"…know what they want and need, have knowledge and expertise and need to be involved in designing services, both individually and collectively."[5]* Increasingly, professionals working in the field of mental health are recognising also the importance of user involvement, and that they have a duty to listen to and act upon users' points of view.[6]

The focus groups run on behalf of the Commission confirm the value of users to service planning. Participants in the groups were asked to prioritise their issues or concerns, which local auditors could pursue in more detail during their local consultation meetings. This establishment of key priorities will be of interest to all agencies involved in planning and providing adult mental health services.

Exhibits 1 and 2 outline the six shared priorities of people who live in rural and urban areas.

Exhibit 1: Improving the way in which current services are delivered

User involvement and empowerment in their own care

People should be involved in, and be able to make informed decisions about, their own care and treatment. They should be given the information and the opportunity to discuss service options.

Staff attitudes

Mental health staff (including GPs) should have up-to-date knowledge across the range of mental health and distress. Users are entitled to be treated with respect, and as equal partners in their care.

Availability of information

Comprehensive, accurate and up-to-date information should be freely available about community and hospital services provided by all agencies. People should also be given access to full information about medications and their side effects.

"I got no information on side effects … I didn't even know side effects existed"

Some improvements in the way in which current services are delivered can be achieved with minimal extra resources. That the issues covered in exhibit 1 were raised by participants in the focus groups suggests that they are not being addressed by all mental health services in Scotland.

Linked to this is the involvement of users in determining the desired outcomes of their care. Some work has already been carried out on developing user-derived outcome indicators, and establishing pilot projects to develop protocols.[7] The widespread implementation of this approach would go a long way towards empowering users in their own care.

Developing the range and quality of community services will require a detailed knowledge of existing resource use before decisions can be made about further investment, or a redistribution of current resources. This is discussed in more detail in Bulletin 1 of this series - *Patterns of NHS service provision.*

Exhibit 2: Service developments requiring resource re-distribution

Help at a time of crisis

Support and early interventions should be available to help prevent a crisis occurring. Prompt and appropriate action should be taken at times of crisis, including admission to hospital if necessary. Local short stay crisis centres providing a place of safety and support should be provided. This is of particular concern in rural areas where acute beds may be some distance away.

Access to services out-of-hours

Mental health problems do not fit neatly into a 9-5 service. There is a need for help, support and advice to be available at nights and week-ends.

Community care services

There are three key issues relating to community services: **availability, access and quality**. Users want:

• a range of community services

• equity of access to different types of services

• good quality services with consistency in standards of care.

"Who cares in the evenings and at weekends? … Everything closes after 5pm."

It is important that attention is paid to the *substance* of what users are saying. It is easy to assume that words have the same meaning for different stakeholders, whereas the opposite can be true. *"Words like 'crisis services' … are used without reflecting on the fact that they have completely different meanings to users and to professionals. Mental health professionals tend to see a crisis service as a rapid but otherwise traditional intervention; users see it as a non medical alternative, involving a place of refuge without the power imbalances and compulsion of traditional psychiatry."[8]*

This was evident in the Commission's recent data collection exercise where several NHS trusts cited the duty doctor system as a crisis service. While this may be one response, users are making it clear that they believe a comprehensive crisis service requires more than a hospital based response.

In asking for *equitable* access to a range of community services the focus group participants echo a stated aim of the NHS in Scotland.[9] The challenge to providers and commissioners of adult mental health services will be to develop increased community provision, of an acceptable standard, for the people who use adult mental health services.

"Support after discharge from hospital should be standard no matter where you live."

People who live in rural areas

In addition to the priorities listed in exhibits 1 and 2, people who live in rural areas have the following concerns (exhibit 3).

Exhibit 3: Further issues for people who live in rural areas

Co-ordinated care

There is a need for improved communications between all the individuals involved in a person's care including individuals, carers and all staff across professional groups and organisations (including the hospital and community interface).

Access to services

Some services are more difficult to access in rural areas. For example, intensive psychiatric care and occupational therapists and psychologists.

Transport

Not surprisingly, the availability of transport is an important consideration for people with mental health problems living in rural communities. This problem has been highlighted before in Scotland,[10] and should be considered as part of the planning process.

Reductions in services

There is significant concern that services may be reduced, without adequate thought given to the way they fit into the overall pattern of local provision. The two examples given were reductions in acute beds and insecure funding for valued voluntary projects.

Information on mental health problems

This should be freely available for users and carers. This is particularly important when mental health problems first occur.

Welfare rights advice and information

Greater provision is needed. Mental health problems can be made harder to cope with if, as is often the case, they are combined with financial difficulties.

Public awareness campaigns

There should be a greater emphasis on pro-active public awareness campaigns to 'de-stigmatise' mental health problems. Users were clear that they have a role to play in these campaigns.

"Transport is a big issue in a rural area."

Many of these service issues will be examined as part of the Commission's ongoing review of adult mental health services. The Commission's recent data collection exercise in NHS trusts (reported in bulletin 1 in this series) highlighted clear differences in the availability of particular services across Scotland, and we have recommended that, in line with the Framework document from The Scottish Office, health boards, local authorities and other planning partners should assess the level of need for adult mental health services. An essential part of this assessment will be consulting with people who use adult mental health services. For example, the Highland Users' Group has produced a number of valuable reports on different issues affecting local services. These are in a format which can be easily used by local commissioners to inform their decision making.

People who live in urban areas

In addition to the shared priorities listed in exhibits 1 and 2, people in urban areas have the following concerns (exhibit 4).

Exhibit 4: Further issues for people who live in urban areas

Access to independent advocacy services

Users recognise that advocacy is an important mechanism for enabling them to have access to information they need and to make informed choices about their own health care.

Easy access to second opinions

By raising this as a priority issue, it is clear that access to second opinions is not easy to obtain in some areas.

Single sex wards

The Government has made a commitment that single sex wards will be available in all specialties. Trusts should already be working towards this objective, and health boards should be monitoring progress.

Proper medical care

This should be available to all people with mental health problems:

*   treatment should not be denied in instances of self harm

*   physical illnesses should be treated and not put down to a person's mental health problems.

Community based psychiatric nurses (CPNs)

CPNs are crucial to the success of community care. Issues concerning their availability and training should be addressed by health commissioners in collaboration with NHS trusts.

The Scottish Office, in liaison with the Scottish Health Advisory Service (SHAS), has published a guide to good practice in developing advocacy schemes.[11] This stresses the importance of involving those who receive services in their own care. Health boards should be considering ways of implementing the recommendations contained within this guide.

Many of the points raised above are applicable to the delivery of all mental health and social care services. Underpinning them is the need to listen to, and 'hear', what people are saying about the services they receive, and to act upon that information at both an individual and a collective level.

People from minority ethnic groups

Two meetings were held with members of Chinese and Asian communities, in the languages of their choice. In addition, because the meeting with members of the Asian community was with women only, individual interviews were held with two Asian men. Participants in these meetings and interviews have similar concerns to those expressed within the focus groups. However, they raised some issues which are specific to minority ethnic groups, and these are given in exhibit 5. The major issue which concerns people from minority ethnic groups, whose first language is not English, is the way in which language barriers can prevent access to services.

Agencies working in areas with minority ethnic communities need to work with those communities in planning how best to deliver mental health services to meet their distinctive needs. [12] [13]

"If you don't understand my background, you won't be able to help."

Exhibit 5: Issues for people from minority ethnic groups

Knowing what help is available and how to access it

There appears to be a serious information gap for many people from minority ethnic groups. They feel that problems may have to reach crisis point before help is given. Community based minority ethnic projects are valued, and again there is concern about the security of funding for existing projects. Information should be available in languages other than English, and provided in a range of media. This includes information on medications and their side effects.

Language

Participants reported that people who do not speak English may be excluded from some services, or receive only a partial service. There is a lack of professionally trained interpreters, and bilingual staff, in primary and secondary health care and in social care agencies.

Understanding of cultural diversity

Mental health staff need a good understanding of the cultural background of users from minority ethnic communities. Without this it is possible that symptoms and reports can be misinterpreted, or not be recognised.

Confidentiality

Participants were clear that information should be completely confidential, as there is stigma attached to mental health problems in many communities. There should not be an assumption that family members can be used to interpret in all circumstances.

Carers' priorities

Carers share many of the same concerns as users, and are clearly prioritising users' needs over their own. However, it is important that their own needs are addressed separately.

Carers are key players in the provision of care in the community. Indeed they have been estimated to save £2.83 billion for mental health and social services in Britain.[14] This equates to approximately £280 million in Scotland. It is important, therefore, that both their contribution and personal needs are recognised by mental health professionals.

In order to find out what issues are important to carers, two focus groups were held. Exhibit 6 summarises the priority issues for carers. Those marked with an asterisk are the same as the priorities of participants in the user focus groups.

Range of community services*

Carers raised the importance of equity of access to 'essential' community services which are properly funded and of a good quality. This includes activities during the day, in the evenings and at weekends, and respite services.

Availability of crisis care*

'Crisis care' includes early interventions to help avoid a crisis. Carers also want appropriate and promptly provided care at times of crisis.

Multi-disciplinary care*

Carers stressed the need for improved communications between all the individuals involved in a person's care including:

• the person

• carers

• all staff across professional groups and organisations (including the hospital and community interface).

Public awareness programmes*

There should be a greater emphasis on pro-active public awareness campaigns to 'de-stigmatise' mental health problems.

Medical care*

Attention should be paid to the physical well being of people with mental health problems. In particular, physical illnesses should not be dismissed as mental health problems.

Physical environment

The physical environment of all places where care is provided should be of a good quality.

Treatment evaluation*

Users should be given treatment and medication options. They should also be offered the most effective treatments, rather than the cheapest. This point is linked with the availability of information for both carers and users.

Arrangements for discharge and leave of absence from hospital

Raising this as a priority suggests that these arrangements are not satisfactory in all psychiatric hospitals in Scotland. The Mental Welfare Commission and the Scottish Health Advisory Service play an important role in monitoring the effectiveness of local arrangements. However, trusts must take the main responsibility for ensuring that their discharge planning arrangements enable users to receive adequate support in the community.

GP awareness of mental health issues*

As key providers in mental health services, GPs should have a good awareness, understanding and knowledge of mental health issues. This may require health boards and trusts to offer top-up training sessions enabling GPs to keep pace with developments.

Support for carers

Carers need support and assistance, ranging from funding to set up support groups through to education for carers.

Involvement of carers

Often carers are central to the success of a care plan, and carers feel strongly that they should be treated as partners in care. They want informed involvement in care planning, including discharge planning and when changes are proposed to the care plan.

Information for carers*

Carers have the same need for information as users. This includes, amongst others, up-to-date information on:

• the specific mental illness, and prognosis

• treatment options

• medication and side effects

• the Mental Health Act.

"Somewhere in the system there should be someone there for carers."

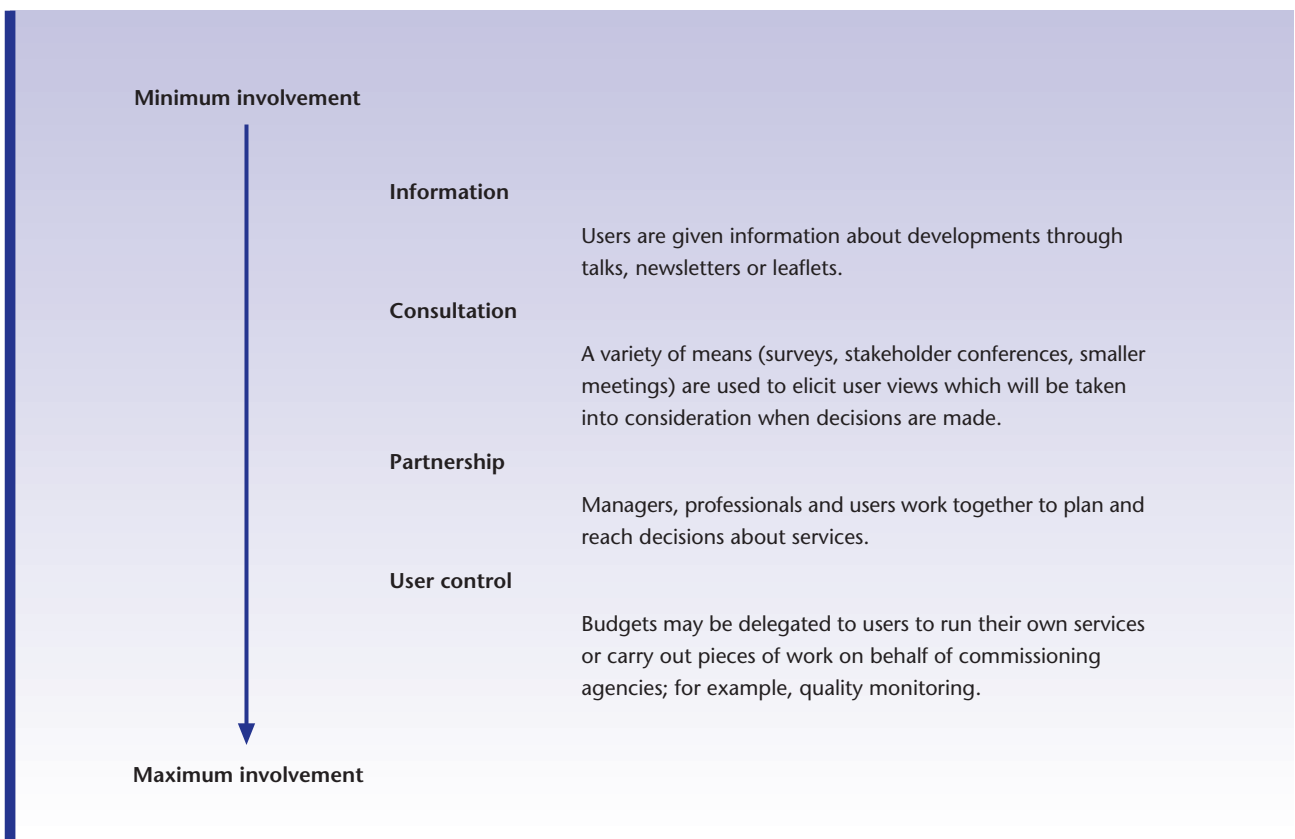*"Things have to come to a crisis before you are taken seriously."*

Local action

Commissioners and providers of adult mental health services are required to consult locally with people who receive mental health services and their carers. The Scottish Users' Network (SUN) is researching the extent to which users have been consulted in the development of community care plans. SUN will be reporting its findings later this year.

'Consultation' and 'involvement' can mean different things to different people. It is important that there is clarity about the level of involvement proposed, and the extent to which this will determine, or inform, local service developments.

Philpot outlines four levels of user involvement [15] which could be extended to cover carer involvement (exhibit 7). This typology may be useful in clarifying the type of involvement to be employed at a local level.

"They listen but they don't hear."

Exhibit 7: Continuum of user involvement

Minimum involvement

Information

Users are given information about developments through talks, newsletters or leaflets.

Consultation

A variety of means (surveys, stakeholder conferences, smaller meetings) are used to elicit user views which will be taken into consideration when decisions are made.

Partnership

Managers, professionals and users work together to plan and reach decisions about services.

User control

Budgets may be delegated to users to run their own services or carry out pieces of work on behalf of commissioning agencies; for example, quality monitoring.

Maximum involvement

The main problem cited by many agencies is that of finding representative people. One of the most effective ways of identifying service users' views is through engaging existing user groups, of which there are many in Scotland. These may be criticised as being unrepresentative but they provide a safe environment in which people can speak freely about their concerns or their ideas for the service.[16]

For those who still have doubts, it is worth listening to what a user has to say about representation:

"The main double standard that service users/survivors involved in planning, managing or training encounter is workers questioning our representativeness. … Would you send your least articulate person to represent your views? Your least confident nurse to negotiate for changes in conditions? … If a person's criticisms are valid, what relevance has representativeness."[17]

To get the most from user and carer involvement, agencies will need to provide:

• practical support

• training opportunities

• funding for independent collective and individual advocacy.

Practical support includes, as a minimum, access to office facilities, such as telephones, wordprocessors and photocopiers; and payment for expenses. For members of minority ethnic groups, it may also involve providing access to skilled interpreters.

Training may be needed to enable users and carers to participate as equal partners in planning meetings and other activities. For example, if users are to be involved in selection panels for staff they should be given the same training which is made available to professional staff.

The recent report from The Scottish Office and SHAS makes clear that for advocacy to be effective *"health boards should develop it as a core element of health care commissioning, and allocate long term funding and support."[18]*

This bulletin is based on work carried out in the NHS in Scotland but its findings and good practice recommendations apply to all those involved in planning and delivering mental health services.

As this bulletin demonstrates, users and carers have important views about services which need to be heard. There is a range of advice available which can help commissioners and providers in obtaining these views.[19] [20] [21] [22] The challenge for professionals is to create effective mechanisms by which users and carers can contribute effectively to the planning, delivery and evaluation of adult mental health services.

"… so much talk - and it never comes to anything."

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