How involved can you get?

A tour de force round what could be one of the big ideas of the '90s – involving users in running your service from frontline to boardroom.

- *13 ways to involve users*
- *2 common models in depth*
- *5 major snags – knowing what they are is half the battle*

by
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ANYONE WHO USES a health and social care service has some right to be involved in what happens to them. No one wants to feel left out: purchasers worry that they don't know what's really going on in the agencies they finance; service managers struggle to oversee the diverse and complicated actions of their staff; fieldworkers complain that decision-makers ignore their suggestions and complaints; and as for service users...

What options do they really have to praise, criticise or change the services they receive? As a service user, you might hope your views would be noted during your interaction with agency staff and fed into the decision-making structure. Most people know that in practice this is a hit-and-miss process; there are too many variables to guarantee that any one user's views will make a difference – even if they are heard. Power does not always corrupt – but lack of it certainly demoralises.

It would be foolish (and offensive) to see users as inarticulate or unwilling to contribute – but naive to assume that without assistance they can make clear, structured comments about the service they received. The right words, the

SUMMARY

A service's users may go far beyond drug users. User involvement is the process by which services systematically learn from their users to achieve a more effective service. Common problems include disempowering users unaccustomed to the bureaucracy and jargon of service management, assuming one user can represent all users, dealing with intoxication, and retaining control if users drive services in unacceptable directions. Two approaches are examined in detail – management committees and user satisfaction surveys.

THE USERS

- ❑ Individuals who contact an agency because they use alcohol and/or other drugs.
- ❑ Those who have previously contacted the agency for these reasons.
- ❑ Carers for the above.
- ❑ The relations and friends of the above.
- ❑ Those who take part in education and training offered by the agency.
- ❑ Those who use the literature produced by the agency.
- ❑ Other workers who may need the agency's advice, information and support.
- ❑ Any member of the community in the agency's catchment area.

ADVANTAGES OF INVOLVING THEM

- ❑ **Higher quality** User information is essential in helping us ensure that the service we deliver is of the quality we intend.
- ❑ **Positive outcomes** The involvement of individuals in responding to their needs and agreeing ways forward is likely to maximise positive outcomes.
- ❑ **Better targeting** As information and intelligence about the clients' needs increase, service delivery can be more tightly targeted for effectiveness and efficiency.
- ❑ **Higher morale** Staff who deliver services which are wanted, in ways which produce positive outcomes, are likely to feel more rewarded and relate better to service users.
- ❑ **Wider support** Agencies which involve users at several levels will in the process also actively recruit people interested in lobbying for and helping the agency.

WAYS OF INVOLVING THEM

- ❑ **Working feedback** Users' comments through their contact or key-worker, and this is fed into team meetings and planning sessions.
- ❑ **Complaints procedures** How an agency provides opportunities for and responds to specific complaints expressed by service users.
- ❑ **Management committees** Users invited to join management in running or reviewing an agency (in detail on page opposite).
- ❑ **Satisfaction surveys** Questionnaires actively encouraging user comments on the service they receive, its setting etc (in detail on page opposite).
- ❑ **Suggestion/comment boxes** Passive resource where users can record suggestions, criticisms, appreciation.
- ❑ **Planning groups** Users invited to join in the discussions of professionals involved in planning services.
- ❑ **Development surveys** Questionnaires seeking user views on development options for an agency and guide future change.
- ❑ **User councils** Autonomous groups of users feeding their views on service provision to the agency's management.
- ❑ **Resource production** Users co-producing leaflets and campaign materials with agency staff.
- ❑ **Service delivery** Deliberate employment of users to carry out tasks, especially outreach type work.
- ❑ **Service research/studies** Involving users in planning what research to do and refining how to do it, and/or in carrying it out.
- ❑ **Outcome determination** The users formally rate their satisfaction with the results of contact with the agency in terms of goals achieved, improvements in quality of life etc.
- ❑ **Focus groups** Interviews are conducted with different groups of users over a period, each set of interviews/discussions providing information on a particular aspect of services.

appreciation and the criticism, often come later, sometimes well after contact has ceased.

To deal with this and other practical problems, systems are required. Such systems go under many names: client satisfaction; patient feedback; consultation; and others. For convenience, we employ the term 'user involvement' to cover this multitude of approaches. User involvement may be simply defined as *the processes by which services learn from those they serve.*

Many alcohol and other drug agencies have experience of user involvement – some successful, some dispiriting. In early 1994 the Regional Service Development Centre in Leeds began a review of some experiences in the north of England, distilling them until we felt we had a clear idea of the different approaches. To identify the most workable approaches we needed to define terms such as 'user' and ask: Why user involvement? What is its purpose?

Why user involvement?

To involve service users, you first need to know who they are. The obvious answer is an alcohol or other drug user who has contacted the service. As we probed further we found agreement that family members involved with the drug-using client could also count as users. Then the man who rang up to ask how to identify crack cocaine was also a user, so was the personnel officer who wanted to know about drug policies in the workplace, and the GP with an urgent referral...

So a service's users may include varied groups which go far beyond the person using the drugs. They can be people who have used the service, those who are now using it, even those who *may* need the service in the future (see *The users* panel). This is the agency's constituency over time and geography – those it serves.

But why should these people be involved in what a drug agency does, how it does it and how that might change and develop? After all, agencies already have an array of guides to what they should be doing: research, their own professional expertise and experience, the specifications of the purchasers, and national guidance.

We might feel that involving users is 'right' or 'fair', but there must be more tangible, positive, reasons to devote resources to this source of guidance. What might user involvement offer an agency? The various anticipated outcomes (see *Advantages of involving them* panel) amount to a more effective service as the primary benefit of user involvement.

Five common snags

If we know who the users are, and agree they should be more involved, what are the options for how we go about it? Obviously different subgroups of 'users' may require different approaches if they are to be properly involved. For brevity, the options discussed here are limited to service users who have, or have had, a substance-related problem themselves.

During our work we identified more than a dozen models of user involvement being employed or considered by agencies, from the humble suggestion box to giving users a hand on the reins of management power (see *Ways of involving them* panel). Some are used with others to generate user involvement at different levels or for different purposes.

Each of these models (and there are probably more) has its advantages and disadvantages. To examine some of these we looked at experience with two approaches to user involvement in detail – management committees and satisfaction surveys (see opposite). Many of the pros and cons can be identified from an agency's own experiences, or learned from other agencies. These need to be explored before choosing and implement-

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Users on the board

Inviting service users onto management committees is a controversial tactic on which agency staff had very mixed opinions. 'User members' offer committees access to new experiences and may give users a real sense of involvement. Their input may be crucial to understanding the cutting edge of the agency's activities. Many agencies surveyed believed the idea might benefit both parties if done properly, but felt the problems were difficult to overcome. Views on these fell into four groups, which relate to the 'user profiles' presented on page 12.

Representativeness Staff questioned how an opiate user could be representative of a client with alcohol-related problems. This prompts questions about how users get on to committees – are they elected democratically by the body of service users, or chosen by agency staff/management? The first option requires such a body to be properly constituted and supported so it is capable of electing representatives. The second may lead to 'suitable' users being chosen: angry, challenging and 'difficult' users might not get a look in, yet their views may be more pertinent to service development. It also has to be asked whether management committees which have their own internal problems could function with constant challenge at this level.

Current or former users? A second problem was familiar to agencies with experience of service users on committees. Users still in treatment had been known to attend 'under the influence', devaluing their contribution in some eyes. An alternative is to recruit only former service users who are substance-free. However, doubts were raised about their ability to represent current service users. Some ex-users were known to have less than sympathetic attitudes to those still drinking or taking drugs; others might be convinced that their own approach to overcoming problems was the path for all current clients. (By now, the ideal 'user member' on a management committee needs to be an articulate, non-disruptive substance-free current service user who can represent the needs of all the various diverse populations requiring services from the agency – a being so unusual as to risk being representative of no one!)

Dwindling enthusiasm When first approached many users were enthusiastic, but experience was that often this was short-lived and attendance dwindled (often true of committee members in general). Committees became frustrated at the absences and tended to abandon user representation. This is linked to...

Men in suits Current service users told staff that they found the prospect of sitting in meetings with a group of 'businessmen in suits' a daunting one. Such perceptions, whether well-founded or not, seemed to be a factor in some users' decisions not to get involved.

◀ *Drug and alcohol* ▶ *workers in the north of England had mixed feelings about two of the most common models of user involvement*

The scary part comes when we succeed – the loss of our power

Measuring satisfaction

User satisfaction surveys are a common approach to user involvement and potentially one of the most misleading and useless. What are the snags?

False positives Satisfaction surveys often produce results which reflect well on the agency. This may be because the service *is* good; more often, the results mask dissatisfactions. Put yourself in the user's shoes and ask questions such as:

- Do want to be too critical of someone doing their best to help me?
- Do I believe my feedback is confidential?
- If I give a negative response, what will happen to the treatments/facilities offered here?
- Am I in any position to judge at the moment?

Another issue is how satisfaction ratings relate to outcomes. Should we ask if the user is satisfied with the *services*, or satisfied with their *outcome*? The first may be positive, the second negative. Is it OK to be nice to people but do them no good?

The lack of detail in surveys and the way they guide responses can also produce misleadingly high ratings. Responses may reflect satisfaction at a superficial level – the way staff behaved or the buildings; underlying opinions may not be voiced, especially if the survey is badly constructed. Users may express satisfaction with a drop-in service but really mean they are pleased to have such an option. Probing may reveal specific complaints or suggestions about opening hours, facilities, and so on. Clients asked, 'Did you like the apples and the bananas?' may answer 'Yes', but really have wanted to complain about the oranges.

Under-resourcing Effective surveys need resources – for printing instructions and forms, distribution, staff time for this and for explanations to users, administration, software for analysis, time to interpret and write up, and time to repeat the whole thing with amendments. Agencies saw this as valuable work, but did not have the resources to pursue it as well as they'd like.

Response rates were often low. Surveys sent through the post had a low return rate, but having them filled in on site threatened anonymity.

Commitment to act Neither staff nor clients had guarantees that survey results would be acted on. Surveys conducted because it was the 'done thing', or because of political pressures, might then be filed into obscurity. Commitment to debate the results from managers, committees and purchasers should be a prerequisite.

These snags can be overcome, but only with commitment, clear thinking and enough resources. With these the exercise may become valid and reliable. For example, clear design, reply-paid envelopes, and evidence that responses make a difference, can increase response rates.

Satisfaction surveys might be complemented by 'development surveys'. These ask users to rate potential *changes* to the service. Offering users a chance to prioritise a set of realistic developments gives them a legitimate say in the process.

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ing any particular model(s). But before venturing down *any* of these routes, it is important to look more generally at how things can go wrong. User involvement implies a relationship between user and agency, and relationships, however dynamic, are often unequal. What should we look out for if we do commit ourselves to user involvement?

1 The 'disempowered' user One potential source of friction is the gulf between the intense, often inward-looking world of health/social care services and the communities outside. Users catapulted into this world are immediately placed under stress. They may become depressed or furious at an apparent (or real) lack of action. The power to comment, criticise or praise is not much of a power if nothing you say makes any difference. They may unintentionally be disempowered by professionals who have spent 15 years in this environment – and if they have no power, the anticipated benefits for the agency will fail to materialise.

How does this happen? Most users do not mark their time by management and review meetings, where ideologies sometimes seem to overcome common sense – and where planning and financial cycles dictate that by the time you've thought of something, it's too late for another year.

They do not necessarily share or accept the prioritisation of resources that services have to consider. After all, frustration with the pace of change, and with the chronic inability to pay for something which seems badly needed, is evident enough even in paid professionals – and at least they get status and money to compensate for the angst.

The language or jargon of any service can also confuse and block outsiders. We "address core needs assessment and share the conclusions in a non-directive manner" rather than decide what we think people need most and tell them.

2 The 'selfish' user Most of us want what we think is best for ourselves – what's best for others comes later, even more so when they may take resources or opportunities away from us. It is unrealistic to expect a teenager injecting heroin to be interested in responses to older drinkers, if those responses do nothing to improve services to injecting heroin users. Exceptions are where there are shared facilities or aspects of service that affect both groups – such as home visiting or evening clinics.

Acknowledging the users' personal motivations should improve user involvement in the long run, not disable it. Some people in the field still say "drug users just want more drugs" as if this is an argument against bothering to consult anyone. Even if it is true of an individual, it is still a legitimate expression which needs to be recorded. Good models of user involvement can identify and deal with this issue within the context of wider ones. The 'selfish' user leads us on to a third issue.

3 The 'representative' user We cannot truly be representative of anyone but ourselves. All we can show is that there are some things we have in common, but this should not be overestimated. A black Nigerian woman should no more be expected to speak for all black communities than a white Yorkshireman be expected to speak for men in general.

This also holds true when considering the substances used. Dividing these into two camps – alcohol v. drugs – can distort user involvement. The generalisation that drinkers have different concerns to drug users suggests that 'drug users' – encompassing people taking solvents, amphetamines, street heroin, tranquillisers, travel sickness tablets and steroids – all have the same needs. They don't. Elevating a service user into a 'representative' slot to satisfy a service's user involvement ambitions can be destructive for both user and agency.

4 The 'intoxicated' user To state the obvious, alcohol and other drugs affect mental states. Some professionals argue that users who are in treatment or still markedly dependent on a substance may not be in the best state to make decisions about services. From this point of view, ex-users (ex- to the agency and/or ex- to the substances) are the best source of feedback.

Relying on ex-users might allow for distancing and rational judgement but – as many smokers know from their contacts with reformed smokers – ex-users are not always the most tolerant in their judgements about those who still have a substance problem: "This model worked for me, so it will work for you".

User involvement needs to allow for this by looking for comments and suggestions at the start of, during, and after agency contact. Returning briefly to the idea of communities and other professionals also being users, information might be fed in even *before* contact: "What do you think *should* be available if a substance use problem arises?"

5 The 'empowered' user The scary part comes when we succeed in user involvement – the loss of our power. What if the users do not get demoralised and go home? What if – through turning up at all the meetings, starting radical user councils, and filling in all the forms in triplicate – they start to drive the agency in a direction which the purchasers cannot support politically, and which the staff do not think is in the users' best interests?

Taking power back from users may be more taxing than giving it to them in the first place, so most approaches to user involvement make sure that the reins are only loosened, not handed over. While this may be uncomfortable for some, it is pragmatic and needs to be honestly acknowledged. Users will not thank us for pretending that they can change things when they can't.

The evident pitfalls may at first depress initiates into user involvement, but are not presented here as arguments against it. Most of us have no wish to revert to the time when feedback was a rare letter of thanks or a report on the latest overdose death. Service users are the reason we have services (and jobs) at all, not an awkward element that disrupts what we do.

One positive note may be the growth of 'consumer audit', which by its name and nature moves user involvement towards 'professional acceptability'. To see user involvement as a required part of service audit is to take it seriously, not to relegate it to something we will do if we have time and if anyone is particularly interested (or vociferous).

RECOGNISING THE potential problems in advance gives us a chance to make user involvement work, to get somewhere – like checking the map before you set off, not when the road has disappeared and the wheels are spinning on mud. The Regional Service Development Centre is now supporting a number of agencies in developing their own approaches to user involvement. We believe that if we foresee and then actively seek to avoid the pitfalls, the journey will be well worthwhile for all concerned. ❍

The survey of services on which this article was based was conducted jointly with Richard Cyster and Jacqui Chamberlain. The Regional Service Development Centre welcomes enquiries and comments from others interested in user involvement. Phone 01132 448277 or write to the RSDC at Unit 51, 36a Call Lane, Leeds LS1 6DT.