MANAGING TO LISTEN

A GUIDE TO USER INVOLVEMENT FOR MENTAL HEALTH SERVICE MANAGERS

BY TERRY PHILPOT

Better Futures

PROMOTING & SUPPORTING GOOD PRACTICE
MANAGER, STAFF & USER EXPERIENCES
READING & RESOURCES
PROBLEM SOLVING

The purposes of this publication

This publication is intended to offer practical assistance to mental health service managers who want to initiate or develop user involvement.

Its aims are:

- ***to draw on the experiences of managers, staff and users;***
- ***to identify problems and offer solutions and ideas based on those experiences;***
- ***to identify ways of promoting and supporting good practice with both staff and users.***

'Better Futures is a people-focused initiative and one of the most important parts is the way we are able to tap into the experiences of those using the service and those caring for them. The experiences of people using services today will help shape the way services are delivered to the people of tomorrow.'

Don Mortlock, Director of Corporate Planning, Leeds Community and Mental Health Services

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Published by the King's Fund Centre
126 Albert Street
London
NW1 7NF
Tel: 071-267 6111

ISBN 1 85717 075 X

A CIP catalogue record for this publication is available from the British Library

Distributed by Bournemouth English Book Centre (BEBC)
PO Box 1496
Poole
Dorset
BH12 3YD

The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

Produced by the Publications Unit

Photographs of Swindon PLC

Better futures, better services

In 1992, the King's Fund Centre (KFC) financed a two-year project in five localities – Clwyd, Leeds, Salford, Swindon and Tower Hamlets – to improve opportunities and services for people with serious and long-term mental health problems. The project has been named *Better Futures*.

Each area's programme is determined by local needs, what has been able to be negotiated, and the shape of existing services. The KFC has involved service users, families, purchasers and providers, health (including family health services) and social services authorities. Importantly, the work has been carried out by those in the localities, rather than by the KFC so that, when the KFC withdraws, the work is more likely to take root.

'Users are questioning us in the same way that we, as individuals, are questioning others, like GPs or consultants. This is a theme running through society generally which makes it more acceptable in your own work.'

Mike Williams, Mental Health Services Manager, Clwyd Social Services Department

WHAT PROGRESS?

Each locality has its own programme, but three main areas of work have emerged. These are:

- **user participation** – helping users to speak for themselves through self-advocacy and to have a real say in the shape of services which meet their needs;
- **a focus on individuals** – in three localities (Clwyd, Leeds and Swindon), small groups of professionals have worked together over a 12-month period to improve the quality of life of specific individuals and to learn from their experiences (these are called 'action learning sets'). The work has relevance for individual needs assessment and care planning;
- **planning a community mental health service** – in Tower Hamlets, unlike elsewhere, the bulk of the work is strategic and is concerned with reprovision of acute services from the local psychiatric hospital and the development of a pilot local mental health service in Bow and Poplar.

In Leeds, Swindon, Salford and Clwyd, an essential part of *Better Futures* has been the stimulation of user participation. In Tower Hamlets, there are user-led self-help groups and MIND has appointed two part-time advocacy workers, but user participation in service planning and development is only beginning.

MANAGING TO LISTEN

As *Managing to Listen* is concerned with helping to bring users to the forefront of service planning, it is based on the work in Clwyd, Swindon, Salford and Leeds. It draws on visits to the localities, plus extensive interviews with people who represent the wide range of interests which the KFC has drawn together, that is users, managers and other staff in health and social services and the voluntary sector, and purchasers and providers. Discussions with Rose Echlin, *Better Futures*' Project Manager at the KFC, and the reading of some of the more significant and practical parts of the now burgeoning literature on the subject have also contributed to this publication. (A list of useful publications is given on p.12, including those referred to in the text.)

The ideas and experiences which have been drawn on have derived mainly from provider agencies, since providers continue to dominate planning in mental health. This is gradually changing as health authorities become more confident in commissioning services and are starting to develop their own links with service users. For that reason, *Managing to Listen* is as relevant to purchasing agency managers as to those working as providers.

FROM INTENTION TO ACTION

'If managers start feeling disempowered, you are moving in the right direction'
Peter Hewitt,
Director of Social Services, Salford Council

As long ago as 1968, the Seebohm report on the structure of personal social services advocated 'citizen participation' and recommended individual and group participation in the planning and provision of services. But while user involvement has long been on the agenda of service planners (and, more recently, that of providers), it has often been honoured more in the breach than the practice.

The NHS and Community Care Act 1990 is based on the idea that users' needs should be at the centre of service planning. In 1991, guidance from the Social Services Inspectorate stated unequivocally: 'The whole rationale for this reorganisation is the empowerment of users and carers.'

USER INVOLVEMENT

So, what are user involvement and participation, and how do they differ from consultation and advocacy?

Involvement is a blanket term which covers all sorts of activities, from membership of planning groups of users to training staff and running services.
Participation has a precise meaning – taking part in decision making – but, through frequent use, has come to have the same general meaning as involvement.
Self-advocacy and advocacy are frequently confused. Self-advocacy is when users themselves make their views known either individually or collectively. When individuals are unable to stand on their own, they may require an advocate to speak on their behalf.
Empowerment is often linked with user involvement. Managers cannot give power to service users, even through giving funding, but they can help to create an enabling environment in which users can do things for themselves.

Involvement or participation can be expressed as a continuum ranging from minimal involvement to user-run services. Different points on the continuum may all co-exist within a service (see Figure 1). *Better Futures* has touched on all these areas, but the main project work on user participation has been in partnership and consultation.

In a ministerial statement following the publication of *Caring for People* (1989), the White Paper which foreshadowed the 1990 Act, the then Secretary of State for Health, William Waldegrave, said: 'We must be on

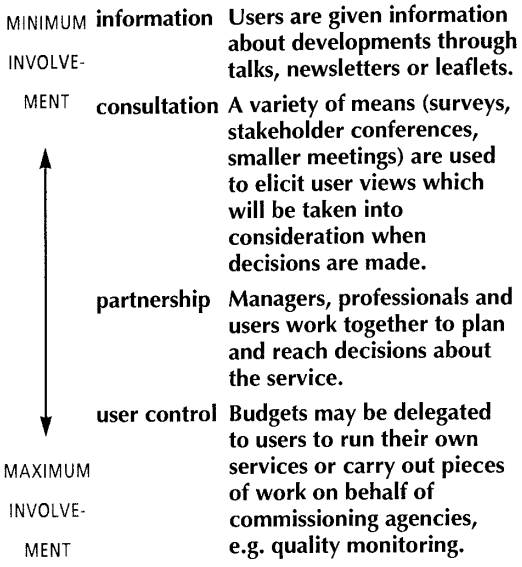


Figure 1 A continuum of user involvement

the side of the user rather than the provider, to ensure that services are provided efficiently with emphasis on quality.' He also spoke of 'management systems powered by the voice of users'. But how is this to be achieved? Users, even when involved, can often be made to feel, at best, that they are icing on the administrative cake, at worst, powerless. The obstacles are formidable: users are not part of a management or a staff culture; they do not spend their days thinking about planning services; they are not always familiar with the internal politics of an organisation; they do not have the administrative backup which managers take for granted; they are not always used to how an organisation works – from the way agendas are put together to the way a meeting operates. But these obstacles are not insurmountable.

'So many meetings are processes, cogs in a wheel and you need the overview to know where you are in the process.'
Lindsay Jackson, formerly Senior Planning Officer, Leeds Healthcare

Some users have had, or do have, through their professional lives, a high-level organisational experience. Many do not. Users' organisations have a different rationale and culture from health and social services agencies.

MAKING USER INVOLVEMENT A REALITY

The principle about user involvement is all but won (even if not always accepted in practice). It is now backed with the force of ministerial guidance and exhortation. But if user involvement is to become a working, practical reality what do managers need to know and to do?

Service managers are in a unique position to draw users to the centre of their concerns: it is they who can lead, promote, set examples, provide practical support, empower and assist. But the dialogue is not just between the managers and the users, or about the users working with the managers. Managers have a responsibility to set the tone of the *whole* organisation, from the regime in a day centre to the conduct of high-level planning meetings.

User involvement needs to be absorbed by the whole tenor, attitudes and policies of an organisation. Two recent reports have endorsed this view. Both Parsloe & Stevenson (1993) (looking at practice across a number of social services departments) and Marsh & Fisher (1992) (looking at Bradford and Westminster services for children) have said that training people in an atmosphere which, while not unsympathetic to user involvement, has not itself absorbed the underlying values and principles, is to sow seed on stony ground. For Parsloe & Stevenson empowerment is 'both a process and a goal' – part of the process can be achieved by moving toward the goal.

The tone of the organisation will be set when users are there, an accepted part of the team. Their presence and acceptance will cause a new dimension to enter into deliberations, provoking a new way of looking at policies and practice. What happens when this is not the case was explained by a team leader with Clwyd Social Services Department, who said: 'Involving users is something that's in my head but not always to the forefront because there is no blueprint, no policy.'

Managers need to remember these helpful hints when working with users:

- make sure users understand why they are being involved and what the boundaries of their involvement are;
- if users offer suggestions, respond to them even if, on occasion, it is to explain why something cannot be done;
- be prepared to take criticism, as well as positive comments.

The intention of *Managing to Listen* is not to assist managers to create a three-paragraph 'mission statement' accepting the principle of user involvement so that everyone can then forget about it. Instead, by drawing on the successes and difficulties of four of the *Better Futures* localities, and the experiences of managers, clinicians, other staff and users involved, *Managing to Listen* aims to show what needs to be done in practice to turn good intentions to reality. In doing this, the words of Andrea Phillips, a user in Swindon, should be heeded:

'The quality of user involvement is important for us. It's what it does for us – giving confidence and a sense of value – that's what's important, more important in many ways than what we can offer them [the agencies].'

Getting started

There is no right way of getting things going, but the better ways involve service users. Ideas from the localities may be helpful.

- A 'user involvement month' of activities in Salford brought users together and became a stepping stone for further developments. The month included public meetings (with a panel drawn from senior managers in health and local authorities), talks, social events (a dance, a barbecue, a karaoke evening), an information day, and a video day showing cinema films which have tackled mental illness.
- 'Brighter Futures in Wrexham' was initiated by a psychiatrist as a 'learning exercise in empowerment'. Users and staff planned a conference to bring local users together and to identify issues and concerns. Two research advocates (chosen for their life experience and empathy with people with mental health problems, rather than any professional knowledge) were nominated to explore these issues further and write a report. The user members of the organising group have continued to meet with one of the research advocates acting as a facilitator, and they plan to establish themselves as an independent group in separate premises from the local service.
- A search conference, drawing together people from different backgrounds and including service users, elicited in Salford a wealth of ideas which are being taken forward by a project group. Some service users have set up a committee to plan a Saturday afternoon and an evening social club.
- Self-help groups may be more attractive to service users than self-advocacy groups in areas where life is hard and services few, particularly those which operate out of hours.
- The Community Health Council (CHC) was funded by Tower Hamlets Health Authority to consult local users on their view of services. The report, compiled by an independent user consultant, highlighted the need for a worker to help the fragmented user groups organise. The CHC bid successfully for joint finance for a development worker and, in the meantime, some tentative steps are being taken with users joining locality planning groups.
- Also in Tower Hamlets, MIND was funded to research the views of people from minority ethnic backgrounds; workers with the Bangladeshi and Afro-Caribbean communities have held consultative conferences so that the users and families with whom they work could speak out. The development task over the next two years is to make links between the work done in these communities and statutory planning groups.

NEEDS AND NUMBERS

'The principle must be to look at the most effective way of people participating.'

Grier Thompson,
Liaison Officer,
Salford Social Services Department

The number of users actually involved is always likely to be small. In none of the localities does the number of users directly involved with health and social services (as opposed to those attending meetings of user groups) exceed 15. There are reasons for this: some users may have a very real fear that, if they criticise, they will lose the services that they have now; others may have mixed feelings about the service – gratitude as well as frustration and anger. Managers also need to remember that participation can take a toll from service users and they may occasionally need to miss a meeting or withdraw for a longer period to recover their energies. Besides, users are no different from other members of the community: on a cold night, they may prefer the television set.

Finally, policies on reimbursing expenses notwithstanding (see below), many users will be in lower-income groups and may not have their own transport.

STRATEGIES TO MEET USERS' NEEDS

When there are comparatively few users directly involved with authorities, managers need to avoid the easy way out – of seeing one user as 'the user involvement' person. They should also recognise that different, flexible and more informal strategies need to be developed for user involvement. These include the following.

- Meetings should be held in informal surroundings, (e.g. church halls), as well as statutory ones, or in familiar ones (e.g. day centres).
- Using different venues for meetings may encourage more people to be involved, particularly in rural areas where transport is poor and distances are greater. This may result in a constantly changing group of people, with a consequent lack of continuity. However, this may be overcome by having, as in Swindon, locality planning.
- Since in some places self-help groups are better at attracting users, they can be a resource in the consultative process as well as self-advocacy groups.
- Although voluntary agencies are often very close to what is happening locally, managers should beware of the danger of 'consultation by proxy' by assuming that to consult voluntary agencies is to consult users. Managers should also ask users which channels they prefer.
- The base of representation and participation needs to be broadened by complementing formal meetings with questionnaires, suggestion boxes, surveys and one-to-one interviews.
- Managers should make themselves available to local user groups rather than always expect users to be involved in agency structures.
- Users, like staff, will experience stress under pressure and, like them, may require support. This means that they should be granted the right to withdraw a little or refuse extra responsibilities, without being seen as having failed or being allowed to think that they have failed.
- A senior manager should have direct responsibility for user involvement and users should have direct access to that person.
- More than one user (and preferably more than two) should always be invited to meetings. Anyone who is not a staff member might easily feel intimidated faced with a phalanx of 'them'. Where the meeting is small, and only one user may be required, the user should be asked if he or she would like to be accompanied by an advocate or friend.
- Where there is formal representation on a committee or group, substitutes should be allowed to attend.
- Whoever wants to attend a meeting should be allowed to do so, although there will need to be ground rules to ensure that there is not too great a turnover.
- Users should be encouraged to come to meetings through informal channels. For example, a letter of invitation could be handed over by frontline staff (e.g. a community psychiatric nurse), rather than posted, then discussed, support given if required, and a lift offered to the meeting if needed.

Defining roles

'There can be confusion in roles: what the health authority wants of the user and what the user wants. The health authority sees a need to change procedures and sees users being able to help in that. Users want to change attitudes in the way that services are delivered.'

Andrea Phillips, Swindon user

Users need to be made clear about what their role is. It is difficult enough if users feel that they are being thrown into the deep end by entering into a strange culture with a language and procedure all of its own; such a situation is exacerbated if users are not sure in their own minds what they are doing there.

Managers and users may come to meetings with different agendas. There may be gaps in managers' understanding about what involvement can achieve, even about what it is. They may not be clear themselves about the extent to which they want to involve users.

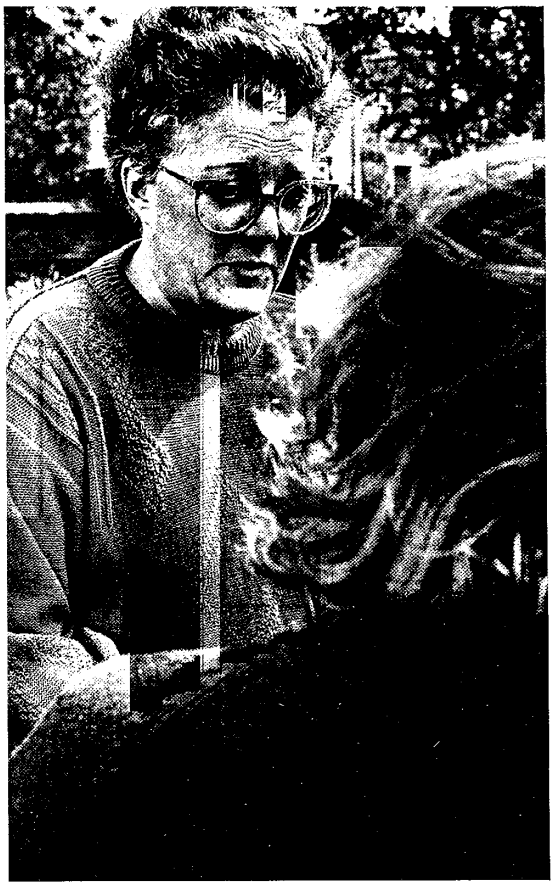
If there is a clash between the extent to which managers and users believe involvement is possible, then managers should discuss this and explain why it is. Confidentiality is sometimes given as a reason for not involving users, but this is often not a problem. Alan Croxford, Team Manager, Colwyn Bay, Clwyd Social Services Department, produced a structure chart to explain who did what and how the users, as participants, fitted in.

Outside of the regular meetings in which users will take part, managers could consider arranging informal meetings for users to discuss among themselves how they see their roles, inviting managers to join in if they wish.

Users need to be told what the constraints and pressures on staff are. They will not expect that their words will be the final ones, but they do need to know what weight will be given to their views. In Clwyd, they felt that this had not been made clear to them.

'TRIAL BY SHERRY'?

Managers may confuse involvement with consultation. Some authorities involve users in staff appointments and some do not; some involve users in appointments of certain grades of staff but not in others. If users are to be involved in any way, they should be involved *meaningfully*. The worst kind of involvement in staff appointments is the 'trial by sherry', asking users along to the 'get to know each other' meetings for potential recruits but not to the interviews.



In the beginning, nothing should be off the agenda – from the standard of food in the clinic canteen to 'Why couldn't I get a community psychiatric nurse when I wanted one?' To discourage users raising issues may seem to them, after possibly years of discouragement, to be just another example of professional obfuscation. As involvement proceeds, users will start to identify the most appropriate ways and fora in which they can pursue specific issues. Not to set parameters, to leave users unsure, is to confirm and reinforce the imbalance of power.

Independent user groups need to be free to develop some of their own agendas and increase their own networks. Staff can sometimes be territorial about user groups within their service and may, with good intentions, try to prevent access to users from outside. Although there can be difficulties, it is worth working on these central–local links so that independent groups represent the range of user views in a district or borough.

LET'S MAKE IT WORK: practical assistance

EXPENSES AND PAYMENT

'People should be properly compensated. It's a way of valuing them.'

Rosemarie Williams, Team Manager in Wrexham, Clwyd Social Services Department

It is no good wanting to involve users unless they can get to meetings easily and do other work at no financial cost to themselves. So, making expenses available and devising a system for swift and easy reimbursement is important. There should also be a clear agreement about whether the health authority or the social services department will be responsible for payments.

Managers also need to lay down clear guidelines about what expenses will be reinbursed and when it is appropriate to claim a fee. It is best if local users and managers agree on these guidelines together. However, there is another aspect of financial reinbursement to be borne in mind, as Peter Clarke, Chief Executive, Salford Mental Health Service, suggested:'It is important not to get in the position where the natural contribution and flow of dialogue starts to be financially managed.'

In a rural area like Clwyd, expenses will also be higher (taxis are more likely to be used than buses) and authorities need to plan for this. But even the best-intentioned managers may have difficulty in balancing what will be a cash-limited budget. Even if taxis are used in a cost-efficient way by picking up a number of users on a roundabout journey, they may not be efficient in terms of time.

In the four localities, the system of paying expenses (which can also include telephone and postage) differed. There is nothing wrong with that so long as the system employed suits users and meets accounting requirements.

In one locality, expenses were met through the mental illness strategy group. Group members were paid an honorarium of £42 a week, the maximum allowable as therapeutic earnings, including expenses. (Therapeutic earnings increased to £43 per week on 14 April 1994.) This was a good way of recognising group members' contributions, but those who were not members of the group felt this was inequitable. As therapeutic earnings have to be paid on a regular, weekly basis, they are not suitable as a means of rewarding users who may only attend occasionally. Besides, since therapeutic earnings have a limit, it may mean that a user will be paid less than he or she might otherwise be expected to get if not on social security. For example, regular trainers (including user trainers from outside the area) would expect to be paid much more for staff training.

In Swindon, there was a lack of consistency: a carer who took part in an action-learning set was paid £30 for half a day, whereas a user who had been involved in a search conference, core group and other activities, had not been paid, but was paid for training funded by the social services department.

In Leeds, users got £10 a meeting, paid quarterly, from which they had to meet expenses. The co-ordinating group spent a lot of time working out a formula which did not involve small claims for expenses, since any system along these lines might have cost more to administer than the value of the payment itself. The flat-rate system was adopted by the joint consultative committee, who set the rate at £20 per quarter. User and carers from all client groups who take part in community care planning meetings now receive this payment.

Child care costs can be an important factor in allowing some people to attend meetings, and are likely to take a big slice out of what are still quite modest honoraria. If these costs have to be met, the size of the honorarium should be adjusted accordingly.

Payment systems need to be much more flexible than those for meeting staff expenses. Some users complained of waiting three months for their expenses to come through. This could be avoided if a system were available, as it was in one area, where a staff member claimed an advance from the finance office and paid users at the end of meetings, who then signed receipts for the money.

ADMINISTRATIVE SUPPORT

Users are not only being asked to work with staff who have assured salaries and can claim expenses without trouble, they also have to team up with professionals who have a vast array of administrative and other support. Offering administrative backup is one way in which authorities can show that they are taking user involvement seriously. Some examples of this are:

- in Clwyd, users have been provided with computer equipment and have access to secretarial help and photocopying facilities. Office space is also available;
- in Swindon, a service user is employed to offer administrative and clerical assistance to the user network's development officer;
- in Swindon, People Like Us (PLUS) group members feel that it is good practice to provide papers in advance of meetings;
- in Clwyd, informal briefings are given to users before meetings;
- in Salford, funding is available from the mental health service for travel and other expenses for a group facilitator if groups require one;
- in Salford, a newsletter, in an unusual pocket-sized format, is produced by the Salford Users' Group and is circulated to all local users. It carries news of all the local user groups, as well as information about Salford-wide activities.

A DEVELOPMENT WORKER

'When there was not a will to listen to service users, then I wasn't listened to.'

Helen Hamilton, Development Worker, Swindon

In Clwyd, Salford and Swindon external user consultants were contracted to encourage user involvement. Salford also used other consultants. Swindon was unique in employing a development worker. Opinions differ less about the value than the difficulties of employing such a person and so Swindon's experience offers some lessons. Helen Hamilton, a trained social worker and ex-user, was employed in a project which was jointly financed but managed by the local Council for Voluntary Service. This arrangement allowed sufficient distance and independence.

A resource centre, established after her post came into being, was funded by the Mental Illness Specific Grant and managed by the National Schizophrenia Fellowship. This enabled the worker to be based close to PLUS the user group and MIND, both of whom shared the premises.

The advantages of employing a development worker

- The post allowed action to be stimulated and change made within voluntary agencies due to its association with the Council for Voluntary Service.
- There were clear policies (e.g. on anti-discrimination) which could be used as a check for policies elsewhere in services.
- The statutory agencies indicated their commitment to user involvement by funding someone with a specific remit to encourage it.

The problems of employing a development worker

- The responsibility for all user involvement and user matters can too easily be passed over to the worker.
- Too many duties were loaded on to one person.
- The post was not user-led, though three users worked voluntarily with the worker.
- There were no 'visible allies' within services with whom the worker could make a common cause.

A DEVELOPMENT FUND

As well as a development worker, the experience of *Better Futures* is that it is essential for users to have a development fund at their disposal to get things moving. Four of the localities received grants of £4000 each from the KFC and have used them creatively to fund visits, support small self-help groups, hold workshops with external consultants and promote training. In most of the localities, users' expenses and subsistence costs for meetings, which fall outside those agreed for reimbursement by the agencies, are met from their fund. This enables more users to get involved. Swindon users, for example, visited user groups in Brighton and Nottingham and, as they had a particular interest in training, hired consultants to train them as trainers.

TRAINING

'I don't want to become another staff member who has been mentally ill in the past.'

Joe Higgins, Swindon user

Training is important if users are to be effective. They need to understand the way health and local authority systems work – from their most mundane aspects, such as the committee system, to the most rarefied, such as the hierarchy, and managerial and professional cultures. But, as one manager pointed out, users can be over-trained and their unique perspective lost, or at least lessened, by their becoming almost a part of the system.

It is important to make use of health and local authority training departments. Not only do they have knowledge and expertise which can be tapped, but also working with users will help to change and shape for the better the training department's attitudes and perspectives which will in turn influence the kind of staff training they offer.

Whatever kind of training is required should be for users themselves to determine. Staff may have some role in training, but the danger of using professionals is that users will be trained in a culture different from their own. There is enough experience now of user involvement and of users who have established themselves as highly skilled trainers of professionals to call on experience from outside the area if it is not available locally.

In all four localities, some training was provided, planned or felt to be needed. When available, it consisted of imparting skills and knowledge of issues like:

- participation in management, planning and other groups;
- committee skills;
- self-advocacy and advocacy;
- assertiveness;
- chairing committees and other meetings;
- making presentations.

Going on a training course is often daunting – the trainee is admitting a deficiency. At times, it is good to be away from familiar surroundings; at others, being on familiar ground helps trainees to feel safe. If users prefer to be trained at day centres, for instance, trainers and managers should bring the training to them. If they prefer to be somewhere else, then attractive facilities should be sought. There is nothing more off-putting, nor which suggests (however unwittingly) that managers do not give a high priority to training or do not value those being trained, than finding oneself in unsuitable or down-at-heel surroundings.

As well as receiving training, users are often interested in graduating to becoming trainers themselves. As one Swindon user said: 'It's not just about being trained, it's about us being able to give training to workers.' To this end, users may also require tuition and practice in training techniques; these are best provided by experienced user consultants. Although some users do want to get involved in training staff, it can be difficult if a user knows that his or her community psychiatric nurse is in the audience, so many prefer to do training in neighbouring districts.

What about the workers?

For decades, staff – be they managers or practitioners – in almost all services have provided services that they see as meeting clients' needs. In services for very vulnerable groups, this has been underpinned by a belief that users are not able to speak for themselves and cannot themselves know what the most appropriate service is.

User involvement is the counter-argument to that kind of service provision. There are still, in many services, rearguard actions by some staff and management to keep things as they were: at best, to pay lip-service to user involvement, at worst, to try to ignore it.

One user said: 'The health authority doesn't see it as their role to empower users to participate.' Another sent an open letter to the strategic planning group saying: 'Area representatives are not seen as necessary or particularly welcomed by some staff and that is hindering the representatives in what they deem to be their duties.'

Paternalistic services have encouraged paternalistic staff attitudes. Yet many staff are themselves disempowered. They understand the need for user involvement, even if they are unclear about (or misunderstand) what it means in practice. User involvement can both be a shock and appear threatening to staff.

Managers wanting to make user involvement a reality need to take staff with them. Their starting point must be to recognise negative staff reactions, and to help staff overcome them. Training is one way of doing this but, importantly, *training which involves users*. Critical to the success of a user involvement strategy is the commitment of middle managers because it is they who will influence the culture of the agency.

WHAT CAN BE DONE?

- Communication is the key to any strategy. When an agency adopts new policies, *everyone* must know what they are and the reasons why they are being adopted.
- *All* staff must be included in any attempt to change organisational culture – receptionists and others on manual and administrative grades, as much as managers, nursing and medical staff, and social workers. Users may have much more contact with the former than the latter, and the first contact with a health or social services authority may be through a receptionist who, for better or worse, can set the tone of the whole organisation.
- Staff need time to be able to discuss what is happening. Communication does not mean issuing fiats from the senior management group, the trust board or the social services committee.
- Staff training needs to be a priority. One way of showing staff the importance which management attaches to training is to ensure that agency cover is provided for staff absence. If training is fitted in with other responsibilities, one of its effects will be to inconvenience staff, and this will not help them to see it as a positive experience.
- Training budgets encompass all kinds of staff training. Ring-fencing money for training on user involvement will ensure that this is not fighting with other training bids. When managers calculate

the cost, they need to take account of the costs of arranging staff cover.

- Users should be employed as trainers. Just as training for users should induct them into a culture which their presence is seeking to change, so using users as trainers can help to change staff perceptions and understanding.
- A culture needs to be created which enables staff to see user involvement both as part of their professional commitment and as part of the provision of high-quality, cost-effective services.
- With the current fashion for performance appraisals and objective-setting, user involvement and service responsiveness to users can be made a specific item for managers' individual performance reviews.
- In Salford, the social services department has written 'user involvement' into its community care plan.

What can user involvement achieve?

It is all very well to talk about user involvement, but what can it achieve? The four localities offer a number of examples.

- In Salford, the health authority commissioned a group of users to research alternatives to hospital and out-of-hours services in other parts of the country. The crisis house proposed by service users was judged too expensive, but the user group went on to run a workshop for purchasers and users where they agreed on a telephone helpline as a second priority. Clwyd users also identified the need for a helpline and this has been included in divisional plans.
- In Clwyd, a job description for a project worker was radically changed for the better by being commented on by users. Similarly, the process of interviewing and selecting a project worker in Swindon was strengthened by a user taking part.
- With the exception of Leeds, which has well-established user groups, all the localities started to develop user participation from a low base. Three localities have new user groups and a fourth has gained funding for a development worker. In Clwyd and Swindon, users were involved in strategic planning, and elsewhere they have taken part in local planning and community care planning. Their own agenda has included training for themselves and staff, developing a patients' council, campaigning for out-of-hours services, creating links between local user groups, developing self-help groups and securing funding for themselves.
- In Clwyd, a traditional 10am to 3pm day centre now incorporates a Saturday drop-in (with the possibility of a Sunday one). Asking users about what the centre should provide led, among other things, to doing away with an institutional tea-urn in favour of an informal coffee bar run by users and attended by both them and staff. Allowing users to purchase furnishing themselves bypassed local authority-specified suppliers and gave a less institutionalised look to the revitalised centre. A project worker has been employed for a year to encourage users to take full control.
- In Leeds, users made it known that they wanted to have the opportunity to run a day centre on their own, and now they run it one day a week themselves.
- Leeds Mental Health Advocacy Group organised a conference to bring together all the user groups and self-help groups in the city. Users ran a crèche, organised transport and provided an all-day coffee bar. A user-run theatre company took part in the day as well as members of the Manchester-based Hearing Voices Network (a mutual-help group).

THE WAY AHEAD

Success demands:

- a commitment from all managers;
- senior managers agreeing a policy on user involvement and making sure that middle managers know what it is and what is expected of them and their staff;
- a policy on paying users who take part in planning and other activities that is agreed early in the process of developing participation;
- middle managers being given scope and flexibility to try different approaches;
- independent user groups being free to develop their own agendas and increase their own networks;
- a clear strategy for the twin thrust of training for users and training for staff;
- specific funding (which includes a development fund for users to make use of) to develop ideas and see that users' costs are adequately met;
- multi agency support for user participation to prevent users being seen as lobbyists for one agency or presenting a purchaser or provider view.

There is no blueprint for user participation. Some ideas listed here may work in some places but not in others. Key factors in designing a strategy must also take into account the context and the makeup of the population.

A LAST WORD

'To anyone embarking on such a project, it can seem overwhelming at the beginning. My message is: when despondency and isolation creep in, keep going. It's a most rewarding learning experience.'

Manager involved in developing user involvement, quoted in *Consumer Participation in Community Care*

Further reading

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Other resources

The following have also produced helpful materials, including some on training:

Good Practices in Mental Health
380-384 Harrow Road
LONDON W9 2HU
Tel: 071 289 2034/3060

King's Fund Centre
126 Albert Street
LONDON NW1 7NF
Tel: 071 267 6111

Mental Health Media Council
The Resource Centre
356 Holloway Road
LONDON N7 6PA
Tel: 071 700 8129

MIND
Granta House
15-19 Broadway
Stratford
LONDON E15 4BQ
Tel: 081 519 2122

Open University
Walton Hall
MILTON KEYNES
Buckinghamshire MK7 6AA
Tel: 0908 653 231

Survivors Speak Out
34 Osnaburgh Street
LONDON NW1 3ND
Tel: 071 916 5472

UK Advocacy Network (UKAN)
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ISBN 1-85717-075-X