

## **Introduction to user involvement**

Services often ask the question "Why won't our users get involved?" A better question might be "Why on earth would our users want to get involved?" There is a debate within the user movement about whether engagement can ever achieve significant change, or whether users will always be co-opted into the service of a disempowering and inhumane system. We are arguing from the different perspective that service users can indeed make real impacts on services, but that for them to do so requires services to accept and respond to far more radical challenges than any they have experienced to date.

Enhancing the involvement of people who use mental health services in the delivery, planning and evaluation of those services has been a priority for a number of years. Despite this, it is fair to say that progress has been patchy.

### **Why involve service users?**

On the most basic level, an incentive to engage with service users relates simply to the fact that people who are fully involved and consulted about the course of their care will be more likely to follow it through. It is essential for users to be enabled to discuss and debate alternatives. This will stimulate debate and challenge the dependency fostered by long-term involvement with services.

Ultimately service users have direct experience of what works, what doesn't; what can be experienced as positive and what is essentially demeaning or unhelpful. As the process of medical psychiatry moves from a view of illness and vulnerability, based around long-term hospital care, towards a model of coping and opportunity (itself driven by service users) the user's voice is essential in challenging the presumptions that inevitably flow from old orthodoxies.

### **Challenges to involvement**

Historically, the two biggest barriers to user involvement in services have been professional attitudes and the health service's traditional inability to distinguish between 'consultation' and 'information'. The former, based at least partly on the rigid client /staff division so typical of the old asylums (and, still, many 'modern' services) leads to assumptions whereby any criticism of services can automatically be seen as pathological, and, even more perniciously, that any service user capable of representing an alternative point of view is by definition not representative of the 'incapable majority' (the so called 'talking dog' syndrome). The second aspect is reflected in the fact that where user involvement has been attempted, it is often at a very late stage of the process; major decisions are made and users (or front line staff) invited to rubber stamp them.

For service users to make a real impact, adequate levels of representation are required. This must involve people who are actually representative of the community served (and the community potentially in need), support systems and significant human and financial resources.

Significant user involvement requires genuine commitment on the part of services to a candid dialogue with its clients, including a willingness to engage in constructive

debate, and, indeed, to consider and make fundamental changes in the way it approaches people, their problems and their aspirations.

### **Define your service user**

User representation seeks to give voice to service users in planning and evaluating all aspects of service provision. Rarely is it possible to involve *all* users of a service in all stages of the process, however, and so user representatives will generally be sought. Right from the outset it is important to distinguish between representative users and user representatives. A local advocacy service, for instance, may well have in-depth contact with service users and a more or less accurate impression of their views on it. Advocates (paid advocates in particular) will not usually be themselves active users of the service in question. Their input can be valuable, but it is not the same as involving service users themselves, with all the potential benefits to those users that can come from this.

Most services where user involvement has been developing for some time have a number (sometimes as few as one or two) users who are involved in everything. This may be because they have relevant skills, because they get on well with the Chief Executive or because there actually isn't anyone else interested in getting involved.

Are these individuals actually representative? We have experience of services whose clients were predominantly young men of African or Caribbean origin consulting with user reps who were white, middle aged and middle class. These people may have gone through significant distress but their experience cannot be that - or perhaps even relevant to that - of the client group served. More commonly, service user reps are at the tail end of their own involvement with services and may not have had recent experience of, for instance, inpatient care. This leads to 'ex-user syndrome' - continuing to fight the battles of yesteryear - or alternatively, 'outrage fatigue', the condition of failing to see residual problems in the light of improvements already made.

Of course, people in acute distress, perhaps in contact with services for the first time, may not be best placed (or willing) to become involved in developing future services. Their views are, however, crucial, and so structures need to be in place to access and respond to them. This suggests that systems need to be wider than the committee processes and formal systems that tend to be most organisations starting points.

### **Why won't our users get involved?**

Why on earth should they? Too often, the role for service user representatives involves attending committee meetings on a monthly (or less frequent) basis. At these meetings they are often a single user in a room full of people, usually experienced, senior professionals, who work with (or sometimes against) each other on a daily basis. The agenda, at least will have been decided before they arrive and positional papers and proposals drafted and circulated. Automatically, in these circumstances, the user rep is isolated, perhaps patronised and certainly marginalised.

The role is inherently reactive. There is no opportunity to develop a distinct user

agenda, to consult the user community or to check back with peers. In reality, there is no single user voice, but one person, or at most two or three, will be expected to represent the totality of the user perspective. Any 'contentious' opinion they offer will immediately be dismissed as *unrepresentative*. For all this, they may get their travel expenses, perhaps lunch and, if they're lucky, a token payment. If they continue to attend, they may or may not see progress in whatever it is that the group has been convened to discuss. More often, they will see very little progress, or simply find that the group functions as a reporting site for decisions and developments made elsewhere.

Rewarding - let alone fun - it is not.

In fact, if this is what user involvement consists of, it is hardly surprising that there is a reluctance to come forward, attend meetings, put forward points of view. Simply, there is very little in it for the service users themselves. Mental health professionals have incentives to go through this sort of thing. At the least they are being paid for it, at best they are hopefully pursuing a genuine agenda for constructive change. Similar incentives must be in place for users. A criticism of some user reps is that they only get involved to distinguish themselves from other, less 'capable' users. In the absence of opportunities to deliver effective change, this can be a hard critique to answer.

### **A better structure for meetings**

User involvement does not have to be focused on a formal process of meetings, but as this is how most developments are planned and discussed, meetings will inevitably be part of it. As part of a wider structure, the following may help to make meetings more constructive and attractive to user reps.

- Time and resources (space, money and administrative/personal support) to organise and consult prior to meetings, including the opportunity to convene meetings of users groups or forums, meet with managers for initial discussions of any proposals to be tabled, and to propose agenda items of their own. This will include the opportunity to seek clarification - from a named individual - of any obscure points (or language!) in papers to be tabled (which must be circulated in good time, of course) and to submit proactive proposals.
- Full background briefings on the purpose or purposes of the group. Managers will (or should) be familiar with the national and local policy agenda, the financial and other constraints within which the system operates and similar. User reps (and the groups they are representing) may well not be and active steps should be taken to convey this information through face to face meetings, question and answer sessions and briefing papers. At crucial stages in a development process, relevant managers and clinicians should attend meetings of user groups (rather than vice versa) to outline their thinking and progress (or otherwise) to date.
- There should always be more than one service user representative present at all but the smallest meetings. NO meeting should go ahead (or sub group be

convened) without user reps being present. This may suggest practical difficulties, but it is an essential means of demonstrating commitment to the ideal.

- Formal meetings are not natural processes. Provide training in meeting skills for potential user reps. Be prepared to revisit the structure of meetings to make them more 'user friendly' - it won't just be the user reps that benefit.
- User representative must be enabled to feedback the outcome(s) of the meetings to their constituencies and have the opportunity to communicate any discrepancies between the opinions they expressed at the meeting and significant numbers of members of the groups involved.

### **It's not just committees, though....**

Although formal meetings and groups are perhaps where most significant decisions are made, the process of engaging with service users is of course much wider than that. Effective mental health services are those that actively engage clients in the planning and delivery of their own care, but many service users could contribute constructively to service development who would never want to attend formal meetings.

### **Engagement or co-option?**

An aspect of user involvement that causes continuing controversy is whether users should aspire to involvement in or with services at all. Radical separatist elements in the 'user movement' argue that the changes needed to provide services that people who use them would value and respect are just too fundamental for the hierarchies within those services to contemplate. As a result, user representatives have been co-opted into humanising an inhumane system, side-lined into rubber stamping pre-ordained decisions or making changes to detail at the very end of the 'consultation' process. Too often, those service user representatives have been patronised, ignored or exploited. They have been isolated, under valued and set up to fail by being given inadequate resources, inadequate support and inadequate opportunities to organise and mobilise a valid constituency. The process of engagement has been personally damaging to some individuals involved and frustrating to very many more.

On a deeper level, some users argue that the radical agenda of the user movement of old has been subverted into discussion of the minutiae of current provision. Arguments about the necessity for an end to compulsory treatment as a whole (or specifics such as ECT) and an aspiration to dismantle medical psychiatry have been replaced by discussions about information leaflets and the opening hours of local day centres. The committee-based nature of many planning processes has excluded many service users and this in itself has led to questions about just who is representing whom. Better, some argue, for service users to organise independently of services, create their own support structures and work for change outside of existing provision.

There is much validity to these arguments and certainly a need for a user voice entirely outside of services, able to comment on and criticise any aspect of policy or provision without fear or prejudice. We would argue, however, that it **is** possible for service users to engage constructively with services on a local and national level and

make meaningful changes - changes which have a real and positive impact on people's lives now and in the future. This involves compromise, negotiation and debate. The two positions are not mutually exclusive. Indeed, the very strength of the user movement is its very diversity.

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