

## More voice, more choice

Allan Johnstone, the NTA's new user and carer programme manager, explains why providers can no longer afford to ignore the opinions of users.



Most healthcare professionals understand the logic that lies behind the old adage 'the customer knows best'. For years, the evidence has shown that, if a service asks about and then responds to the views of users, its work will tend to be more effective. And yet, despite this knowledge, applying the logic of user participation is far from standard practice in the drug treatment sector.

As a result of the clear case for user involvement things are changing, but progress will become swifter as pressure from government – as well as patients – grows and as professionals become more aware of the obligations on NHS-funded services to involve users.

### Cultural change

Involving service users and carers is not new – legislation has required public services to consult with their users for over 30 years. What is new is the obligation since 2002 for NHS funded organisations to involve, as well as consult, people on decisions about the way services are commissioned and then run.

Section 11 of the 2001 Health and Social Care Act has had far-reaching effects across many structures and organisations within the NHS. Yet in the substance misuse field, some organisations have been slow to capitalise on the potential for improving services. Sectors within the NHS that work with 'hard to reach' groups may not have recognised that new decision-making structures are required. But we need

only look at the experience of organisations that have meaningfully involved people to realise that, if done correctly, it need not be difficult.

A more common reason for not capitalising on the benefits of user involvement, is a failure to recognise its true value. Some organisations pay lip service to the concept by concentrating their efforts on consulting, rather than actively involving people in real decisions. It is the move away from this paternalistic view of involvement that concerns most in the health sector.

The Audit Commission report, *Drug misuse 2004: Reducing the local impact*, made it clear that the experience of service users and their carers will be central to the further improvement of services and the NTA is committed to increasing involvement at national, regional and local level.

### Mounting evidence

According to national research, the benefits derived from meaningful involvement should be incentive enough to help bring change. In May 2004, the Department of Health published a review of 12 pieces of research into patient and public involvement. According to the review, when organisations sought and responded to the views of users, the outcomes were overwhelmingly positive. Involvement led to changes that helped improve health, cut waiting times, cut the rate of non-attendance and raised the satisfaction levels of patients and staff.

In the drug treatment sector, examples of best practice show that the views and experiences of service users and their carers are often an untapped resource. They tend to know what impact treatment and medication will have on their quality of life and the state of their health. They also understand how failings in the system can adversely influence their treatment. Using this knowledge has helped to improve services.

In the view of the NTA, designing services around the needs of patients and carers is not only the 'right thing' to do, but also potentially cost-effective. By encouraging drug users to be involved in decision-making and take an active role in maintaining and managing their own health, the NTA believes that the sector can improve effectiveness and quality.

### Tailored solutions equal results

This is not to say that effective user and carer

involvement is easy. Some organisations have made the mistake of trying to fit people, or user groups, into existing processes.

Their labours have shown that, to be truly effective, organisations need to be strategic from the outset. They need to ask themselves how, where, when and why users and carers should be involved, either individually or collectively. Only by doing this groundwork will solutions be developed that work for everyone. And only when these solutions are in place, should organisations attempt to fully engage people in service reviews, development or planning.

Nor should organisations view involvement as a quick fix; experience shows that it often requires a change in attitudes and management/clinical practices.

### Minimum standards

The goal of the NTA is to provide the guidance and framework that enables organisations to develop their own solutions – solutions that differ but all meet the same simple standards, wherever a service user happens to live. These standards include the availability of basic information and support about user involvement; access to advocacy schemes that can provide independent advice for users trying to access or improve a service, and regular requests for feedback (and input) from the end-user by providers, commissioners and strategists alike.

### Changing habits

With this vision in mind, the NTA has put a lot of work into getting the right structures to help evaluate the effectiveness of its own work. At a national level we have appointed a user and a carer to our Board, as well as establishing two national advisory groups to help inform research and policy. At a regional level, we have been establishing user and carer forums to seek wider input and share best practice between organisations.

This work is already bearing fruit with more users and carers than ever involved in the latest treatment planning round. There is also a greater desire amongst activists to become more organised and seek new recruits to their ranks. This increase in capacity has enabled the NTA to involve more people in research work, the review of policy and the Agency's inspection work.

The Agency also has in place a programme to help providers. Later this year the NTA will publish a *Guide to Service User Involvement*, as part of a range of support tools. The service framework for commissioning and delivering treatment – Models of care – is also being strengthened to ensure that users and carers are heard. And, this year, the NTA is planning a national user satisfaction survey, the information from which will help to improve and benchmark treatment.

The NTA is determined that the involvement of service users in the planning and delivery of treatment should become standard practice. The journey will not be easy but, if services can reflect more the needs of users, the benefits for society will be considerable.