

Pre-course reading and preparation

You should refer to your organisation's service user involvement/participation policy. If your organisation does not appear to have such a policy, you should familiarise yourself with the policy of a similar organisation.

Things to think about:

Have you seen or heard of this policy before? What do you think of it?

Do you know what obligations your service has with regards to service user involvement?

Why is service user involvement a desirable part of providing services to those affected by drug and alcohol issues?

The following article was published in a special edition of Drink and Drugs News (DDN) in February 2008, covering the first annual DDN/Alliance Service Users Conference – *“Nothing about us without us”*.

One of the most frequently recurring themes at *“Nothing about us without us”* was that of image – the image service users had of themselves, or the image that service providers and wider society had of them. When it came to truly effective user involvement, negative self images, it was felt, could go beyond feelings of stigmatisation, individually or collectively, to become a barrier to being heard – or even feeling able to speak out – in the first place. ‘You’re talking about people who’ve never been listened to in their whole lives,’ said one delegate. ‘At school, by their own families, wherever.’ This lack of self-confidence was then compounded when faced with the new – and often bewildering – language of user involvement. ‘It’s full of acronyms and jargon, and that’s an obstacle that’s used against us,’ said another delegate. ‘Respect is a word that’s bandied around so often, but often it doesn’t mean anything at all.’ Many of the delegates spoke of how easy it was to be intimidated when dealing with service professionals, clearly a major barrier if involvement was to be genuine. ‘The dialogue on the streets is a very different kind to the dialogue you need in these situations,’ one stressed.

Every profession develops its jargon and acronyms, which – bewildering as it may be to someone from the outside – can become an intrinsic part of doing the job, so what’s the solution? ‘There’s got to be a middle ground,’ said one delegate, and some called for the establishment of a professional code of service user involvement, to help ensure respect and clarity on both sides. A consultation could be launched on the best way to go forward, it was suggested, perhaps using service user forums to contribute ideas and suggestions. ‘We agree that there is lots of jargon surrounding the commissioning and provision of drug treatment, and we need to try and simplify this as much as possible,’ said south east regional manager at the NTA, Hugo Luck. ‘We could all probably do better. Everyone has their own jargon, slang, call it what you will, and can lapse into it despite our best efforts, whether it is clinical talk or street slang concerning names for drugs. The important thing is to create an environment where people feel they can stop whoever is talking and ask them what they mean. This can be through agreeing ground rules in advance, taking an advocate along to explain things, or providing a glossary to demystify the language.’ On the issue of a professional code of conduct he pointed out that there is a drug service users’ charter, developed by SCODA/DrugScope in 1997 and referred to subsequently in the Quality Standards for Drug and Alcohol Services (QuADS) and a number of NTA documents. ‘There are also very clear statements in the recently published clinical guidelines regarding the way patients should be treated’ he said. ‘This includes the right to dignity, respect,

and involvement in the planning and delivery of one's treatment.'

Acronyms and jargon were likely to remain a key issue in user involvement, said Jimi Grieve of the National User Network, so it was essential to come to terms with that and act accordingly. 'People don't know about this when they start out, so we need to pay real attention to style and linguistics in bringing up the next generation,' he said. It was also fundamental that user involvement be kept real and relevant. 'We have to be very, very canny and careful how we plan conversations – we have to be targeted, solution-focused and results-focused, and to evolve and mature as a movement.' This would involve concentrating on succinct arguments and what the movement really wanted to achieve, he stressed. Being confrontational would simply serve to perpetuate the 'them and us' culture. One way to build a stronger identity was for user groups to become more involved and networked with each other, it was felt. This way experiences – good and bad – could be passed on and advice offered when another group encountered problems. The use of online forums for sharing experiences was seen as a key way of building an identity, but it was important for groups and their members to respect other peoples' viewpoints, regardless of whether they were using, on a prescription or abstinent. 'It's whatever works for you – you shouldn't judge.' Some delegates, however, felt that service user involvement ultimately only got as far as the consultation level and no further, and that often it was only the 'easy wins' that were taken on board.

The more difficult issues were the ones less likely to be acted on, even though they might be the things that most needed addressing. 'This raises the issue of how user groups and their representatives can be seen to appropriately represent the needs of drug users,' said Hugo Luck. 'The NTA acknowledges that it is difficult to engage a range of different users in one group – it's important to try and get the views of a range of service users or local users in order not to be tokenistic. If user groups feel that their views are not being heard, and have raised this previously with their service or DAAT, then they should bring this to the attention of their NTA regional team, who will raise it with the DAAT in question.' William Pryor, however, raised the controversial issue of how much identifying with user groups was itself a route to freedom or a trap. 'Are you just stigmatising yourselves by belonging to these groups?' he asked. Most felt that this was not an issue – that self image and society's view played a far more important role. 'I'll be a recovering user for the rest of my life,' one delegate said.

It was felt across the board that user groups themselves recognised the value of the work they were doing and the contribution they were making. 'We're not victims of society,' said one delegate. 'We need to do things for ourselves – no one at the NTA would be in a job if it wasn't for us.'

Things to think about:

What did you think about this article?

What issues did it raise for you?