



The National User Network, better known as NUN, is gearing up to make sure user involvement emerges from the drug strategy review with a stronger voice than ever.

DDN talks to NUN's chair Jimi Grieve and vice chair Francis Cook.

Together we stand...

Service user groups have been springing up all over the country for some years now, and the idea of regional forums is not new. The National Drug User Development Agency (NDUDA), then the National Treatment Agency's National User Advisory Group (NUAG) tried to harness the passion of service users for fair treatment and a place at the policymaking table.

But somehow it didn't last. NUAG representation was patchy. Some reps spoke up for their region, some were there by default because no-one else put themselves up for the job. So the group was in danger of mirroring the postcode lottery that they were there to cancel out by campaigning for better treatment.

Enter the National User Network, also known as NUN, formed by a handful of service users who wanted to take over a flagging programme of user involvement and inject some grass roots autonomy. With more than a handful of 'the usual suspects' on board – people who had previously voiced frustration at the way things were, including some who have become part of the backbone of the harm reduction movement – feelings were running high that there should be strong user

representation coming up to the end of the ten-year drug strategy. Grant McNally, founder of the UK Assembly on Hepatitis C; Andrea Ethimiou-Mourdant of the Mourdant Trust; and Eliot Albert of UKHRA identified the need for NUN and orchestrated its 'call to arms', according to current chair Jimi Grieve.

With John Howard of Reading User Forum and Simon Parry of Southampton-based user group Morph as its first (joint) chair, NUN set about drawing up a detailed plan for a national movement that would survive beyond any changes to the NTA. With rumours rife that the NTA would dissolve in 2008, the group minuted that 'we need to ensure there is some sort of "treatment watchdog" in place to check DATs etc are providing good treatment services and aftercare'.

With robust debate ('the usual process of arguments, fights and squabbles – you know how it goes!', according to Grieve) NUN agreed on a mission statement: 'To promote and support user involvement in all aspects of care, treatment and service development.' Their remit covered drug use in its widest sense, whether licit or illicit, alcohol,

volatile substances or prescription medication. They made a commitment to sharing safer practice, support anyone who needed it, challenge prejudice and discrimination – and make sure they had an active dialogue with policymakers that would ensure their views counted.

As an umbrella body for other user involvement groups, NUN was determined from the outset to nurture a supportive network. The agenda would come from challenging bad practice countrywide, while providing 'a network for upcoming groups and individuals to "plug into" when starting up'. They declared their determination to foster a professional approach, building bridges within the current UK user movement at the same time as getting users included in NHS patient involvement initiatives.

Looking ahead to their long-term survival, NUN's early brainstorming drew up objectives for a full-time fundraiser, a career structure for volunteers who got involved in the group, and plans to establish a National Service Users Charter. 'Obviously some of these goals are easier to achieve than others – but we

need to know what they are and nothing is impossible,' declared chairs Parry and Howard in minutes of their second meeting.

Taking the chair in the second year, it's been Jimi Grieve of Hertfordshire User Group's job to keep up momentum, step up the group's profile, and 'up the ante' in a period of uncertainty. With his vice chair Francis Cook, Grieve realised he needed to gather practical and tangible support to make sure the group was rooted firmly enough to be effective. Setting up a Yahoo group to make communication easier, Grieve held elections online, resulting in a new board with eight trustees.

Meeting with trustees at the National Drug Treatment Conference in March gave the group the impetus they needed. Being 'fully formed', with legal processes reviewed, and charitable status applied for, has brought plans for funding bids closer, says Grieve.

'We want to find best practice, collate it and distribute it, whether it's about blood-borne viruses, overdose prevention or relapse prevention. We want to be a supermarket of innovations, with a range of tools on our shelves for harm reduction.

'When new guys pop up and say "what do we do, where do we go?", we'll send them to one of the services in our network and say "have a look at this"... we find good practice, innovative projects with a proven track record that are supplying local demand or unmet need, and just try and network.'

Apart from sheer enthusiasm, the other element that's fertilised their growth has been legislation obliging all health-related agencies to consult service users and carers, Cook points out. From being one of the 'pacesetters of the 80s and 90s', campaigning for change, he's now come across groups 'who've used consultants to get user involvement on board'.

With the direction of travel clear, there's just the small matter of funding to find and sustain. Drug testing company Altrix have given 'a big hand up' with the money for a dedicated website. Exchange Supplies and the Conference Consortium have donated conference places, which has helped the group 'piggyback onto national events', and have given space for the group to meet at their events. There are plans afoot to apply to the Big Lottery to get enough money to support mentoring.

Plans are ambitious, but Grieve is keen to emphasise that 'we are highly holistic and solution focused – and that starts locally, regionally, nationally.

'We are about supporting the little guy in his locality, enabling him to network, get funds, get training, and get templates for better practice.

'We're also about keeping user involvement going when all the money disappears,' he adds. 'Because we'll get swept under the carpet if we're not careful.' **DDN**

Get in touch with NUN by emailing Jimi Grieve, chair, at jamesgrieve@ntlworld.com (tel: 07757 826744) or Francis Cook, vice chair, at francis.cook@ntlworld.com (tel: 0151 647 2162).

To join NUN go to http://health.groups.yahoo.com/group/national_usernetwork



Glass getting fuller

Last year we talked to Kevan Martin about his fight to start up the North East Regional Alcohol Forum, to give much-needed support and representation to alcohol service users. Sixteen months on, NERAF has become a force to be reckoned with. **DDN** catches up with him.

'Over the past year we've gone very, very proactive, and are putting things right in the appropriate ways,' says Kevan Martin. 'Rather than just criticising, we're taking practical steps. And what we're aiming to do is ensure that everybody going into treatment is offered effective aftercare.

'We work with the providers and the PCT, sitting down with all of them, spotting things that are going wrong and doing what we can to amend them. The PCT's now listening to the advantages of peer support, and all the agencies are now referring onto us. We've got NERAF available alongside the 12-step model, an alternative to AA – so people have a real choice.

'Service providers like us, because it's another avenue for them. I've heard instances of service providers being very dubious about user involvement, but it's been accepted like a breath of fresh air up here, because it's making practical differences.

'We haven't set up to criticise, but to help out. We've been invited to the table on our merits, not because we've demanded it. People have come to our meetings to hear what we're doing, then wanted to support us.

'The PCT has just given us £15,000 a year for the next three years – purely for user involvement. New Deals for Communities have allocated us £150,000 over three years to provide a detox and aftercare service, with a detox nurse from the PCT to do home detox in the community. One of our mentors will make sure people have long-term peer support at home.

'When people are setting up groups such as ours, they have to be careful that they're more professional than the professionals. When our lot go to meetings people are expecting alcoholics to walk in the room. When they see someone walking in smartly dressed and articulate, they're welcomed with open arms. And that's the reception we're getting up here – open arms.

'If you go in with a confrontational attitude, it's going to have an adverse effect, the opposite of what you want. It would have been easy to just have a pop at everybody, but it would have done nobody any good, particularly the service users needing treatment. What we're good at, is saying "look, we're here to help you out". And that's the way it's got to be, because if people try to set up groups with their own agendas, saying "we're best", they're going to get laughed at.

'We've got four paid staff now, and 18 mentors. Mentor training gives people the motivation to learn more. We've got one gentleman, a retired coal miner who was made redundant when the pits shut down, and turned to drink. He's stopped drinking, has done the mentor training, and is now in college brushing up on reading and writing skills.

'We've had other people who are doing counselling and complementary therapy courses, following mentor training. Some are now doing their first year in social work training. What we're saying, is that while you're trying to address your drinking problems, you've got to replace your time drinking with some-

thing else. People are finding out that there's life after addiction.

'It's little steps all the time, but if you look at how we've developed over the past 12 to 18 months in particular, we've come on in leaps and bounds. I'm still very conscious that it's early days, and still holding on tight to the reigns. If we go too quickly, we're going to have a diluted service, which affects quality – which affects the people we're working with. We've got a quality service and we want to retain that.

'More and more people are getting in touch with us now, and since speaking at the Drugs and Alcohol Today conference this week the number of hits on our website has gone through the roof! But it's great.

'If we can offer advice, we'll do it. Just pick the phone up and we'll tell you how we've done it, because we don't want to be a stand-alone agency – we want this going all over the country.

'I think really it will be up to us to try and kick something off nationally – and we'd be willing to do it, because if it's benefiting people in the North East, it's going to benefit people in other areas of the UK as well. I can't wait for the day that NERAF becomes the National Executive of Regional Alcohol Forums!'

To get in touch with NERAF, visit the website at www.neraf.org or call 0191 5656688/5145852

DDN's interview with Kevan Martin, 'A glass half full' (30 January 2006) is on our features archive at www.drinkanddrugs.net