

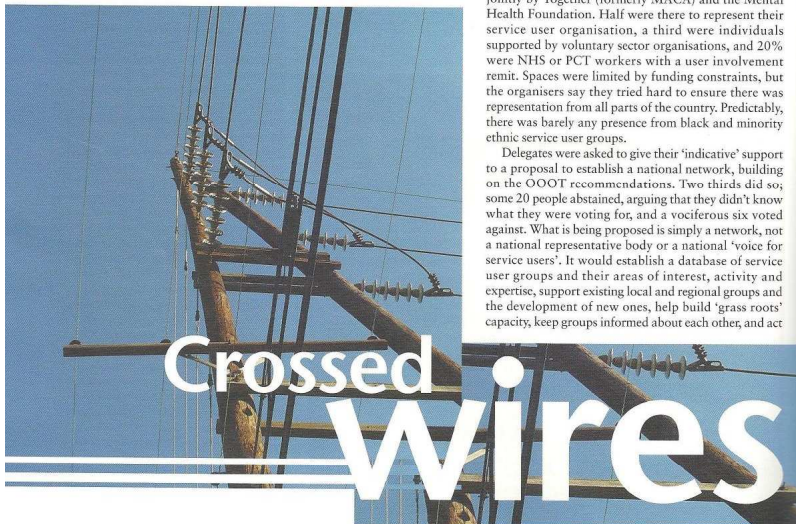
The time for doing nothing is over. If we don't do something now, my fear is we will lose this window of opportunity.' So says Anne Beales, director of service user involvement at Together and one of the people behind the latest attempt to bring together the many service users groups in England and Wales to set up some form of national organisation.

Scotland's national service user representative organisation Voices of Experience (or VOX, as it will be known) will come formally into being this autumn (see box). But attempts to form a national organisation in England and Wales have so far foundered, partly on political divisions, partly on lack of resources. Survivors Speak Out, which formed in 1986 but has faded out in recent years, had a national membership but did not claim a representative role. UKAN (the UK Advocacy

Network), founded in 1992, claimed nearly 300 members at its peak, but is currently struggling to find funding to enable its survival. In 2002 a national survey supported by the Sainsbury Centre for Mental Health (SCMH) was able to identify nearly 900 active service user groups in England, the majority with between 50 and 100 members and most (77%) with funding. The report, *On Our Own Terms* (OOOT), published in 2003, called on the National Institute for Mental Health in England (NIMHE) and the main voluntary sector mental health charities to fund and support service user groups to 'build stronger local, regional and national networks'. But the momentum faltered amid fears that the independence of the service user 'movement' would be compromised by funding from non user-led organisations.

Last month 150 mental health service users met in Birmingham on 8 March at a national conference funded jointly by Together (formerly MACA) and the Mental Health Foundation. Half were there to represent their service user organisation, a third were individuals supported by voluntary sector organisations, and 20% were NHS or PCT workers with a user involvement remit. Spaces were limited by funding constraints, but the organisers say they tried hard to ensure there was representation from all parts of the country. Predictably, there was barely any presence from black and minority ethnic service user groups.

Delegates were asked to give their 'indicative' support to a proposal to establish a national network, building on the OOOT recommendations. Two thirds did so, some 20 people abstained, arguing that they didn't know what they were voting for, and a vociferous six voted against. What is being proposed is simply a network, not a national representative body or a national 'voice for service users'. It would establish a database of service user groups and their areas of interest, activity and expertise, support existing local and regional groups and the development of new ones, help build 'grass roots' capacity, keep groups informed about each other, and act



Will service users ever agree to a national organisation? Catherine Jackson reports on the latest development in a long-running saga

as a 'clearing house', referring requests for information and representation from government and statutory bodies, the media and such like to those groups with an interest or involvement in the subject area. 'It will enable groups to increase their strength and their voice, not take it away,' Emily Brown, deputy director of service user involvement at Together, told the conference.

The vociferous nay-sayers included representatives from UKAN and the UK Federation of Smaller Mental Health Agencies, which both argue that they already provide the basis for such a network. 'UKAN has been

8 April 2006 mentalhealth today

around 12 years and would be a way of taking this work further. We did it quite successfully while we had funding and have got experience,' argues Patrick Wood, UKAN training and development worker. 'The network would not be an independent group if it was managed by the Mental Health Foundation and Together. The fundamental principle is that it should be a genuinely user-controlled organisation.' Philip Dixon Phillips, past chair of the UK Federation, agrees: 'Why reinvent the wheel? We keep having these outpourings of how it's going to happen and we keep going round in circles and it never happens.'

The conference team was clearly bending over backwards not to be seen to be presenting the network as a representative body. But some of the conference attendees wondered why. Heather Straughan asked: 'Why can't it be a national user voice? Aren't we going to have more effective, faster change by joining together?' The difficulty is that the service user 'movement' has historically always been exactly that: a groundswell of many different people, in many groups, with different politics, priorities and views, brought together by a broadly common aim to win for people with mental health problems the rights, autonomy and choice enjoyed by all other law-abiding citizens. They also have a healthy suspicion of 'being done to', as conference participant Alan Leader, a member of the patients council at St Clements Hospital, east London and a long-time survivor activist, put it: 'What we have been avoiding talking about is trust in representation and accountability. If someone is going to represent me, I have to trust them and they have got to be accountable to me. That is why you need networks locally first, and then build up.'

Jan Wallcraft, NIMHE expert-by-experience fellow and author of OOOT, argues that historical and political differences can be accommodated within a network: 'We need to have those debates out in the open and find out what we have in common, because at the moment people are stabbing each other in the back and that is dividing the service user movement. We need to talk about it, even if we end up disagreeing,' she told the conference.

But other participants, like Vincent Bethune from Birmingham Mind, were clearly frustrated that internal disputes could block action that is desperately needed, in his view, to address the pressing problems of today, particularly for black and minority ethnic groups: 'It's a duty of care for everyone. I think, get it together and get on with it. I am not involved in in-fighting. I would rather see someone do it and we can argue about it afterwards,' he told MHT.

Armed with the conference majority mandate, Beales and Crepez-Keay now intend to take it to the next stage, resources permitting. It currently relies on the continued support of Together and the Mental Health Foundation, which are funding the time they put into the work. Beales says the movement can't afford to dither: 'I think the willingness of the government to have service user involvement will get scarcer as the resources run out. We need to get something in place now that can't be undone.'

'We will now seek funding to get a co-ordinator, premises, development worker and to set up the database and a website. From the indicative vote, people want something to happen. But it will be a referral agency, certainly in the first instance. I don't think the trust is

there for it to be a campaigning organisation. We aren't ready yet. We need to empower and build people up.'

David Crepez-Keay agrees: 'There was a genuine desire to get a network up and running for the benefit of everyone. Clearly there was a range of views as to what that might look like. To me, it's about creating the mechanism, rather than getting hung up on whether it's representative. Then people can do what they like with it. Personally, I would like to see an independent service user led and owned organisation that was a distinct entity with its own structure, but that is not our role. The network may facilitate that happening or become it, but to me that is not a priority. The priority is to get some resources in to co-ordinate a very impressive range and level of local activity so it can be more influential and people can talk to each other more effectively and efficiently. There is a pressing need for that.'

How did they do it?

VOX in Scotland emerged from a loose coalition of 12 groups that originally came together in 2002 to discuss how service users should respond to the proposed new Mental Health Act (now in place). A conference in 2004, funded by the Scottish Executive, produced a clear mandate from service users that they wanted a national organisation. A steering group then set about developing a business plan, with which they persuaded the Scottish Executive to provide £100,000 annual funding for the next two years. It is 'hosted' by the Mental Health Foundation, which will provide office space and payroll and logistical support for a development worker. It will be an individual membership organisation with explicit political as well as networking and capacity-building aims. It will also have two seats on the Scottish Parliament's cross-party group on mental health and two seats on the health department's national mental health delivery group. 'We are sitting at the big tables already. The Scottish Executive is keen for service users to be seen to be there and it is meaningful, not just tokenistic,' says VOX's interim secretary Shaun McNeill, managing director of Glasgow-based Advocacy Matters. 'I have a healthy cynicism but their past record is pretty good. We are set up structurally to protect our independence. There's almost an expectation that we will be adversarial. I am sure they would be surprised if we weren't.'

Whatever emerges from the Birmingham conference, there will soon be a national representative service user body in England. As part of its Making a Real Difference national programme to improve service user and carer involvement in its own workings, NIMHE is to set up two national structures, one for users and one for carers, whereby local groups would feed into regional groups that would have representation on two national groups with a seat each on NIMHE's management board. NIMHE South East Development Centre (SEDC) will shortly invite expressions of interest from outside organisations to conduct a 'scoping review' to establish existing capacity at local and regional level. Following this, it will invite tenders, again from independent organisations, to establish and maintain the two networks. Says Malcolm Barrett, social inclusion lead at SEDC: 'We needed proper representation, a real caucus of service users with their own voice, independent from but supported by NIMHE. This is about making NIMHE listen better to the service user voice. If as a by-product we help the service user movement develop, they can call the shots then. This is capacity building.'