

**National Service User Network Conference
Jury's Inn, Birmingham, 8th March, 2006**

“Our Future - Doing it for Ourselves”

‘At least the men in the room will get the message’ said Tina, intentionally brandishing the substantially expanded message on her teeshirt:

TOKEN
USER
REPRESENTATIVE
DESIGNATE.

Throughout the day, the acronym remained a brilliant reminder of what the conference was **not** about.

The Purpose of the Conference

Captured in an extract of what Anne Beales, Director of Service User Involvement for ‘Together’, herself a service user, said in her initial address as Chair of the morning section of the conference, this is consolidated in the Principles and Proposed Structure document for a National Service User Network examined and amended by the conference.

Let’s hear Anne first:

“The reason we’re here today is to identify, or begin to identify, our training needs. some of us won’t have any training needs while people like myself will have huge training needs. I go to too many meeting where I don’t have a clue what they’re talking about.....so we do need training - many of us do, some don’t... Some of us need support from others who have spoken at conferences or are trained - so we can learn from each other.

We need to get a flavour of what priorities we need now so we can ensure that services are delivered differently. Many of us have been told about crisis resolution teams that shut at five o clock. *But they’ve reached their targets!* We need to say - what is our agenda? Our agenda is often so, so different from that of the voluntary sector, the statutory sector and we need to make sure that our agenda - what is important to us - is heard. And it needs to be heard at the highest level. And - um - its a shame that Rosie couldn’t come along today!

We face a choice. In the past, we as a group of people have had people who have been our champions; we’ve had people who have spoken up for us; we’ve had

The Network will focus on making links which will ensure that the widest range of service users are connected, supported and accessible on an ongoing basis.

There are two key elements which will ensure that the network is sustainable in the long term:

- Adherence to core principles, activities and structure
- A flexible structure

This will offer a strong foundation plus the ability to adapt and change with the different and changing needs of service users.”

The conference voted to take the document forward with amendments, particularly those which will ensure an elected and democratic body which is fully accountable and fully independent.

The Conference Activities

I was pleasantly astounded to be able meet and talk to users from Cornwall (including a beautiful dog), Devon, Somerset, Berkshire, London, Sussex, Surrey, Wiltshire, Hertfordshire, Swindon, Leicester, Birmingham, Smethwick, Wolverhampton, Sheffield, Yorkshire, Lancashire, Durham, Shropshire and Glasgow.

According to Anne there were 173 delegates altogether, the majority representing service users sponsored by various user organisations and individual service users. UKAN had a good presence there, interested in being part of the proposed network. There was a small presence from NIMHE and other ‘partnership’ bodies including a commissioner body.

There were two special facilities for delegates’ use: a well managed ‘chill out’ room; and a Video Box - a separate private opportunity for the filming of the expression of individual issues. This was available for anyone at the conference.

Special mention of Frank Bangay, a real legend in the Service User movement since the 1970s, who gave some strongly delivered and emphatically punctuated readings of his own poems. A huge delight and a highspot.

The speakers (other than Anne Beales) were:

Tina Coldham (her of the flamboyantly expanded teeshirt). Tina, a service user herself and a National Development Consultant for the Health and Social Care

Advisory Service (HASCAS) presented an brilliant overview (interspersed by some very funny moments) of the HASCAS survey and review of the state of service user and carer involvement in the National Institute of Mental Health in England (NIMHE) and the resultant report "Making a Real Difference". She covered the key points of the report. In summary: "What's working well? There is a breadth of involvement...and a sort of developing regional infrastructure ...There's also capacity building - enabling and building up people to do stuff effectively...There's also steps being taken to strengthen diversity...There a some payment policies, but all a bit different...

But it is a mixed picture...Carer involvement is further behind than user involvement...There is also a lack of accountability, and somebody used the phrase 'usual suspects...And we also found that user and carer involvement is not integral to the work of NIMHE...user and carer involvement needs to be part of the culture - it needs to be something that isn't an add-on, something that's done separately...It needs to be something that's threaded through all that happens...And also involvement needs to be clear - Whose agenda is it?...there's an underlying ambivalence about user involvement - so yeah its OK - sort of take it or leave it. So if anything, there's little practical working in terms of users and carers...if you go to the table, you know the senior level managers...there is sometimes 'skilful dismissal' - they (users and careers) know they're being dissed, that they're being pushed aside - in a skilful way...relationships at different levels are not clear in terms of what happens at local - on the ground level... and what happens then at regional activity. There no sort of joined-up-ness...

Now EbE - Experts by Experience...I think there's a lack of transparency, particularly around recruitment. I think the way it was set up to begin with was good,... but you know, things tickle along sometimes, and I think again some of the usual suspects - perhaps they were there. People weren't sure they were there and why they were there. So the role and remit was a little bit unclear...lost a bit of authority and had little impact on what was going on...when it was initially set up I thought it was a really good idea and I think they had a channel to the top. But I think the power has dissipated a bit...

So what needs to happen? We need to systematically embed within NIMHE user and carer involvement and as we said, as part of the culture - its not an add-on thing...We need to have clear purpose and outcomes...users and carers need to know what they're doing and why they're there...Also managers and other people need to be clear about that - they're off track...There needs to be accountability and influence (by users and carers) on decision making. We need to be able to make decisions...we need to enable people to take part...We need to reach out and broaden our esteem and cross barriers...And its often said that 'all these people are in a difficult to reach group'. Rubbish. If you ask them how to reach out to people you can do it. You make it happen! That's a really poor excuse... And, everything should be accessible (information)...also accessible for people with

different sort of problems, for instance those with learning difficulties where they need things in a slightly different format...also people with sight impairments...we need to think about these things. We also need to think about training and practical and emotional support and personal development...its important to make it happen. We also need to strengthen and connect existing networks. And this is for NIMHE, but think about what we're doing here today...

We also need a single payment policy...You spend so much time negotiating how you can get your hands on the money that they owe you - its unbelievable... and we really do need this in NIMHE...and excuses are: well we contract to a trust and they do pay users or they don't pay users - its inequitable. Its not fair if you live over here you get that amount and if you live over the road you get something else...Lets reward people and at least pay expenses - cash on the day. If you've coughed up out your own money, you need that back as soon as possible.

Its in the report. There's a lot of information there and all the recommendations are being worked up into an action plan. And there is a project lead to take it forward (present in the room). NIMHE have taken it on board - and some of it not easy - some of it is a bitter pill to swallow in places." (The full report can be found on www.nimheneyh.org.uk). Tina then went on to present an audio of her colleague on the report, Patricia, who she introduced as a black service user.

The Workshops - feedback

- **Identify what will assist the service user movement to be effective.** "The top three things were: 1. Service user union - individual, local, regional and national - with independent funding. Including a website which would be used as an information sharing resource; 2. User led standards - so users monitoring best practice, payments, expenses and benefits, and teams listening to and acting on real objective service user voices, including evaluation and feedback on service use which has been independently carried out; and lastly: work with the Department for Work and Pensions, Officers of Parliament and Housing to reform benefits making them work for mental health. And that's in the voluntary, sessional - so people who work in the voluntary / sessional part-time / full-time, receiving training, and during the changeover period between benefits and employment or education."
- **Identify leadership training needs for service users.** "The first thing we came up with...is resources. Training needs money to fund it to happen properly and when we are a trained force of people, we need the resources to pay for the expertise that we bring...the second point that we had was about equality and diversity, and again it was partly about recognising our expertise - we're worth every bit as much as people who are so-called

professionals in the field. We have our own expertise. And we all work differently, and we all come from different backgrounds - and we need to recognise and value that and be prepared to value as much, people who don't want to access training...they need to have their voice to. Our third point was about training needing to be flexible. We're all at different places with what we've got happening already. We all have different bits of expertise that we can share with each other. We don't need to re-invent the wheel, there are lots of different training packages out there that we could share. Some people will want very small bits of bite-size training. Some people will want things that are wider and more all encompassing. So we need to be flexible and to meet people where they are in terms of their training needs."

- **Identify the priorities necessary to improve our experience of using mental health services or support.** "The first thing we thought about was education. We should start in the schools - the service users to do the training and basically explain in the schools what mental health is...what the problems are...Stigma...positive public awareness...Focus and review best practice, medication and treatment...don't just experiment on us...Simplify and expand Direct Payments input and research into criteria regarding access to benefits...Continuation of funding for service user involvement...Service user networking (with a database which particularly currently has information on organisations which have facilities for the formation of patients' councils and service user training)...Existing services to be publicised and advertised so that more people will know where to go...rather than being just shoved into a dark corner...Professionals re-educated (much applause)...The whole system needs overhauling...Service user self-help, like mentoring...Listening to young people (the person presenting this feedback was herself a young teenager)."
- **Review the principles and proposals of how we should organise nationally.** "...we revisited Jan Wallcraft's³ vision in terms of what she did around her report and the work she did...on her own terms. And then there was a lot of history that was played out, and also lots of tensions that were played out as well. I think we've got to be mindful of that but think a bit ahead - think a bit forward...we must use our energy to go forward (There were members of this workshop who had been involved with the 'On Our Own Terms' project and who were critical of Jan Wallcraft, also part of the workshop, for taking all the credit and not hearing the voices of some users). The principles need a bit more work...Whatever this thing, this entity is, it needs to be user run and user owned. People worried about the

³ The workshop paper was by Jan Wallcraft and the draft examined is appended to this report

host agency - who that is...its important that this network is democratic and accountable to its network members - '*and elected*' (from the floor) and elected... '*and independent*' (from the floor) and independent..." The workshop also agreed that the principles and the structure should be rural proofed.

and back to the speakers:

David Crepaz-Keay.

David has a twenty five year history of involvement in mental health, first as a service user, then as a campaigner. He is said to be "...an eloquent and passionate campaigner against discrimination on the grounds of mental health history." (conference flyer)⁴

David chaired the afternoon session of the conference during which he underlined the origins of the conference: "This conference hasn't come out of the ether; it isn't something that Anne and I decided on an idle afternoon in December...it started for me...with Jan Wallcraft's work...and one of the things that Jan will talk about a little bit later is learning lessons from what we've done. So this is another part of doing that - this whole exercise is another part of learning lessons from what's happened so far - but its also a stepping stone to doing better things. Which is not to say that what's gone before isn't important - its incredibly important. I know from my point of view I wouldn't be standing here talking to you at all if it hadn't been for some of the people in this room."

David went on to name three people: Frank Bangay. "I became aware of the power of storytelling through the work of people like Frank and Peter Campbell." ..."Alan Leader is an unsung hero of the Survivor movement and his direct action pack has really been an inspiration to me for three quarters of the stuff that I think that I've done ever since." "Jan Wallcraft...lots of people who do stuff... you get criticised for doing stuff. Jan does a lot of stuff, and without a fantastic bit of work called 'On Our Own Terms' none of us would be actually in this room - I think that's fair to say...But I'm also looking out into this room and seeing the future - because the future is what we make out of this opportunity we've got."

⁴ From participation in internet discussion networks I am aware there is some negative feeling towards David from some users because of the content of a previous website. This was my first face to face experience of him and my impression is he is genuine and committed to the user and carer cause - and a positive power for the user cause. I think we should also take note of Tina's comments that "We need to move forward - we need to expend our energy on positive developments."

Emily Brown.

Emily is the Deputy Director of Service User Involvement for 'Together'. Importantly too, Emily is young. She is "...based in the North of England " "with a specific remit for the Midlands and the North" " (Emily) developing and supporting service user involvement and healthy working practices within together and external services (conference flyer). Emily's spot was about "What we are suggesting and what we're not suggesting."

Emily started off with a statement which was fundamentally disappointing to me personally "...it's (the network) **not** about providing a national service user voice. We need to recognise and address and manage the fact that there will be external pressures for a national voice...We need to recognise, and we do recognise that other groups, organisations, individuals are doing that on different topics across different groups of people and across different geographic areas. A national network is not a representative body.

A national network would support existing groups - that's the power of the network. Its not one organisation replicating or taking over. It's not asking groups within that network to sign up to one thing in particular to one organisation. It's about supporting groups and providing support to each other in that network.

There are very few issues that haven't been addressed before, but currently its hard to make those links. It's hard for someone in Lancaster to find out if someone in Surrey has been doing a pretty similar piece of work already and how they've found their own solutions - it's a bit hit and miss...What the network can do is provide those links in a much more coherent way, so that organisations and projects can learn from and use those solutions that have been found elsewhere as a starting point. A network would link groups around a particular topic...

A national network wouldn't be an overarching body that implements policy and practice. Groups develop their own structures, their own aims, their own ways of working to meet their own needs. Groups need ownership of their own processes of development and reaching their solutions. A solution or impulse intimated by another group, even a service user led group is not much different to have been done by an agency without us - which is one of the things we have said all the way along needs to change.

What a national network could be would be a support to groups by providing a library of policies - examples of what has worked so the groups will still have ownership - but they have easier access to the ideas and suggestions that can get them started on the way.

It will be important to us to find a balance between principles and values, but also not having a particular policy line. For example: all groups need to have an understanding of equal opportunities, but they won't all be achieved in the same way, or have the same equal opportunities issues to address.

...Workers for a network would support groups - that would be their role. They'd do that by keeping an eye on policy, finding out about new developments or initiatives that may help or hinder involvement, issues that come up in mental health in general that network members want to keep abreast of and be involved in. At the moment it can be really hard to find out what's going on - you hear from a person fourth or fifth hand and suddenly actually the event was two weeks ago, so it's too late...

Workers will keep in touch with existing groups, building up databases of groups, building an awareness of groups and who has particular areas of interest and who has particular areas of expertise and experience, so that if a consultation comes out, they will send to the people who are most involved and who have most interest in that area...Again, being up to date with consultations, it's about passing information on at the earliest stage possible. All groups need to hear about it at the same time so it leaves less to chance.

The workers will put positive effort into the groups that are least well resourced - so that's about supporting the small and new groups... sharing the experience of the long running groups - supporting the groups who have the talent but not the profile...

So these are some of the ways that a national network will support and strengthen an infrastructure within the service user movement. It won't be something that distracts from groups but will, in fact, enable groups to increase the strength of their voice."

Chandra Fowler and Matt Gregory.

Chandra, well known and respected throughout the service user movement, is currently Head of Policy, Research and Participation with the Revolving Doors Agency: "...the only UK charity that focuses exclusively on the needs of people with mental health problems who come into contact with the criminal justice system." (conference flyer). He himself "...has had personal experience of mental health problems, street homelessness and problematic drug and alcohol use, some of which brought him into contact with the criminal justice system." (conference flyer).

Matt is a service user who, from personal use of Revolving Doors' services, moved on to become a valued employee of Revolving Doors. A prime example of a very positive result from user led services.

Chandra began by saying: "I was asked to say something about some groups of service users who are even less heard than many of the other service users

here today. And there's two specific groups that I would like to talk about briefly. Those two groups have one thing in common as well - and that is both of these groups are service users who end up having contact with the criminal justice system. And something that doesn't often get talked about...in fact I know a lot of mental health service users involved in service user groups who keep their own contact with the criminal justice system secret.

There's a bit to do around this. Its a big issue. There are already problems of course in the media around the image that mental health service users have and I think it makes a lot of mental health service users apprehensive about talking about the fact that there are quite a lot of mental health service users who do get into contact with the criminal justice system.

So I would ask that we might open up these issues for a lot more discussion...The first group is people who are users of forensic mental health services. And I'm very glad to say that there is some representation here today from forensic mental health services users, and thank you very much for coming. Its not a group who get heard very often and I would like to see in the future, their presence here as well - up front telling us about their experiences. I've had the honour of working with groups of forensic mental health service users over the last couple of years and have seen them doing inspirational work. Very early stages of service user involvement in this area but there are people who are breaking new ground and doing very important work. And I think that needs to be heard.

The other group are people who have mental health problems but are denied services, or who find that the services that are on offer are not services they wish to engage with; who end up getting in trouble and end up often within prisons. And I'm not talking about a small number of people. When we look at prisons, were talking about 60 - 70% of the...population of prisons has at least one mental health diagnosis. And large numbers have one, two, three or four diagnoses. We're talking about a very, very big problem...When I go into prisons and talk to service users, and I've been lucky enough also to have organised service user discussion groups within prisons... and I think it's great that these opportunities are slowly starting to happen. I come across people with a huge amount of mental distress and very little support for their problems - both while they're in prison and also when they leave prison and go back into the community, And often leave to no housing or poor housing; to very little prospects of income, to no advice...People will leave with a few pounds in their pockets and are put into a hostel for the night and left to their own devices. It's not surprising that many of these people end up back again within the criminal justice system. There's a huge group of people that aren't represented..."

Chandra then handed over to Matt Gregory who told us that at first he'd got involved in employment with Revolving Doors because he "...was asked to do it by one of the workers there" and "I needed the money" and "not out of the

goodness of my heart...well actually it was a little bit out of the goodness of my heart - I wasn't that desperate for the money...So it was just basically being asked to do it and just seeing how much it would help as well - what I could actually achieve by doing user involvement...training and stuff like that..." "Some of the good things have been...being trained to give talks at conferences like this - obviously the training weren't that good (amid laughter) also training on being giving people interviews...I've also met some of the best people I've ever met...I've got a lot of respect from the staff of Revolving Doors because I've got the personal experience of being in the police station, I've got the drugs experience - so if they want to know about drugs, they just come and ask me."

Chandra then said: "...we got some funding last year and Matt is now a member of staff...we have more who are now employed and we hope to expand that...we are able to engage with the Home Office, the Office of the Deputy Prime Minister and the Department of Health and try and influence them. And I think we need that kind of knowledge...having a very mixed organisation and a diverse staff population and we've got a wide range of skills and it puts us in a strong position to do that. To finish...the reason I came here today is because of the initiative about setting up a network, and especially for the smaller size groups like the one at Revolving Doors this is incredibly important. Were talking about a group of service users who are already isolated - they don't have access to a lot of services... its important, as a group, for them to feel they are part of a wider service user movement. We hope that the setting up of a network will increase the opportunities for that. And its really, rally important that this goes ahead...We'd like to see, at the end of the day, some action that's moving forward, so we can say today is a point in history that we can look back at and say: 'something started here that is going to make a difference to the coming years to the service user movement as a whole.'"

Jan Wallcraft.

Jan is Operational Manager for the Service User Research Group for England (SURGE) and also works for NIMHE, as an Fellow for Experts by Experience, co-ordinating service users and carers who feed into NIMHE policy. She was the "...first co-ordinator of MIND's user network, MINDlink, she went on to help set up UK Advocacy Network, and was a member of Survivors Speak Out's national committee. Importantly, she was the lead in the publication of "On Our Own Terms" (Sainsbury Centre) from which the 'Principles and Proposed Structure' document central to this conference was developed. She started by addressing an anomaly felt by a few people present at the conference who had also been involved in Jan's research:

"David called 'On Our Own Terms' Jan Wallcraft's vision. I don't think I could quite claim it as my vision because it's based on this report where we did go

out and talk to about three or four hundred service user groups, and if you average it out that each of those groups have fifty members or so that's a lot of service users represented in that and I tried to distil what they were saying. But I do have a vision and I hope that vision is in tune with the visions that people have here too..."

She continued to say that the structure Emily described is absolutely spot-on. She added: "She said that it should not be seen as the voice of service users and there were questions about that. The problems with it being seen as the voice of service users is that every government office and every mental health planner will want it to represent service users and that could be quite a danger is you've got three people in an office or whatever and they're seen as being the reps. That's what we definitely do not want it to do. What we do want it to do though is be a place where every service user group can have a sign up too...All those groups can be networked and...when the planners want a representative the...right person can be found from the existing groups who are signed up to it. And so it won't be speaking on behalf of users but it will be directing the people who want a user voice to the right place to find that. Also trying to build capacity so that people are better able to get their voices heard..."

We need to get the service user movement to discuss some very key issues. A couple of the crucial issues are things like what we think about medication...are we for it or against it. Obviously, there's a wide diversity of views about treatment and what kind of treatments but we need to have that debate and find out what we've got in common about that. And even more important: what do we think about pharmaceutical companies coming in with funds and trying to offer those to service user groups. There's a huge diversity of views on that... ("Yes, why not? I have no moral qualms about taking money from them if it means we can do useful work with it." ----- "It doesn't seem right to me...I wouldn't want it to be a matter of policy for the survivor movement." ---- "it's like taking money from the devil." On Our Own Terms, 'Debating our differences.')

National voices. Series of voices. Many voices. Training people in media skills...learning people how to speak out in the media...People say oh Marjorie Wallace is the voice of the poor, downtrodden service user. I don't think so! Here we've got masses of media talent...you know from just talking to people they've got plenty to say, they just need their confidence built up so they can go and say that to their local journalist, their local media, or to the regional or to the national media, and we can actually get a real voice...We need to be in the national newspapers saying what we're about...that's going to be the quickest way of eliminating stigma. We could do it in six months...We could make sure that any TV programme that wants to represent mental health issues has to...go through this network and get authorisation otherwise they'll get endless...streams of complaints from service user groups which could be orchestrated around the country...You don't go to Marjorie Wallace to get Sane's advice...come to our

network. That's the sort of vision I have...

Finally, the last bit of my vision is that we start to develop our own alternatives such as the sick management thing...the expert patient programme or whatever we call it. Its being done by people like the Manic Depression Fellowship and Hearing Voices Network. We think that developing self-management courses...The government's sponsoring the Expert Patient Programme, which is fine as it goes but its not specifically for mental health...we need something which is more mental health oriented or which builds on the EPP or which builds on what the existing organisations are doing. Why can't we back the Manic Depression Fellowship to get money to roll out their programmes which are excellent programmes for people with those specific issues? Where's the money for the things that are coming from the user movement? We can do it ourselves!

One of the best things I was involved with was MIND's lottery millennium funding. Its a simple idea: they get money from the lottery and they give it to service users who've got a vision, who've got a dream, who want to achieve something. They're given like 3000, 4000 pounds to get some really high level, high class training on whatever it is they want to do. And then they go and do it. But...that person then has a responsibility to give something back to the community based on what they've learned. There's somebody creating the Borderline website for people with borderline PD; somebody else wanted to do something about former servicemen in war; somebody wanted to renovate furniture in old people's homes; somebody wanted to make a sculpture and sink it in the local harbour for people to dive and visit - all sorts of crazy and wonderful ideas came out of that - lots of complementary therapy projects...all sorts. But...you could abolish most of the mental health system if you just gave people the money to create their vision and then give something back. (applause) I think I shall stop there while I'm winning." (A shout from the back: "Give us your salary!")

Winding up and Going Forward:

The conference finished with a short session of questions from the floor and a vote to determine the future direction. Unfortunately, and for me, this was the only failing of the whole event, the vote session was inadequately handled and presented (David admitted as much to me afterwards). The main vote was whether or not to accept and take forward the Principles and Structure Proposals document. This came as something of a surprise to many of the delegates who hadn't been at the Principles and Structure Workshop for, although the document was in everyone's conference packs and everyone had been exhorted to read the document at the beginning of the conference, many hadn't and there was a rush to do so at the last minute. There were quite a few complaints that the document should have been published as essential reading with adequate prior notice. In

addition, David failed to differentiate between the original document and the document draft as amended by the Workshop. The eventual vote though, after some votes were changed to yes after the issue had been questioned and the decision from the chair was that it applied to the amended draft, was overwhelmingly for taking it forward. There was then a decision that a small steering body would need to be put together which could attract funding. We now await developments.

Mike Cox.

29th March, 2006.