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# Spanner in the works

## obstacles to practical user involvement and pathways around them

**What are the processes by which user involvement in the drugs field can be enabled and supported, or by which it is hampered and obstructed?**

Andria Efthimiou-Mordaunt is the editor of *Users Voice* magazine of the John Mordaunt Trust, which enables drug users to have a campaigning role in advocating for non-criminalizing drug policies, and updates folk on HIV, hepatitis and addiction treatments.

Many users are enthusiastic about user involvement, but I would like to make some suggestions for them based on my own, sometimes painful, experience. I would encourage users to engage with this work as a skills and/or career building move, eventually making sure they are paid like every other drug-worker.

User involvement work is very tough. You will be up against draconian drug policies, conflicting research evidence, disillusioned drugs users and drugs workers who are resistant to changing outdated and oppressive treatment regimes. There are heroic examples all over the world of what drug users can do for themselves if given the opportunity. In the UK, The National Drug Users Development Agency (NDUDA) has managed to bring some of the groups together, for which they deserve due credit. Another of their achievements was to organise nominal funding of

the groups through Comic Relief. This has been invaluable to sustain some of the groups and magazines we produce, for this we owe them a debt. But for many of us, the course of true user involvement doesn't run smooth.

### Different agendas

The short answer to user involvement? Lack of resources, knowledge base, skills, understanding and support from the field. And users are often unwell. But it has to be acknowledged that we often have different agendas and this inhibits unity. There is great diversity in user group models:

- Some groups only want to work in the trenches on harm reduction, needles and drugs etc.
- Some want to advocate for better drug/alcohol services.
- Some prefer to do client advocacy work.
- Others want to be a self-help group

for those trying to get stabilised or drug-free.

- Others want to be part of a dynamic force of change that brings back harm reduction as our main drug policy paradigm.
- Still others are driven to campaign for this country's drug laws and policies to be radically overhauled, to have government regulate and control the drugs markets.

### Money, money, money

Funding of course is a major issue. If it is difficult for user groups like the Methadone Alliance to get funding to do advocacy work, it is damn near impossible to raise funds to give users the skills to organise, let alone challenge drug policy. Funding is often random and ad hoc. I was approached by an ex-user drug project manager at a conference who asked me whether I could come and help establish a group in his area. I said I would be glad to if they would contribute to the John Mordaunt Trust. They were happy to do that.

I'm left wondering why some agencies in the drugs field can come up with a few bob, when most can't or won't. When we have discussed this with colleagues in the field, the consensus seems to be 'where there is a political will (to support us) there is a way.' But there doesn't seem to be much of that around and so user involvement is down near the

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bottom of the list of priorities of most workers.

### Moving forwards ourselves

But as we know, there are several well-functioning drug and alcohol user groups around the country. What can would-be user activists learn from their experience? A few tips:

1. Group members need previous experience of any of the following: lobbying health authorities, fundraising, oratory, admin skills and/or group development expertise.

2. Local users who are already eager to organise. Beryl Poole and Al Drake in Brent are a very good example of local user activism.

3. Workers in the area need to be committed to user empowerment, and willing to provide refreshments and travel costs (at least) to group members.

4. Groups should discuss whether to begin with burning-issues sharing. Some arrive having just been traumatized by cops, ripped off, strung-out, and/or many other social problems. They need space to clear their heads before being able to work. This also works as an essential bonding strategy, and ultimately helps groups stay together.

5. Supportive but firm ground-rules, for example at meetings you must be 'straight' enough to function, drug talk should focus on our work rather than personal use. This is for the protection of ex-users, as well as

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ensuring you keep focused on the work agenda.

6. Group members need to be housed, have scripts and caregivers (where necessary), and an interest in developing the skills they already have.

7. Group members must care about themselves and other users lives.

8. And, it needs to be said, where activists are paid, they can be expected to take on more responsi-

bilities and, in turn, they take the work much more seriously.

### The bigger picture

The signs for user involvement and more generally more flexibility within drug policy are encouraging. The National Treatment Agency (NTA) has asked us for advice to develop this work in the UK. In an



effort to get more users into treatment, increasing heroin prescribing and the provision of shooting rooms are being actively considered. The Home Affairs Select Committee is currently 'gathering evidence' on whether UK drug policy is working, but it will probably be a while before we see significant changes. But users cannot just sit and wait for the world to change around them. Current

experience shows that, despite all the spanners thrown in the works, user groups can make a positive contribution to the lives of those with drug problems. But it is important to:

- Be clear about the goals and objectives of the user group, seek advice from people who do similar work. You will need a lawyer for the paperwork.
- Be realistic about how much time you have to do user involvement

work each week, month etc. Think about your health-care here: some users are perfectly healthy but many are not. Be honest with yourself, and ask for help when you need to.

- Decide from the offset if your remit is local or national.
- Find professional allies, *ones whose actions speak louder than best-intentioned words.*

• *Read.* I cannot say this enough, you need to keep up with all the rapid changes going on in many areas of our work.

• Get training in the skills you do not have and practice the ones you do.

• If you find you do one thing well, stick with it. You will be far more helpful to the movement, and yourself, if focused.

• Take care of yourselves so you can do the best in giving care to others.

• Finally, keep your eyes on the prize: no AIDS or hepatitis among us and freedom to choose drugs in a caring society if we need to, without fear of jail, or any other imposed institution for that matter.

It is rumoured that user activists are control freaks (and get hurt easily when our work goes unacknowledged). I am not sure about this one as I see several of my non-user colleagues behave similarly. Most users have enormous loss and grief issues inside, so things can cut deep. We have to learn to credit each other's achievements more. Never let yourself forget how fortunate we are, we have survived.

*We are still here* ■