

Peter McDermott

Flavour of the month

Users in service provision

The issue of user involvement in drug service provision has made it to the political agenda, but is it there for the long term.

I have been advocating user involvement in drug service provision for over fifteen years so you might imagine I would consider this to be a matter for rejoicing.^{1,2,3,4,5} Yet, I have serious concerns about the way this issue has become 'flavour of the month' among drug service commissioners and providers.

It seems that a number of major problems associated with user involvement have received little consideration by those seeking to develop this area. I will attempt to outline some of the problems and suggest ways towards beginning to tackle them.

Obstacles to user involvement in the drugs field

There are a variety of models for user involvement in drug services. The Dutch Junkiebond exemplifies the quasi-political drug user self-organisation. In peer coalitions, like Edinburgh's Crew 2000, drug users engage in development and delivery of education and prevention strategies.⁶ Other groups play a more consultative role, as focus groups and having representation on drug agency management committees, or even Drug Action Teams.

Over the last fifteen years or so, I have been involved in groups employing many models, each has its strengths and weaknesses. But all are hampered by a number of factors.

The first is the relationship between drugs services and service users. Despite sincere attempts to tackle this issue, for the last thirty-five years or so the relationship between service users and providers has been characterised by mutual antagonism.

Many users see drugs agencies as

having one single useful role in their lives – the provision of a clean supply of legal drugs. There is really only one way for anyone addicted to opiates to exist without continual engagement in illegal activity – to get a maintenance prescription.

Opiate agonist maintenance is not all that drug services offer. But, it is the *most* common form of contact that illegal drug users have with a drugs agency. The result is that it has come – for users at least – to be a model for the entire relationship between users and workers.

The relationship between users and service providers should be a therapeutic alliance but the dominant characteristic is mutual antagonism. Drugs workers control access to the one thing we users regard as important. Drugs workers have the responsibility to see that we get some, but not too much. The result is that we consider you not as partners in a journey towards improved health and social stability but like guards in a concentration camp – obsessed with control and monitoring the minutiae of our lives.

How can we change this? User involvement may go some way to reverse this process, but first we must address the major obstacle to the development of user involvement in the drugs field: the extreme structural inequality in the relationship between drug users and drugs agencies.

The differential is not just in economic and educational advantage but, most importantly, it is a differential of power. We can hardly expect to eradicate class differences in society as a whole, but we need to be sensitive to them when planning

services, training staff, designing protocols, and so on. But, the power differential is something we can work towards addressing. I hope that having the field engaged seriously with drug user organisations at planning and policy level is one way we can begin to address this.

Self-organisation

Over the past two or three years there has been significant growth in drug user self-organisations: a number of new groups have started up across the UK. They now have a national umbrella organisation, the National Association of Drug User Groups (to assist groups through networking), and a development agency, the National Drug Users Development Agency (to assist with organisation and community development).

This should make the process of consultation and collaboration much easier. If we want to build a proper alliance – to involve patients and clients in the pursuit of common goals – then all we have to do is contact our local user group. And if one does not exist, we just raise some money and start our own. This sounds, and is, facile.

Though rarely spoken of in public, some services have learned that this path is often just is not tenable. There are a number of reasons why:

At the moment most user groups are not currently able to make a meaningful contribution. Even the most developed user-run projects are still in their infancy. For example, the National Drug Users Development Agency consists of one worker on a half-time salary. The Methadone Alliance⁷ has similar resources.

Both of these organisations employ



Peter McDermott is a writer, researcher and consultant. He is a member of the UK Harm Reduction Alliance's executive committee, and a patron of the Methadone Alliance. He has also been a patient of NHS drug treatment services since 1975. Current projects include writing drug prevention materials for Lifeline and the creation and management of websites for a number of drugs projects.

His forthcoming memoir, 'Groin shots: stories from the dark side of the spoon' will be published by Canongate.

drug users with a professional background and training. In contrast, the majority of such projects are forced to rely on volunteers, most of whom lack higher education and professional training.

There are some extremely bright and talented individuals in drug user organisations, who are more than capable of contributing. But, it is another reminder that profound structural reasons thwart user

their contribution in the short term is likely to be limited.

Other alternatives are: recreational drug users, often with a history of employment in the drugs field but attempting to walk a difficult personal tightrope between being in and out of the closet;^{2,3} or ex-users, who tend to have a different mind-set and a different agenda to those who actively use illegal drugs, or currently use services.

What tends to be missing is a rational view that drug users are the same as everyone else – just like drugs workers, some good and some bad, some clever, some less so.

organisations from being the viable force I hope they will become.

Workers who wonder why it is so difficult to establish a vibrant and dynamic user group, tend to overlook an important fact – *drugs are still illegal*.

Many workers seem to forget this, or imagine that somehow their own concerns should not necessarily apply to their clients.

Even though more people are prepared to talk about their own drug use openly in a social setting, it is a dismissible offence in most workplaces. What is true for recreational drug use is a thousand times more so for people with patterns of dependent or problematic use.

Dependent drug users are a heterogeneous population with members from all points on the social spectrum, but if you have a job you want to keep, if you have a mortgage, or life insurance, or car insurance or a driving license, then keep your head down. To reveal that you are an active drug user puts all of these in jeopardy.

Consequently, drug users who have the skills, education, and life experience that could make them effective advocates and leaders are forced to stay away by self-preservation. Too often, the people we end up with are chaotic users who have little to lose. While such people may benefit from their own involvement

What is to be done?

I have written about these problems in the past, and people have taken me to task for being negative – describing problems but failing to offer solutions. At that time nobody actually acknowledged that there was a problem in the relationship between drug services and their users.

There are indications that this is beginning to change. There is a growing commitment to a more egalitarian and less oppressive style of services and a genuine desire to recognise that service users must help to determine what future drug services should look like.

The most pressing question we face at the moment is, how do we get there from here?

I think that it will inevitably be a long process. Despite the drugs field's history of novelty seeking and its tendency to reach for a 'quick fix' (no pun intended), experience should have taught us that there *are* no quick fixes. Making it up as we go and relying on PR rather than substance is not enough to address this particular issue.

Recent changes in the field have started to raise standards. In the future agencies will not get away with shoddy, under-theorised and poorly run services, which have little or no significant impact on the lives and well-being of their clients, that have characterised some drugs projects in

the past.

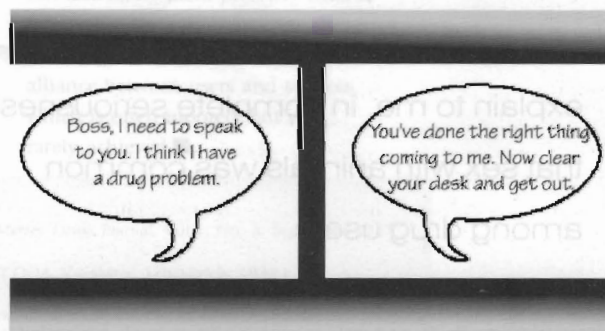
But positive change will only come about, in my view, with commitment to a profound shift in attitudes and significant structural alterations in the relationship between service users and those who provide services for them.

Attitude change

It is a sad fact that drug treatment workers' attitudes towards drug users can be characterised by two extreme stereotypes. The traditional view – commonly held but rarely articulated – regards drug users as scum of the earth, untrustworthy, unreliable, and prone to lying and thieving. I once had a qualified social worker explain to me, in complete seriousness, that sex with animals was common among drug users.

More recently, an alternative view of clients has emerged, albeit equally stereotypical and just as fallacious. These workers take an overwhelmingly positive view of drug users, as oppressed people whose insights are automatically worthy of attention and credibility and who can do no wrong.

What tends to be missing is a rational view that drug users are the same as everyone else – just like drugs workers, some good and some bad, some clever, some less so. Workers who have been in the field for a long time generally reach this conclusion. Professional training needs to counter both the stereotypes and establish the client/patient as a human being with a problem – no



different to anyone suffering diabetes, depression or other health problems.

Another area where attitude change is essential is in how the service being provided is viewed. It is curious that in the USA, reviled home of the 'war on drugs', methadone treatment is not seen as a

substitute addiction but as recovery. The Americans with Disabilities Act made it illegal for employers to discriminate against methadone patients.

Many – perhaps even most – of those who work in methadone treatment in the UK see it as a sin and moral weakness. The patients no longer use street drugs but there is implicit concern that they are still doing a ‘bad thing’. If treatment providers have such a negative and moralistic view of the treatment, how can we expect public attitudes to drugs and drug problems to change?

Structural changes

Unfortunately, these attitudes do not exist solely in a handful of individuals. In the same way that racism and sexism was not limited to individuals but became embedded in institutional structures, so the negative stereotypes of addicts and addiction are within the fabric of treatment services. This produces an effect analogous to institutional racism, which could be termed ‘institutional addictophobia’.

Many standard practices of drug treatment consequently have nothing to do with the interests of the patient, but are based on the view that all our time and energies are devoted to lying or cheating the system. With the result that much of what passes for addiction treatment is little more than a regime of disciplinary scrutiny – a tendency which has worsened in recent years.

Some personal experiences as

documentary proof of my travel plans – flight reservations, hotel bookings and so on.

What does this achieve? I assume nobody doubts my intentions but the procedures are based on the assumption that everything I tell the service is a lie. Therefore, everything must be documented.

On one occasion I was invited to speak at a conference in the USA at short notice. The team took the decision that I should not be allowed to go. Apparently, those against tried to justify refusal with a perverse democratic argument: they would not do it for ‘Billy Baghead’ – they suspect he wants two weeks supply at once to get wasted – therefore they should not do it for me. This despite the fact I had been invited by eminent figures in international drugs research who could vouch for the lack of notice.

Fortunately, my enlightened consultant psychiatrist saw this refusal for the nonsense that it was – for the first time ever he overturned the decision of the team. But what was the logic that informed the team’s perverse decision?

In my experience a great many drugs workers fear and feel threatened by genuinely articulate and empowered service users. This tendency hardly bodes well for strategies of user involvement in services.

Another example is urine tests. It is at least 20 years since I regularly used illicit drugs. Over the last seven or eight years I have not used any illicit

prescription accurate. So what’s the point?

Both these practices (and many like them) are grounded in institutional addictophobia, which perpetuates practices with no purpose other than to humiliate and infantilise users, to extend our dependency rather than empowering and liberating us. Unlike other



addictophobia?

health service patients, we cannot seek alternative treatment in the private sector because doctors there are almost as stigmatised and as persecuted as users are as patients.

I am happy to acknowledge that urine tests and supervised consumption *can* help to save the lives of chaotic people desperately seeking stability. Unfortunately, due to the unconscious addictophobia in drug treatment, workers believe that nobody would freely opt to seek such help, so it is imposed as a condition of receiving drugs. Is there another health area where patient compliance is enforced through coercive procedures of this type?

These attitudes and practices must be challenged. There are workers who object to such humiliating practices, but the hierarchy of modern drugs services means any challenge from them is likely to result in the worker being marginalised, even dismissed.

Service consumers need to start speaking for ourselves – to engage as equal partners in dialogue about the

I once had a qualified social worker explain to me, in complete seriousness, that sex with animals was common among drug users.

illustration: much of my work involves consultancy on a range of issues – often for drugs services – but sadly no longer in the region where I actually live. This means that I need to travel to visit clients occasionally, perhaps four or five trips a year. Whenever this happens I have to give at least two weeks notice and provide

drugs at all. Nevertheless, I am still subject to the regular humiliation of random urine tests.

Why? Who does this help? Certainly not me – I know I am not using drugs. Not my key worker – I am not presenting with any problems, other than those related to the service’s consistent inability to get my

nature of drug treatment services in the UK. But not as a token gesture, an afterthought, another box ticked in some notional quality manual as a pretence we are engaged in 'good practice'.

We need fundamental changes to the core ethos of what passes for drug treatment and drug services in the UK.

The future for drug user self-organisations.

An obvious way to tackle such problems is through robust drug user self-organisations. Unfortunately, the last fifteen years have taught me that this is more easily said than done.

The majority of user groups in the UK consist of little more than one or two enthusiastic amateurs. Some have had grants from charities like Comic Relief. Others exist only because drugs workers drag users along in their wake, offering inducements of travel or status.

Their dominant activity, with notable exceptions, appears to be touring drugs conferences and whining about their lot to politically correct professionals who encourage them in their dependence. This is not, to my mind, what a drug user's self-help movement should be.

If drugs workers and users are ever to see genuine changes in the way services are run and in the ethos of the therapeutic relationship, they will have to be approximately equal partners in the project. To accomplish this the user movement *has* to be assisted through its present period of embryonic development.

Important beginnings have been made. The Methadone Alliance, and Adapt[®] are doing sterling work in advocacy. Crew 2000 and the Healthy Options Team produce harm reduction based drug prevention materials. The National Drug Users Network provides an information exchange, and Comic Relief has funded a half-time post for the National Drug Users Development Agency.

The process has begun, but there is a long way to go. But, if we are committed to drug user involvement in service provision the establishment of a vibrant patients' movement is essential.

To achieve this the drug user self-

organisations need to develop through a programme of research to identify what works. This information must be disseminated throughout the drugs field – to workers and users.

There is now a wide range of practice among drug user organisations – some of which receive funding from national or local governments.

The Netherlands gave the first model of user advocacy with the Junkiebond, there user groups are involved in creating national drug policy. Australia has its national organisation, the IV League, and the US federal government has funded advocacy groups, including in New York Gay, Lesbian, Bi-sexual and Transgendered People for Recovery.

Unfortunately, we do not have accurate accounts of what these organisations actually do, no comparisons of how successful they are at achieving aims and objectives. We need to examine these models carefully – what they say they do and how successful they are in practice – and feed that information to nascent drug user self-help organisations in the UK.

It is not just information about and models of organisational structure that we currently lack. I have implied throughout this article that a good advocacy service is the key to change relations between drug user and drug services. There is a wide range of abilities in the user movement, but few have experience of professional practice. Consequently they lack the skills to identify the pressure points and policy forums, the places where wrongs can be righted, bad practice can be revealed rather than concealed, and change can be made.

We need to thoroughly research

the resources available to drug user organisations, and come up with a manual or programme, which prevents each group from repeating research and skills development from scratch. Provision of information, rather than ever more insubstantial funds, will make the difference between an effective drug user movement and a moribund one.

There is a range of ways to disseminate the information – manuals, training or the internet – but the first stage must be to research and collect the information. People can then go on to learn about the management of such groups, the institutional structure of drugs services and their funding, how to do effective advocacy, and so on.

Without such a resource drug user self-organisations will continue to be little more than forums for complaining. Without the information they will never be able to mount an effective challenge to the problems of structural inequality and institutional addictophobia that undermine treatment agencies, rendering them ineffective agencies of social control rather than genuine therapeutic alliances of patient and healer.

There is more than enough evidence that demonstrates the important role drug users can play in transforming the drug strategy of any district.

By embracing such an approach we can give people the skills and the self confidence that they need to make real and lasting changes to effect personal transformations. We can also show them precisely what is achievable through their own efforts, resulting in a genuine therapeutic alliance between users and services, which is often mooted, but very rarely achieved ■

References

1. Peter, (1987). Merseyside Users Group. *Mersey Drugs Journal*, Vol.1, No. 3. Sept./Oct. 1987
2. McDermott, P. (1991) 'Coming clean'. *SCODA Newsletter*, Feb/March, 1992
3. McDermott, P.(1992), 'Coming clean revisited: a response to Bill Gordon'. *SCODA Newsletter*, Feb/Mar, 1992.
4. McDermott, P. (1992) 'User friendly? User run!' *Druglink*, Nov/Dec, 1992
5. McDermott, P. (1993) 'The personal touch'. *Druglink*. Jul/Aug. 1993
6. McDermott, P. (1993) Crew 2000: Peer Coalition in Action. Nov/Dec 1993
7. Methadone Alliance website <http://www.methadone.org.uk/>
8. Adapt user group website <http://www.adapter.freeserve.co.uk/>