

Mat Southwell

The long march To inclusion

One of the most significant features of the public sector at the end of the twentieth century has been the substantial impact of the consumer and patient's rights movements.

A number of high profile scandals have highlighted the need for better accountability, more openness and a clear focus on evidence-based practice.

Sadly the impact of this movement on the drugs field has been so limited that in 1996 the government's Effectiveness Review had to remind drugs services that the Patients' Charter did apply to its clients.^{1,2}

The linking of user involvement to new funding has given services the push that was desperately missing when altruism was the only motivating force. Many were committed in principle to user involvement but it just never made it off the bottom of the agenda.

Over the last three years government has been trying to find more dynamic engagement with the emerging drug user movement. The National Drug Users Networks, a comprehensive alliance of all types of drug user groups across the UK and Channel Islands, challenges the perception of drug users as helpless and unmotivated.

Government, to its credit, has begun to open its consultation processes particularly in drug treatment and blood-borne viruses. The realisation that drug users can play an important role in the modernisation of drug services is slowly being recognised. While some key gains have been achieved, this has been slow to be translated into core funding for the drug user self-organisations (groups run by and for drug users).

A number of reasons have been

given as to why government has been unable to establish a meaningful funding relationship with drug user self-organisations over the last three years. The government was concerned that they would end up funding organisations that would campaign against their own Ten Year Drug Strategy.³

Drug user self-organisations have been formed to clearly separate the service user and patients rights functions from other aspirations within the drug users movement.

The continued lack of progress

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highlights a more deep-seated desire in the drugs field to only want to hear drug users when they are speaking in support of current policy.

This has been reflected in professionals seeking to form more 'reasonable' drug user groups to replace those that were questioning local policy and practice. This seems to fundamentally contradict the purpose of engaging consumers.

Funding consumer groups does not represent an abdication of control over the policy agenda. The

intention is to hear consumer views, in all their diversity, as part of forming the rich picture, which underpins strategic planning.

Secondly, there have been concerns about legitimacy of our movement. Like all community organisations the search for democracy is a journey. A key struggle for the National Drug Users Development Agency, to form a legitimate national organisation with a membership of local and special interest drug user groups, has been its lack of funding.

Frustration

It is frustrating to be continually asked to justify our legitimacy while funding bids that would secure our capacity to move to a democratic model are continually blocked.

By contrast, Comic Relief saw the same problem within local drug user groups and set up a small grants fund that has enabled many groups to formally constitute themselves and to expand communication structures with other local drug and alcohol users.

Thirdly, there has been the question of representation as government highlights the need to engage us alongside other drug or alcohol consumer groups (e.g. ADFAM and the Twelve Step Movement).

We support all moves to engage consumers but it does seem somewhat perverse to fail to fund an organisation that represents over forty drug user self-organisations because you might also want to consult other



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networks.

This excuse has also been widely used at a local level but evidence from both Trafford and East London highlights that effectively supported drug-user organisations lead to the development of a range of drug users groups with different specialist

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focuses. Concerns have been raised about the type of information that drug user organisations might provide. We were engaging with one senior official about a proposed major change to drugs treatment practice and the need to consult drug user groups. This person quite seriously pointed out that these comments would not be viewed at face value because people who were taking drugs gave them.

Outdated view

This view is clearly informed by the continued pathologising of drug use. Even if one wishes to defend such a position, it is worth noting the comparative progress of mental health consumer groups with the inaction in the drugs field. This view also seems to support an outdated view of professionals as objective and impartial when recent scandals have highlighted that professional bodies defend their own vested interests.

It is clear that there remains substantial ambivalence in the professional field about moving to a new relationship with drug users. Traditional clinical practice focuses power in the hands of professionals.

When drug users seek to resist the prescriptive treatment options on offer to them, the response is to impose more draconian sanctions and controls on those needing help.

Grant McNally has highlighted how this promotes the institutionalisation of drug users.⁴ This happens to such an extent that people lose faith in their capacity to control change in

their own lives.

Undermining drug users' self-belief frustrates their capacity to control or cease using drugs. It also reduces the likelihood of drug users finding a new partnership relationship with drug services.

Friedman and colleagues have

argued that drug user organising has immediate benefits to the individual drug users, which they describe as 'redemption through social struggle'.⁵

Given this analysis one has to question the logic of locating drug user involvement posts in drug services. As Brager and colleagues have noted: 'Many sponsors would be more likely to support the rights of constituent groups if such autonomy did not pose a threat to their own survival and developmental needs'.⁶

Where professionals have sought to control the scope of drug user involvement, it is clear that this approach has actually led to greater conflict between drug user groups and professionals. This can easily be explained, generic community development theory confirms that if you offer consumers more participation without any increase in power, you actually cause them to become more alienated than if you had not engaged with them at all.

A number of recent professionally led initiatives on user involvement only seem to reinforce fears among

users that professionals will stampede to user groups as user involvement becomes the new 'sexy' approach. The fact that professionals have the resources to overrun the drug users movement does not mean that it is the right thing to do.

An essential part of community participation is creating the capacity among consumers and offering them the space to have control over their own destiny. Perhaps the first step for most drug services should be a review of their own values and approaches towards drug users and some honest reflection on historic mistakes.

In trying to understand the last three years of development work between government and drug user self-organisations, one cannot ignore the delivery problems that undermined New Labour's good intentions in their first term.

The formation of the National Treatment Agency (NTA) launched in April 2001 has seen a sudden increase in momentum and a serious commitment to engage drug users. In part this progress reflects the bringing together of some key players in the NTA who had shown integrity in honestly working on their own reservations and concerns about engaging the drug users movement.

In part it also reflects the involvement in the NTA of some key players from outside the specialist drugs sector who haven't grown up with some of the pathologising of drug users.

Many will now be watching the NTA to give a national lead on user involvement. It is no longer good enough for government to assert one thing in policy while failing to match this with adequate resources. Early signs are very positive but after three years the consumers movement in the drugs field cannot be left hanging on much longer ■

1. Department of Health (1996) *Task force to review services for drug misusers: report of an Independent Review of Treatment Services in England*, London: Department of Health.

2. Department of Health (1987) *Patients charter*, London: Department of Health.

3. HMSO *Tackling drugs together - a ten year drug strategy* London: HMSO (1994 - this was the date of the consultation doc rather than the final report).

4. McNally, G. (2001) *Drug user involvement: from aspiration to reality*. Presentation at University of Kent 'Drug Policy in Crisis Conference'.

5. Friedman, S., Southwell, M. et al (2000) 'Harm reduction, a perspective from the left' *International Journal of Drug Policy*.

6. Brager, Specht & Torenzer (1973) *Community organising*, Columbia University Press.