

Nothing about us, with

User involvement, past, present a

DRUG users are among the most vilified and demonised groups in society. They are the 'dope fiends' and 'junkies' of the popular media. Even among some of those charged with their care, they are tagged as 'undeserving troublemakers'. No wonder, then, that they should want a voice to challenge the treatment policies and practices that often dominate their lives. But equally, it should come as no surprise that the road to user involvement has been littered with bear traps.

PIONEERS

Like any embryonic campaigning group, the drug user movement had its pioneers and champions; people who made the early running to try and make things happen. Prepared to give over substantial amounts of time and energy, they had the passion and commitment to build up momentum from virtually nothing. They were trying to break through the barriers of professional apathy and hostility against a backdrop of personal, physical and mental traumas of all descriptions. Much of their emotional distress became sublimated in the movement itself, resulting in

a self-destructive fracturing into different alliances and ideologies.

Erin O'Mara of user's magazine *Black Poppy* uses expressions like "exhausting" and "deeply emotional" to describe her ten-year battle at the frontline and says candidly that user involvement "has been littered with the corpses of new groups and fed up members". Mat Southwell, who founded the now defunct National Drug Users Development Agency, talks of, "the insidious and destructive cycle of in-fighting that too often distracts and destroys user groups".

The competing ideologies were more than subtle debating points – some wanted a politicised movement majoring on the right to use drugs through a radical reform of the drug laws while others wanted an umbrella movement that would have more of an advocacy role. Some simply wanted to empower users to fight the battle at a local level. This highlighted the lack of a clear vision of where user involvement should start. As Grant McNally, another user movement veteran observes, "we were trying to put the roof on a house that hadn't been built yet".

PROGRESS

But it would be wrong to deduce from all this that no progress has been made. Those campaigning for users' rights have had a decade of meetings with health professionals and government civil servants, spoken at conferences, run workshops, organised training, published magazines and slowly managed to get this issue onto the treatment agenda at a national, regional and local level. And there have been some notable organisational successes. In 1988, a group of former Phoenix House residents, most of whom were living with HIV, set up the first HIV/drug support group, which eventually became Mainliners. The Methadone Alliance (now simply 'The Alliance') has become a highly effective advocacy group, mediating between individual users and professionals where problems arise. Elsewhere in this issue are examples of local groups trying to make a difference to the lives of drug users.

The NTA has backed a new initiative to rekindle the idea of a national forum – the National User Advisory Group. This new grouping still has to tackle the basic questions around the nature of user involvement. But, says Grant McNally, it now operates in a different climate. "Lines have to be drawn under the past. The newer local groups don't want a top down organisation telling them how it is. People are tired of personalities".

"What they want is advice on devising policies, how to set up groups and legitimise them and really simple stuff like running a meeting and writing the minutes. The user movement has failed to deliver on this nationally". The group also wants to build on the work done in QuADs in developing core service users' charter standards. "What are the criteria for ticking off the boxes?" asks McNally.



The history of drug user involvement in the UK is a catalogue of dead ends, brick walls and frustrated ambition. But while the signs are encouraging and some of the lessons of the past are being learnt, there is still a long way to go. By **Harry Shapiro**

“And more importantly, what are not? It’s not just about paying for somebody to go to a conference.”

McNally believes that user activists can learn from others and points to the hepatitis C mentoring conference in 2001, “the first time anything like that had been done”. But he also admits his hope that hepatitis C “would be the glue to bind the user movement the way HIV never did” has failed to materialise. Others think that the drug field is too insular and needs to look beyond itself to find the best examples of how the customers of health and social care services can influence the services on offer.

Maggie Rogan of Lifeline points out: “in the area of social care and disability (whose US activists coined the title of this article) customer care training was being delivered to workers by local chambers of commerce back in 1984. The idea that people were involved as customers and knew exactly what was going on, was tangible even then. It’s all about the difference between what’s important to somebody as opposed to what’s important for somebody”.

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PREJUDICE

But she acknowledges that it is professional prejudice towards users which hampers progress: “You can talk about this in the social care field because people are ‘deserving’. In the drugs field they are perceived as not deserving, so it is not only more about what’s important for them, but also what’s important for the community.”

While applauding all the effort past and present, including those from the few professionals who are moving beyond tokenism, Sara McGrail of the Office for Public Management remains sceptical that much can be achieved unless services themselves become more proactive in delivering care that intrinsically involves users. “How can you have ‘user involvement’ whatever that means,” she says, “when in a room of 20 users only three have seen their care plan?”

She says the problem for users taking the initiative

to complain about services is that it immediately becomes pathologised by people saying ‘that’s part of your illness – what you want is more drugs’. She wants to see services taking a problem-solving approach working with users to actually re-design services around users’ needs at a very basic and mundane level. “That’s more important than redesigning policy,” says McGrail. “Until you realise that you have rights, no amount of telling you that you have them is going to make any difference.”

INSPIRATION

User involvement is undoubtedly the flavour of the month at a national level. But in a highly politicised arena like drugs, priorities can change rapidly and it is unlikely that the user movement has much of a future if it relies solely on government funding. Nor is the government likely to back radical developments. But the field has to think radically, and could do well to look to the general social care world for inspiration. There we find genuine attempts to engage the service user as a customer, to have ownership of the intervention – from service design through to the individual’s experience of that service.

One example is the Advanced Directive, a scheme whereby a mental health patient can work with their service to pre-plan for a scenario where they are incapable of making rational decisions. Those with physical and learning disabilities can even engage in determining how part of their care budget is allocated. Do they really want to go to the day care centre or would they rather the money be spent on bus rides with a support worker? This is the difference between what’s important to somebody as opposed to what is important for them. Initiatives like these could directly transfer into the care of drug users. For example a Pre-Relapse Plan could be drawn up outlining what a drug user wants to happen to their care or that of their children should chaotic use return. Or a user might be involved in deciding how part of the aftercare budget was spent. What’s more important to them – weekly acupuncture sessions or two days of childcare so they can get a part-time job?

One size does not fit all. Drug users are not a homogenous group and there is no reason why the user involvement in services should not be equally diverse – not least because some involved users do not experience service delivery, while some are very involved in a particular service with no desire to engage with the broader issues.

But given the status of users in society, it is doubtful they will be able to effect radical change by themselves. It will need an active partnership with Drug Action Teams, as well as commissioners, service managers and workers to fashion a service experience which values dignity and self-respect for every customer who comes through the door. ■