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findings

INFORMING CHANGE

Drug user involvement in treatment decisions

Government policy now clearly states that those with drug problems should be involved in decisions relating to their own treatment. However, the nature of such involvement in everyday practice is less clear. This study, by researchers at Glasgow University's Centre for Drug Misuse Research and Oxford Brookes University's School of Health & Social Care, explored demand for user involvement, the various forms that user involvement can take, what constrains it and what might improve practice.

- Being involved in treatment decisions means different things to different stakeholders. Clients associated user involvement with being able to communicate effectively with staff; referrers tended to equate it with informed consent; staff from community treatment services focused on clients exercising some choice within treatment programmes; and staff from residential treatment services prioritised participation in group treatment processes and in the governance of residential communities.
- At the start of their treatment, clients were happy to defer to staff expertise and identified no clear desire for treatment decisions to be user-led. After three months, most clients were still happy to defer to staff, although some had become keener to participate in decision-making.
- There was little overt conflict between professionals and clients, and this mostly occurred in the residential treatment units where there were detailed rules of conduct and highly structured programmes. Underlying tensions or 'hidden dissent' were more common in both the community and residential services and could lead to clients dropping out of treatment prematurely.
- Many practitioners were in principle committed to involving clients in decision-making. However, limited resources and service availability, strict agency criteria, lengthy administrative procedures, and statutory requirements could all constrain choice of treatment.
- The research identified a number of preconditions for effective user involvement. These included ensuring that clients do not feel rushed in making decisions, do receive clear explanations of treatment requirements and procedures, have opportunities to ask questions, and feel safe and secure. The cornerstone of effective user involvement was a willingness on the part of both professionals and clients to listen, communicate and negotiate with each other.
- A group of users, practitioners and other experts made recommendations for effective user involvement in decision-making. These covered commissioning, referral, information-sharing, consumer choice, treatment contracts, detoxification, substitute prescribing, induction groups, and waiting lists.

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The rise of user involvement

Although the principle of user involvement has been slow to take hold in drug treatment, both the National Treatment Agency in England and the Safer Communities Division of the Scottish Executive have recently committed themselves to involving drug users in treatment decisions. There is also a strong user involvement movement in the drug treatment field, with regional users' forums and user consultation and representation at Drug (and Alcohol) Action Team level.

Despite this, experts have argued that there is a disjunction between the kinds of services drug users say they want and those that they are actually offered. Drug users entering treatment in the UK mostly identify abstinence as their main objective, yet most service provision is focused on 'harm reduction'.

This study is concerned with drug users' involvement in decisions about their own treatment. Previous research suggests that the benefits of involving drug users in decisions about their treatment are likely to include increased client retention and client satisfaction; negative effects might include slowed decision-making processes and frustration at being unable to make meaningful service changes.

The different meanings of user involvement

Clients emphasised that user involvement was not about leading or directing treatment decisions, but about having opportunities to communicate and negotiate with staff over treatment issues. In particular, clients highlighted the importance of mutual respect, willingness to listen, and openness to compromise:

> "That they [agency staff] actually take in what you are saying and [are] listening … That is the main thing that they [agency staff] really do understand the situation, so that they can understand what treatment you need." (Client)

Referring staff were explicitly committed to working consensually with clients, but they sought to achieve consensus by persuading the client of the reasonableness of the staff viewpoint, rather than by negotiated compromise. There was a tendency to equate user involvement with informed consent, though it might be described as informed choice:

> "It's that informed choice. Um, having to have enough knowledge of what they [clients] are actually wanting to talk about and be able to show them the pros and cons of each [type of service]. And then make them think again about what will work for them. And say: 'Well, you've told me you've done this in the past and that in the past […]. But I would think that the best way from what you're telling me is to go this way, rather than that way.' " (Referrer)

Community treatment staff tended to perceive user involvement as being about clients exercising some treatment choices and decisions, whilst residential staff focused on clients actively participating in group treatment processes and making decisions about the governance of the residential community.

Experiences of user involvement

Only one client in the study reported that the support she had been offered was wholly inappropriate for her needs. There was no evidence that clients were being forced into harm reduction services when they really aspired to abstinence. On the contrary, clients often said that they had been actively involved in making decisions about the treatment they were given. Moreover, most clients did not approach new treatment episodes with fixed views or expectations about the support they would receive. Rather, they assumed that drug agency staff would be the experts who would help and guide them through the treatment process.

The majority of clients retained this view three months later, often arguing that drug users should comply with aspects of treatment that they did not necessarily want, if professionals told them it was beneficial. Others, however, became more confident in their own decision-making processes over time. For example, the following residential client had initially been very happy to *"go by their [agency] rules"* at the start of treatment, but subsequently became very critical of his lack of choice in programme activities:

> "As soon as you were off your detox, you had to go to the PE … I had been using drugs for about ten or fifteen years and they want you to run a mile. And I explained to them that I'd been smoking heroin for fifteen years, I wouldnae make a mile. But their attitude was: no, you've got to do it. And there was the therapeutic drumming. You go in this sort of room and everyone is banging drums and stuff. I tried to explain to them that I had an ear infection. No, you still have to go … Pretty crazy that. Every addict is different. There's no one treatment for everybody." (Client)

Conflict and user involvement

Study participants only occasionally reported instances of overt conflict between professionals and clients. These mostly occurred in the residential treatment units where there were detailed rules of conduct and highly structured programmes that constrained clients' behaviour or required them to participate in organised sessions.

This did not mean that professionals and clients always agreed on treatment decisions, however. In fact, underlying tensions or 'hidden dissent' were very common. Clients were often irritated by aspects of treatment programmes that they did not understand, or by staff who treated them negatively or disrespectfully, or by professionals who did not seem fully to understand their problems. When such hidden dissent occurred, clients responded with a variety of strategies, for example, changing their address to an area where residential treatment was thought to be more readily available. But hidden dissent could also lead to clients discontinuing treatment prematurely.

Constraints on choice

A range of factors could prevent clients from receiving the exact type of support they wanted at the precise moment it was desired, and these constraining factors often varied from area to area. Thus, some (but not all) referrers reported that budgetary constraints restricted their ability to access a particular service for a particular client. Other referrers highlighted that there was a lack of specialist provision for certain groups of users, such as those with a history of violent behaviour. Statutory requirements relating, for example, to substitute prescribing or child protection could also affect the type of treatment offered.

In consequence, referral could become a lengthy process that involved professionals juggling competing priorities with decisions made at some remove from the client. Problematically, good communication with clients during this period was not always achieved:

> "I was begging them to get me in here [residential unit] because I was clean, you know, and I just needed the therapy … I kept getting pushed away to the side … I mean I was phoning about twenty times a day." (Client)

Constraints on client involvement in treatment decisions, as opposed to referral decisions, were greater in the residential units (where all clients were expected to participate in the overall group treatment programme) than in the community agencies (where some clients reported requesting and securing small changes to treatments such as their methadone dosage). Importantly, most clients who had arrived in drug treatment services following referral from the criminal justice system did not report themselves as coerced, but rather as willing collaborators in treatment.

Enabling effective user involvement

Whilst the research found that there were many difficulties in involving drug users in treatment decisions, it also revealed some important preconditions for effective participation. For example, clients should not be rushed when making decisions, but should be given clear explanations of treatment requirements and procedures so that they can make informed choices. To this end, they need supporting materials that are easily digestible and appropriately presented. In addition, they require sufficient opportunities to ask questions, and should be made to feel safe and secure. Underpinning each of these preconditions, and thus the cornerstone of effective user involvement, was the need for both professionals and clients to listen to each other's views, communicate together, and negotiate over differences of opinion.

Recommendations for further debate

A closed e-mail consultation group – comprising a small number of practitioners, service users and other experts and using the Delphi method – was convened to help develop policy and practice recommendations.

These suggestions (abbreviated below and not listed in any order of importance) are intended to stimulate debate on how best to involve drug users in treatment decisions.

- Drug agencies should consider using accessible mediums, such as videos and CDs, to communicate information to service users about what they can expect from treatment.
- Referrers should brief their clients on the likelihood that they will find treatment a difficult and challenging experience.
- When signing treatment contracts and other formal documents, service users should be given the opportunity to re-visit the contract with their key-workers at a later date.
- Community prescribing agencies should consider the benefits of facilitating induction groups, where those starting on methadone or alternative substitutes can meet other service users and share their experiences.

- Those responsible for administering detoxification treatments should consider involving their clients in decisions regarding the length of the detoxification period and the type of substitute medication to be used.
- Commissioning bodies should seek to provide access to a range of effective drug treatment services and pay particular attention to shortfalls in services for those with specialist or complex needs.
- Agencies that refer clients to residential treatment should have clear guidelines, which are both evidence-based and consistent with national guidance, for assessing the suitability of service users.
- If clients have a clear preference for a particular treatment, which they can justify despite being presented with alternatives, their choice should be accepted whenever possible. If a practitioner is concerned that a user's choice of treatment carries risks, these risks should be made clear to the client and strategies to reduce these risks should be included, whenever possible, in any treatment plan.
- If there are problems with accessing the users' preferred service – for example, because of limited availability or lack of resources – the service user should be fully informed of how the treatment programme differs from that originally identified and the option of additional forms of support or transfer to a different agency at a later date should, whenever possible, be documented.
- Service users should be given a realistic estimate of the length of time referral for drug treatment will take, and be informed as soon as possible if any delays occur. Referrers should consider increasing the level of support available to their clients during this period, and never ignore any phone call or request for information they receive.

About the project

The project was undertaken by Michael Bloor and Nick Jenkins of Glasgow University's Centre for Drug Misuse Research and Joanne Neale and Jan Fischer of Oxford Brookes University's School of Health & Social Care, with assistance from Lee Berney of St George's Medical School.

The research involved four drug services, two community-based and two residential facilities. The findings are based on 187 depth interviews with treatment clients (both at the start of treatment and three months later), staff members, and referrers of service users. The project additionally benefited from the contributions of service users and service providers in both the Project Advisory Group and the Delphi Group.

For further information

The full report, **Drug user involvement in treatment decisions** by Jan Fischer, Nick Jenkins, Michael Bloor, Joanne Neale and Lee Berney, is published by the Joseph Rowntree Foundation (ISBN 978 1 85935 564 0, price £13.95). You can also download this report free from www.jrf.org.uk.

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