Drug user involvement in treatment decisions

Jan Fischer, Nick Jenkins, Michael Bloor, Joanne Neale and Lee Berney

This report discusses the involvement of drug users in making decisions about their treatment.

In recent years, user involvement has become a key principle in the delivery of health and social care services in the UK. But whilst it is a valued concept, it is one that is not easily implemented in practice. This research explores a range of related issues, including:

- The nature and extent of user involvement

- The desire for involvement amongst practitioners and service users

- Likely constraints on involvement

- The impact and relative importance of involvement on treatment outcomes.

The report concludes with recommendations for facilitating user involvement in drug treatment decision making.

The research is based on an in-depth investigation of drug service users' and practitioners' experiences of user involvement in four specialist treatment agencies: two community prescribing agencies and two residential rehabilitation centres, in England and Scotland.

It will be of interest to staff and service users from across the agencies, those referring users for treatment, commissioning bodies and policymakers in this field.

JOSEPH ROWNTREE FOUNDATION

Drug user involvement in treatment decisions

Jan Fischer, Nick Jenkins, Michael Bloor, Joanne Neale and Lee Berney

JOSEPH ROWNTREE
FOUNDATION

About the authors

Jan Fischer, School of Health and Social Care, Oxford Brookes University

Nick Jenkins, Centre for Drug Misuse Research, University of Glasgow

Michael Bloor, Centre for Drug Misuse Research, University of Glasgow

Joanne Neale, School of Health and Social Care, Oxford Brookes University

Lee Berney, Faculty of Health and Social Care Sciences, St George's Medical School, University of London

Contents

Acknowlegements

Executive summary

In recent years, user involvement has become a key principle in the delivery of health and social care services in the UK. This report discusses the involvement of drug users in treatment processes, specifically in making treatment decisions. It is based on an in-depth investigation of drug service users' and practitioners' experiences of user involvement in four specialist treatment agencies – two community prescribing agencies and two residential rehabilitation centres – in England and Scotland. Data were collected between July 2005 and June 2006, and involved qualitative interviews with 79 service users (59 of whom were successfully reinterviewed three months later), the 27 treatment agency staff who keyworked them and 22 practitioners who had referred them into treatment. The research explored a range of issues including:

- the nature and extent of user involvement

- the desire for involvement among practitioners and service users

- likely constraints on involvement

- the impact and relative importance of involvement on treatment outcomes.

Chapter 1

Chapter 1 reviews the literature on user involvement in health and social care services.

Key points
- In recent years, user involvement has emerged as a central principle in the delivery of health and social care services.

- The precise meaning of the term 'user involvement' is ambiguous and differs across treatment contexts.

- The outcomes associated with user involvement are, to date, unclear. For example, they have been linked positively with retention in treatment and client satisfaction, but negatively with slower decision-making processes and client feelings of frustration.

Chapter 2

Chapter 2 explores how referrers, staff and service users from across the agencies talked about their views and experiences of user involvement.

Key points
- Clients tended to describe user involvement in terms of a diverse range of interlinking activities and treatment characteristics, which included: exercising choice, communicating with staff, the extent of flexibility and coercion in treatment, having the ability to influence treatment structures and being given opportunities to support other service users.

- Practitioners tended to prioritise different forms of user involvement from their clients. Referrers focused on clients having a say in identifying and selecting services and agency staff highlighted users' roles in early treatment decision making. Some residential staff also emphasised service users' participation in the governance of therapeutic communities.

- Experiences of user involvement were contingent on service users' preferences for involvement, their length of time in treatment and the approach of the treatment agency itself.

Chapter 3

Chapter 3 examines some of the ways in which the principle of involving drug users in decision making can be constrained in practice.

Key points
- User involvement can be limited by users' deference to staff expertise.

- Differences in power relations between staff and their clients can lead to overt and, more often, latent forms of conflict. If not adequately addressed, such conflict can result in users prematurely leaving treatment.

- While many practitioners were highly committed to involving their clients in referral decision making, service users' choice of treatment could be constrained by limited resources, administrative procedures and agency policies regarding client suitability. Some users attempted to circumvent policies and procedures, especially when seeking access to residential treatment.

Chapter 4

Chapter 4 explores the conditions under which user involvement in treatment decision making can be effectively implemented and how it can contribute to positive outcomes.

Key points
- Willingness on behalf of staff and service users to communicate and negotiate with each other appears to be the cornerstone of effective user involvement.

- Ascertaining client motivation, providing clear information and matching client expectations with treatment services are important preconditions for involving service users in referral decision making.

- Service users not feeling rushed, receiving explanations, being able to ask questions and feeling safe and secure are important preconditions for user involvement in treatment decision making.

- User involvement can contribute to clients feeling satisfied with treatment. This, in turn, can lead to them staying engaged with services for longer and potentially having better treatment outcomes.

Chapter 5

Chapter 5 concludes by arguing that user involvement is difficult to define and understand. While it is a valued concept, it is not easily implemented in practice. Ten recommendations for facilitating user involvement in drug treatment decision making are then made. These emerged from early analyses of the data but were subsequently refined through a closed email Delphi group involving practitioners, policymakers and service users. An abbreviated version of the recommendations is provided below. Drug treatment agencies should consider the advantages of 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 revisit the contract with their keyworkers at a later date and discuss any areas of concern.

- Community prescribing agencies should consider the advantages of facilitating induction groups, where those starting on methadone or alternative substitutes can meet other service users and share their experiences.

- All those responsible for administering detoxification treatments should consider the benefits of involving their clients in decisions over the length of the detoxification period and the type of substitute medication to be used.

- All commissioning bodies should seek to provide access to a range of effective drug treatment services and should 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 that are both evidence based and in line with

national guidance for assessing the suitability of service users.

- If service users have a clear preference for a particular treatment, which they can justify after being presented with alternatives, their choice should be accepted wherever possible. If the practitioner is concerned that the user's choice of treatment carries certain risks, these should be made clear to the client and strategies to reduce these risks should, whenever possible, be included in the treatment plan.

- If there are problems with accessing the users' preferred service – because of limited availability or resourcing, for example – 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 included in the treatment plan.

- Service users should be given a realistic estimate of the length of time that 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 time and no phone call or request for information from service users should go unacknowledged.

1 Background, aims and methods

Introduction

User involvement can occur when making policy decisions about what services should be provided, in planning and designing new services, and in delivering and evaluating existing services. Examples of user involvement within drug treatment include:[1]

- users contributing to Drug (and Alcohol) Action Team treatment plans or other strategic planning

- users sitting on the committees of drug services

- users working as paid employees or volunteers in drug agencies

- users delivering education and training to other users and professionals

- newsletters voicing users' views

- surveys collating user feedback

- self-help and peer-support groups

- users delivering treatment to each other within therapeutic communities

- users being involved in planning their own treatment.

This report focuses on the involvement of drug users in making decisions about their own treatment. However, the present chapter will set the scene by exploring the development of user involvement within the health and social care field more generally. It will also critically examine the concept of user involvement before briefly outlining the aims and methods of the study on which the remainder of the report is based.

The rise of user involvement

The origins and development of user involvement have variously been related to the anti-psychiatry movement of the 1960s, the rise of consumerism, the emergence of self-advocacy and pressure groups, the growth of community action, New Right policies and the increase in public willingness to question expert knowledge in late modern society (Barker and Peck, 1987; Davies, 1988; Taylor et al., 1992; Thompson, 1995; Small and Rhodes, 2000). During the 1990s, many public services took important new steps to increase user involvement and user choice by introducing charters (such as the Citizen's Charter and the NHS Patient's Charter). Subsequently, the NHS plan (DoH, 2000) highlighted the need for health services to be more patient-centred, and the NHS and Social Care Act 2001 made it a legal duty for every NHS organisation to consult and involve patients and the public in its activities.

Today, user involvement is commonplace in health fields as diverse as cancer treatment, mental health, learning disabilities and maternity services. Developments have been slower in drug treatment, but steady progress has been made and a strong user involvement movement now exists (as exemplified by The Alliance, Mainliners and Narcotics Anonymous). Although drug user representation at the level of national policymaking remains poor, local Drug (and Alcohol) Action Teams are involving users through user groups, user involvement co-ordinators and user consultations. In addition, regional users' forums have been established, and both the National Treatment Agency (NTA) in England and the Safer Communities

Division of the Scottish Executive have written user involvement clearly into recent policy documents:

> Service users should be involved in all key aspects of decision-making in relation to their care.
> (NTA, 2006, p. 1)

> Your views will be heard and used to develop your personal plan.
> (Scottish Executive, 2006, p. 4)

In short, user involvement has become an important concept in UK health and social care policy and practice. This is because asking those who use services what they need and want seems likely to improve provision by making it more sensitive to their problems and preferences (Barnes and Wistow, 1992). Equally, user involvement can empower individuals by allowing them greater control over their lives, helping them to build confidence, increasing their self-esteem and initiating mutual support mechanisms (Croft and Beresford, 1990; Meade and Carter, 1990). It has also been argued that user involvement is an important democratic right and an ethical requirement (Crawford *et al.*, 2002). Nonetheless, the concept of user involvement has repeatedly been criticised and some of the reasons for this are discussed below.

Defining user involvement

Within the health and social care literature, concern has been expressed that the term 'user involvement' is often applied loosely and imprecisely (Croft and Beresford, 1990; Small and Rhodes, 2000). Thus, 'user' is used interchangeably with 'patient', 'client', 'consumer' and 'customer', although these four categories are not identical. For example, 'patient' suggests illness and vulnerability, whereas 'customer' indicates someone proactively exercising purchasing power. The boundaries between current, future and ex-service users are unclear and differences between subcategories of user (such as carers and care managers) are sometimes overlooked. Users include both lone individuals and more powerful groups of individuals uniting together. Furthermore, some individuals may not want to be defined as a user and it has been argued that the definition should not be imposed on anyone (Osborn, 1991; Hutchinson *et al.*, 1995).

'Involvement' is employed similarly vaguely to encompass choice, collaboration, consultation, control, empowerment, engagement, information, participation and partnership, etc. These various related concepts are sometimes portrayed as a continuum or hierarchy, with each representing a different level of involvement. For example, Poulton (1999) utilised a pyramid that depicted information as the lowest level of involvement and participation as the highest. Arnstein (1969), meanwhile, developed a ladder that illustrated the extent to which different forms of participation in city planning actually involved citizens. According to this seminal paper, the two bottom rungs of the participation ladder (manipulation and therapy) were essentially forms of non-participation; the next three rungs (informing, consultation and placation) were little more than tokenism; and only the top three rungs (partnership, delegated power and citizen control) indicated genuine citizen power.

Barriers to user involvement

In addition to the lack of a clear definition of user involvement, the existing literature has pointed to reasons why user involvement can be difficult to achieve (SDF, 1996; Rose *et al.*, 2002; Hodge, 2005). Organisational barriers include entrenched policy and practice that fail to react to users' views, and limited resources that restrict service providers' capacity to meet users' demands. Agency staff can be resistant to involving service users, professionals often have different views from their clients and power imbalances can result in users' views being overruled. Further problems might include service users having unrealistic demands or being too vulnerable to participate, users' lack of interest in becoming involved, users' beliefs that professionals are the experts who know what is best for them and the unrepresentative nature of those who participate in user groups.

In respect of substance misuse services, it can be particularly difficult to involve individuals who are very chaotic and dependent, especially if they breach treatment protocols and misuse treatment facilities (Neale, 1998). The illegality of drugs and drug users' related criminal activities can potentially undermine their claims to have a democratic right to be involved in service provision. Moreover, a high level of blame culture within the drug treatment field means that drug users are often seen as undeserving and not consulted, despite policy statements to the contrary. Additionally, many drug user groups do not possess the infrastructure, funding, resources, or capabilities to hold service providers to account (Garrett and Foster, 2005).

Recent debate around the relative merits of services oriented towards abstinence and harm reduction for problem drug users neatly captures some of these tensions (McKeganey *et al.*, 2004; Martin, 2005; Nelles, 2005; Roberts, 2005). Thus, research has shown that most drug users entering treatment identify abstinence as their main treatment goal. If users' views were truly central to drug treatment decision-making processes, abstinence-based services would predominate. However, this is not the case since most UK service provision is focused on harm reduction. This apparent disjuncture between what drug users say they want and what they are offered and receive is commonly explained by factors such as clients' naivety regarding the difficulties of becoming abstinent, and their lack of understanding of the full range of treatment options and treatment processes (McKeganey *et al.*, 2004; Nelles, 2005).

Outcomes of user involvement

In terms of actually assessing the benefits of user involvement, commentators have recently noted that outcomes are often unclear or unknown and hardly ever measurable (Crawford *et al.*, 2002; Rose *et al.*, 2002). Furthermore, there is some evidence that involving service users may be associated with negative effects. These include difficult relationships between staff and patients, increased user dissatisfaction with current services, user stress and frustration at being unable to effect positive changes, slowed decision-making processes, and policymakers and administrators manipulating user involvement to legitimise their own decisions (Gray *et al.*, 1995; Crawford *et al.*, 2002). Rose *et al.* (2002) also note that government demands for agencies to demonstrate user involvement

may mean that user activities become a formal procedure to be 'ticked off' and that changes therefore often remain at the level of tokenism.

In a recent Scottish study of 859 drug users, exactly half reported that they had been included in decisions about the help that they had received during the first three months of their last drug treatment episode. Those who felt that they had been involved were more satisfied with their treatment, had stayed in treatment for longer, and reported a range of positive subjective and objective drug and lifestyle outcomes. Nonetheless, user involvement had a slightly stronger association with how users felt about their progress than with actual concrete improvements in their behaviour and life circumstances. Moreover, it was not possible to conclude that involvement had caused positive treatment outcomes since those who did well may simply have felt more involved retrospectively. Equally, both good treatment outcomes and involvement may have been caused by other intervening factors, such as highly experienced agency staff or very motivated clients (Neale *et al*., 2006).

Research aims

In the remaining chapters, we report on a qualitative study of illicit drug users' involvement in decisions about their own treatment. To our knowledge, this aspect of user involvement had not previously been investigated in any detail, so the aims were primarily exploratory. However, the following questions were used to guide our investigations.

- What is the nature and extent of user involvement and to what extent do users and providers feel that users should be involved?

- What is the nature and extent of conflicts of opinion between service providers and service users, and how are these conflicts of opinion resolved?

- How do external factors (such as, the availability of resources, agency philosophies, and local and national policy) impact on treatment decisions?

- How do user involvement, user aspirations and user motivations for seeking treatment impact on treatment retention and treatment outcomes?

- What is the importance of user involvement relative to other aspects of treatment service and delivery (e.g. the quality of the building, the attitudes of the staff and the availability of wrap-around services)?

Since qualitative research seeks in-depth information from relatively small samples and sacrifices representativeness in order to maximise validity, we make no claim that our data or findings are representative of treatment decision making across the UK. Our intention was rather to provide detailed insights into treatment processes and to produce new information that might usefully inform future policy and practice.

Research methods

The research involved semi-structured interviews undertaken in four case study drug services: two specialist community prescribing

agencies (one in Scotland and one in England) and two residential rehabilitation agencies (one in Scotland and one in England). Data collection occurred between July 2005 and June 2006. Seventy-nine new treatment clients were interviewed within a week of starting treatment and 59 were successfully reinterviewed three months later. Interviews were also conducted with 27 agency staff who keyworked these 79 clients and 22 individuals (from a range of specialist and generic agencies) who had been involved in referring them into treatment (see Table 1).

Of the 59 clients reinterviewed after three months, 40 were still in treatment and 19 had left treatment. This is broken down by agency in Table 2. Although the follow-up sample included a mixture of clients both in and out of treatment after three months, it should be noted that those clients who were not reinterviewed were more likely than those who were reinterviewed not to be in treatment (since those not still in treatment were more difficult to trace for reinterview). It would also be reasonable to hypothesise that those individuals not still in treatment at three months would have less positive views of their treatment episode than those who were still in treatment. Thus, our follow-up findings may somewhat understate drug users' criticisms of service provision.

The interviews conducted with the clients and agency staff also incorporated a

Table 1 Breakdown of interviews

Agency	First client interview	Follow-up client interview	Staff interview[a]
Residential, England	20	15	4 (covering all 20 clients)
Community, England	20	16	3 (covering all 20 clients)
Residential, Scotland	20	14	10 (covering all 20 clients)
Community, Scotland	19	14	10 (covering 18 clients)
Total	*79*	*59*	*27*
Referrers to English agencies	12		
Referrers to Scottish agencies	10		

a Because staff members in any given agency were responsible for multiple clients, each staff interview provided information on more than one client.

Table 2 Clients' treatment status at follow-up

Agency	Still in treatment at follow-up	No longer in treatment at follow-up	Total
Residential, England	6	9	15
Community, England	15	1	16
Residential, Scotland	7	7	14
Community, Scotland	12	2	14
Total	*40*	*19*	*59*

developmental vignette, a qualitative research technique previously described in the drug misuse literature by Hughes (1998). This vignette told the story of a fictional drug user's treatment career and interviewees were asked to state how they thought the protagonist would respond to a number of key events relating to user involvement (see the Appendix for the full vignette). Drug users who were reinterviewed after three months were also asked to complete the Treatment Perceptions Questionnaire (TPQ) – a short questionnaire designed to measure client satisfaction with addiction services (Marsden *et al*., 2000) – and an additional single question relating to how much they had been included in any decisions about the help that they had received. Finally, a Delphi group of drug treatment practitioners, policymakers and drug users was convened to respond to

early findings and to assist in drawing up recommendations. This was conducted by email as a closed, facilitated, electronic discussion group.

Plan of the report

Chapters 2 to 4 draw on the interview data to report on clients', staff's and referrers' views and experiences of user involvement (Chapter 2); factors that constrain user involvement in practice (Chapter 3); and how and when effective user involvement might occur, including positive treatment outcomes (Chapter 4). The final chapter incorporates findings from the Delphi group, and presents conclusions and recommendations for practitioner and policy audiences.

2 Views and experiences of user involvement

Introduction

Given the varying definitions of user involvement evident in the literature, it seemed important to begin by investigating how users, staff and referrers understood the concept when applied to the drug treatment setting. The rise of user involvement as a key concept in drug treatment policy and practice also indicates a need to ascertain exactly how much clients were involved in drug treatment decisions and the reasons why they and the professionals who worked with them might want to encourage this. The chapter will therefore explore the interviewees':

- understanding of the meaning of user involvement

- experiences of user involvement in the four case study agencies

- reasons for believing that user involvement is important.

The meaning of user involvement

Limited initial understanding

At the start of their interviews, most interviewees indicated only limited understanding of what user involvement might mean in a drug treatment context. Practitioners tended not to have uniform views regarding how they could involve their clients in decision making, and often appeared to re-evaluate their opinions during the course of the interviews. Clients likewise formulated opinions as their interviews progressed. Furthermore, those who were reinterviewed after three months often demonstrated a much clearer understanding, particularly in terms of how they had been involved in their own recent treatment episodes. To what extent this increasing awareness reflected greater familiarity with the concept of user involvement through participation in the study and/or greater treatment exposure is uncertain, but does not detract from the value of the information that resulted.

Types of user involvement

By the time of their second interviews, clients tended to describe user involvement in terms of various types of interrelated activity and treatment programme characteristics. These included the following.

- *Being able to communicate effectively with staff.* For example, did staff listen to their concerns, treat them with respect, make them feel like their views and feelings mattered, empathise with their problems, explain treatment procedures to them, and talk to them honestly and openly *(community and residential treatment)*?

- *Having choice about the services they received.* For example, were clients able to decide what medication or dosage of medication they were given *(community treatment)* or select which residential agency they would attend *(residential treatment)*?

- *The flexibility of staff and the treatment agency in terms of meeting an individual client's needs or wishes.* For example, could treatment protocols be changed or revoked if clients were encountering

problems or had strong views about the support that they wanted (*community and residential treatment*)?

- *The amount of coercion or involuntary elements within treatment programmes.* For example, did clients have to submit to urine testing in order to receive medication (*community treatment*) or could they opt out of particular therapeutic activities (*residential treatment*)?

- *Being able to shape treatment structures.* For example, could clients change aspects of service delivery or modify treatment programmes for all clients of the service and not just themselves (*community and residential treatment*)?

- *Users supporting each other.* For example, did services encourage clients to develop formal or informal peer support networks or employ ex-users as agency staff (*residential treatment*)?

Referrers and drug agency staff also recognised that user involvement comprised a diverse range of interlinking activities. However, professionals often prioritised different examples of user involvement from clients. For example, clients overwhelmingly focused on the importance of listening to users' concerns, making them feel valued, empathising with their problems, or explaining treatment procedures to them. More commonly, referrers cited users being involved in deciding which agencies might be suitable for them to attend and agency staff spoke of clients being involved in decisions made during early treatment stages:

By the end of their assessment, when we are looking at possible treatment options, we should be discussing them with the client and reaching agreement on basically what is achievable, what is appropriate and what service can be provided for them.
(Community staff member, Scotland)

In addition, some residential service staff argued that user involvement meant participating in the everyday governance of the therapeutic community; this might include playing a larger role in the induction of other new clients or making choices about what members of the community would eat. Nonetheless, there was a suggestion that such elementary forms of consultation and involvement could be somewhat tokenistic – a view expressed by the following staff member:

It's like we've got a menu suggestion board up and people will make constant suggestions and every now and again the chef will throw on one of the suggestions. So the menu stays almost the same with a few kind of, you know, tokenistic things thrown in, such as Afro-Caribbean food, etc., and I think that's wrong.
(Residential staff member, England)

The contingent and contradictory nature of user involvement

Although clients, referrers and staff primarily focused on 'whether or not' a drug user was able to participate in an activity, rather than on 'how much' and 'in which ways' they were involved, their understanding of user involvement was broadly consistent with its use in the general health and social care literature. That is, their descriptions of the concept showed it to be multifaceted and complex. Meanwhile,

the contingent and contradictory nature of user involvement for particular drug users was also evident in clients' remarks.

Thus, many clients argued that whether or not a drug user could, should or would want to participate would depend on the individual (particularly how ready they were for treatment) and the length of time they had been in treatment (with those who had been in treatment for longer often considered better able to make useful decisions than those new to treatment). Clients' statements likewise revealed that service users might want to be involved in some treatment decisions but not others. Furthermore, they might even desire participation while simultaneously wanting staff to use their professional knowledge to make treatment decisions for them. As this community service client explained:

> I do want to be involved in decisions, but I also think at the end of the day the staff are specialists and they know what they are talking about.
> (Community client, England, first interview)

The only aspect of user involvement that was never portrayed as contingent or contradictory by any of the clients interviewed was the need for good communication between service users and professionals. In this regard, clients repeatedly emphasised that they could never participate in aspects of their treatment unless staff listened to them and took their views seriously, provided them with information from which they could make choices, discussed their treatment and progress with them, and negotiated with them when there were problems and differences of opinion. Indeed, effective communication and

negotiation were deemed crucial prerequisites to all other kinds of involvement, including the ability of staff members to provide useful expert advice:

> That they actually take in what you are saying and listening means that they are understanding your situation more. And that is the main thing that they really do understand the situation, so they can understand what treatment you need.
> (Community client, England, follow-up interview)

Experiences of user involvement

In practice, clients from the residential services were actively involved in 'delivering their own treatment programmes' through their routine participation in group work and house activities. Nonetheless, they were less likely than the community clients to report that they were 'involved in making decisions about their own treatment', and this seemed to relate to two factors. First, residential services operated relatively structured therapeutic treatment programmes that could not easily be modified to meet individuals' preferences and needs. Second, the clients of community services tended to voice greater desire for involvement (at both their first and second interviews) than the clients of residential services.

This symmetry between desires and the level of involvement in decision making offered by the community and residential services suggested that a degree of client matching (and by implication user involvement) had already successfully occurred at the referral stage. This was consistent with the finding that both community and residential clients were generally happy with the type of service they

were being offered. Indeed, residential service users often reported that they had received detailed information about life in the agency to which they were being referred. For example, many had seen leaflets and brochures and some had made preliminary assessment visits. In consequence, clients attending residential services tended to want and to anticipate a more disciplined and less flexible service than those seeking support in the community.

Importantly, however, both the community and residential clients reported overall low levels of involvement in decisions about how services should be delivered, both to themselves and to other services users. Thus, no clients described being involved in designing or making any major changes to treatment structures or programmes. Instead, they only discussed making choices that related to fairly minor aspects of their own treatment process. These included choosing an additional form of support (such as counselling to accompany their medication) *(in a community service)* or deciding between two weekend leisure activities *(in residential treatment)*. In addition, some users (mostly in the community services) had requested and been granted slight modifications to their personal treatment plans or medication. As this community client explained:

> *It went up to 80 ml* [of methadone] *and they were on about putting it up. But I have asked if they could start reducing it. So from 80 ml, instead of going up to 90 ml, they took me down to 75. So I will try 75 for so long and then maybe* [go] *down to 70.*
> (Community client, England, follow-up interview)

Confirming clients' general belief that the appropriateness of involvement depended on the individual and their length of time in treatment, some service users reported that their level of involvement in decision making had increased between their first and second interviews. These individuals attributed this change to staff investing more trust in them, the fact that they were now more stable than previously and (in the case of residential service clients) the successful completion of their detoxification. A small number of these clients could not, however, clarify how they had been more involved – citing only their good progress in treatment as evidence. In other words, it seemed that feeling (rather than necessarily being) involved was sometimes associated with making good treatment progress.

Further to the above, it was evident that users' desire for involvement in treatment decisions changed over time. Thus, users were mostly content with the relatively low level of involvement they were receiving at their first interviews, but often desired more involvement three months later.[1] This pattern was not, however, entirely straightforward. At second interview, there were many clients who still did not want much involvement in treatment decisions, particularly if they felt that they were making steady progress. Furthermore, it was clients who had had a disagreement with agency staff, or who were unhappy with the direction their treatment was taking, or who had left treatment prematurely who most strongly argued that they wanted more control. This is clearly illustrated by the following client, who initially did not want to participate in any treatment decisions, but changed his mind after his treatment failed:

I think it should all be decided by them [staff], *because, at the end of the day, at the start of your treatment you're not really capable of deciding what is best for yourself.*
(Residential client, England, first interview)

I just think, if the people had more say, they'd feel more comfortable in the things, especially for the newer people.
(Same client, follow-up interview)

In terms of users' accounts of their experiences of communicating and negotiating with agency staff, patterns were somewhat mixed. At first interview, clients were generally happy with the interactions they had had with agency staff – although the English residential service users often complained that staff were not around and so they were left to their own devices. At follow-up interviews, many clients remained happy with staff–client relationships, but others voiced concerns. In particular, a number of users felt that information had not been shared with them, their views had not been heard, or staff had failed to confer with them over important decisions. Others also complained that staff had been uninterested in their problems, unsympathetic to their needs, or looked down on them as clients. In a number of cases, such problems had immediately preceded clients abandoning or being discharged from treatment. However, this connection between staff–client conflict and premature departure from treatment should not be overstated, and is considered in more detail in Chapter 3.

Staff views of the extent of user involvement in treatment decision making revealed some clear differences between those working in the community and those working in the residential services. For example, a number of community-based staff emphasised that users were fundamentally involved in treatment decision making because it was impossible to proceed without the client's voluntary compliance. Moreover, they felt that an individual client's treatment plan should ideally be user-led. This, they argued, was because clients did not have to attend community services (unless they were being referred via the criminal justice system). Equally, they were often very well informed about treatment options and frequently arrived with clear opinions about what was or was not acceptable to them:

I mean, at the end of the day, I can only do what they want to do. If I believe passionately about something, then I will go out and say all the pros of the way I'm thinking. But still, at the end of the day, it has to be for the client to decide.
(Community staff member, Scotland)

I think that clients are quite autonomous and I think that is the way it should be really. I think a lot of our patients – you would be very surprised – are quite wise about their medication. What they want, what they won't have, what they will do, and what they won't do. And I think with that sort of autonomy, you know, just like in any other adult situation, there are consequences to every action and I think our clients kind of air that more.
(Community staff member, England)

Residential staff, meanwhile, tended to discuss how their core treatment programmes were designed to be the same for everyone and thus not easily adapted in response to individuals' needs or preferences. Nonetheless, users were still involved in decisions about their treatment whenever possible:

They certainly have a say in it in the sense that within a week you have to agree a detailed treatment plan with the patient and with the head of treatment here. If the patient thinks it is wrong, they can certainly say so. The patient can't really dictate much more than that. I mean, they can't come in here with their own ideas about what they can and can't do, but they do certainly have a say, yes.
(Residential staff member, Scotland)

It's a very clear balance really. I mean obviously we're meeting individual clients' needs within the framework of a therapeutic community. But we can't ever get into a situation of running 36 programmes for treatment, because you're throwing the baby out with the bathwater. You actually lose what is [the] *therapeutic community. So what people buy into when they come here is we say, 'We can meet your needs. We'll meet your cultural needs; we'll meet your religious needs; your dietary needs; your health needs; educational needs.'*
(Residential staff member, England)

Furthermore, residential staff emphasised how clients helping each other (both informally and formally in group sessions) and the employment of ex-users as paid members of staff were important types of user involvement that were actively encouraged in their agencies. Indeed, therapeutic community practice is based on the principle that clients need to be actively involved in the everyday life of the community. This is so that they can see parallels between their difficulties and the difficulties of other community members, experiment with new ways of relating to others, and draw inspiration and commitment from others.

The importance of user involvement

As indicated above, clients' views about the appropriateness and feasibility of user involvement for particular individuals were often contingent and even contradictory. Nonetheless, there was widespread agreement that the concept was in principle positive. Chapter 3 discusses further barriers and constraints to implementing user involvement in drug treatment decision making, while Chapter 4 discusses when and how user involvement can be successful. The prior question of why user involvement in treatment decision making should be encouraged and facilitated will be considered here.

At their first interviews, users argued that they should be involved in decisions about their own treatment for two main reasons. First, they had specialised knowledge of their personal circumstances, including their hopes, needs and states of readiness for change. This, when combined with the views of professionals, provided crucial background information for any important decisions that had to be made. As this individual argued:

They [staff] *should have an input because the doctors know what they're talking about. And I should have an input cos I know what's best for me.*
(Community client, England, first interview)

Second, some users reasoned that they should be involved in treatment decisions because it was their 'right' to have control – over both their body and their treatment:

It should be down to me whether I want Subutex or whether I want methadone. It should be down to me, not anyone else … Because it's

me who is taking them. They're not taking them. It's my body and I don't wanna get it poisoned by methadone, cos methadone's a lot worse than heroin.
(Community client, England, first interview)

At their second interviews, a number of clients still maintained that they had a right to be involved. However, the argument that users had important knowledge that would improve decision-making processes and outcomes had become more central. Reasons for this change in emphasis might have reflected some users' increasing disenchantment with treatment services and/or loss of faith in professional expertise. Equally, it could have reflected clients' greater insights into their circumstances, problems and needs, and growing confidence in their ability to help themselves:

We're the experts, [you] *know, at the end of the day,* [you] *know.*
(Community client, Scotland, follow-up interview)

Referrers, meanwhile, argued that user involvement should be promoted in treatment decision making because it provided an important opportunity for empowering clients and engaging them with services – that is, users would feel that they had greater ownership of their treatment and this would help to increase retention. Not dissimilarly, staff from the community services reasoned that user involvement improved the rapport between staff and clients, and motivated clients to succeed. Residential staff, on the other hand, suggested that involving users in decisions about their treatment was an important way of demonstrating to clients that they were being taken seriously.

Finally, many referrers and some staff stated that user involvement was important because it was likely to contribute to improved treatment outcomes. Nonetheless, these professionals often qualified this by emphasising that user involvement was only one of many factors – and far from the most important factor – that contributed to treatment success. Equally, professionals tended to define treatment success rather narrowly in terms of abstinence and harm reduction (that is, drug use) outcomes. This was in contrast to drug users who commonly identified a much broader range of treatment goals – such as better family relationships, securing a stable home, obtaining a job, going to college, or living a drug-free 'normal' life.

This discrepancy between professionals' and clients' views of what constituted a successful treatment outcome repeats some of the tensions underpinning the abstinence versus harm reduction argument identified in Chapter 1 (cf. McKeganey *et al.*, 2004). That is, professionals and clients may have different and even incompatible views about what is achievable and realistic. Here, professionals seemed to be focusing on drug treatment goals, while their clients were looking to broader (and arguably longer-term) lifestyle changes. Positioning these as oppositional aims is unhelpful since both are integral to treatment progress. However, it is important to recognise that these tensions and differences of opinion commonly exist. Indeed, unless these differing perspectives are openly acknowledged and debated, misunderstandings and even conflicts of opinions between clients and staff are likely to result.

Summary

Despite the widespread acceptance and use of the term 'user involvement', drug agency clients, staff and referrers had not given much thought to what the expression might mean in a drug treatment context, and particularly as applied to drug treatment decision making. The interview process provided them with opportunities to reflect on the subject in more detail and generated interesting information on their views and experiences.

Both service clients and professionals recognised that user involvement comprised a diverse range of interlinking activities relating to communication, choice, flexibility, freedom from coercion, shaping services and mutual support. However, the examples of user involvement that were cited varied by respondent group – with clients prioritising communication, referrers focusing on choosing services and staff discussing decisions made early in the treatment process.

In addition, clients were keen to emphasise that user involvement could mean different things, to different drug users, at different times. Thus, the appropriateness of user involvement was contingent and contradictory. Nonetheless, clients universally believed that basic communication (listening, empathy, sharing information) and negotiation between service users and professionals were essential prerequisites to all other forms of involvement. In this regard, clients' statements indicated that drug users prioritised forms of user involvement that featured near the bottom of the hierarchical representations of involvement discussed in the literature (Arnstein, 1969; Poulton, 1999).

On balance, community clients reported being more involved in day-to-day treatment decision making than residential clients. Nonetheless, residential clients had often actively desired and chosen structured and inflexible programmes; hence they were happy to be less involved. Actual experiences of user involvement in decision making were, meanwhile, relatively limited in both types of service. Frequently, clients reported that their involvement had increased between their first and second interviews, but this seemed at least in part to be associated with how happy individuals were with their treatment progress. Thus, clients who were doing well were more likely to report being involved, with those doing less well reporting both a desire for more involvement and more communication problems with staff.

Community and residential staff also discussed differences in the types of user involvement occurring in their services. Community service staff were more likely to describe their treatment programmes as being user-led. Residential staff, on the other hand, focused on the opportunities their agencies provided for involvement in treatment (rather than involvement in treatment decision making) and the employment of ex-users. Overall, however, there was widespread agreement that user involvement in treatment decision making was important. For users, this was primarily because they had specialised knowledge about themselves and their circumstances. For professionals, it was because user involvement was a potential means to better treatment outcomes and could demonstrate to users that their views were being taken into account.

3 Constraints on user involvement

Introduction

While the consumer may be 'king', user involvement is not an absolute value. Just as the term 'user involvement' means different things to different people, and finds different expression in different forms of service provision, so also user involvement is constrained by, and emergent from, a range of cross-cutting values and influences. These influences are the subject of this chapter of the report, where we deal with differences of perspective between clients and staff, and with various factors (users' views included) that shape the choice of an appropriate treatment agency.

Expectations and expertise

In common with findings on client expectations in other areas of service provision beyond drug treatment services (e.g. Bloor, 2001), most of the clients interviewed in this study came to services in the expectation that drug treatment agency staff would be the experts who would guide them through treatment. Indeed, not all clients appreciated or were even aware that there was an opportunity for them to be involved in decisions on their own treatment. Deference to staff expertise was frequently coupled with little prior thought as to how interactions with staff might play themselves out. As this community agency client explained:

> I have never really thought about it. I just take it as it comes. I shall be as polite as I can, and talk as normal as I can to them, and hope that they respect me.
> (Community client, England, first interview)

It might be thought that deference to staff was wholly a product of these prior unformed expectations and that, once users found themselves required to conduct themselves in ways that they found uncomfortable or painful, then this deference would disappear. In some instances this was true. Thus, one residential agency client was eloquent at first interview about his wish *not* to be involved in decisions about his treatment:

> I'm happy enough to be here and place it in their hands. I have tried to do it for myself in the past and I have fucked up every time … The best I can do is get my arse through these front doors and work my hardest. But I cannae make any more decisions ... I'm no good at making decisions … I'll go by their rules.
> (Residential client, Scotland, first interview)

But subsequent experience had made him critical at follow-up interview of the requirement that, following detoxification, all clients should participate in the same programme of activities:

> As soon as you were off your detox you had to go to the PE you know? I had been using drugs for about ten or 15 years and they want you to run a mile. And I explained to them that I'd been smoking heroin for 15 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 into this sort-of-room and everybody is banging drums and stuff. I tried to explain to them that I had an ear infection. No, you still have to go, you know? … Pretty crazy that. Every addict is different. There's no one treatment for everybody. If there was a cure which you could put in a jar and sell … There is

no such thing as a one-for-all cure. How can they say that everybody would benefit from going to PE, going to therapeutic drumming, doing this, doing that? I found that quite odd.
(Residential client, Scotland, follow-up interview)

However, it was not the case that most clients lost this deference to staff expertise. Instead, responses to the 'Davie' vignette (see Appendix) indicated that the majority of clients (both at initial and at follow-up interview) believed that, when Davie's therapist insisted that Davie should comply with his treatment contract and attend his first-day group session, even though he was anxious and uncomfortable, then he should indeed go ahead and attend the session. Only two follow-up interviewees believed that Davie had 'the right' not to attend, while many cited the future rewards that would follow present compliance:

If he wants his recovery enough he will just stick to the structure really.
(Residential client, Scotland, follow-up interview)

It can only benefit him in the end.
(Residential client, Scotland, follow-up interview)

The notion that such treatment decisions can be *user-led* was notably absent in these responses and, in contrast, the expectation that Davie would, should, or must attend group sessions was consistently viewed as a taken-for-granted aspect of the treatment programme. Thus, most users did not start a treatment episode seeking user involvement and, even where subsequent experience might be predicted to reduce compliance, most of them continued to defer to staff expertise.

Conflict and latent conflict

Deference to staff expertise was not so total that no client–staff conflicts occurred. Where conflicts do occur they may impact on treatment, but they may also throw light on processes of user involvement. Where overt conflicts were reported by clients, they occurred most commonly in the two residential units. This was likely to be a consequence of the therapeutic regimes in the residential units, with their hierarchy of statuses, detailed rules of conduct and highly structured programmes of activities (Kennard, 1983). Such regimes are structured in ways that carry a potential both for conflict and for means of conflict resolution. Conflict was normally resolved by client conversion to the staff point of view. Although some staff responding to the vignette (including some residential unit staff) thought that it was wrong for Davie's therapist to insist that Davie attend his first-day group, the majority of staff believed that there were therapeutic benefits to compliance, which should override Davie's wishes. For example:

Yeah, definitely right [for the therapist to tell Davie to attend] *because … addicts will avoid everything given the chance, an' an' an' helpers – for me – that allow addicts to avoid, umm, are not helpers, they're usually enablin' him t'stay sick.*
(Residential staff member, Scotland)

Likewise, disputes reported by clients would normally be resolved by clients accepting that their disputatiousness was inappropriate:

[Recently] *I've been quite angry and 'don't you tell me what to do' … I am 27 and I've got to stop acting so young … I do need my*

arse kicked basically, I do. But em, I suppose everybody's the same – they don't like getting told what to do. Nobody does. But if it's gonna keep me alive then I'm gonna listen.
(Residential client, Scotland, follow-up interview)

Rules for new residents, such as 'no visitors', or 'no music', or 'no television', might be initially disputed but were subsequently endorsed after the reasoning behind the rule had been clarified, as with this new client:

I started listening to dance music and I would think of all the good times I had had with dance music on Valium and smoking a joint. So for the first six weeks there's no music or television. It's just really focusing on you because these things make you isolated if you sit and listen to music, and really you should be in the community and talking to people and focusing on you, you know what I mean? So it [the rule] *is a good idea.*
(Residential client, Scotland, first interview)

However, the rationales for all house rules were not sufficiently well explained as to be accepted by all residents – either at the point of entering treatment or three months on – and it was not uncommon for some service users to feel either frustrated or perplexed in the absence of adequate explanations:

I mean it was like all these rules and these structured things that were supposed to be taking you somewhere but it was, it was taking you somewhere where you're never gonna be again so that's not preparing you for the, er, your life on the outside again.
(Residential client, England, follow-up interview)

Likewise, the residential units have formal procedures for resolving disputes between clients and between clients and staff. Clients

who contested the applicability of unit rules to their particular case when the rule was enforced by a member of staff might nevertheless accede where that staff decision is backed by the client's peers in a formal community meeting:

What happens in them [community meetings] *is people get put up for concern, like whether it be health or if they're doing something wrong, so that it's voiced in front of like the whole community, so that we're aware and we can help that person.*
(Residential client, Scotland, follow-up interview)

The depiction of the therapeutic process as a process of conversion of the client to the therapist's view of the client's condition and of the appropriate treatment is a depiction of long standing (Balint, 1957). It is one that applies with particular force to the workings of residential drug treatment units, which seek, through removal of the drug user from his/her former environment, and through an elaborate social structure and close oversight of resident performance, to resocialise residents into new patterns of thought and of behaviour (Bloor and Fonkert, 1982). It sits comfortably with user *participation* in treatment, but uncomfortably with a consumerist approach to user involvement, which sees service delivery as user led. Where staff viewed clients as incapacitated from rational decision making (during detox) and resistant to participation in a treatment programme that staff regarded as of proven benefit, then user involvement in treatment decisions would not get staff support. Instead, staff may stress user involvement, not as consumer choice, but as active participation in their own and others' treatment, and as participation in the everyday governance of the

therapeutic community. Expressions of client preferences that ran counter to unit rules and to the treatment programme would usually be contested by staff – most often with a view to eliciting (through discussion) client compliance, rather than a negotiated compromise.

In the community agencies, conflicts might occur over the speed with which an intervention could be accessed and over prescriptions – over dose levels, over prescriptions being withdrawn, over refusals (for safety reasons) to replace prescriptions where they had been lost or a bottle had been dropped. Although most staff were explicitly committed to working consensually with clients, agreement was ideally sought by persuading the client of the reasonableness of the staff viewpoint, rather than by negotiated compromise. There were, naturally and inevitably, frequent mismatches of perspectives between staff and clients, with clients often being seen as having unrealistic expectations. Staff therefore tended to seek agreement by achieving informed consent rather than by compromise. As one staff member put it:

> It's that informed choice, um, having to have enough knowledge of what they're actually wanting to talk about and be able to show them the pros and the cons of each ... 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 and it hasn't worked and I'm offering this and that and the other … so you need to make that choice. But I would think that the best way from what you're telling me is to go this way, rather than that way.'
> (Community staff member, Scotland)

However, overt conflict was reported by clients to be much less common than the latent conflict that occurred where clients mutely disagreed with the service being offered but accepted it as being non-negotiable:

> I mean she is the doctor at the end of the day and if she don't think it right to give them [Valium] to me… So maybe she thinks that I … but if she doesn't give them me and I go and buy them off the streets anyway so …[tails off].
> (Community client, England, second interview)

This acquiescence masking hidden dissent was, however, conditional. In discussing Davie's likely reaction in the vignette to having his methadone script reduced, although a very few clients believed that Davie would acquiesce ('Ah don't think he'd be too happy ah suppose wid he, know what ah mean, but nothin' much ye can dae aboot it is there?'), most believed that he would react with anger or aggression, or use on top, or simply leave treatment. Only four clients at follow-up interview believed Davie would actually leave treatment, so the adverse consequences of hidden dissent should not be overstated, but clearly one scenario where user involvement in decisions is missing is that, if clients are unhappy with staff decisions about their treatment, then they will break off contact with the service. And retention in treatment is increasingly being considered the mark of an effective drug treatment service (see, for example, Simpson *et al.*, 1997).

Where there are imbalances of power, as there are between staff and clients, and where clients are desperate to achieve particular valued ends (whether those ends are realistic or not), then attempts by them to covertly achieve those ends by manipulation are only

to be expected. Some staff, especially those in the residential agencies, viewed many of their clients as both manipulative and dishonest. Clients, in contrast, represented themselves as being honest about their circumstances:

> *I mean, just one thing my mum said is just to make sure I'm honest, do you know what I mean? There's no point in me coming down to somebody unless I'm being honest, cos otherwise I'll not get the help I need, do you know what I mean? So there's no point in me trying to hide anything.*
> (Community client, England, first interview)

However, a number of clients did report resorting to manipulation or subterfuge of various kinds in order to obtain particular desired services (see below).

Barriers and constraints to accessing services

Within a consumerist approach to health care, service users being able to select and subsequently access the treatment that they themselves have chosen, from a marketplace of possible interventions, is viewed as a means of empowering the individual to take control of their own care, thereby perhaps contributing to positive treatment outcomes. But user choice is just one aspect of an array of factors influencing access to treatment services. These factors differed between community-based and residential services.

Since the community-based services in our study were 'frontline' services, accessing such services was unproblematic for users and indeed many interviewees reported their surprise at how easy it had been to obtain

help. Only a small minority reported delays or barriers, such as the temporary closure of service over the Christmas period, or the prior necessity (in the case of one service) of being registered with a GP.

Some interviewees had actively sought a community prescribing service and arrived at the agencies through their own initiative or following information from other agencies such as local pharmacies. Others had arrived in response to encouragement or pressure from families and partners, but nevertheless represented themselves as willing participants in the treatment process. Others again had arrived following referral from other services including the criminal justice system. Importantly, these latter interviewees, too, did not report themselves as coerced, but rather as willing collaborators in a treatment process that was not only required but also potentially beneficial:

> *My way of looking at it is that, for me yes, I am at that stage in my life, yes I would do anything – if I needed a kick up the backside well my backside is there, kick it … Because otherwise I will just run circles round myself… It's* [Drug Treatment and Testing Order] *good for me because I don't look at it* [as] *compulsory.*
> (Community client, England, first interview)

Many users of community services could not be described as actively involved in accessing services, unless one defined involvement as ready compliance.

Only two users interviewed at the community agencies had attended there seeking referral for more intensive forms of service provision. In one case, the interviewee was looking for a referral to a detox facility, which in

fact operated an open-door policy. In the second case, the interviewee reported that she had been told that the agency would not be prepared to fund her desired form of treatment, leading to her anger and frustration.

Naturally, users interviewed at the residential agencies described a more complex access process. The majority of interviewees described a collaborative process:

> They [referring agency] *said, 'What do you want out of it?' and that. So I told him what I wanted out of it and he said, 'Well do you want me to have a look through a few* [brochures] *… get some out for you to read and that and then we'll go on from there sort-of-thing?' So that's what we did.*
> (Residential client, England, first interview)

In a few cases, users described themselves as playing little role in the referral process, with their residential places being organised for them, sometimes as part of a Drug Treatment and Testing Order (DTTO), sometimes by a drugs worker taking on an advocacy role on their behalf. But there was also a minority of interviewees who reported having to consciously adopt various strategies to obtain a residential treatment. These strategies included: going through the motions of looking at other possible treatment options; persistent callbacks; waiting for an available place; and changing their address to a different trust (England) or health board (Scotland) area that was seen to possess more funding for residential services:

> I went to my woman and I said, 'Pack my gear; I need help'. I broke down. She went: 'We'll get help for you' …. And my uncle had gone through this programme in here for alcohol and he's still

> sober today. Em, she phoned him and he said, 'Bring him through, we can get him into place through in X town. But he's got to come to X town and say he's homeless'.
> (Residential client, Scotland, first interview)

As the above quotation implies, some interviewees at least were also aware that representing their drug use and their personal circumstances as highly chaotic might also help them access residential treatment.

Interviews with referrers confirmed both the importance of collaboration ('you can't force anyone into anything, so if they know what they want then we'll go out of our way to try and get it') and the importance of high client risk in predisposing to a residential referral. However, a number of referrers also reported circumstances that disqualified clients from sovereign choices about treatments. Some clients were thought to have limited knowledge of the options and, relatedly, some were thought to have unrealistic expectations of treatment (especially residential rehabilitation), seeing it as a magic wand that would engender full recovery and be the start of a new life ('it's so often not that way').

Further, the referral process is a formal deliberative procedure involving budgets, guidelines, formal criteria and senior managers, a process at some remove from the client him/herself and therefore from direct user involvement. For example:

> There would be a pot of money allocated from health and social services and there is also money available for clients who are involved with Criminal Justice from Probation. And at times we can apply for additional monies through the Drug Action Team … The client

needs to be falling within a priority. That is how you justify an access. The panel meets monthly, sort of managers from the community teams … The person's case is presented and they will make a decision whether or not to fund the placement or not.
(Referrer, England)

There are therefore a number of constraints, which may impact on the referral decision and which may work against client preferences being realised. These constraints are of variable force in different areas: for some referrers, budgets were not a difficulty, for others they were. Since our interview sample includes agency staff already referring clients to expensive residential treatment, it is not surprising that most of our referrers do report that budgets are sufficient ('funding's never an issue, I've never had anyone refused funding'), where need has been adequately demonstrated; a more common reported constraint is a lack of certain kinds of specialist provision, for example for users with a history of violent behaviour:

Obviously we have to justify why we need a facility, because you're talking about a lot of money, you know we're talking about a helluva lot of money, but it's the worker justifying the reasons why this facility's gonnae help with the client's future development … [the funders] *do provide sufficient amount*[s] *of funds, an' our problem is an insufficient amount of places.*
(Referrer, Scotland)

Some local criteria were more restrictive than others (for example, specifying a unit cost for residential places, which rules out referrals to some establishments) and the case that needed to be made for a particular placement might

be more or less elaborate, and more or less time-consuming for the referrer; some local procedures might take longer than others for a decision to emerge. In some services, high caseloads and staff shortages might give these administrative issues more force. There are also statutory requirements (applying of course to both community and residential services) that have to be met, for example on substitute drug prescribing and on child protection. Constraining factors might thus inhibit, to varying degrees, the translation of client preferences into referral placements.

There was a potential for inconsistency in some referrers' criteria for residential treatment. According to our sample of referrers, prime candidates for residential services were those for whom community-based treatments had been previously ineffective, who were chaotic users and whose support network had broken down and/or who were at risk of violence. But, alongside chaotic use and circumstances, a degree of commitment or motivation was also regarded as important, as was realism in expectations. Thus, users seeking residential treatment and committed to tackling their drug use might find that achieving a (temporary) stability might paradoxically lessen their eligibility for residential treatment as a chaotic user. Some users were aware of the chaotic use criterion and interpreted it as penalising those motivated to attempt to stabilise their use:

My GP said something crazy like, 'The only way you're going to get into [residential treatment] *or the only way they're going to kinda listen to you is if you end up in casualty'.*
(Residential client, Scotland, first interview)

Relatedly, although National Treatment Agency targets state that no drug user should have to wait longer than three weeks to access residential treatment, this might clash with the referrer's desire to ensure that their client is fully prepared for residential treatment. Lack of readiness for treatment might be seen by referrers as a barrier to user involvement in treatment choices:

> I like them to feel comfortable rather than, 'I am going to rehab tomorrow'. You know, another three weeks or a couple of weeks to do some extra work with them will make it a much more comfortable transition.
> (Referrer, England)

While the need for preparatory work and the inculcation of realistic expectations is readily understandable, users might find the delay a considerable source of anxiety. Some users might be concerned that their placement might evaporate if they were arrested, while others might be desperate for a placement to bolster a current attempt at abstinence:

> I was begging them to get me here because I was clean you know. And I just needed the therapy. For me it's not getting clean that's the problem, it's staying clean. Uh … I kept getting pushed away to the side … I mean I was phoning about 20 times a day.
> (Residential client, Scotland, first interview)

The previously cited delay (of up to a month before referral to a residential treatment was agreed by line management) was not typical, but clearly good communication with users in this interim period is important. This was reportedly not achieved by all referrers.

Summary

User involvement in treatment decisions was a value broadly subscribed to by all parties in the treatment settings, although (as we saw in the previous chapter) user involvement can have various meanings. Clients did not expect treatment to be user-led and many clients expected to be fairly passive recipients of guidance from staff. Many staff, for their part, elided user involvement with informed consent. Clients might criticise staff for poor communication and staff might criticise clients for unrealistic expectations. Imbalances in power in the treatment setting might lead to hidden dissent from clients, leading on in turn to possible manipulative behaviour and/or to possible loss of client contact.

While accessing desired services was frequently non-problematic and a collaborative exercise between user and referrer, a number of administrative and budgetary contingencies might militate against client preferences being realised. Most of the referrers in our interview sample were not experiencing budgetary constraints and were more likely to cite shortages of certain kinds of specialist provision. However, some referrers reported restrictive unit cost criteria that would rule out referral to some residential treatment facilities, and administrative decision-making processes that could cause delays and act as a deterrent to hard-pressed staff wishing to make a case for particular referrals. A degree of inconsistency could be detected in some referrers' criteria for residential treatment, where evidence might be sought of both chaotic drug use and domestic circumstances on the one hand, and motivation for change on the other hand. And the

perception by some referrers that clients may need a period of reflection to develop realistic expectations of future residential treatment may clash with clients' perceptions of the urgency of their need for treatment.

4 Enabling effective user involvement

Introduction

Previous chapters of this report have shown how involving drug users in treatment is not straightforward. The concept of user involvement is difficult to define and often poorly understood. Clients and service providers may have different expectations about what user involvement should involve and some structured treatment programmes cannot easily accommodate user involvement in treatment decision making. In addition, structural factors beyond the control of individual agencies can constrain genuine opportunities for active user participation. Despite these evident problems, this chapter will explore how and when effective drug user involvement in treatment decision making might occur by focusing on three topics:

- interviewees' receptivity to communication and negotiation

- preconditions for effective user involvement in referral and treatment decision-making processes

- positive outcomes associated with involving users in treatment decisions.

Receptivity to communication and negotiation

Chapter 2 showed how clients routinely identified good communication and opportunities for negotiation with staff as both forms of user involvement in their own right and essential prerequisites to all other forms of involvement. Chapter 3, however, explored some of the constraints to such involvement – particularly power imbalances between staff

and clients, and clients' expectations about the role of professionals as experts. Here, we will consider the extent to which drug users and staff were, in practice, willing to communicate and negotiate. This issue is important since, without such willingness, any user involvement in treatment decisions would appear to be severely compromised.

At their first interviews, clients unequivocally portrayed themselves as wanting to be open and honest with staff. They also emphasised that they did not wish to be awkward or difficult. Rather, they wanted to be helped, and so appreciated that they needed to communicate their problems in order to ensure that they received the most appropriate treatment. Equally, clients wanted to talk – often at length – about their needs, fears and hopes for the future. At their second interviews, clients reinforced their desire to be open and honest, but added that they wanted to be pushed and challenged. Moreover, many stated that they appreciated the opportunities that they had had to talk with staff, often stressing how much they would have liked these opportunities to have been more frequent.

In addition to their evident desire to communicate, clients at both first and second interviews presented themselves as being open to negotiation and willing to compromise. They also advocated joint decision making and mutual respect between clients and professionals. Although some clients had very strong views about the kinds of support they did or did not want (and would even covertly pursue this if staff disagreed), others were receptive to different views and willing to try things at a professional's suggestion. For example, even clients who reported that they

personally disliked methadone and its effects believed that the vignette character, Davie, should try a prescription if the drug worker thought it might help. Moreover, Davie should feed back any problems to the agency so that the treatment could be adapted to his needs:

> *I think he should dae it and gie it a go. He should dae it, gie it a try and see if it does work oot. He can tell them if it's no working oot … They might need to gie him a bit mere meth. It might no haud him. He should tell them if he's still taking heroin or whitever.*
> (Community client, Scotland, follow-up interview)

As indicated in Chapters 2 and 3, staff were generally less likely than clients to emphasise talking with service users and listening to their views as key forms of user involvement. Some staff certainly recognised the need for negotiation, but their primary objective was usually to convert the user to their own point of view. Despite this, it would be unfair to state that agency staff were unwilling to communicate or negotiate. Indeed, many (from all four agencies) saw their role as being a mentor or guide to their clients. So, they wanted to offer users information and suggestions, and not simply issue them with directives or ultimatums. As this staff member commented:

> *All we do is try and guide the clients in the right way. But we don't dictate to them and say, 'You will feel like this' … We just sort of guide them in the right direction; point out little things that maybe they are not aware of.*
> (Residential staff member, England)

Evidence of both clients' and staff's willingness to negotiate and compromise could,

meanwhile, be detected in their respective tendencies to self-critical awareness. Thus, neither clients nor staff maintained that they were always and in all circumstances right. On the contrary, they often sought to learn from past mistakes and improve future outcomes. For example, staff were often aware that the services they offered to drug users could be modified and improved, and made suggestions regarding how this might be achieved. Some clients also identified situations in which their own previous behaviour had harmed their treatment progress, but then explained how they would not let such mistakes happen again because they were wiser and/or more motivated now.

Preconditions for effective user involvement

Having established the willingness of interviewees (and particularly clients) to engage in communication and negotiation over treatment decisions, this section will examine how these two core activities interlink with a number of other preconditions for effective user involvement. These further preconditions relate to referral and treatment processes, and emerged as the interviewees reflected on how users might best be more involved in treatment decisions.

Preconditions for effective involvement in referral decision making

One of the most important areas of decision making in drug treatment relates to where and what form of intervention users will ultimately receive. Recent guidance produced by the National Treatment Agency argues that practitioners should, wherever possible, factor patient choice into their decisions (NTA, 2006).

In accordance with this view, many interviewees felt that user involvement should begin before the user was referred. Three preconditions for developing this in practice were:

1 ascertaining client motivation

2 providing clear information to potential clients

3 matching client expectations and treatment services.

Ascertaining client motivation
Many clients recognised that users could only really be involved in their treatment if they genuinely wanted help and were prepared to engage in a lot of hard work to confront their problems and move forwards. Equally, once help was genuinely desired, appropriate support needed to be provided quickly. Referral was therefore more likely to be effective if users were genuinely motivated for treatment, and professionals recognised and responded to such commitment. This was facilitated if users were honest and open, and did not attempt treatment when they were not ready.

According to clients, the kinds of factors that were most likely to motivate them to engage with services were being 'sick' of drug-using lifestyles, wanting to lead a normal life and wanting to improve family relationships (particularly with children and parents). Some individuals were motivated by fear that their children would be taken into care; others had concluded that the best motivation was wanting to stop using drugs for oneself rather than for anybody else. A number of clients believed that motivation for treatment was so important to engaging them with services that even quasi-coerced or compulsory criminal justice

treatments could succeed so long as users were committed to change:

> *I think it* [compulsory treatment] *could work, but I think it depends where your head's at. I think if you want to do it, if you've got every intention of doing something, I can't see why you can't.*
> (Residential client, England, first interview)

Staff also recognised the importance of client motivation, but additionally emphasised how this could vary over time and often in unpredictable ways. Thus, clients who initially seemed disengaged from services might adapt and settle in. In other words, it would be premature to dismiss clients who appeared resistant to treatment at referral since they could over time become more committed and succeed:

> *I've had patients in here that would on the face of it have been very voluble, have spoken a lot about, 'I don't want to be here. Blah, blah, blah.' Then within a fortnight they have settled in and they do well, they move into long-term stability.*
> (Residential staff member, Scotland)

Providing clear information to potential clients
Referrers, staff and clients all agreed that those seeking help needed to be given information about the various treatment options available to them. Indeed, without such information, they would not have sufficient knowledge to participate in decision-making processes. With such information, they would be better able to make educated choices and prepare themselves mentally for what they were likely to experience. Some professionals, however, also argued that the information provided at this very early treatment stage had to be accessible – in terms of both the amount of material given and the way it was presented. This was because

those whose drug use was chaotic could have problems understanding very detailed information and difficulty making decisions. As this referrer explained:

> *There is a lot of them* [registered rehabilitation units] *– something like 500 names in there* [book of rehabilitation units]. *So … you can sit down with somebody just thinking about it, plonking a big book in front of them and say, 'Choose somewhere'. A lot of the time people don't know, you know, and they just kind of look at you for advice really.*
> (Referrer, England)

In contrast, information that was easily digestible and appropriately presented did not cause confusion, and was enthusiastically welcomed and much appreciated by potential clients:

> *The drug worker from* [name of agency] *told me about it* [residential agency] *and gave me some leaflets about it. Brilliant! Bits and bobs about it, and it sounded alright.*
> (Residential client, England, first interview)

Matching client expectations and treatment services

Clients and professionals both recognised the importance of matching service user expectations to treatment services. Again this required good two-way communication between drug users and professionals – since professionals had to provide information on what was available, while users had to explain what they wanted and understand what they would receive. When differences of expectations arose or treatment options were restricted, compromises and negotiations had to occur. This was particularly important in respect of

residential services where individuals were effectively about to commit themselves to a whole new way of living and behaving. Thus, it was essential that they accurately understood and were genuinely happy with such issues as how long the treatment would last, what it would involve, and which rules and regulations existed. Reinforcing this point, a number of clients discussed how they had left treatment prematurely because they had misunderstood the nature of the treatment they would receive:

> *I went there* [residential service] *believing that I was only there for re-entry, purely to settle back into the community … But as it turns out … it never worked out like that. I had to start from induction, then primary and then to seniors. And there was no recollection of going to re-entry because I wasn't settling in the area, which really annoyed me.*
> (Residential client, England, follow-up interview)

Preconditions for effective involvement in treatment decision making

Once referral had taken place and individuals had entered treatment, user involvement could potentially have occurred in a diverse range of ways. For example, clients could have made decisions about who would treat them, what treatment they would receive, when they would meet with staff, or how long their treatment would last. Chapter 2, however, indicated that clients' actual experiences of involvement across all four services were relatively limited – relating largely to fairly minor aspects of their own treatment process. Moreover, this was commonly consistent with the relatively basic forms of involvement that users actually desired.

In this section, three preconditions for promoting user involvement in treatment decision making that clients considered important to them will be considered. These are:

1   not being rushed

2   receiving explanations and being able to ask questions

3   feeling safe and secure.

Once again, good communication and negotiation processes played obvious underpinning roles.

Not being rushed
In order to be effectively involved in treatment decision making, clients emphasised that they could not be rushed. The process of recovery from addiction was widely recognised as hard and long. It generally required them to relive many past painful experiences and confront unpleasant memories. Equally, it could mean enduring physical discomfort and cravings while subjecting themselves to strict treatment rules and regimes. As this residential client explained:

> *It has been a very hard process, especially when I think back … We were just in a meeting there and I had to write down ten serious consequences in terms of what drugs have done to my life. The shame, the guilt, the ways of obtaining money, the things that you go through, the lies, the deceit ... It disgusts me, thinking back to the things that happened.*
> (Residential client, Scotland, first interview)

Recognising the difficulty of the task before them, clients often stressed that they needed to take things at their own pace. This

might include not having any substitute drugs decreased too rapidly or being permitted to take time to settle into a residential service before they had to participate in intensive group work or therapeutic sessions. More commonly, it simply involved being given sufficient opportunity to talk unhurriedly to drug agency staff:

> *I usually sit and talk to* [name of staff member] *for at least three-quarters of an hour. We do end up sitting talking about everything, we do. Sometimes, like if they've got appointments, they will try and talk over their appointment, know what I mean, and still that person will be waiting but they will go out and see them eventually, but they don't rush you or anything like that, they don't … 'Aye, talk, aye, whatever, you feel free', know what I mean? They don't rush you or anything like that, never, never.*
> (Community client, Scotland, first interview)

Receiving explanations and being able to ask questions
Receiving explanations and being able to ask questions were also important preconditions for enabling service users to be involved in treatment decisions. In this regard, clients appreciated being able to ask about a diverse range of issues. These included what they had to do, why they had to do it, the reasons for particular rules or procedures, how their treatment would likely progress and how this would probably make them feel. Answers to such questions could help clients to make informed choices about both the treatments they accepted (or declined) and how they behaved (for example, whether or not they complied with agency protocols). Equally, it could help to allay their fears and concerns.

In contrast, the absence of explanations could leave clients confused, anxious, demoralised and even angry – particularly at the start of a new treatment episode when they were more likely to be feeling vulnerable and apprehensive. This is evident in the following quotations from a community and residential client respectively:

> *I came down and sat for … I don't know, about an hour or something like that. And then I saw some guy and he came through saying, 'So why are you here?' And I felt a bit at first, 'Why am I here then?' Do you know what I mean? I was told it was part of my licence conditions.*
> (Community client, Scotland, first interview)

> *I didn't know I wasn't allowed to bring anything up, a hi-fi, whatever … And I went out and spent money and bought cranberry juice, things that I drink.* [Staff member] *took half my things off me. I was angry about that.*
> (Residential client, Scotland, first interview)

Feeling safe and secure
A further factor that facilitated user involvement was feeling safe and secure. This was most evident when users perceived that the treatment environment was friendly and supportive – a feeling that could be generated by staff in the community services, but by both staff and other users in the residential units. For example, a number of residential clients emphasised the sense of belonging and purpose they gained from users helping each other, sharing their experiences, offering new friendships, providing advice, being understanding and generally looking out for each other. Such relationships routinely occurred informally, as well as within the context of the more structured group work

that was integral to the therapeutic community setting:

> *People share about stuff that happened to them, or things that's going to happen within the next couple of days. All we'll do is give them feedback on maybe a better way of doing it, or maybe using your experience. 'Maybe if you do it this way, this'll maybe help you', you know. People are dead supportive.*
> (Residential client, Scotland, first interview)

> *The therapeutic groups are good. You've got people in your group to help you. They see you as you are and it's like they're telling you what's wrong.*
> (Residential client, Scotland, follow-up interview)

Staff could also offer security and safety to their clients in a variety of ways. A friendly face and greeting often went a long way towards making drug users feel better about themselves and about their treatment. However, clients particularly appreciated it when staff were understanding of their problems, optimistic and encouraging about their treatment progress, and not critical or judgemental if they relapsed. Furthermore, they were clearly touched when staff appeared to be genuinely concerned about them and their welfare.

Many staff likewise recognised the importance of building up trusting relationships with clients in order to work effectively with them. Such relationships, they felt, required staff to have good interpersonal skills – particularly given that many service users were fragile and could find it difficult to talk. Equally, these relationships needed time to form and develop:

> *In the first few days, I like to build a therapeutic relationship with them. And once I've got the*

therapeutic relationship, I can work with them, challenge them. In the beginning, it is really, really important, especially the first few weeks in treatment, to try and build up a relationship with my patients.
(Residential staff member, Scotland)

Positive outcomes associated with involving users in treatment decisions

Chapter 2 considered why interviewees believed that user involvement should be encouraged. One reason identified by many referrers and some staff was a belief that user involvement would be likely to contribute to improved treatment outcomes. It is, of course, impossible in a study of this kind to prove any direct causal relationship between involving drug users and positive effects. Indeed, as referrers and staff both acknowledged, user involvement is only one of very many factors contributing to treatment success. Nonetheless, it is useful to examine actual examples of positive outcomes that interviewees directly attributed to clients participating in decision making.

In practice, most clients and staff felt able to identify instances in which particular forms of user involvement seemed to be having a beneficial effect. For example, having information about a service (perhaps through speaking to someone or seeing a brochure about a rehabilitation unit) often made clients feel more committed to their treatment. Additionally, many clients argued that participating in treatment decisions increased their confidence and made them feel more independent. Moreover, involvement seemed to make some less likely to resist treatment:

I think if you're forced into something, you tend to kinda back away from it, you know what I mean?
(Community client, Scotland, follow-up interview)

A number of staff also reported that those who were motivated for treatment were more likely to engage with services and subsequently do better. However, these staff tended to recognise that both motivation and engagement were difficult to assess, and successful treatment was difficult to predict.

Involving clients additionally appeared to have the capacity to prevent treatment breakdown. For example, one reason why some clients had prematurely left treatment between their first and second interview was conflict with staff (which had resulted in the client either abandoning their treatment or being discharged for bad behaviour). According to some clients, these serious disputes might never have occurred if initial minor disagreements had been appropriately confronted and addressed through better listening, understanding, explanation and compromise.

Other common reasons clients gave for dropping out of treatment before their second interview were becoming disenchanted with the treatment, unexpected family or other personal problems and difficult withdrawals during the detoxification stage of residential programmes. Here, again, clients indicated that better communication with staff – particularly staff listening to them more, being more compassionate and being more flexible to accommodate their personal circumstances – might have persuaded them to stay. Although residential staff believed that formal democratic structures (rather than individual negotiations)

were the most appropriate place to debate treatment rules and complaints, it seemed that these were not always sufficiently responsive for those in very immediate distress. For example, this client believed that she would not have discharged herself against medical advice had staff shown her more sympathy and been more willing to accommodate her desire for benzodiazepines:

> *They were wantin' me to get up in the morning an' make toast for everybody at half six, an' that. I'd already been up a' night, so I hadne been to sleep. So I was like a walking zombie, but I still couldne sleep an' ma head was poundin' an' ma whole body was a' shakin'. I was sweatin', I was bein' sick an' they were gein' me an anti-sickness pill … You'd think they'd at least gave ye one Valium or something … See if they would have gave me two Valium tae help me sleep ah'd a stayed.*
>
> (Residential client, Scotland, follow-up interview)

User involvement and satisfaction with treatment

As noted in Chapter 1, all drug users reinterviewed after three months were asked to complete the Treatment Perceptions Questionnaire (TPQ), as a measure of their satisfaction with treatment. They also completed one additional question relating to how much they had been included in any decisions about the help that they had received. The TPQ was scored from 0–40 where 0 represented the lowest level of satisfaction with treatment and 40 the highest level. The additional user involvement question was scored from 0–4 where 0 was the lowest level of involvement and 4 the highest. Mean scores for each of the four case study agencies are shown in Table 3.

Table 3 shows that the mean TPQ score for satisfaction with treatment across all agencies was 24.6 out of a possible 40 – with the community service clients reporting slightly higher mean scores (27.1 and 26.0) than the residential clients (24.8 and 20.7). Although there was little difference between the mean user involvement scores for each of the four agencies, the pattern of involvement scores broadly mirrored the pattern of satisfaction scores. Thus, the English community service scored highest and the English residential service scored lowest on both accounts.

Table 3 Mean TPQ (satisfaction) and user involvement scores by treatment agency

Agency	Number of users	Number of users still in treatment at follow-up	TPQ satisfaction score	Single user involvement question
Community service, England	16	15	27.1	3.4
Community service, Scotland	10 [a]	9	26.0	2.5
Residential service, Scotland	11 [b]	7	24.8	2.7
Residential service, England	15	6	20.7	2.2
Total	*52*	*37*	*24.6*	*2.7*

a   Four missing cases.
b   Three missing cases.

While these data do not prove that user involvement is associated with satisfaction with treatment, the findings are consistent with an association. Moreover, this association appears to be reinforced by clients' comments that user involvement improved how they felt:

> It makes you feel at ease, really, knowing that you are not pressured into doing anything you don't want to do.
> (Community client, England, follow-up interview)

In Table 4, the mean TPQ (satisfaction) and user involvement scores for clients in treatment and not in treatment at their second interviews were compared. Those who remained in treatment had a mean TPQ score of 26.0 and user involvement score of 2.9. This compared with a mean TPQ score of 21.1 and user involvement score of 2.4 for those who were not in treatment. In other words, those who stayed in treatment for longer appeared to be both more satisfied with, and more involved in, treatment. Again, however, the data are limited. Thus, they cannot explain the causal direction of that apparent association, or indeed whether or not the apparent association was caused by one or more other intervening factors, such as levels of staff expertise or client motivation (see also Neale *et al.*, 2006).

Summary

Although there are many difficulties in involving drug users in treatment decisions, this chapter has shown how participation might be both achievable and desirable. For example, both clients and staff appeared willing to communicate and negotiate – two fundamental forms of user involvement. Indeed, contrary to the notion that those who abuse drugs are manipulative and hostile (De Leon, 2000), clients presented themselves as open, honest and receptive to different points of view. They were also very keen to talk about their problems whenever they could and appeared willing to negotiate and share decision making. For their part, staff emphasised that they did not want to dictate to their clients, but rather preferred to act as mentors and guides.

The interviews also provided valuable insights into a number of other important preconditions for effective user involvement. At referral, engagement with treatment required clients to reflect honestly on their motivation and seek help when they were committed. Levels of motivation could, however, change over time and in unpredictable ways. Thus, clients should not be dismissed as uncommitted if their initial motivation seemed low. Clients needed to be given information that was both

Table 4 Mean TPQ (satisfaction) and user involvement scores by treatment status at second interview

Treatment status	Number of users	TPQ (satisfaction) score	Single user involvement question
In treatment	37[a]	26.0	2.9
Not in treatment	15[b]	21.1	2.4
All	52	24.6	2.7

a   Three missing cases.
b   Four missing cases.

manageable and comprehensible, so that they could make informed treatment choices. Additionally, negotiations were likely to be necessary to ensure that client expectations and treatment services matched. Once treatment had started, users often needed to be given time and space, explanations and opportunities to ask questions, and a safe and secure environment in order to feel able to open up.

While the data collected could not prove any direct causal relationship between user involvement and treatment outcomes, most clients and staff felt that user involvement had beneficial effects. For example, it could make clients feel more committed to treatment, and increase their confidence and personal autonomy. It also appeared to have some potential to prevent treatment breakdown. These findings were supported by very basic quantitative data, which indicated associations between user involvement, treatment satisfaction and treatment retention. Treatment satisfaction is, of course, an important measure of treatment success in its own right. Treatment retention, meanwhile, is known to improve treatment outcomes (Simpson, 1981; Simpson and Sells, 1982; De Leon, 1985; Hubbard *et al.*, 1989; Ball and Ross, 1991; Simpson *et al.*, 1997).

5 Conclusion and recommendations for practice

Introduction

In this final chapter of the report, our intentions are twofold. First, to highlight our main findings as they relate to our five principal research questions (outlined in Chapter 1). And, second, to list ten recommendations, in no order of priority, for facilitating user involvement in drug treatment decision making. These recommendations emerged from early analyses of the data and were refined through a closed email discussion group with a select number of practitioners, policymakers and service users.

The nature and extent of user involvement in drug treatment decision making

The forms of user involvement

As Chapter 1 highlighted, what user involvement is and what it means in practice can vary across different treatment contexts. Our research has shown that there was substantial variety in how users and their keyworkers felt users could, or should, be involved in making treatment decisions.

In the residential agencies staff tended to place strong emphasis on the importance of group work in promoting user participation (see also Ward, 2000), yet felt that the core components of the treatment programme should not be adapted in order to suit individual preferences.

In the community agencies staff often emphasised the value of flexibility and tailoring services to meet individual needs, although a commitment by staff to user involvement could sometimes shade into a commitment to securing informed consent from users on treatment decisions.

While basic forms of user involvement in decision making (Poulton, 1999) were evident in all four treatment agencies, there appeared to be greater potential for service users to be involved in day-to-day decisions in relation to their own care when opting for treatment in the community agencies. In contrast, the potential for service users to be involved in the formal systems of governance and in delivering support to other service users was higher for those receiving treatment in the residential agencies.

Preferences for involvement

Far from all of the service users we interviewed wished to be highly involved in decision making. Many service users saw staff as experts and were happy for them to take the lead in organising their care, which was a view shared by many practitioners. Similarly, users' preferences for different treatment approaches varied considerably. While the value of choice and flexibility in treatment was emphasised by some, others stressed the benefits of highly structured and pre-arranged forms of intervention. Furthermore, while some users' preferences remained consistent at initial and follow-up interview, others had changed their position in the light of their recent treatment experiences.

Conflict and disagreement between staff and service users

The nature and extent of conflict

Overt conflicts between users and staff in drug treatment services are uncommon; imbalances

of power between users and staff mean that users' dissent from staff views is often hidden. Because of the structured programme of activities in residential rehabs, the scope for conflict is greater in these services than in community services. Hidden dissent, by its nature, is likely to remain unaddressed and could lead to users taking an early exit from treatment.

The causes of conflict

While most users were willing to defer to the expertise of staff, there was also potential for practitioners to be seen as remote and lacking in understanding. Furthermore, the rules of treatment did not appear sufficiently well explained as to be understood by all the service users who took part in this research. Consequently, when service users are required to abide by rules for which they do not understand the rationale, or are refused special dispensations during stressful periods such as detoxification, then the potential for conflict and attrition is high, especially if practitioners feel that users are trying to manipulate the situation or have unrealistic expectations of the treatment process.

The role of user involvement in preventing conflict

There is a fine line between constructive and counterproductive forms of confrontation and, while it is impossible to eradicate the risk of treatment breakdown, basic forms of user involvement could help reduce it. Treating users with respect, listening to their concerns and providing explanations as to the reasoning behind what they are being asked to do are key principles in avoiding conflict, and many of our

recommendations focus on achieving this in practice.

The effects of external factors on user involvement

User involvement is one factor in a spectrum of priorities in drug treatment and Chapters 3 and 4 of this report highlighted the various ways in which involvement can be both enabled and constrained in practice.

Funding, targets and service availability

Referrers committed to user involvement will seek to provide their clients with both choices and information, and indeed many of the users who took part in this research reported receiving such a service. Equally, some referrers reported having to juggle their clients' preferences with competing priorities, to reconcile user preferences with local guidelines on appropriate referral, to ensure that their recommendations to funders were able to demonstrate that the preferred placement represented value for money and to work within the context of local service availability. There was a shortage of certain kinds of specialist provision. As such, it was not always possible for users to access their ideal treatment service. Finding a pragmatic compromise between the ideal and the available is likely to have required considerable skill and negotiation from all concerned.

Client–staff ratios

In order to avoid tokenism, involving users in the decision-making process requires both time and commitment from practitioners. Several staff members from across the agencies,

however, reported working within the context of high caseloads and staff shortages, and tended to see such pressures as having a substantial impact on the quality of care and one-to-one support they were able to offer their clients.

Staff approaches

While staff members were often committed to the principles of involving and empowering service users, it was not uncommon for practitioners to feel that some of their clients brought unrealistic expectations to the treatment process or were not yet at the stage where they could make effective decisions. These factors are likely to have a substantial impact on the extent to which practitioners work in partnership with service users, especially when there is a lack of clear consensus regarding what form of intervention is required.

The effects of user involvement and motivation on treatment outcomes

The effects of user involvement

As Chapter 1 of this report has highlighted, the outcomes of drug treatment are influenced by an array of factors and it is practically impossible to assess the relative influence of each and every one. This is especially true in the case of user involvement, given that it has proved extremely difficult both to define and to measure (Crawford *et al.*, 2002; Rose *et al.*, 2002). While this is the case, Chapter 4 argues that feelings of involvement can contribute to users being more satisfied with the intervention and therefore deciding to remain in treatment for longer. As one would perhaps expect, those service users who had left

treatment early tended to report less satisfaction with the service (compared with those who had remained in treatment), and frequently expressed a desire to have been listened to and consulted more over key issues. In this respect, user involvement and retention in treatment can go hand in hand and, by facilitating the former, agencies have the potential to increase the latter.

The effects of motivation

As with all individuals, service users' motivations are continuously subject to evaluation and reformulation. As such, their motives are constructed as much through reflection – in formal interview settings or sessions with drugs workers, for example – as they are catalysts for action. However, both staff and service users tended to place great importance on users being 'genuinely' motivated to address their substance misuse. Genuine motivation tended to be viewed by both parties as an important factor in the treatment process in order, for example, to ensure that service users entered treatment with a strong commitment to addressing their substance misuse. However, this is not to say that, in order for intervention to be successful, users must have the 'correct' form or level of motivation. Users tended to seek treatment at these agencies for a variety of reasons and, indeed, some practitioners felt that even those who initially showed very limited evidence of motivation could still achieve positive outcomes.

Involvement and informed consent

Without a certain degree of user involvement informed consent cannot be ascertained. Service users were unanimous in their

desire for information sharing and effective communication between themselves and staff, which are necessary in order for them to give their informed consent to treatment. The importance of informed consent is difficult to underestimate and can substantially reduce the potential for conflicts, misunderstandings and subsequent user attrition. As such, Chapter 4 of this report highlighted the importance of matching client expectations to treatment services at the referral stage, as well as creating a supportive treatment environment where users are able to ask questions and are provided with detailed explanations. In doing so, Chapter 4 highlighted the need for informed consent to be an integral aspect of the treatment process and not confined to pre-treatment discussions.

The importance of user involvement in drug treatment

User involvement and treatment success
While basic forms of inclusion and consultation are important – and actively desired by service users – more participatory forms of involvement in decision making tended not to be seen by either practitioners or their clients as the key ingredients to a successful drug treatment. Staff members, for example, tended to emphasise retention in treatment and reduction in drug use as the primary objectives rather than, for example, responding to what the user wants. In an ideal world, however, these two should go hand in hand.

Involvement and satisfaction
The service users we interviewed tended to enter treatment with high hopes and aspirations, and had set themselves ambitious

goals to reduce or eliminate their drug use and establish a non-dependent lifestyle. In this context, their feelings of involvement in the treatment process were often intricately related to the extent to which they felt the intervention helped them to make progress in achieving their objectives. If it did, users tended to feel satisfied with the process regardless of how pre-structured or how flexible the intervention was perceived to be. Similarly, those users who felt treatment had not helped them to make progress frequently showed signs of dissatisfaction, of wanting to have been listened to more and were often, quite understandably, disappointed with the outcome.

The benefits of user involvement
In short, user involvement in decision making can promote feelings of satisfaction among service users and can also be important in maintaining motivation, as well as building confidence and self-esteem. Treating users with respect, listening to their concerns, providing information and establishing effective channels of communication between clients and practitioners are all practical and achievable means of facilitating user involvement in drug treatment. These forms of involvement were actively desired by users and have the potential to contribute to their staying in treatment longer and potentially doing better as a result.

Recommendations

The following recommendations were developed through a closed email Delphi group, where a select number of practitioners, policymakers and service users were invited to comment on a list of draft recommendations,

which emerged from early analyses of the data. These draft recommendations were then refined in the light of members' comments. We adopted this procedure both because we recognised that there is typically a gap, or at least a difference in the degree of abstraction, that needs to be addressed between research findings on service provision and everyday service practice, and because (in a study of user involvement) we wished to give service users and practitioners a formal opportunity to participate in the process of drawing out the practice implications of the research. These recommendations are meant to stimulate debate. We are aware that our research was unable to address all aspects of user involvement in treatment decisions (for example, the project was not designed to address how diversity – such as ethnic diversity – may impact on user involvement) and that there are many practical difficulties (including resourcing) in implementing enhanced user involvement. We are aware too (see Chapter 1) that user involvement can be defined in different ways, focusing variously on the planning of services, the conduct of therapy, the governance of treatment facilities and the choice of treatment. These recommendations are designed to address the last of these foci (user involvement in treatment decisions). We recognise that some services have already adopted some of the practices discussed in these recommendations (listed in no particular order) below.

1　Drug treatment agencies should consider the advantages of using accessible mediums, such as videos and CDs, to communicate information to service users about what they can expect from treatment. This information should include details on the rules and regulations of treatment and the likely consequences of breaching them. It should also highlight areas of the treatment programme that users are likely to find challenging or difficult and how they can manage these situations appropriately. Videos and CDs that include the stories and experiences of other service users may well help to communicate this information effectively.

2　In addition to information provided by the agency, referrers should brief their clients on the likelihood that they will find treatment a difficult and challenging experience. These briefings should cover areas of possible disagreement between staff and service users, and the channels through which users can appropriately voice their concerns.

3　Even though they may have been given detailed information about the agency, practitioners should not expect service users to be able to give their informed consent at the pre-treatment stage. When signing treatment contracts and other formal documents, service users should be given the opportunity to revisit the contract with their keyworkers at a later date and discuss any areas of concern.

4　Agencies should consider whether those starting on methadone maintenance or other forms of substitute prescribing should be able to meet other service users currently on such prescriptions and have the opportunity to ask them about their experiences. This could be provided through regular 'induction groups' held within the agency and facilitated by agency staff.

5 All those responsible for administering detoxification treatments should consider the benefits of involving their clients in decisions over the length of the detoxification period and the type of substitute medication to be used.

6 Commissioning bodies should seek to provide access to a range of effective drug treatment services and should pay particular attention to shortfalls in services for those with specialist or complex needs.

7 In order to ensure consistency, agencies that refer clients to residential treatment should have clear guidelines for assessing the suitability of service users, which are both evidence based and in line with national guidance.

8 Practitioners should avoid seeing service users as having unrealistic expectations of treatment and instead see them as based on alternative sources of information. If service users have a clear preference for a particular treatment, which they can justify after having been presented with alternatives, their choice should be accepted wherever possible. If the practitioner is concerned that the user's choice of treatment carries certain risks, these should be made clear to the client and strategies to reduce these risks

should, whenever possible, be included in the treatment plan.

9 Ideally, referrers should seek to access the service that has been mutually agreed upon and is considered most suitable in meeting the client's needs and aspirations. If there are problems with accessing such services – because of limited availability, for example – these should be identified at the earliest possible opportunity. If a compromise needs to be reached, 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 to transfer to a different agency at a later date should, whenever possible, be included in the treatment plan.

10 Referrers need to be aware that the waiting period between deciding on and accessing services is likely to be a very difficult time for service users. At the outset, service users should be given a realistic estimate of the length of time the referral will take to complete 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 time and no phone call or request for information from service users should go unacknowledged.

Notes

Chapter 1

1   A more comprehensive list is provided in OUT (2003).

Chapter 2

1   There was no firm evidence that involvement in treatment decision making decreased between first and second interviews in any of the agencies. However, during the study period, the English community agency did experience some staffing shortages that negatively affected the amount of time workers had to spend with individual clients.

References

Arnstein, S.R. (1969) 'A ladder of citizen participation', *Journal of the American Institute of Planners*, Vol. 35, No. 4, pp. 216–24

Balint, M. (1957) *The Doctor, His Patient and the Illness*. London: Pitman

Ball, J.C. and Ross, A. (1991) *The Effectiveness of Methadone Maintenance Treatment*. New York: Springer

Barker, I. and Peck, E. (eds) (1987) *Power in Strange Places: User Empowerment in Mental Health Services*. London: Good Practices in Mental Health

Barnes, M. and Wistow, G. (1992) 'Understanding user involvement', in M. Barnes and G. Wistow (eds) *Researching User Involvement*. Leeds: Nuffield Institute for Health Services Studies

Bloor, M. (2001) 'Plenary address: on the consulting room couch with citizen science', *Medical Sociology News*, Vol. 27, No. 3, pp. 19–40

Bloor, M. and Fonkert, D. (1982) 'Reality construction, reality exploration and treatment in two therapeutic communities', *Sociology of Health & Illness*, Vol. 4, pp. 125–40

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. and Tyrer, P. (2002) 'Systematic review of involving patients in the planning and development of health care', *British Medical Journal*, Vol. 325, p. 1263

Croft, S. and Beresford, P. (1990) *From Paternalism to Participation: Involving People in Social Services*. London: Open Services Project / Joseph Rowntree Foundation

Davies, A. (1988) 'Users' perspectives', in S. Ramon and M.G. Gianichedda (eds) *Psychiatry in Transition*. London: Pluto Press

De Leon, G. (1985) 'The therapeutic community: status and evolution', *International Journal of the Addictions*, Vol. 20, pp. 823–44

De Leon, G. (2000) *The Therapeutic Community: Theory, Model, and Method*. New York: Springer

DoH (Department of Health) (2000) *The NHS Plan: A Plan for Investment, a Plan for Reform*. London: HMSO

Garrett, D. and Foster, J. (2005) 'Fumbling in the dark', *Druglink*, May / June, p. 12

Gray, R., Fitch, M., Greenberg, M. and Shapiro, S. (1995) 'Consumer participation in cancer service planning', *Journal of Palliative Care*, Vol. 11, No. 4, pp. 27–33

Hodge, S. (2005) 'Participation, discourse and power: a case study in service user involvement', *Critical Social Policy*, Vol. 25, No. 2, pp. 164–79

Hubbard, R.L., Marsden, M.E., Rachal, J.V., Harwood, H.J., Cavanaugh, E.R. and Ginzburg, H.M. (1989) *Drug Abuse Treatment: A National Study of Effectiveness*. Chapel Hill, NC: University of North Carolina Press

Hughes, R. (1998) 'Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour', *Sociology of Health and Illness*, Vol. 20, No. 3, pp. 381–400

Hutchinson, M., Linton, G. and Lucas, J. (1995) *User Involvement Information Pack: From Policy to Practice*. London: MIND South East

Kennard, D. (1983) *An Introduction to Therapeutic Communities*. London: Routledge

McKeganey, N., Morris, Z., Neale, J. and Robertson, M. (2004) 'What are drug users looking for when they contact drug services: abstinence or harm reduction?', *Drugs: Education, Prevention and Policy*, Vol. 11, No. 5, pp. 423–35

Marsden, J., Stewart, D., Gossop, M., Rolfe, A., Bacchus, L., Griffiths, P., Clarke, K. and Strang, J. (2000) 'Assessing client satisfaction with treatment for substance use problems and the development of the treatment perceptions questionnaire (TPQ)', *Addiction Research*, Vol. 8, No. 5, pp. 445–70

Martin, P. (2005) 'Critique of "What are drug users looking for when they contact drug services: abstinence or harm reduction?"', *Drugs: Education, Prevention and Policy*, Vol. 12, No. 4, pp. 257–9

Meade, K. and Carter, T. (1990) 'Empowering older users: some starting points', in L. Winn (ed.) *Power to the People: The Key to Responsive Services in Health and Social Care*. London: The King's Fund

Neale, J. (1998) 'Drug users' views of prescribed methadone', *Drugs: Education, Prevention & Policy*, Vol. 5, No. 1, pp. 33–45

Neale, J., Bloor, M., Berney, L. and Fischer, J. (2006) 'Feel good factor', *Druglink*, January / February, pp. 20–1

Nelles, B. (2005) 'Comment on "What are drug users looking for when they contact drug services: abstinence or harm reduction?"', *Drugs: Education, Prevention and Policy*, Vol. 12, No. 4, pp. 255–6

NTA (National Treatment Agency) (2006) *NTA Guidance for Local Partnerships on User and Carer Involvement*. London: National Treatment Agency

Osborn, A. (1991) *Taking Part in Community Care Planning: The Involvement of User Groups, Carer Groups and Voluntary Groups*. Leeds / Edinburgh: The Nuffield Institute for Health Services Studies / Age Concern Scotland

OUT (Oxfordshire User Team) (2003) *A Practical Guide to User Involvement and Peer Education*. Oxford: Oxford User Team with support from the NTA and Oxfordshire DAAT

Poulton, B.C. (1999) 'User involvement in identifying health needs and shaping and evaluating services: is it being realised?', *Journal of Advanced Nursing*, Vol. 30, No. 6, pp. 1289–96

Roberts, M. (2005) Comment on 'What are drug users looking for when they contact drug services: abstinence or harm reduction?', *Drugs: Education, Prevention and Policy*, Vol. 12, No. 4, pp. 261–3

Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wykes, T. (2002) *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCSDO). London: NCSDO

Scottish Executive (2006) *Draft National Quality Standards for Substance Misuse Services*. Edinburgh: Scottish Executive

SDF (Scottish Drugs Forum) (1996) *Policy Statement: User Involvement*. Glasgow: SDF

Simpson, D.D. (1981) 'Treatment of drug abuse: follow-up outcomes and length of time spent', *Archives of General Psychiatry*, Vol. 38, pp. 875–80

Simpson, D.D. and Sells, S.B. (1982) 'Effectiveness of treatment for drug abuse: an overview of the DARP research program', *Advances in Alcohol and Substance Abuse*, Vol. 2, pp. 7–29

Simpson, D.D., Joe, G.W., Rowan-Szal, G.A. and Greener, J.M. (1997) 'Drug abuse treatment process components that improve retention', *Journal of Substance Abuse Treatment*, Vol. 14, pp. 565–72

Small, N. and Rhodes, P. (2000) *Too Ill to Talk? User Involvement and Palliative Care*. London: Routledge

Taylor, M., Hoyes, L., Lart, R. and Means, R. (1992) *User Empowerment in Community Care: Unravelling the Issues*. Bristol: University of Bristol School for Advanced Urban Studies

Thompson, J. (1995) *User Involvement in Mental Health Services: The Limits of Consumerism, the Risks of Marginalisation and the Need for a Critical Approach*. Research Memorandum No. 8. Hull: The Centre for Systems Studies, University of Hull

Ward, D. (2000) 'Totem not token: groupwork as a vehicle for user participation', in H. Kemshall and R. Littlechild (eds) *User Involvement and Participation in Social Care: Research Informing Practice*. London: Jessica Kingsley

Appendix

The 'Davie' vignette

Davie is 19. He started smoking hash when he was 14 and soon moved on to speed and E. When he was 17, he first tried smoking heroin. After a year he started injecting and his habit quickly grew to £80 a day. He was injecting so often that he eventually lost his job and now his girlfriend has left him. Davie thinks he is no longer in control of his drug use and decides to seek help.

What do you think Davie will do?

Davie goes to see a local GP and tells her that he has been injecting heroin for a year and now needs help.

What happens when Davie tells the GP he needs help?

The GP says she doesn't treat drug users in the practice and he'll need to go to a drug treatment clinic in town. She gives him a phone number and Davie phones and makes an appointment. He is offered an assessment the following week. The staff at the clinic are very friendly and Davie is told that he can have a daily script of 40 ml of methadone if he agrees to weekly counselling from a drug worker.

What does Davie think about this offer?

Davie thinks that 40 ml is not enough to hold him, but decides to give it a go. Within a few weeks, he starts using heroin on top of his methadone. One day, he turns up at the clinic gouching. The staff tell him that his script is being reduced.

How does Davie react when he is told that his script is being reduced?

Davie decides that he isn't happy and drifts out of contact with the service. Soon, he starts using cocaine as well as heroin and, after a few weeks, he is feeling paranoid and anxious all the time. He decides he wants a place in a rehab and recontacts the clinic to see if they can help him.

What do you think will happen when Davie returns to the clinic?

The doctor at the clinic says that there is a long waiting list and that Davie might not be suitable for a rehab. Davie is annoyed at this, but agrees to try and wait. He is put back on a script of 40 ml of methadone and is told that he is more likely to get a place in the rehab if he doesn't use on top. Davie agrees to this and provides clean urine samples on a number of occasions.

Why do you think Davie does this?

Davie has to wait four months before a place becomes available at a rehab. The rehab is 50 miles from his home town but looks very nice in the brochure. A friend tells Davie that it is a very good place to get clean. Davie is given an admission date and tells his family about his plans. Before he accepts a place in the rehab, Davie is asked to sign a contract. The contract involves agreeing to a set of rules and regulations, such as not having visitors, getting up by eight every morning, keeping the rehab clean and tidy, and taking part in group therapy sessions.

How does Davie feel about signing the contract?

Davie feels uncertain about the contract, but signs anyway. On the first day, he asks the staff whether he really has to go to the group sessions. Davie has never been comfortable talking to big groups of people and he feels quite anxious. The therapist insists that Davie knew what to expect when he signed up to come to the rehab and it really is in his best interests to join in the group activities.

Is the therapist right or wrong to tell Davie to attend the group sessions? Do you think Davie will attend the group sessions?

Davie attends the sessions and soon starts to enjoy them. He quickly strikes up a friendship with Alex, who is also in the rehab. Everything is going well until Alex tells Davie he has some heroin and invites him to his room for a smoke. The following day, staff call a group meeting because they have evidence that some of the house members have been using. Davie can't decide whether to come forward and own up.

What do you think Davie will do and why?