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User involvement and desired service developments in drug treatment – service user and provider views

Schulte, S., Moring, J., Meier, P.S. and Barrowclough, C.

ABSTRACT

Aims To investigate the existing level of user involvement at selected agencies, to examine views about user involvement from both service user and provider perspectives and to compare desired service developments.

Design/Measurements As part of a larger project, a series of semi-structured interviews were carried out between 2001 and 2003.

Setting Community-based drug services in Northern England.

Participants Forty-six service users and 51 service providers.

Findings The level of service user involvement was low overall, with 16% of services having no user involvement at all. Nevertheless, service users expressed a desire for a high level of user involvement, compared with the low aspirations expressed by service providers. Service users' first priority for desired service developments was reduced waiting times, whereas service providers wished for increased provision of complementary therapies.

Conclusions The study highlights important discrepancies regarding both desired level of user involvement and priorities for service developments between service users and providers. Given the current policies in this field and evidence that user involvement and closer partnerships between users and providers enhances treatment effectiveness, this lack of concurrence might be of major concern and working towards better understanding and balancing users' and providers' needs is highly recommended.

Keywords: *drug treatment, service development, user involvement*

INTRODUCTION

In the UK user involvement has now been identified as an important element in the development of effective drug treatment services. As described in framework for drug treatment services *Models of Care* (National Treatment Agency, 2002) the benefits of user involvement include improvements in drug treatment services due to better understanding of user requirements, avoidance of service features that are unacceptable to users, greater understanding and communication about drug services between users, staff and managers, resulting in more effective use, increased user participation in decision-making within drug services, and overall the development of partnerships between staff and users, for example working together on specific projects.

The concept of 'user involvement' comprises different assumptions which are influenced by certain political and social developments (Barnes, Carpenter & Bailey, 2000). For instance the consumerist approach in the 1990s stated that individuals using health services should be seen as customers/consumers rather than patients. In the mid-1990s 'empowerment' models emerged and argued for a democratic point of view, aiming to weaken hierarchical structures and claiming equality and respect in the performance of treatment (Beresford & Croft, 1993). In the late 1990s the focus moved to the 'stakeholder model' that was strongly related to the consumerist approach. This model was based on the acceptance of power inequalities but nevertheless advocated for the incorporation of all involved key parties such as professionals, service users and the general public as being the most appropriate way to balance divergent perspectives.

However, the term 'user involvement' is still a vague one covering many approaches. Chamberlain (1994), in a review of methods used by drug services in one UK region, identified a

set of methods that have been used to determine the views of service users such as user feedback via comment books and suggestion boxes, user satisfaction surveys and questionnaires, complaints/complements procedures, user groups and councils, employment of users and ex-users by agencies, service user involvement in developing literature such as writing leaflets, and involvement in management committees. Although Chamberlain's review identified a range of methods, the extent of usage in different agencies was not reported.

User involvement is still an under researched area in drug and alcohol service provision whereas many studies have been carried out in the mental health field emphasizing its importance and promising outcomes. Evidence demonstrates that user involvement has a positive impact on factors such as compliance, clients' satisfaction and overall treatment effectiveness (Anthony & Crawford, 2000). Supporting this, Thornicroft & Tansella (2005) found that actively involving users in service provision resulted in improved long-term effects and in the case of a client's relapse the need for compulsory re-admission could be significantly reduced through a previously agreed 'joint crisis plan'.

The National Health Service (NHS) has acknowledged the importance of user involvement as it is explicitly stated in the *Service Framework for Mental Health* (Department of Health, 1999 & 2003) and its reform policies (Department of Health, 2002a), and it has established a legal duty on Trusts to work towards partnerships between professionals and service users. However, reports of clients' experiences indicate that they are still not adequately listened to and their own background of experience and expertise is not being valued appropriately (Rush, 2004).

Calpin-Davies (2004) argues that the roots of the problem lie in the lack of communication between professionals and clients resulting in a different set of assumptions and expectations regarding treatment delivery.

Overall, though user involvement has become an important issue in current health care provision, it is still an area revealing divergent perspectives which are influenced by factors such as politics, societies, moralities and particularly divergent individual perspectives which are not yet satisfactorily shared.

In order to make a step forward in this field, this study set out to examine a) user and provider perspectives on the nature and extent of user involvement currently available at community-based drug services, b) both parties' desired levels of user involvement, and c) users' and providers' priorities for service development. As relatively little is known about the area, it was important to enable users to communicate their views freely, thus the researchers used a semi-structured interview approach. To obtain a wide range of different views, interviews were carried out in services across the north of England. Service user involvement and commentary in the research process has been achieved through user advisor involvement in planning and implementation of the study.

METHODS

The study comprised three main stages with the first one involving a series of semi-structured interviews carried out with 46 service users and 51 drug service providers at different locations across the North of England. In the second stage a more detailed investigation of service provision was carried out examining actual pathways for new clients seen at five community drug services within a six-month time frame. The third stage of the study included the development of the 'Drug Users Needs Assessment Schedule' (DUNA) and its utilisation in examining the needs of drug users presenting at five drug services.

For the purpose of this paper with its focus on both user involvement and desired service developments, the main sources of information are the interviews with drug users and service providers. Findings from the further two stages of the study will be reported where relevant in the discussion.

Interviews with service providers

Service recruitment

A list of statutory and non-statutory drug service agencies was drawn up from local service directories. One hundred and seventy four drug treatment services were identified within the study area which overall covered 10 localities (county areas or part-areas): Cheshire, Derbyshire, Greater Manchester, Lancashire, Lincolnshire, Merseyside, Nottinghamshire, South Yorkshire, Staffordshire and West Yorkshire. The catchment areas of the identified services varied widely with services located in rural parts covering a large geographical area whereas in other parts many services were set covering smaller areas. Thus the aim was to recruit at least half of the services in those county areas with a small number of services and at least one third of the services in areas with larger numbers. Details of the catchment area and locations of service providers' interviews are provided in Table 1.

At initial contact services were provided with information about the study and asked if the agency manager or senior member of staff with good knowledge of all aspects of the service would be willing to participate in a semi-structured interview.

Data collection

Fifty-two services were approached to participate in the study and only one declined on the basis of being too busy to take part. The service provider interviews were conducted between November 2001 and June 2002 at 33 statutory and 18 non-statutory services. The interviews took about 60 minutes to complete, although for a few large services this was about 90 minutes.

During each service provider interview, the research interviewer recorded data onto data sheets. In view of the amount of data to be collected and as a check on data recording, all of the service providers were additionally asked for permission to tape record the interview with only four service providers refusing to have the interview taped, stating that they would feel more comfortable if the interview was not recorded. Following each interview, the researcher listened to the tape recording in full and re-checked the data recorded on the sheets.

During the semi-structured interviews with service providers, information was obtained about interventions and activities currently provided, what changes and/or improvements they would like to see in their service and what is the current and desired level of user involvement. The obtained answers were analysed using content analysis (Weber, 1990). Observed key themes were coded and descriptive accounts produced. The questions utilised in the interviews are shown as headings with the outcome data in the results section below.

Interviews with service users

Client recruitment

Forty-six service users were recruited by a number of methods such as contacting user groups within the locality, providing information about the study in reception areas of drug agencies and

needle exchanges, and via key staff at drug services. Clients were initially approached by agency staff directly or by letter asking if they would be willing to talk to the researcher.

Participation in the study was entirely voluntary with written consent obtained before the interview. Additionally, each service user was asked for permission to tape record the interview to facilitate data recording. Only one service user declined to be tape recorded, indicating that he would feel more comfortable in the interview if it was not recorded. Each interview participant was reimbursed for out-of-pocket expenses and time in participating in the interviews.

The recruitment of service users was broadly focused on the same geographical locations as the service manager interviews and the number of clients recruited in different county locations is shown in Table 1.

(Insert Table 1 here)

Data collection

The majority of the service user interviews were conducted between January and July 2002. Due to research staffing difficulties there was a delay in conducting some interviews and a small number of interviews were conducted in February and March 2003. The interviews took approximately 60 minutes to complete. Each service user was asked for permission to tape record the interview with only one service user refusing to have the interview taped, stating that he would feel more comfortable if it was not recorded. Additionally, the research interviewer recorded notes onto data sheets.

The semi-structured interviews aimed to obtain demographic information and service users were asked what treatments they have received within the past two years, what changes and/or improvements they would like to see in the services and to what is the current and desired level of user involvement. In order to encourage service users to give as much detail as possible, probes and question rephrasing were utilised if necessary.

RESULTS

Characteristics of the service users interviewed

Twenty-eight (61%) of the service users were male and 18 (39%) female. Their mean age was 32 years and the majority of clients were White British or White Irish except for two people who described themselves as White other and Asian other.

The service users self-identified their main drug of use: 40 (87%) reported heroin, five (11%) used amphetamines, and one (2%) methadone. The median duration of illicit drug use was nine years, with a range of three months to 35 years.

Desired service developments

The main client concerns for service improvements were shorter waiting times, increased staffing and resources and increased psychological counselling and aftercare provision. Service providers mentioned increasing provision of complementary therapies including acupuncture, increased overall resources and staffing, greater provision of psychological interventions and

structured counselling, and an increase in shared care provision. Table 2 illustrates the different areas mentioned by both groups in more detail.

(Insert Table 2 here)

Current service user involvement

The reported areas are shown in Table 3. The level of service user involvement was low overall with eight services (16%) reporting no service user involvement at all. The most frequent type of involvement was satisfaction questionnaires, but only one third of the agencies had utilised these. Just over a quarter of the services had user groups. Detailed information about areas of current user involvement is shown in Table 3.

(Insert Table 3 here)

Desired user involvement

All of the service users supported the idea of some type of user involvement in drug services. Three quarters of the users felt that ex-users should be involved as workers in the agencies, whether this was on a voluntary basis or as paid members of staff. A majority of clients (69%) also desired involvement in staff recruitment and 67% would like to have user groups. Additional involvement in promoting services (67%), satisfaction questionnaires (62%) and management committees (60%) were also desired by two thirds of the interviewed service users. However, users did not mention a desire to be involved in activities such as service development, away-days, staff training and research. Further information about reported areas of desired user involvement is shown in Table 4.

(Insert Table 4 here)

Overall, the aspirations of the service providers regarding user involvement are quite low. Involvement in management committees, publicity/promotion of the service, and satisfaction questionnaires were desired by about half of the agencies. Twenty of the agencies (41%) desired user involvement in the service as volunteers, helpers or staff members. About one third of the agencies desired user groups, user involvement in away-days, and as participants in staff interview panels. The desire for user involvement in service development staff training and research are all quite low. Surprisingly, four agencies indicated that they did not want any service user involvement at all.

DISCUSSION

From the service user perspective, the top three desired changes regarding service development were reported as reduced waiting times, increased staffing and resources, and increased psychological and counselling services. Waiting times are now being addressed through clear guidance and targets from the National Treatment Agency for Substance Misuse and since the study was conducted, waiting time periods have been reduced significantly by the majority of services (National Treatment Agency, 2003). By 2004 the maximum acceptable length of wait has been set at two weeks for inpatient detoxification, GP prescribing and structured counselling, and three weeks for specialist prescribing, structured day care and residential rehabilitation programmes.

Increased staffing and resources has also been one of the major concerns expressed by both service users and providers. This aspect appears to be a crucial factor as it was the second most frequently mentioned issue for both groups. The issue of shortage in staff and resources has to be addressed on the policy level as discussed in *Models of Care* (National Treatment Agency, 2002). Increased psychological/counselling services were a concern expressed by both clients and service providers. This stands in contrast with the information given regarding treatments/interventions offered to clients which has been obtained previously in the interview where a large percentage of the agencies (84%) reported that they already provided psychological/counselling approaches. The same inconsistency was observed regarding service providers' desire to increase the provision of complementary therapies. The majority of the interviewed services (76%) reported that they already covered the provision of complementary therapies and thus it is surprising that it has been the most frequently mentioned area of improvement. A possible explanation could be that this type of intervention is actually supposed to be covered and actively provided at the services but due to factors such as limited resources and lack of qualified staff the extent of actual provision may fall short of desired levels.

The level of service user involvement reported by service providers was low overall with satisfaction questionnaires being the most commonly used means, though even these were only used by one third of the interviewed services. Given this low level of current user involvement it is surprising that service providers' aspirations for user involvement in their services were low as well. These findings draw a contrasting picture compared to the strongly expressed desire to increase user involvement that has been reported by the service users. This discrepancy is important in view of current attempts by the NTA to make drug services more attractive to their users. In particular the different perspectives as regards establishing higher levels of user involvement appear to be an area that needs to be addressed. As mentioned earlier, evidence

demonstrates that incorporating users' views can support client engagement, compliance and satisfaction levels (Thornicroft & Tansella, 2005).

For instance, Abdul-Quader (1992) reported on the benefits of employing ex-drug users as 'paraprofessional' staff in drug services. The study highlighted that those factors such as a similar past history of drug use, an ability to communicate in a familiar style of speech, and building a trusting relationship proved to be helpful for current drug users.

Hossack & Wall (2005) argued that recovering drug-users constitute a rich resource in drug treatment through providing support by their own real-life example. However, the authors underline that despite the potential benefits of user involvement, it is still much under-utilised in current service provision. This is reflected by the findings of the study reported here that many services involve their clients only to a limited extent and overall activities remain patchy.

This gap also emerged in a study conducted by O'Connell, Tondora, Croog, Evans & Davidson (2005) where the perception of treatment performance in mental health and drug services was investigated. Nine hundred and sixty-seven service directors, providers and clients completed the 'Recovery Self Assessment' (RSA) tool which aimed to define strengths and weaknesses in service delivery. Their study has shown that service user involvement was the least rated item throughout the 78 services and strongly indicated the need to address this lack of provision.

Thus raising awareness and educating staff about the nature and positive outcomes of user involvement would be an important step in closing this gap. As stated by the NTA in partnership with *The National Institute for Mental Health in England* (NIMHE) it is impossible to get insight into a service user's perspective and experience without asking them (National Treatment Agency, 2003).

Another way to achieve greater agreement between clients and service providers could be to increase the number of ex-users being involved as workers in the services. This was the most frequently mentioned desired improvement expressed by the interviewed clients and may help to facilitate a better balance between the users' and providers' perspectives.

Furthermore, the establishment of Patient Advice and Liaison Services (PALS) within all NHS and primary care trusts might prove to be helpful. One of the aims of PALS is to work towards active patient representation in service improvement and development activity in all services. In the guidance provided to support implementation of PALS (Department of Health, 2002b), people with drug or alcohol dependency difficulties are identified as one of the groups of people who may require particular assistance from PALS in enabling their voice to be heard.

An area of potential bias in the presented study is the method used for client recruitment. It was a requirement of the approving multi-centre ethical committee not to approach clients directly but to contact them via service staff. Whilst this approach facilitated recruitment of service users across a wide area and from as many service locations as possible, there is the potential disadvantage that it may have resulted in recruitment of higher proportion of clients already active in user groups and service user involvement. Another limitation of the study is the missing information about current user involvement from the clients' perspective. Additionally to the question about desired user involvement, it would have been useful to ask the clients about their perception of current activities.

In conclusion, it is worth mentioning that improving the incorporation of service users' views is not only important in terms of treatment effectiveness and attractive services but furthermore, can have a positive impact on a variety of factors affecting drug and alcohol users in their

everyday life. Being more involved and given the voice to contribute to changes and improvements may help decrease the mechanism of social exclusion and break the chains of stigma. Service users having the chance to actively contribute to the service's features and environment and working together with service providers in partnership may be beneficial for all parties involved.

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References

1. National Treatment Agency. *Models of care for the treatment of drug misusers. Part 2: Full reference report*. London, National Treatment Agency; 2002.
2. Barnes, D., Carpenter, J., Bailey, D. Partnerships with service users in interprofessional education for community mental health: a case study. *Journal of Interprofessional Care* 2000; 14: 189-200.
3. Beresford, P. & Croft, S. *Citizen involvement. A Practical Guide of Change*. MacMillan, London; 1993.
4. Chamberlain, J. *User involvement in Drug and Alcohol Services*. Unpublished report; 1994.
5. Anthony, P. & Crawford, P. Service user involvement in care planning: the mental health nurse's perspective. *Journal of Psychiatric and Mental Health Nursing* 2000; 7: 425-434.
6. Thornicroft, G. & Tansella, M. Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiologica e psichiatria sociale* 2005; 14: 1-3.
7. Department of Health. *National Service Framework for Mental Health*. Department of Health, London; 1999.
8. Department of Health. *Patient and Public Involvement in the New NHS*. Department of Health, London; 2003.
9. Department of Health. *NHS Reforms and Healthcare Professions Act*. Department of Health, London; 2002a.
10. Rush, B. (2004). Mental health service user involvement in England: lessons from history. *Journal of Psychiatric and Mental Health Nursing* 2004; 11: 313-318.
11. Calpin-Davies, P.J. (2004). Opinion Piece. Service user involvement: a new idea to revive an old failing. In: *Journal of Nursing Management* 2004; 12: 1-4.
12. Weber, R. (1990). *Basic Content Analysis*. London: Sage.
13. National Treatment Agency. *Opening Doors*. Issue 1. London, National Treatment Agency; 2003.
14. Abdul-Quader, A.S. Injecting drug users and female sexual partners of drug users outreach on the Lower East Side of New York City. *British Journal of Addiction* 1992; 81: 681-688.
15. Hossack, A. & Wall, G. Service users: Undervalued and underused? *The Psychologist* 2005; 18: 134-136.
16. O'Connell, M., Tondora, J., Croog, G., Evans, A. & Davidson, L. From rhetoric to routine: assessing perceptions of recovery-oriented practices in a state mental health and addiction system. *Psychiatric Rehabilitation Journal* 2005; 28: 378-386.
17. Department of Health. *Supporting the implementation of patient advice and liaison services. A resource pack*. Department of Health, London; 2002b.

Table 1: Location of service providers' and service users' interviews

	No. of drug treatment services in catchment area*	No. of service interviews	No. of service user interviews
Cheshire	10	4	2
Derbyshire	4	2	2
Greater Manchester	37	10	10
Lancashire	21	4	7
Lincolnshire	17	5	4
Merseyside	32	10	5
Nottinghamshire	8	4	N/A
South Yorkshire	15	5	6
Staffordshire	3	1	5
West Yorkshire	27	6	5

*Only parts of some county areas were included in the study catchment area.

Table 2: Service users' and providers' views on desirable service developments

Desired changes	Number of service users desiring change (N = 48)	Number of service providers desiring change (N =51)
Reduced waiting times	14 (22%)	N/A
Increased complementary therapies	2 (4%)	15 (29%)
Increased staffing/resources	10 (22%)	11 (22%)
Increased psychological/counselling services	9 (20%)	11 (22%)
Increased after care provision	6 (13%)	N/A
Increased shared care provision	3 (9%)	10 (20%)
Improved staff attitudes	6 (13%)	N/A
More outreach services	N/A	9 (18%)
More structured day care provision	4 (11%)	9 (18%)
More information about service availability	5 (13%)	N/A N/A
More relapse prevention	N/A	7 (14%)
More leisure/lifestyle activities	5 (13%)	N/A
More residential rehabilitation services	4 (11%)	N/A
Improved needle exchange services	1 (2%)	6 (12%)
Wider choice of prescribing interventions	4 (11%)	5 (10%)
Increased user involvement	4 (11%)	N/A
More services for stimulant/poly-drug users	4 (11%)	5 (10%)
Young peoples' services	4 (11%)	N/A
More family/child protection support	4 (11%)	N/A
Improved crèche/childcare facilities	2 (4%)	5 (10%)
More services for women	N/A	5 (10%)
Improved in-depth assessments	3 (9%)	N/A
Service rules more lenient	2 (4%)	N/A
Service rules stricter	2 (4%)	N/A
More inpatient detoxification places	2 (4%)	N/A
Improved environment/facilities	N/A	5 (10%)
Housing services	2 (4%)	N/A
Telephone helpline when services closed	1 (2%)	N/A

Table 3: Service provider reports of existing user involvement in their agencies

Areas of user involvement	Number of agencies (N = 51)
Satisfaction questionnaires	17 (33%)
User groups	13 (26%)
Volunteers/helpers/staff	13 (26%)
Suggestion boxes	7 (14%)
User forums	7 (14%)
Management committee	6 (12%)
Service promotion/publicity	5 (10%)
Involvement in choosing treatment/care	4 (8%)
User publications/magazines	3 (6%)
Clinical governance	2 (4%)
Service developments	2 (4%)
Staff interview panels	1 (2%)
Research	1 (2%)
Service away-days	1 (2%)
No service user involvement	8 (16%)

Table 4: Consumer involvement desired by service users and providers

Areas of desired user involvement	No. of service users (N=48)	No. of agencies (N=51)
Volunteers/helpers/staff	31 (73%)	20 (41%)
Staff interview panels	31 (69%)	15 (31%)
User groups	30 (67%)	19 (39%)
Publicity/promotion of service	30 (67%)	25 (51%)
Satisfaction questionnaires	28 (62%)	24 (49%)
Management committee	27 (60%)	29 (59%)
User forums	4 (9%)	9 (18%)
Service development	1 (2%)	5 (10%)
Health education	1 (2%)	2 (4%)
Service away-days	N/A	16 (33%)
All aspects of service	N/A	7 (14%)
Staff training	N/A	3 (6%)
Research	N/A	2 (4%)
Clinical governance	N/A	1 (2%)
Parent/family group	N/A	1 (2%)
No service user involvement	N/A	4 (8%)