Extending the boundaries of consumer participation: Involving significant others in service evaluation

Tracey Brooke and Lynda Berends
Turning Point Alcohol and Drug Centre Inc.
54 - 62 Gertrude Street, Fitzroy, Victoria 3065.
E-mail: traceyb@turningpoint.org.au

ABSTRACT

Turning Point Alcohol and Drug Centre in Melbourne recently completed an evaluation of residential rehabilitation services for the Victorian Department of Human Services. Four residential rehabilitation services were evaluated to assess the extent to which they met their funding and service requirements. Evaluations undertaken by Turning Point are designed to be inclusive, with a degree of ownership among all involved, such as alcohol and drug clients, service providers, and service purchasers. In the past, challenges have existed for researchers in accessing client populations. This was not a problem for the current study, however, as most clients were in residential treatment and readily accessible. The challenge of the current study was to extend the boundaries of consumer participation to include significant others of those in treatment.

As part of the evaluation, significant others of people in treatment were asked to participate in key stakeholder interviews. The interviews focussed on service strengths and suggestions for improvement. The findings of the research also indicated that the needs of significant others of those in treatment warrant greater consideration and support. This paper discusses the practical challenges of involving significant others in evaluation, such as recruitment and appropriate interview techniques. The paper also explores issues of ethical responsibility evaluators should consider when involving significant others in evaluation.

Drug and alcohol residential rehabilitation services have a long history in Victoria. While substantial variations in treatment occurred in the past, services currently funded by the Department of Human Services (DHS) are required to meet a standard set of key specifications. They are also subject to regular evaluations that monitor performance and inform the ongoing improvement of the service system (DHS, 1997).

The genesis of the current paper occurred during a process evaluation of four residential rehabilitation services undertaken by Turning Point Alcohol and Drug Centre Inc, on behalf of the DHS. The findings of that evaluation are reported elsewhere (pending report, DHS 1999). Our focus for this paper was on ethical and access issues related to involving the significant others of those in treatment in program evaluation. For the current study, the term 'significant other' was broadly defined to encompass 'traditional' family members, as well as partners and carers of the client in treatment.

THE EVALUATION

Process evaluation is concerned with service delivery (Owen, 1993). The orientation of these evaluations is documenting what is occurring at the service(s), in addition to the formulation of suggested improvements to service delivery (Owen). Typically, a range of approaches to data collection are applied. Patton (1997) explained that the evaluator incorporates "any and all data that will help shed light on evaluation questions, given constraints of resources and time" (p. 297). This strategy recognises the

need for varying data collection methods according to situational needs and supports obtaining results that are realistic, valid and believable (Patton).

Diversity in data collection and analysis was a feature of the evaluation undertaken by Turning Point. Approaches used included interviews and focus groups with key stakeholders, service visits, and the examination of established data sets. The evaluation focussed on "the real and specific: actual primary intended users and their explicit commitments to concrete, specific uses" (Patton, 1997: 21). This approach required a thorough understanding of who the clients are for residential rehabilitation. It also necessitated the consideration of ethical issues involved in accessing and engaging with clients. These issues are explored below.

CLIENTS IN RESIDENTIAL REHABILITATION TREATMENT

DHS (1997) funded residential rehabilitation treatment in Victoria requires the provision of a 24-hour staffed program and an average three month length of stay. Programs target individuals who have undergone a drug/alcohol treatment program and have not been successful in reducing or overcoming their substance use problem (DHS). The fundamental goal of treatment is to ensure lasting change and assist reintegration back into community living (DHS). Residential rehabilitation services provide a treatment option for individuals who may have home settings and/or social circumstances that make non-residential treatment options less feasible. Among the key service requirements of residential rehabilitation is the need "to provide appropriate services for carers and families of those affected by alcohol and drug use" (DHS, 1997: 20).

Literature on accessing hard to reach populations in alcohol and drug research has focussed primarily on injecting drug users due to the illicit nature of the activity. As significant others of drug dependent people have not featured in program evaluation literature, we have been reliant on research that examines their role in treatment. This literature provided direction as to the practical and ethical considerations of involving significant others in the evaluation.

A recent meta-analysis of research literature identified that involving families in the treatment of problematic substance use is more effective than treatment centred solely on the individual (Stanton and Shadish, 1997). This is an important consideration given one task of the evaluation was to assess the level of significant other involvement in treatment at the services. Other research has demonstrated that significant others have needs that should be considered separately from the drug dependent client. For instance, the significant others of individuals who are drug dependent are exposed to high levels of stress, with elevated risk of contracting stress related physical and psychological disorders (Orford, 1995). An international review on alcohol and the family (Orford, 1990) discussed the negative impact of excessive drinking on families in terms of economic insecurity, social embarrassment, reduction of social contact, violence, increased anxiety and high divorce rates. Indeed, it has been argued that just as associations exist to support those managing a serious illness in the family, an organised response is warranted for those caring for a drug dependent family member (Blythe, 1994). Despite these findings, studies show a lack of services for significant others of drug dependent people (Orford, 1990; Toumbourou, 1994).

The involvement of significant others in treatment includes a number of practical considerations, in particular their willingness and ability to participate (Toumbourou, 1994; Faisandier, 1998). Further, as treatment is generally agency bound, it has been argued that services may find it difficult to determine who significant others are in the client's life (Scott, 1994). Involving significant others in treatment may also prove difficult when there is conflict in the family. Toumbourou (1994) suggested that treatment within Therapeutic Communities, one approach of residential rehabilitation treatment that focusses on community as the mechanism for addressing substance misuse, targets anti-social behaviour that may be linked to poor family effectiveness. Other research, however, has demonstrated that although family connections may be conflicted, drug users are still in contact

with their families. For example, a recent study of the first 100 clients at the Youth Substance Abuse Service Residential Withdrawal Unit in Victoria showed that 41% of the young people were living with their immediate family prior to treatment admission (Holgate and McDonald, 1999). This research provided a strong argument for involving significant others in evaluation, and indicated that residential rehabilitation clients are an important resource for recruiting significant others.

There are a number of components, then, in relation to involving significant others in program evaluation. Firstly, it is recognised that family and social circumstances may not be supportive of the client's community reintegration, suggestive of concerns with these environments. Secondly, given the possible benefits to the client, the provision of appropriate services for significant others is warranted. Thirdly, as significant others of clients may experience elevated levels of stress, they will benefit from the support provided. Finally, given the level of connectedness between clients and their significant others, clients are a potential source for recruiting significant others to research. Although residential rehabilitation programs focus on those who are drug dependent as the primary clients of treatment, other clients include the significant others of these individuals. As such, they should be incorporated in approaches to the evaluation of service delivery. The process for involving significant others in the evaluation is described below.

METHODOLOGY

Recruitment of Significant Others

A number of strategies were used to aid recruitment. Initially, flyers and posters advertising the project were distributed to services. The flyers described the purpose of the evaluation and listed the services involved. Details on data collection, the timing of the project, participant confidentiality and contact names and numbers were included in the promotional material. Service staff were asked to display the posters and bring the project to the attention of potential participants. It was requested that every client and significant other receive a flyer advertising the project. A similar approach was used to inform other key stakeholders and service staff of the project.

The evaluation involved visits to the services that varied from three to five days each. A minimum lapse of two weeks occurred between the distribution of the flyers and the site visits for the evaluation. During this period no participants were recruited as a consequence of the flyers. This was true for all potential groups; significant others of service clients, key stakeholders and service staff. It should be noted that the use of flyers was just one of the approaches applied for recruitment across these groups.

During the site visits, service staff and clients were involved in interviews and/or focus groups for the evaluation. Two focus groups with ex-clients were conducted at another location. A total of 51 clients/ex-clients took part in focus groups across the four residential rehabilitation services. At the close of discussions, participants were asked to provide contact details for significant others who may be willing to partake in telephone interviews for the evaluation. Names and telephone numbers were given to the evaluators, and clients/ex-clients described their relationship with the individual(s) named. When these details were provided the evaluators also requested that, where possible, participants inform contacts they would be receiving a call from the evaluators.

Ethical Issues

The American Evaluation Association stipulated five principles to guide the conduct of program evaluations. These principles comprise: systematic inquiry, competence, integrity/honesty, respect for people, and responsibilities for general and public welfare (Shadish, Newman, Scheirer & Wye, 1995). In a more generalist document on ethical conduct in research involving humans, the National Health and Medical Research Council of Australia included respect for the dignity and well-being of

participants and the need for experienced, qualified and competent researchers (NHMRC, 1998). Although these principles are all relevant to the evaluation of residential rehabilitation services, a number have particular salience in relation to involving significant others of those in treatment. Attention to respecting the dignity and well-being of participants, behaving with integrity and honesty throughout the research process, and ensuring researcher competency provided direction for the evaluation, particularly with respect to approaches to recruitment and data collection.

In keeping with these principles, various elements of researcher preparation were required prior to conducting the interviews. Preparation included learning about the residential rehabilitation programs, common characteristics of the client group, and possible experiences of significant others in relation to residential rehabilitation treatment. First hand knowledge of the services where the clients were in treatment (obtained during site visits) was valuable, allowing the evaluators to operate from an informed perspective in relation to aspects of the particular service. A knowledge of the services available to significant others was also important so that evaluators could provide referral information if participants requested counselling and support.

The Interview Process

Interviews with significant others were conducted by telephone. Contact was scheduled at times considered convenient for potential participants. Contact was made in the evening on weeknights (between 8:00 and 9:30 pm) or on Sunday afternoons.

Semi-structured interviews were conducted for the research. The interviews commenced with an introduction to Turning Point and a brief explanation of the nature and purpose of the project. Requirements of interview participants were described, including the fact that participation was voluntary and confidentiality would be maintained. Key questions focussed on participants' connection with the service, their impressions of the service and any suggestions they may have for service improvement. At the close of the interviews, participants were informed of the availability of a final report on the evaluation and provided with contact details for evaluation staff at Turning Point, if requested. A number of ethical and access issues arose from the inclusion of significant others in the evaluation process, and are detailed below.

RESULTS AND DISCUSSION

Accessing Significant Others

Clients at one service did not proffer any contacts during the focus group (n=9 participants), explaining they were not in communication with significant others or that the significant others would not wish to be involved. This finding was interpreted as a product of characteristics of the client group at this service, many of whom were long term homeless and disconnected with social networks.

Forty-two clients/ex-clients involved in focus groups remained from the three other services. Of these clients/ex-clients, 16 (38%) provided contact details for significant others. This was consistent with Holgate and McDonald's (1999) study which reported that 41% of clients at a Victorian residential withdrawal program were in close contact with their families prior to treatment entry. Table 1, below, shows the number of interviews arising from contacts made for the evaluation.

Table 1: Significant others involved in interviews

Responses to request for interview	Number of responses
Number of contacts provided	16
Additional contacts provided	2

Agreed to interview	14
Did not agree to interview	0
Contact not possible	2
Two participants at interview	2
Total number of participants	**18**

Fourteen of the original 16 contacts agreed to participate, while two could not be reached by telephone. There were no refusals for participation. Two participants provided details of additional contacts for the evaluation and two interviews involved discussions with two participants each. The vast majority of participants were mothers of clients. Three siblings of clients were also interviewed, and in one case the two carers of a client's children took part in an interview. The total number of significant others interviewed for the evaluation equalled 18.

Where individuals agreed to take part in the interviews, it was ascertained whether the time of contact was convenient for the interview, or if the evaluator should call back at another time. All individuals contacted agreed to take part in an interview during the initial call. The interviews took from 15-30 minutes, depending on the participant.

Although representativeness was not a primary goal of recruitment, the probable bias in the sample must be acknowledged. As clients acted as gatekeepers for the involvement of significant others in the evaluation, those disconnected from their families and carers did not proffer any contact details. In addition, significant others contacted by the evaluators also had the option to decline participation in the evaluation. Potential participants were therefore drawn from a restricted pool.

The role of gatekeepers, such as funding bodies and institutions, in facilitating research access has been well documented (e.g., Punch, 1986). For most researchers, institutions and/or bureaucratic process, rather than client populations, pose barriers to accessing the population under study (Punch, 1986; Sieber, 1992). Sieber (1992) suggested, "It takes a thoughtfully negotiated relationship with a gatekeeper to become trusted and accepted" (p. 129). Given the time constraints of the site visits, the evaluators had very little time to develop a relationship with clients. We were on-site for a matter of days and requested contact details for significant others at the end of focus group discussions with clients. Although clients providing contact details were asked to inform their significant other to expect a call from the evaluators, the majority of participants were not aware this may occur when they were contacted. Factors including distance and the residential nature of treatment may have impeded communication between clients and their significant other. Treatment stage may also have influenced clients' ability to communicate with significant others due to restrictions on access as isolation from past drug taking/high risk lifestyles is a recognised ingredient of the Therapeutic Community approach to treatment (DeLeon, 1995).

Significant others contacted responded positively to the opportunity to take part in the interviews. The high response rate supports the effectiveness of the approach used. We identified three distinct advantages with this approach. Firstly, the site visits enabled informal contact to occur between clients and evaluators. Secondly, the focus groups provided clients with an opportunity to understand the nature of the questions; that interviews would focus on the service and not the client. Finally, the focus groups provided an opportunity for clients to witness the style and personality of evaluators and gauge their integrity and competence in relation to the evaluation. The suitability of the evaluators to the task and the willingness of clients and their significant others to support the evaluation process was reflected in the rate of recruitment.

Aspects of the program being evaluated may have influenced the level of response to our request for contacts. Residential rehabilitation programs customarily rely on sense of community to support behaviour change and reintegration into the broader

community (De Leon, 1995). Healthy communities proffer both benefits and obligations for their members. Through the evaluation process, we became temporary members of the residential rehabilitation community during site visits and clients may have responded to our request for contact details partly as a consequence of their commitment to that community. This element of the recruitment process further supports the need for personal contact between evaluators and gatekeepers to facilitate gaining access to significant others.

Views Of Significant Others

While the positive rate of recruitment supported the inclusion of significant others in the evaluation, findings in relation to their views on residential rehabilitation services provided valuable insights on the needs of significant others as clients of these services. Recent literature suggests that significant others vary greatly in their response to problematic substance use and their ability to cope with its effects (e.g., Dear, 1994). This was reflected in current findings. Some significant others acknowledged they required no assistance from the service, or were satisfied with their current level of involvement. For many significant others, however, the interviews provided an opportunity to talk about concerns related to their situation.

Some significant others commented on the need for more family contact, guidance for families as to their role in treatment and support in response to the stress experienced. These experiences are highlighted in the comments made by mothers of three clients.

> (The service is) failing the family unit. (They) need more family contact. There has been no communication with the family since (client) started at the service. The family could inform them on childhood issues. The family are in the dark about what they should be saying. We've been through a tough time and there's nothing for us.
>
> There is very little interaction between parents and staff. We need more information about the program, what happens, like an introductory meeting for parents. So far all information has been provided by (the daughter). I don't know that much about it. I would like more contact.
>
> I'm not sure what happens there. I'm getting mixed messages. I wish they would be clearer in the information they give.

Another mother described her difficulties in accessing the services currently available for significant others.

> I need a ready reference of where to go to for help. I only found out what was around through friends. It was like trying to put a jigsaw together.

Satisfaction with the level of information and support provided by the service meant some significant others did not feel the need for involvement in the client's treatment.

> I have a good understanding of how (the service) works. I've tried to distance myself from (service). I can tell that (daughter) is gaining from the program. It's not my problem. I don't need regular contact with (service).
>
> I leave (the program) to the workers. They were excellent at explaining the program. Very supportive. It is now (son's) call. He knows we support him. We have purposely backed off, need to respect his privacy.

It is possible that residential rehabilitation treatment provides a form of respite for significant others, as one client's mother explained, "Once she is in treatment, I'm fine". This finding suggests the level of need among significant others may change when the client is no longer in treatment.

A number of participants described the direct impact the client's drug use has had on their lives. The sister of one client explained,

> My parents were frightened he was going to hurt them. They don't want to let him back into their lives. He stole my father's retirement money and spent it on drugs in one week. We expected to find him in the morgue. We thought he was beyond help.

A mother of another client described her feelings of failure.

> I feel lost and useless. I'm a psychiatric nurse and didn't realise my daughter was a junkie, much to my shame. It didn't enter my head.

The findings in relation to significant others of those in treatment may be condensed into three areas:

- the need for information, on aspects of treatment and on the services available for significant others,
- the need for emotional support, in response to feelings of distress and failure, and
- the need for advice, in relation to practical issues relating to having a drug dependent individual in the family.

These findings will inform the ongoing improvement of service delivery and thus constitute an important aspect of the evaluation. A more global finding of the current study concerns the significance of the research process and its implications for evaluators and participants involved, a subject discussed further below.

Addressing Ethical Considerations

Punch (1986) notes "... there is no consensus on the key ethical questions raised by our research. There is no hard and fast way to calculate the costs and benefits of social scientific research" (p. 81). Other social researchers have commented that some risks and benefits cannot be accurately identified before the research is performed and, conversely, that one subject's risk may be another's benefit (Sieber, 1992: 75). The evaluation team endeavoured to anticipate possible risks and benefits to participants through an organisational ethical facilitation process prior to the site visits. The sample of comments provided above shows the complexity of issues significant others may encounter in their relationship with a drug dependent person in treatment. Ethical concerns of the evaluators arising from these expressed needs were twofold. Firstly, our ability to adequately respond to the needs of significant others as expressed in the interview. Secondly, our ability to report on an identified need that did not nicely 'fit' within the evaluation brief. These two concerns are discussed below.

The need for clear role definition is often an issue at Turning Point as it is an organisation where both researchers and clinicians may be involved in research with client populations. While the clinician takes the "hands on" responsibility for trialing a new clinical intervention (eg. counselling), the researcher is expected to adopt a "hands off" role when evaluating the intervention. For the current study, our role as "impartial" evaluators was blurred as we also took on the role of providing information and support to significant others. Orford (1994) suggests that informational support is one of the main types of support that people in stressful circumstances find useful. The interviews focussed on a topic some participants may have found distressing. Our response, working within the parameters of the evaluation and with consideration of ethical issues involved, was to act in multiple roles. Firstly, we collected data for the project following guidelines stipulated by ethical principles. Secondly, we provided support and information within the limitations of our skills and knowledge. A level of empathy was required given participants' circumstances. Information on referral services also allowed participants to access counselling and other forms of support from qualified sources if they so chose.

A related concern was the question raised about the extent and nature of services required by significant others. Our data was insufficient for the development of clear conclusions and the evaluation did not have scope for expansion to address the question raised. Our capacity was limited to suggestions on the utility for further investigation of the issue. Hopefully this suggestion will be realised in the near future. The evaluation process did, however, provide valuable insights on ethical and procedural considerations for involving significant others in projects of this nature. Finally, a number of principles for involving significant others in evaluation emerged:

1. Significant others are important stakeholders in alcohol and drug treatment provision and should be involved in program evaluation.
2. Innovative strategies are required for recruitment. This has implications for the design and resourcing of program evaluation.
3. Thorough preparation of evaluators is necessary to address ethical considerations that may arise through the involvement of significant others in program evaluation.

REFERENCES

Blythe, A. (1994). Addiction and the family - New endeavours in therapeutic communities. In the proceedings of the 1994 APSAD National Conference Alcohol, Drugs and the Family. Melbourne: ADF.

Dear, G. (1994). Do families really need treatment? In the proceedings of the 1994 APSAD National Conference Alcohol, Drugs and the Family. Melbourne: ADF.

DeLeon, G. (1995). Residential therapeutic communities in the mainstream: diversity and issues. Journal of Psychoactive Drugs, 27 (1) (Jan-Mar): 3-15.

Drug Treatment Services, Department of Human Services. (1997). Victoria's alcohol and drug treatment services. The framework for service delivery. Melbourne: Human Services Promotions Unit.

Faisandier, S. (1998). Evaluation and ethics: getting the job done and respecting people's rights. Evaluation News and Comment, June 1998: 12-13.

Holgate, F. and McDonald, P. (1999). 100% Dependent. The first 100 Young People at the YSAS Residential Unit. Melbourne: Youth Substance Abuse Service.

National Health and Medical Research Council. (July, 1998). Draft statement on ethical conduct in research involving humans. http://www.health.gov.au/nhmrc/ethics/statem1.pdf

Orford, J. (1990). Alcohol and the family: an international review of the literature with implications for research and practice. Research Advances in Alcohol and Drug Problems 10: 81-155.

Orford, J. (1994). Empowering family and friends: a new approach to the secondary prevention of addiction. Drug and Alcohol Review 43: 417-429.

Owen, J. M. (1993). Program evaluation. Forms and approaches. Sydney: Allen & Unwin

Patton, M. Q. (1997). Utilization-focused evaluation. The new century text. Edition 3. USA: Sage.

Punch, M. (1986). The Politics and Ethics of Fieldwork. Qualitative Research Methods Series 3. USA: Sage.

Scott, D. (1994). Protecting the child: Toward family centred practice in child welfare and the alcohol and drug fields. In the proceedings of the 1994 APSAD National Conference Alcohol, Drugs and the Family. Melbourne: ADF.

Shadish, W. R., Newman, D. L., Scheirer, M. A. & Wye, C. (1995). Guiding principles for evaluators (New directions for program evaluation, no. 66). San Francisco: Jossey-Bass.

Sieber, J.E. (1992). Planning ethically responsible research. A guide for students and Internal Review Boards. Applied Social Research Methods Series Volume 31. USA: Sage.

Stanton, M.D. and Shadish, W.R. (1997). Outcome, attrition and families treatment for drug abuse: A meta-analysis and review of the controlled comparative studies. Psychological Bulletin, 122 (2): 170-191.

Stanton, M.D., Todd, T.C. and Associates (Eds) (1982). The Family Therapy of Drug Abuse and Addiction. New York: Guildford.

Toumbourou, J. (1994). Family and social influences in illicit drug treatment. In the proceedings of the 1994 APSAD National Conference Alcohol, Drugs and the Family. Melbourne: ADF.

Toumbourou, J. (1994). Family involvement in illicit drug treatment? Drug and Alcohol Review, 13, 4: 385-392.