

CONSUMER PARTICIPATION

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The concept of consumer participation can be traced back to at least 1978 when the World Health Organisation stated ‘People have the right and duty to participate individually and collectively in the planning and implementation of their healthcare’.

ASeTTS has always prided itself on being sensitive and responsive to clients’ needs. When the clientele consists almost entirely of people from a wide variety of culturally and linguistically diverse backgrounds, this is no simple task. Clients are regularly asked what they want, sometimes on a one to one basis or through community consultations. This feedback has tended to focus on the needs of that particular individual, family or cultural group. This type of approach is completely valid but does not really provide the client with an opportunity to input into the planning, delivery and evaluation of ASeTTS’ services at an agency level.

There are degrees of participation as illustrated in the following table (source unknown). Most consumer participation strategies fall somewhere between the two extremes.

<i>PARTICIPATION LEVEL</i>	<i>PROCESS</i>	<i>OUTCOMES</i>
Communication	Agency makes all decisions; then informs others of reasons	Informed clients
Feedback	Agency solicits feedback from clients about services already in place	Agency has information on which to base further decisions, but may or may not act on this information
Information sharing	Agency makes decisions based on exchange of information, and then informs others	Perspective of Agency & clients/staff broadened
Consultation prior to implementation	Agency actively invites comment on plans before they are finalised	Possibility that client input can result in modifications to plans that are already well advanced
Consultation on implementation	Agency solicits views on how to implement new projects	Opportunity for greater involvement by clients for implementation of new project
Consultation during the process	Clients are involved throughout the decision making process, their views are considered in Agency decision	Opportunity for greater understanding of issues and shared responsibility by all parties. Agency will hear views of clients and consider them, then decide if client views are to be incorporated

Client involvement in the process	Clients are consulted about specifics as they are being formulated and early enough in the process for their views to have a real bearing on decisions made	Agency has the view that client views must be fully incorporated into any planning/ service decisions and acts accordingly. Any differences between agency and client perception are worked through until both parties are satisfied but ultimately decision making rests with Agency
Joint decision making/ Working partnership	Clients and Agency are involved in making mutually agreed-upon decisions on specific issues at all times	All parties responsible for & committed to effective implementation
Client control	Clients are well represented on Management Committee, all planning, ideas etc require endorsement by the client reference group	Clients run the organisation; staff effectively work for the clients rather than for a Management Committee. Management implements wishes of clients and acts in advisory rather than decision making role.

ASeTTS recognised the need to establish infrastructure to encourage and enable clients to express their needs and input into the development & provision of services. The organisation was successful in securing funding from Mental Health Division of WA Health Department to further Consumer Participation. One major strand of this was the establishment of a Client Reference Group to oversee the planning, delivery & evaluation of the services offered by ASeTTS. A member of this group is now a voting member on the ASeTTS' Board.

The formation of some consumer groups is driven by dissatisfied consumers. Other groups, as in ASeTTS' case, form up at the instigation of the service provider who has recognised the validity of such groups. At the time of inception of the group, the prospect of a client reference group met with little enthusiasm from staff. As is often the case with organisational change, there were varying degrees of resistance and skepticism. Some staff were supportive in a passive way ie funding had been received to do this, so it had to be done. Concerns were also expressed that clients would not be able to function within a group situation or that the experience might cause retraumatisation. It was generally not appreciated or anticipated how such a group might benefit the organisation.

Nevertheless a group was formed within about six weeks, comprising people from five different countries. One of the initial difficulties was explaining to clients and ex clients the concept of consumer participation. Many of ASeTTS clients come from countries ruled by oppressive, dictatorial regimes. In such countries, people are not encouraged to voice their opinions. Also some cultures have a stoic nature where people learn to accept and even expect suffering and hardship as part and parcel of life. Also, other countries have no concept of 'welfare' and are unfamiliar with the idea of the state providing assistance.

Nobody involved with the group had any clear idea how it would evolve. It was realised early on that to enable the group to be effective, the members needed to be trained so that they understood how ASeTTS operates, how it is funded and the challenges it faces as an organisation.

One year on, the group has provided major insights into matters concerning food security issues, alternatives to individual counselling, how to describe counselling (some cultures have no equivalent word) and contributed to improvements in the day to day operations of ASeTTS. A significant contribution was made concerning a substantial donation received by ASeTTS that was to be spent on programmes for young people. The client reference group was adamant a good proportion of the money should go towards educational type programmes that would have long term benefit. This was a very different emphasis from those initially proposed by staff that were premised more on having fun and social interaction. The outcome has been the development of a leadership programme, to be run in collaboration with other organisations.

Staff attitudes have changed as the group has progressed. One staff member commented that initially she had concerns as to whether the members could function well in that environment, and if in fact the group would be an added stress. She is now enthusiastic about the benefits of the group to its members.

Individual group members hold the group in high regard. Two people said that when they first joined the client reference group, that is all they thought about, as it gave them a focus apart from their own fears and insecurities. It was a place where they were given value and significance as individuals. For some of ASeTTS clients, who may have spent years fleeing war and conflict, the group is a rare opportunity for them and their opinions to be sought out and valued. The members of the group are mainly people with professional skills which, so far, they have been unable to use in Australia. The client reference group provides an opportunity where people can use their skills and training. This is very important in developing a sense of wholeness and wellbeing and rebuilding confidence and self esteem. It is apparent from the care taken by some group members that they feel very committed to the group, as it has awakened aspects of themselves that had lain dormant for some time, and has given them something productive to do with their time.

Members of the group have provided insights into their situation which has affected perception of clients and their needs, and had a bearing on attitudes that underpin the services offered by the agency. Nevertheless, at this time, the group operates mainly at the level of providing feedback and opinion on current service delivery. The development from a group that provides feedback and comment on services already in place, to a group that is proactively participant in decisions concerning service delivery and planning, is a gradual process requiring cultural change throughout the organisation.

If you would like further information please contact ASeTTS

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