



## POLICY POSITION

### Consumer Representation

## Introduction

Consumer representation and involvement is a valued process that has been incorporated into many aspects of product development, service development and delivery and evaluation across many sectors. The private and corporate sectors use such techniques as market research, focus testing and consumer satisfaction questionnaires as tools to ensure that their “customers” are included and their opinions are valued and considered. Within health care, such consideration is often overlooked. While sectors such as mental health have made significant steps forward in obtaining legitimate roles in representing its constituents, people who inject/ use illicit drugs are not afforded comparable respect or are seen as having anything of value to offer to the professional sector. Within the Alcohol and other Drug Sector (AOD) particularly, professionals often take the place of people who inject/use illicit drugs to express consumer views and opinions. More often than not, such views are nothing more than the professionals view point and have little if any meaning to the group they are attempting to represent. This position paper then will address and explore the role and value of consumer representation within various contexts that is self determined and supported by AIVL and its member organisations.

## Discussion

Historically, the management of illicit drugs and the people who inject/use illicit drugs has been a criminal justice issue. This inherent criminality has resulted in not only the discrimination that exists for people who use/inject illicit drugs but disempowerment and lack of voice for the community. The threat of HIV/AIDS to the broader community ensured that a shift occurred in the way in which people who inject drugs were viewed by the blood borne virus (BBV) sector which was informed by the development of the various national BBV strategies. Such a change of perception allowed for people who inject drugs to become involved in policy development, service development and to be seen as experts in their own right, alongside the development of state, territory and nationally based drug user organisations. However, criminality remains and results in a bizarre juxtaposition for representatives of the drug using community and one that remains largely unacknowledged. The nature of representation is overt and requires public admittance or the assumption by others that one engages in an illegal activity. Such public risk taking is taken for granted by the sector. This criminality feeds ongoing and often hidden tokenism and discrimination that occurs when members of the drug using community act as representatives within various forums.

Currently there are elements of consumer representation from the drug using community across the country that is largely coordinated by drug user organisations within their jurisdictions. However, the representation of people who inject/use illicit drugs is not equitable across the country. Important bodies and committees that should have representation from the drug using community within them are allowed to conduct their business legitimately while blatantly ignoring the vital role that such representation would provide.

AIVL agrees with the Consumer Health Forum of Australia who defines consumer involvement as being:

“...the consumers of services, policies or particular organisations being involved as members of government, professional bodies, industry or non-governmental organisation committees, with the role of voicing consumer perspectives, taking part in making decisions and communicating these decisions to fellow consumers”.<sup>1</sup>

AIVL recognises the unique value and diversity of the individuals who comprise the drug using community, and views consumer representation very much as a means towards the

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<sup>1</sup> Consumer Health Forum - <http://www.chf.org.au/> (consumer representation). July 2003

empowered participation of the community of people who use/inject illicit drugs and are affected by services or policies.

There are currently many sectors that would not be able to legitimately function without appropriate consumer representation; however the illicit drugs industry continues to ignore the very people that it serves. In doing so, the industry ignores the networks and expertise of many individuals and each of the drug user organisations that exist in Australia. The following are examples of some of the reasons that are often used to reinforce not appointing consumer representatives:

- ✓ One person alone cannot represent the community
- ✓ Engaging consumer representatives conflicts with organisational policy
- ✓ Consumer representatives are unreliable
- ✓ Financial costs
- ✓ Supporting consumer representatives takes too much time

AIVL acknowledges that for some organisations consumer representation is challenging as it can be exposing and for some be even threatening. However, transparency and accountability is of the utmost importance in service delivery, policy development and within advisory structures. AIVL believes however, that such barriers have been overcome and meaningful representation can be achieved, as is stated in the Queensland Government's Health Position Statement: "Consumer and Community Participation *to promote community engagement in health*"

*"Building relationships between consumers and health service providers based on trust, respect and the sharing of power and knowledge is an essential foundation for engaging consumers and communities. Consumer participation in health involves a shift in the traditional roles of consumers and providers where knowledge and power are vested in the provider and the consumer is a passive recipient. Establishing better relationships between consumers and providers involves understanding each other's perspectives, developing a shared understanding of the issues and joint involvement in decision-making. To be effective, these relationships need to be based on trust and mutual respect"<sup>2</sup>*

AIVL remains committed to ensuring that the voices of people who inject/use illicit drugs are heard, validated and respected within all of the areas that effect individuals' lives. AIVL does not endorse organisations and structures that do not recognise and dismiss the valuable input that the role of consumer representation can play.

*"Consumer representation on our working group is invaluable, we simply do not as professionals hold the knowledge and expertise that the rep was able to bring. What was obvious to them was not even thought about by us. I can't imagine not having the very people that we work for sitting around the table with us and being involved" - Anonymous*

Experience within AIVL and its member organisations shows that consumer representation not only enhances outcomes but ensure that they are meaningful and more likely to succeed.

<sup>2</sup> [www.health.qld.gov.au/quality/Publications/ PositionStatement.pdf](http://www.health.qld.gov.au/quality/Publications/PositionStatement.pdf)

## Position

- AIVL believes that people who inject/use illicit drugs have the right to participate as valued representatives within:
  - Government and non government advisory structures
  - Service delivery development, implementation and evaluation mechanisms
  - Product development, implementation and evaluation processes
  - All level of policy development, implementation and evaluation
  - Management and governance structures of organisations that serve people who inject/use
  
- *Consumer representation* will be interpreted (unless otherwise stated) as meaning the participation people who inject/use illicit drugs, through nominated representatives, in committees or forums where policies, interventions or services are planned, discussed, researched, determined, coordinated or evaluated.
  
- The role of consumer representatives is to:
  - Present the perspectives, needs, aspirations and experiences of people who inject/use and thus better inform decision making that will affect drug users
  - Foster genuine community participation in partnership with policy makers, researchers and service providers whose work impacts significantly upon the lives of people who inject/use illicit drugs
  - Help keep the user community and AIVL informed of impending developments, initiatives or changes in policy or service provision.
  - Develop skills and experience within user communities that enhances the capacity of individuals and communities to participate in the management of issues that affect them and to respond to the challenges that face users.
  
- Policy makers and service providers do not discharge their obligation to adequately consult with and consider the interests of consumers merely by appointing a consumer representative. The body or the organisation resourcing the committee or forum has an ongoing duty to:
  - Invite drug user organisations/networks within the relevant jurisdiction to nominate, according to the organisation's processes, appropriate consumer community representatives.
  - Involve consumer community representatives in a genuine and respectful manner as an equal partner in the work of the committee or forum.
  - Consult as widely and thoroughly as possible with drug user organisations and within the user community.
  - Communicate progress, findings, decisions and plans to the communities that will be affected.
  - Provide the requisite support, training and financial compensation for the consumer community representative to develop and flourish in their role.
  
- AIVL respects the right of external bodies to invite specific individuals from the community to participate in committees, consultations or such forums. However, this must be additional to genuine consumer representation, which can only be determined by the community.
  
- Consumer representatives will be chosen using the process of self determination.

## Recommendations

1. That non drug user organisations work with AIVL and the state/territory drug user organisations to develop policies and guidelines to ensure there is appropriate and consistent consumer representation.
2. AIVL calls for non drug using organisations to recognise and accept the process of self determination that is conducted in selecting consumer representatives by drug user organisations and to accept our representatives as a legitimate voice.
3. That organisations, committees, forums etc...ensure that individuals are paid accordingly for their participation. In addition that there is recognition that drug user organisations are not necessarily paid to work on particular issues and that funding will be necessary for representation to take place.
4. Where appropriate AIVL recommends that consumer representation become a requirement of funding contracts and is evaluated and monitored by the funding body.
5. AIVL recommends that the private sector involved in treatment and equipment provision seek consumer representation in all areas of product development, delivery and evaluation.
6. AIVL recommends that all governments work in partnership with AIVL and its member organisations to ensure that consumer representation is sought and achieved within all advisory structures and is included in the terms of reference for such structures.
7. That training and/or resources be developed and provided to those unfamiliar with the role and value of consumer representation to ensure that the role of the consumer representative is experienced as meaningful and valid rather than being tokenistic
8. Organisations build on their capacity and experiences of consumer representation and seek support to enable this process to take place
9. Those organisations external to AIVL and its member organisations become proactive in developing meaningful working partnerships with their state/territory/national drug user organisation and where appropriate develop Memorandums of Understanding (MOU) to assist in the development and ongoing role of consumer representatives.

#### **AIVL Member Organisations**

**ACT: Canberra Alliance for Harm Minimisation (CAHAMA) - 02 6262 5299**

**NSW: New South Wales Users AIDS Association (NUAA) - 02 8354 7300**

**NT: Network Against Prohibition (NAP) – 08 8942 0570  
Territory Users Forum (TUF) – 08 8941 2308**

**QLD: Drug Users Network and Support (DUNES) – 07 5520 7900**

**SA: SA Voice of IV Educaiton (SAVIVE) – 08 8362 9299  
USERS Association of South Australia - 0423653896**

**VIC: Victorian Drug Users Group (VIVAIDS) – 03 9419 3633**

**WA: WA Substance Users Association (WASUA) 08 9227 7866**

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