

Psychology and Substance Use

An Interest Group of the Australian Psychological Society

Convener's report

This newsletter begins the sixth year of activity for the Psychology and Substance Use Interest Group. With a new Executive Committee and renewed energy, we're looking forward to see what we can achieve in 2006.

The last twelve months have been marked by a number of successes, including the publication of a second paper in April 2005, *Perspectives in Psychology: Substance Use*. This was prepared by the APS Working Group on Substance Use, and follows the position paper, *Psychology and Substance Use: Potential Contributions and Professional Training Needs*, which was launched in January 2003.

During the past year we collaborated with the Australasian Professional Society on Alcohol and other Drugs (APSAD) to sponsor a symposium during their conference, Science, Practice, Experience, held in Melbourne at the beginning of November. Thank you to Helen Mentha and Dr Sharon Dawe for organising this event, which was well supported and thought-provoking. The symposium focused on integrating personality theory into addictive behaviours, examining the implications for research and practice. This year's APSAD conference will be held in Cairns. We would like to once again sponsor a symposium – so this is an opportunity for our Queensland members to get involved. We'd love to hear from you.

We sponsored a one-day workshop in Darwin, which was held in conjunction with the Australasian Therapeutic Communities Association. The workshop was designed to assist psychologists and other professionals working

with clients with alcohol and other drug problems and complex behaviours. It introduced participants to the area of alcohol and other drug work, and was specifically targeted at a better understanding of issues relevant for psychologists working with substance use clients. The workshop also highlighted the APS position papers on substance use, and discussed and explored the recommended competencies for psychologists working with substance use clients and professional training needs. Two seminars were also held in Melbourne during 2005.

Thank you to members who responded to my call for input into the National Cannabis Strategy Consultation Paper. We were able to provide a submission, highlighting a number of areas of concern and also drawing attention to some good research and practice models. In general, members endorsed the draft strategy as providing a comprehensive overview of the concerns relating to cannabis use and associated issues. There was considerable concern about the relationship between cannabis use and mental health, and a belief that there needs to be improved shared care arrangements between mental health and alcohol and other drug services – so that once a case manager has been identified, the services share the care and work collaboratively to improve the outcomes for cannabis dependent people with complex behaviours.

The issue of co-occurring disorders (rarely do our clients have a dual diagnosis – i.e. just two presenting issues) continues to concern those of us working in the field. The term "co-occurring disorders" refers to the presence of any two or more disorders in the same person. These may be medical or psychiatric conditions, as well as drug use disorders, including alcohol dependence. Our clients may also have a range of social problems, including homelessness and unemployment. We now acknowledge that clients with co-occurring disorders are the "expectation rather than the exception" across all service delivery systems. The work of psychologists is therefore becoming increasingly important in this field.

An important initiative that will assist in dealing with complex clients has just been released by New South Wales Health. This is the Prevention and Treatment Plan 2005-2009 for Amphetamine, Ecstasy and Cocaine, which is an acknowledgement that patterns of drug use are changing, requiring dynamic, evidence-based and innovative responses from the health sector in partnership with others who are in a position to effect change. Whilst psychologists in NSW may be aware of this document, others will also find it of interest in working with clients with complex needs.

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Convener's report (continued)

I would like to thank members of our past Executive for all their hard work over the last five years. Your efforts have given us a strong base to continue our activities. We look forward to the year ahead, and invite all PSU members to provide feedback on activities you would like to see in your region, information you would like to pass

on to other members, and initiatives you would like to see in place. We hope the coming year is rewarding for all members as we see the group get active again with fresh ideas. Jump in and get involved!

Lynne Magor-Blatch
National Convener

APSAD Conference

This year PSU collaborated with the Australasian Professional Society of Alcohol and Other Drugs workers (APSAD). Dr Allison Ritter, the 2005 APSAD conference convener, supported the collaboration and encouraged us to organise a symposium with Associate Professor Sharon Dawe of Griffith University, representing APSAD.

Our intention was to highlight the contribution psychological research and practice offers us to better understand the relationship between personality traits and substance misuse and the role of individual vulnerabilities and strengths in recovery. We felt the APSAD conference provided the ideal avenue to present current research and hopefully generate stimulating food for thought; therefore, two of our speakers were selected from outside of the AOD field to encourage a fresh perspective on complex presentations common within AOD services. The subsequent symposium, *Integrating personality theory into addictive behaviours: Implications for research and practice*, was extremely well-attended, with a full house and positive feedback.

Dr Dawe opened the symposium with *Personality and addictive behaviours: Where does the field stand?*, presenting a fascinating update on the current understanding of "impulsivity". Dr Dawe focused on the findings of researchers such as Gray, which indicate a multifaceted trait with at least two distinct dimensions of "rash impulsiveness" and reward sensitivity, and the possible neurobiological pathways that may contribute to the expression of these factors. The presentation touched on the implications for treatment, including the likelihood that "Just say no" campaigns would have little impact on impulsive individuals and the potential role of healthy sensation seeking as part of the replacement of substance

use in individuals' lives.

The second speaker, Professor Murray Dyck of Griffith University, presented *Personality and drug use: I feel better now*. Starting with familiar ground, he outlined common underlying processes that may increase a person's likelihood of using alcohol or other drugs as a way to feel better: higher frequency or severity of negative affect or pain; decreased capacity to tolerate negative affect or pain; fewer alternative sources of positive affect; higher valuing of specific drug effects; and higher levels of inhibition. He then went on to highlight some of the DSM-IV diagnoses most likely to correlate to each specific underlying need. Of particular interest was his focus on the relationship between avoidant personality traits and substance misuse, an area often neglected but which frequently emerges in treatment settings.

The final speaker, Dr Carol Hulbert from the University of Melbourne, gave a thought-provoking commentary in *Understanding the complex client: Personality theory in practice*. A highly experienced therapist and researcher, Dr Hulbert succinctly presented key findings on the development and trajectory of Borderline Personality Disorder, including the role of adverse attachment and trauma on the development of brain structures in early development, socio-cognitive processing style (such as ability to reflect or know what is in the mind of the other) and maladaptive schema or beliefs about the self. She brought the session to a close with practical recommendations for formulation, treatment and systemic processes in typical AOD settings where long-term treatment is rarely an option.

Helen Mentha
Symposium Chair

Editorial policy

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Unsolicited articles: The Editor encourages PSU members to contribute unsolicited articles to the newsletter. Publication of unsolicited articles cannot be guaranteed. The Editor, in consultation with PSU representatives, has the final decision for inclusion of material

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Submission of material: Material should be submitted to the Editor by the relevant deadline. Submissions are to be in electronic format only, in Microsoft Word or text only format, and sent via email to the Editor, Helen Mentha, at hmentha@caraniche.com.au.

“It’s My Life”: Ethical issues in AOD research from the consumer perspective

Introduction

AOD research is about our lives and our health – we have a great deal to gain from meaningful engagement and of course a great deal to lose from being excluded.

The importance of consumer involvement in the research that affected us as drug users motivated AIVL to develop and release our National Statement on Ethical Issues for Research Involving Injecting/Illicit Drug Users. This national statement was released in June 2003 after many years of development and work.

The three key areas covered in the statement are:

- Research Ethics Committees;
- Consumer participation in research;
- Ethical issues in conducting research.

These areas will be covered briefly here, but clearly involve a great deal more than can be covered in one brief article.

How did we develop the AIVL National Statement?

Although the AIVL national statement was eventually developed as a “product” (in the new funding speak), of the AIVL National Hepatitis C Policy Program in 2002/2003, there was a long and interesting development process stretching back many years. The difficulties we experienced in developing and gaining recognition for our statement on ethical issues speaks to the difficult history of consumer participation itself in this area of research.

The AIVL document grew out of a set of ethical guidelines originally developed in 1997 by AIVL's member organisation in NSW, the NSW Users & AIDS Association (NUAA) for use in the NSW context. Looking back now I think that the NUAA document was amazing and very brave in many ways. To have seen the need for a document to highlight ethical and participation issues for drug users involved in research at this time was significant and indeed highlights the innovative work and thinking that many Australian peer-based drug user organisations do, and which is often overlooked.

Once the need for a national document was recognised, a modified and updated version of the NUAA document became the basis for a comprehensive consultation process involving all key stakeholders as the first step in developing the new national document.

Although we had initially started out with the idea of developing a set of national ethical guidelines, through consultation the process evolved into the development of a ‘national statement’ rather than a set of guidelines, focussing on the issues from the ‘drug user perspective’ – as this is our area of expertise.

These developments were important because it took the document away from any perception that AIVL was trying to ‘tell researchers how to do their job’ (God forbid); in short, AIVL was trying to develop a very specific document that spoke about the experience of consumers in illicit drug-related research to promote discussion and encourage further action on ethical issues

in illicit drug research, which was in the interests of both consumers and researchers.

Why was a National Statement needed?

For some years now, AIVL, its member organisations and some researchers have been calling for a greater degree of consultation on ethical issues relating to AOD research so that those most affected by the research (and it has to be said, those who have the most to lose from poor research) will have more input into the process, impact and outcomes of such research. In a variety of forums, AIVL and its member organisations have argued for:

- More consultation with consumers in setting the research agenda;
- More involvement of consumers in developing and planning research projects, in deciding where and how research funding is allocated; in carrying out research projects and in the application and impact of the findings;
- More support for peer-driven research.

Drug user organisations are regularly approached to be involved in research projects after the project has been developed and funded, frequently with little or no financial reimbursement on offer and without discussion of formal recognition for involvement or input into findings and outcomes. In other cases, drug user organisations are regularly expected to participate in relevant research projects as part of their ‘core business’ without any recognition by researchers or funding bodies of the impact that this involvement has on the workload of the organisation. Gladly, very recently some of this has started to change but there is still a long way to go.

It seems that the individual experience of drug users in research varies from one extreme to another. Some groups of drug users regularly speak of feeling ‘over-researched’, unclear about the objectives of the research that they are participating in, frustrated that they never seem to hear back about the findings of research they participate in and angry about inconsistent approaches to payment of participants within research projects. Other groups of drug users complain that their issues receive very little attention from researchers and that many key health, social and legal issues are either under-researched or not researched at all.

There are many reasons why injecting/illicit drug users need special consideration in relation to the ethical implications of research not the least of which is their status as an extremely isolated and marginalised group within society. This poor health and social status creates a range of significant barriers to conducting ethical research based on trust, respect and human dignity. Therefore, the key aims of the AIVL statement were to:

- a) Encourage the development of research practice that is of a consistently high ethical standard and is beneficial to injecting/illicit drug users in Australia;
- b) Recognise that drug users and their organisations have valuable experience, knowledge and skills to bring to the research process;

- c) Propose a set of clear principles for involving and working with AIVL and its member organisations in illicit drug research in Australia;
- d) Facilitate a shift from simply 'protecting' individual participants to actively engaging in meaningful partnerships with drug user networks and communities;
- e) Encourage researchers and research institutes to honestly review the values and principles that they bring to the research process and to assess them in relation to their ethical implications;
- f) Encourage discussion about the need for a set of formally recognised ethical standards for research involving injecting/illicit drug users.

Research Ethics Committees

Any changes in the way that ethical issues are addressed within AOD research will need to be driven by the existing research infrastructure. In particular, Human Research Ethics Committees (HRECs) will have a significant role to play in bringing about a renewed emphasis on ethical practice in AOD research.

Consumer involvement in Ethics Committees

One of the most important issues in relation to HRECs is the need to incorporate consumer perspectives into decision making. Both Bastian (1994) and McNeill et al (1994) have questioned the current approach to consumer representation on HRECs. They state that lay persons on ethic committees can be outnumbered in terms of being the single 'consumer' representative on a large committee, may not be supported in their role or have accountability mechanisms back to the relevant consumers, and are often 'generalist' health consumer representatives with little or no specialist knowledge.

Further work needs to be undertaken through the appropriate channels to determine how to support and improve existing HREC structures to actively manage ethical issues relating to AOD research including:

- Improved consumer consultation;
- Potential role of Illicit Drug Use sub-committees or advisory groups;
- Possible expansion of committee membership to include additional members with specialised knowledge and experience; and
- A need for guidelines to support the decision making of HRECs in relation to ethical issues in illicit drug research.

Legal issues

Research into illegal behaviours raises some complex legal and ethical issues. HRECs are increasingly concerned about the legal implications of conducting research into illegal behaviours. These concerns, while justified, must be placed in the context of a realistic appreciation of the law and its practical operation.

The major issue is that of access to information collected in the course of research. At the moment, data collected by researchers on illegal behaviour, including injecting/illicit drug use, do not have legally protected status to protect them from either a search of premises by police officers or a court order to provide information and data. This raises issues in relation to the welfare of both

research participants and researchers and may have implications for others involved in the research process.

Information about illegal behaviours obtained by researchers may incriminate research participants, resulting in direct harm as result of their participation in research. Consequently, it may be no longer ethical to provide participants with absolute assurances of confidentiality even though this may undermine the capacity of researchers to recruit participants. However, to place these concerns in context, experience suggests that the likelihood of the authorities seeking access to research material is relatively small.

In the past few years increasing levels of concern have been expressed within the sector in relation to the potential criminal liability of researchers, although, in reality, criminal liability is only extended under the doctrine of complicity if the complicitor is actively involved in the offence in a blameworthy manner.

The issues in relation to criminal liability become far more complex, however, when applied to peer-based or peer-driven research. Increasingly, drug user organisations are conducting research and the precise legal position of the individual drug users employed as peer researchers is, at best, unclear. The boundaries and distinctions that may be used in a legal case involving a recognised research institution will not necessarily apply in the case of a peer researcher. This is a particular issue if the peer researcher is a 'known drug user' or someone who is 'known' to the police.

Drug user organisations engaged in peer-driven research projects have heard numerous claims of legal problems encountered by peer researchers including police surveillance and harassment of peer researchers and participants, search warrants, and confiscation of research data and participant's details, etc. Not surprisingly, drug users tell each other about poor treatment from police and other service providers, which can act as a deterrent to other drug users considering participation in future research projects. This 'grey' area of criminal liability needs further discussion and resolution so that valuable peer-driven research practices can continue and develop.

Free and informed consent

The issue of gaining written consent for research involving illicit drug users is both complex and difficult. The overwhelming need to protect the identity and confidentiality of participants within the area of research often leaves researchers in direct conflict with HREC guidelines on gaining written consent. While the requirement that all participants sign consent forms prior to HREC approval may be a realistic and important accountability measure for some research projects, additional options for meeting consent requirements need to be developed to accommodate projects where protecting the identity and confidentiality of participants is paramount.

The illegal nature of most drug use also means that the very act of signing a consent form may be considered dangerous and far too risky for many illicit drug users. For many drug users, written consent does not necessarily mean 'free and informed consent', and it does not necessarily guarantee equitable treatment. This being the

case, it is necessary for HRECs to work with researchers and drug user organisations to develop ways of ensuring that research participants in the area give their free and informed consent in a way that satisfies ethical protocols, but does not place drug users in danger.

Power (1998) argues that informed consent is fundamentally about much broader issues than a signature on a piece of paper or even a well designed consent process. She states that by viewing informed consent as a process of participation and respect, we can begin to look at the overall issue rather than getting caught up in whether the single act of gaining written consent constitutes informed consent. Issues such as confidentiality, the potential dangers associated with disclosing an illegal behaviour, the ethical issues associated with gaining informed consent from highly intoxicated people and/or drug users with mental health problems, have all lead to the view that current requirements need to be revised in favour of a more comprehensive and flexible approach.

AIVL believes that peers are the key to ensuring more ethical standards in relation to informed consent in AOD research. By and large, drug users are more comfortable with other drug users and other users often know when someone is uncomfortable or doesn't understand the process. Developing more ethical and effective consent processes will also depend on researchers gaining a better understanding of both the real and perceived concerns that many drug users have in relation to health research. Such concerns need to be taken seriously, whether they are perception or reality, and addressed in a way that instils confidence in drug users.

Peer-driven Research and Ethics Committees

Given that peer-driven research by its nature is largely conducted by peer-based non-government organisations with no direct relationships with HRECs, it has never been entirely clear on how such organisations should proceed in relation to ethics clearance. Unfortunately, rather than there being any move to resolve this issue, those undertaking peer-driven research have simply found themselves isolated in terms of the process and ignored in terms of the important research they are doing. AIVL has recently experienced a range of difficulties and barriers within the existing HREC structure and process in relation to gaining ethics clearance for peer-driven research including: lack of clarity about the process; onerous requirements; difficulties meeting criteria as first-time researchers; lack of expertise by HREC in peer-driven research; our status as 'drug-users' seen as a disadvantage rather than an essential requirement; and a lack of recognition of the training and skills development needs of peer-based NGOs.

Consumer participation in research

While I cannot cover all of the issues relating to consumer participation here, I would like to highlight the key principles for consumers participation and involvement in research:

- Flexible collaboration and partnerships;
- Consumer participation in all aspects of the research process;

- Consumer consultation in the development of research proposals to identify issues and concerns;
- Support for consumer research as an important and valuable component of consumer participation in research;
- Supporting consumer researchers wherever possible in research projects;
- Recognition of consumer expertise in the same way as the expertise of other key stakeholders – that it is respected, properly remunerated, taken seriously, listened to and acknowledged;
- Allocation of adequate resources to support consumer participation;
- Skilled communication with consumers;
- Respect for consumer rights;
- Accessible information for consumers;
- Training for consumers to be effective consumer representatives.

Ethical issues in conducting research

The final section of the AIVL national statement looks at each stage in the research process and identifies key ethical issues in each of these areas. I am just going to identify one or two major issues in each of these areas before I move on to my conclusions and recommendations.

Planning and conducting research

I cannot stress enough the importance of involving consumers in ALL stages of the research process not just to get your ethics clearance, not coming to us once the project proposal is written or worse still, already funded, and not deciding for us what stages of the project we are capable of being involved in or understanding. With the right support and funding we can participate meaningfully in all stage of the process.

Storing, managing and analysing data

Something that rarely happens in my experience is the involvement of consumer reps in the data analysis phase of the research. It is so important because often researchers misinterpret data, take data out of context or trivialize really important issues. Whether people admit it or not, researchers interpret the data and consumers are critical to this process. They can also ensure that the rights and needs of consumers are protected during the report writing phase.

Dissemination of research findings

This is a huge issue that I discuss with researchers all the time in terms of how to improve dissemination. It would be rare to meet a consumer in this area who says that they specifically received the findings of the research they were involved in. This is simply not good enough and there are many strategies including user magazines, forums, web and video based resources that can be used.

Uses of research data

I know there are people who will disagree with me but I believe that it is absolutely the responsibility of the researcher to ensure that their data is not used to the detriment of consumers and researchers need to be putting a great deal more effort into that end rather than

simply accepting the inevitable or acting like disempowered observers. Enough said!

Conclusions and recommendations

Despite my negative assessment of some aspects of research practice in relation to ethical issues, I do want to finish by saying that things are changing in some ways and some areas. AIVL and its members are having more dialogue about consumers participation in research more often (there was a good workshop held at this conference and there are plans I believe to continue that workshop at future conferences.) We are involved in numerous research projects (steering committees, associate investigators and partnerships). The NCHSR has developed a consumer liaison position, invited AIVL on to their Scientific Advisory Cttee and are working in a full partnership with AIVL on a new peer-driven research project (we have the funding & we engaged them on our terms).

So there are some good things happening but we need more discussion among researchers on ethics and consumer involvement. Ethics needs to be seen as a ‘whole of research’ concern – not just about HRECs or gaining ethics approval but an issue from before the ethics application to long after the research has been done.

Future issues include the establishment of a Consumer Ethics Advisory Group, a clear process for consumer endorsement or rejection of research proposals that affect our lives, and continued lobbying for a National Code of Ethics for AOD Research.

AOD resources

The good folk at the National Centre for Education and Training in Addictions (NCETA) are looking out for AOD staff once again, with their new booklet *Stress and burnout: A prevention handbook for the alcohol and other drugs workforce* by Natalie Skinner and Ann Roche.

It continues to amaze me that NCETA exists at all - it was a brave and enlightened move to dedicate an entire organisation (small though they are) to the broader issues of AOD workforce development. It’s a vital role and a fantastic resource for Australia. The booklet can be downloaded from the NCETA website at: <http://www.nceta.flinders.edu.au>

On the topic of training an education, check out the National Training Information Service website for details

PSU National Executive

Please contact us with any queries, concerns or ideas!

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I encourage all of you to access the document from the AIVL website for further elaboration on these issues.

I wanted to finish with some thoughts on “why” we should be concerned about ethics and research and the main reasons I believe are:

- Because it makes for better research;
- It is about treating people with dignity and respect;
- It creates better evidence-based practice and highlights when the evidence is missing and action is needed; and
- It leads to improved health benefits and outcomes for all.

But to finish where I began, the main reason to involve consumers in your research is because your work affects our lives and we have a right to be involved in that.

Annie Madden
Executive Officer AIVL

References

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Power L (1998) Trial subjects must be fully involved in design and approval of trials, BMJ, 316, pp.1000-01.

on nationally accredited AOD competencies at <http://ntis.gov.au>.

And finally, the story of little Opie, the bug-eyed opium molecule was launched at the APSAD conference. Produced by the creative mob down at Turning Point, the seven minute animated film follows the journey of the opium molecule from the poppy, through manufacture into heroin and distribution, through to administration, metabolism and elimination. Government-funded AOD agencies can download this resource for free from the Turning Point website at: <http://www.turningpoint.org.au>.

Helen Mentha