

Lived Experience.

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What is it?

People who have had direct experience with alcohol or other drugs are sometimes referred to as ‘people with lived experience’ (PWLE). This can refer to people across the continuum of drug use from early experimentation through to dependence through to long term recovery.

Family members of people who use drugs may also be considered PWLE as the impact on the family member can be significant.

People with lived experience have taken up various roles within the Alcohol and other drug (AOD) sector, including when actively using drugs, currently not using (otherwise referred to as abstinent) or as family members impacted by the current or past use of drugs by their loved one.

The types of roles PWLE may play include:

Peer Support Work

- working one on one or in group with clients
- using lived experience to support clients and role model positive change
- having a relationship as an equal within a defined role.

Consumer Participation Work

- sharing lived experience in various community settings
- informing policy and program development
- consultancy and advocacy.

Recovery from drug dependence can be seen as a traditional pathway to employment in AOD services, often beginning with volunteering after a period of recovery and possibly later gaining certification for paid employment in the AOD field as either ‘peer’ workers or support workers.

Some people engage with self-help or mutual help groups that can provide various forms of peer support for people struggling with AOD related problems¹. This may include helping people navigate pathways to health services and treatment²; offering harm reduction services such as needle syringe programs; and, providing peer support^{1, 2}.

Self-help groups are usually run by and for group members and are financially self-supporting (e.g. Alcoholics Anonymous)³. An evaluation of peer support groups in Victoria reported that engaging in peer support programs “boosted [the participants] inner strength and courage, as well as their sense of control and ability to make changes to their lives.”⁴

Consumer organisations, such as the Australian Injecting and Illicit Drug Users League, the Queensland Injectors Health Network and the Queensland Injectors Voice for Advocacy and Action, can play a key role in ensuring the voice and experience of PWLE can be represented in advocacy and policy decision making.^{1, 2}

Why?

Peer Work

People with lived experience can have a unique understanding of key issues associated with the use of drugs and can play a critical role in supporting others, whether formally through peer support or informally through self-help groups. PWLE can offer a perspective that enhances the overall relevance of existing support programs and potentially improve the value of care provided.⁵

PWLE's access to, and understanding of, hidden and stigmatised cultures affords insight that is not available to professional workers and consequently involvement of people with lived experience in constructing and implementing services and programs is not only a public health imperative, but is reflective of the ethical need for people to be involved in decisions that affect them and of the human right to participate in cultural life.^{6,7}

The Queensland Mental Health Commission suggested 'peer workers' can help consumers of services to navigate the service system, engender trust and engagement in the system, reduce self-stigma via positive role modelling, and provide training for the peer role in recovery.² It also suggested that peer workers could be engaged to help co-design services. However, it conceded the risk that to identify as a mental health peer may lead to stigmatisation², a concern that is also valid in the AOD workforce.

Consumer participation

Consumer participation in programs to reduce prejudice and stigma can help challenge discriminatory or uninformed opinions.⁸

In many areas of health care ensuring involvement of marginalised individuals in the policy-making process can help to address the issues that most affect the community and help to alleviate or minimise stigma or discrimination.⁷ Engaging drug user associations, ensuring the voices of those affected are always considered and allowing for consumer participation without prejudice are key priority areas to create effective interventions to reduce stigma.⁸

The Queensland Mental Health Commission discussion paper⁹ on lived experience in mental health states: "The lived experience or 'consumer' movement is a human rights movement. Empowerment and participation by people with lived experience is considered essential internationally to progress this human rights agenda."⁹

In Australia, participation in mental health policy by people with lived experience has been promoted since 1992.⁵ The participation of PWLE in relation to AOD is yet to be at the core of policy with the same emphasis as in the mental health sector but consumer participation, particularly in the treatment sector is acknowledged as of growing importance.¹⁰

The involvement of PWLE in program development, policy considerations and other key areas can help ensure that language and representations of alcohol or drug use are non-stigmatising.

Evidence

A number of studies have investigated the role and impact of the employment of people with lived experience on crime prevention, mental health and AOD treatment and advocacy, while the effect of PWLE as drug educators in schools and other community settings appears not to have been the subject of formal research.

The efficacy and value of PWLE in an education context is not clear.

What is evident from the research is an education session that is based on a sharing stories approach, using a fear-based narrative to encourage abstinence can result in a negative impact and increase AOD use¹¹. The role of PWLE in formulating curriculum, or in delivery a curriculum that is based on best practice guidelines has not been evaluated.¹²

The role of PWLE in reducing stigma

In mental health

A meta-analysis by Corrigan et al.¹³ that incorporated 72 studies and over 30,000 participants reported on the impact of three approaches to reducing stigma against mental illness. These approaches were:

- protest, or social activism
- education
- interpersonal contact with a PWLE of mental illness.

Impact was measured by changes in attitudes and to intentional behaviour, while behavioural change was not measured. The authors reported that 'protest' was the least researched, appeared the least effective, and might be counterproductive.¹³

Among adults, both education and contact with a PWLE were effective in reducing stigma. Contact was the most effective mode and face-to-face contact was preferable to contact via a video presentation. However, this result was reversed among adolescents where education was found more effective in reducing stigma than personal contact.¹³

In AOD

National programs that incorporate people with lived experience of AOD aimed at reducing stigma are still in their infancy with few having robust evaluation to their efficacy.

In Queensland, a program developed by AIVL (Australian Injecting and Illicit Drug Users League) called 'Putting together the Puzzle' and delivered by QulHN (Queensland's peer-based drug user organisation) aimed to reduce stigma among health care workers, professionals and students.⁷

This program focusses on reducing stigma and discrimination experienced by people who inject drugs (PWID), people on opioid substitution programs and people affected by hepatitis and other blood-borne viruses. The program has been run in a variety of settings since 2014 (pharmacy group, probation and parole, nurses, GPs and more) but has not been evaluated to determine efficacy.⁷

[Harm Reduction Victoria](#) (HRVic) has been representing the voices of consumers since 1987. HRVic, funded by the Victorian Department of Health and Human Services (DHHS) runs several peer-facilitated programs such as DanceWize, D.O.P.E and the Pharmacotherapy Advocacy Mediation and Support (PAMS) service.

These services are peer-run support and advocacy programs that provide people who use drugs (PWUD) with a non-judgemental place to get support, information or education. They have not, to our knowledge, been evaluated.

Research within other health conditions, in particular mental illness and HIV/AIDS, shows contact with PWLE within a broader educational approach facilitates positive interactions between the public and people with those health conditions, including improvements in attitudes.¹⁴

Educating medical, nursing and health professional students about substance use, including exposing them to people with substance use disorders, can decrease stigmatising attitudes and increase their comfort levels toward working with this population.

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Australian studies among medical students show that contact with illicit drug users in small group settings was associated with more positive attitudes.¹⁸ This finding mirrors other studies that consistently show contact with people who use drugs positively impacts previously held views and prejudice.¹⁸

Contact involves introducing people who use substances to others who may be ignorant to the human aspect and stigma due to lack of shared experience with AOD consumers. Sharing experience via one-on-one contact, social media or through user experience websites, such as Lives of Substance¹⁹, can help break down barriers of distance and beliefs.

Engaging consumers and people with lived experience in policy making, peer support and advocacy ensures an authenticity of any approach.¹⁸

The use of PWLE in AOD treatment

People with experience of AOD problems contribute to reducing drug problems by performing several roles including advisor/counsellor, peer support, advocacy.²⁰

A peer worker utilises their lived experience of drug and alcohol issues, plus skills learned in formal training, to deliver services in support of others. The Victorian Government's Alcohol and Other Drug Program Guidelines assert that peer workers provide non-clinical assistance; they may share their personal experiences in a way that inspires hope and role model recovery.²¹

There is an emerging but incomplete evidence base for the various forms of peer support in mental health and substance dependence.

Unfunded, self-help groups such as Alcoholics Anonymous (AA) / Narcotics Anonymous (NA) are the oldest form of organised peer support. The majority of support for this approach comes from twelve step program reviews^{22, 23} but a thorough evidence review has not been undertaken, and to date, there is no robust evidence of effectiveness for this specific approach.²⁴

PWLE in schools

Although school-based drug education has been extensively researched over the past half century, we have not located any study of the role of PWLE as speakers in schools (and community settings). This means a research base for understanding the value of PWLE in schools and community is lacking.

Research has shown that scare tactics are not effective and may backfire when used in an education setting. However, it is not clear if the negative outcome is due to the presenter (who in some programs are PWLE) or the manner in which the information is presented.^{11, 25}

International and national authorities that provide advice on the practice of school-based drug education recommend that schools do not employ PWLE as drug educators unless they are qualified to teach recommended curriculum. This includes advice published by the United Nations Office on Drugs and Crime,²⁶ an extensive statement of drug education principles published by the Australian Department of Education and Training in 2004,¹² advice which was confirmed by the Queensland Government in 2018.²⁷

School presentations based on PWLE sharing their stories conflicts with best practice derived from systematic reviews of research into drug education.

28-30

Best practice	Program using PWLE
Delivered through a series of structured sessions, often providing booster sessions over multiple years. ²⁶	PWLE focused presentations are typically ‘one-off’, stand-alone sessions, whereas best practice constitutes multiple sessions that enable development and practise of social competency skills over time. ²⁸⁻³⁰
Teachers of alcohol education are advised not to emphasis the risk of alcohol as some students are attracted to risk taking. ^{26, 29}	PWLE may emphasise graphic and sensational tales of woe and negative information to develop a fear of drugs in children, which will ‘scare them straight’. ^{31, 32} This does not address the drivers of adolescent drug use, which are found in social contexts, community and sub-cultural norms, and personal characteristics. ³³
Research into drug education does not support information-heavy and fear-based approaches. ^{11, 25, 26, 28-30}	The telling of graphic stories (by PWLE or any presenter) about illicit drug use and associated problems of overdoses, deaths, crime, violence, suicide, etc., may expose children to secondary trauma. ³⁴
Delivered by trained teachers or facilitators. ²⁶	PWLE usually direct attention to illicit drugs and might make legal drugs appear less important ³⁰⁻³² . Evidence suggests a focus on legal drugs (alcohol and tobacco) yields more promising results than focusing on illegal drugs. ³⁰
Sessions are primarily interactive. ²⁶	Teachers of drug education are advised not to disclose their history of drug use, nor allow students to do so. ³⁵

Evidence gap

There is a need for much more detailed reviewing, evaluation and research around the use of PWLE in the alcohol and other drug and mental health sectors. There are a number of challenges in performing research in these areas and this also needs to be addressed before meaningful evidence can be gathered as to the importance and value of PWLE in both sectors.

ADF position

- 1.** The ADF supports the role of PWLE within service provision and advocacy within the adult AOD treatment field.
- 2.** The ADF supports the role of PWLE in developing policy and guidelines based on health and social well-being.
- 3.** The ADF does not supporting PWLE as drug educators in schools (and sporting clubs) using fear-based tactics (the lived experience as a deterrent) or education alone.
- 4.** Supporting PWLE as drug educators in schools using approaches other than fear tactics is not supported until we have further research exploring potential risks and benefits.
- 5.** Parents and carers to be informed of external providers presenting to students as per schools' normal procedures.

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