

## Standing with the Lived Experience Workforce: Lessons from the states and territories

**Chair:** Elisabeth Yarbakhsh<sup>1,3</sup>

**Chair's email:** [elisabeth@atoda.org.au](mailto:elisabeth@atoda.org.au)

**Discussant:** Chris Gough<sup>4</sup>

**Discussant's email:** [chrisg@cahma.org.au](mailto:chrisg@cahma.org.au)

### Authors:

Anke van der Sterren<sup>1,2</sup>, Elisabeth Yarbakhsh<sup>1,3</sup>, Chris Gough<sup>4</sup>, Natasha Nikolic<sup>4</sup>, Dean Wang<sup>4</sup>, Karen Gorst<sup>4</sup>, Taylor Munday<sup>4</sup>, SUSOS Codesign Project Advisory Group<sup>1</sup>, Patrick Rawstorne<sup>2</sup>, Sally Nathan<sup>2</sup>, Sam Raven<sup>5</sup>, Margie Randle<sup>6</sup>, John Quiroga<sup>7</sup>, Jane Moreton<sup>8</sup>, Roland van Olphen<sup>9</sup>, Kyle Perry<sup>10</sup>, Daniel Vautin<sup>10</sup>, Susan Holt<sup>11</sup>

<sup>1</sup>*Alcohol, Tobacco and Other Drug Association ACT (ATODA), Canberra, Australia,* <sup>2</sup>*School of Population Health, UNSW Sydney, Sydney, Australia,* <sup>3</sup>*College of Arts and Social Sciences, The Australian National University, Canberra, Australia,* <sup>4</sup>*Canberra Alliance for Harm Minimisation and Advocacy (CAHMA), Canberra, Australia,* <sup>5</sup>*South Australian Network of Drug and Alcohol Services (SANDAS), Adelaide, Australia,* <sup>6</sup>*Hepatitis SA, Adelaide, Australia,* <sup>7</sup>*North and West Metro Alcohol and Drug Service, Melbourne, Australia;* <sup>8</sup>*Victorian Alcohol and Drug Association (VAADA), Melbourne, Australia,* <sup>9</sup>*Uniting Vic. Tas, Uniting AOD and Mental Health, Melbourne, Australia,* <sup>10</sup>*Alcohol, Tobacco and Other Drugs Council Tasmania (ATDC), Hobart, Australia,* <sup>11</sup>*Western Australian Network of Alcohol and other Drug Agencies (WANADA), Perth, Australia*

Presenters' emails: [anke@atoda.org.au](mailto:anke@atoda.org.au); [sam@sandas.org.au](mailto:sam@sandas.org.au); [jmoreton@vaada.org.au](mailto:jmoreton@vaada.org.au); [roland.vanolphen@vt.uniting.org](mailto:roland.vanolphen@vt.uniting.org); [dan@atdc.org.au](mailto:dan@atdc.org.au); [susan.holt@wanada.org.au](mailto:susan.holt@wanada.org.au)

**Aim:** It is increasingly understood that a sustainable alcohol, tobacco and other drug (ATOD) sector in Australia must necessarily engage with the lived and living experience workforce (including the peer workforce). Integrating the perspectives, knowledge and expertise of lived and living experience workers enhances service development, strengthens clinical decision-making, and improves health outcomes for service users. This symposium will provide an opportunity for the state and territory peak bodies of alcohol, tobacco and other drug services — in collaboration with peer workers and consumer organisations — to share their experiences of developing, supporting, training, learning from and working alongside their respective lived and living experience ATOD workforces. The five papers that form this symposium highlight the diversity of projects that engage the lived and living experience workforce and show how the peak bodies are engaging with policy, advocacy, workforce development and research in an area of growing importance to the sector.

**Disclosure of Interest Statement:** No conflict of interest is identified by the presenters

## **Prioritising service-user perspectives in project design**

### **Presenting Authors:**

Anke van der Sterren, Elisabeth Yarbakhsh, Chris Gough, Natasha Nikolic, Dean Wang, Karen Gorst, Taylor Munday, SUSOS Codesign Project Advisory Group Patrick Rawstorne, Sally Nathan

**Introduction / Issues:** Recognising the absence of the perspectives of people with lived and living experience of alcohol and other drug dependence from quality improvement processes, the Alcohol Tobacco and Other Drug Association ACT (ATODA) trialled a collaborative approach to involving AOD service users in the development of an experience measure.

**Method / Approach:** The Service Users' Satisfaction and Outcomes Survey (SUSOS) Codesign Project has involved formalising a collaborative partnership between the peak organisation (ATODA) and the local peer-based organisation (the Canberra Alliance for Harm Minimisation and Advocacy—CAHMA). CAHMA led the recruitment of, and engagement with AOD service users in the process—including through co-facilitation of the focus groups—and ATODA brought experience in formal research processes. A multi-stakeholder Project Advisory Group with majority membership by AOD service users and peer workers guided the project process and survey design.

**Key Findings / Results:** Prioritising service user voices in project design and delivery, necessitates new approaches to research. Taking the time to develop trusting relationships and building-in flexibility to accommodate the needs of a diverse research team, can frustrate organisational priorities but ultimately enables a genuine reciprocity of skills and knowledge.

**Discussions and Conclusions:** Multiple stakeholders have collaborated to ensure the views and perspectives of AOD service users are made prominent. The Project has demonstrated that methodological rigour is strengthened, rather than compromised by meaningful collaboration and partnership with AOD service users and peer workers.

**Implications for Practice:** The approach sought to facilitate bringing service users perspectives to the forefront in the design of a new survey and allowed ATODA to test a method for improved engagement by AOD service users in sector research projects. Lessons from this collaboration will inform future co-design projects.

## **Building a Lived Experience Network**

### **Presenting Authors:**

Sam Raven, Margie Randle

**Background:** SANDAS undertook a project to identify the needs of the AOD Lived Experience workforce in South Australia. In response, established a network of AOD Lived Experience Workers in early 2023.

**Method / Approach:** SANDAS consulted with its members to gain support for the establishment of a network. The network was started in 2023 and now meets regularly.

**Effectiveness /Acceptability /Implementation:** Outcomes of the network to date have included: Identification of needs of the AOD Lived Experience Workforce; advocacy towards a professional body; sharing of information; and exchange of knowledge, education, growth, support and challenges.

The network members also identified issues for workers such as: part-time roles; qualifications; lack of senior/leadership positions for peers; need for recognition of specialization; tokenism; stigma; need for clear role definitions; need for improved sector knowledge about peer work; pressure to represent all PWUD; and a lack of support and supervision.

**Conclusions and Next Steps:** SANDAS has utilised the information provided by network members to develop advocacy for resourcing to support this growing workforce. The network will remain part of SANDAS' repertoire of projects for as long as capacity allows and continue to seek funds for a wider project that goes further to meeting the needs of the workforce.

**Implications for Practice or Policy:** As peer work becomes an increasingly valued and intrinsic part of AOD treatment, we must ensure that people and organisations are well supported. This requires adequate resourcing but also a deeper understanding of the value of the work, working in partnership with clinical aspects and how we can make it a safe, sustainable and fulfilling career for those who choose it.

## **Embedding meaningful consumer participation within the AOD treatment sector – challenges and opportunities**

### **Presenting Authors:**

Jane Moreton, Roland van Olphen

### **Background:**

In a bid to elevate consumer voices and prioritise their feedback in the treatment planning process, the Victorian Alcohol and Drug Association (VAADA), in partnership with the North and West Metro Alcohol and Drugs Service (NWMAODS), Association of Participating Service Users (APSU), Youth Support + Advocacy Service (YSAS), Family Drug Support (FDS) and Alcohol, Prescription and Other Drugs (APOD) Family Support, commenced operation of the *Consumer Participation and Lived Experience Project* in February 2021.

### **Method / Approach:**

Working alongside a dedicated group of consumer representatives and peer researchers, practitioners have:

- Implemented a participatory action research model to consult with consumers about their experiences;
- Analysed their feedback;
- Drafted recommendations based on the findings and advocated for system improvements.

### **Key Findings / Results:**

During the first two rounds of consultations a number of key themes and priority issues were identified, most notably:

- Concern from family members/carers about being dismissed/excluded;
- Confusion regarding available AOD supports and how to access them;
- Widespread difficulties navigating the AOD treatment system;
- The need for a more holistic and integrated approach;
- Broad-based support for expanding the role and scope of the lived and living experience workforce.

### **Conclusions and Next Steps:**

While there is broad consensus amongst consumers, service providers, government and other key stakeholders that enhancing consumer participation is important, with some not insignificant gains in recent times, much more needs to be done across funding; establishing new infrastructure, workforce development and training.

### **Implications for Practice or Policy:**

This presentation will provide an overview of our key learnings and challenges, while raising questions about what constitutes meaningful consumer participation, its implications for advocacy and service improvement, and whether such an approach is sustainable (against a backdrop of continual and escalating sector reforms).

## **Working collaboratively to build an independent lived experience organisation in Tasmania**

### **Presenting Authors:**

Kyle Perry, [Daniel Vautin](#)

**Background:** The ATDC has long advocated for an independent lived experience organisation in Tasmania, operating a Lived Experience Advocate Service since 2020. Over this time over 30 advocates have volunteered hundreds of hours, providing insight and expertise across the government and non-government space. Advocates have helped create Australia's first 'ATOD Communications Charter' and Image Guidelines, have held forums, supported conferences, co-developed and reviewed resources, attended interview panels, informed policy, and supported many projects as part of ATOD reforms in Tasmania.

In this presentation, we will discuss the journey so far, the trials and tribulations, as we move towards a truly independent lived experience organisation in Tasmania.

### **Description of Model of Care / Intervention:**

The ATDC has collaborated with the government, the wider community sector, and with people with a lived and living experience of ATODs to establish a strong foundation for a lived experience organisation. This has been achieved through:

- Creating the framework and tools for organisations to evaluate their preparedness to work with volunteer advocates.
- Launching a Lived Experience Advocate Service.
- Building individual and sector capacity through training.
- Working with partners to develop opportunities and promote the lived experience voice.
- Developing various resources, policies, and systems to facilitate and support these efforts.

The ATDC has focused heavily on co-design, collaboration and consultation with advocates and people with lived experience.

### **Key Findings / Results:**

There is enormous value in having a core group of capable and highly engaged advocates dedicated to elevating the lived experience voice, promoting the role of advocates in shaping policy, programs and at the operational level, and providing expertise and nuanced understanding of the lived or living experience of ATOD use.

## **Defining and strengthening the peer workforce in the Western Australian alcohol and other drug sector**

### **Presenting Authors:**

Susan Holt

**Introduction / Issues:** There is a need to secure more balanced representation of alcohol and other drug “peer, lived / living experience” involvement in systems level policy and planning efforts. WANADA, together with the Alcohol and Other Drug Consumer and Community Coalition (AODCCC), sought better understanding of the Western Australian alcohol and other drug sector’s workforce who have a relevant personal experience associated with alcohol and other drugs.

**Method / Approach:** This presentation summarises findings relating to the peer workforce from the WA 2022 Alcohol and Other Drug Sector Survey of service users and other consumers, sector workers and sector leaders.

**Key Findings / Results:** 62% of workers identified as having relevant personal experience of alcohol and/or other drugs, with 2/3 of service users agreeing it was important for alcohol and other drug users to have this experience. In depth analysis of workforce demographics and workers’ perceived influence on sector issues provides clear indication of the need for workers to be included in all sector and systems planning and relevant policy development. Personal safety for workers and systems advocates needs priority consideration, supported by appropriate language choices and the ability to choose whether to self-identify as a “peer” worker.

**Discussions and Conclusions:** Considerable input from the sector and key collaborating partners is required to address existing barriers and to affect meaningful systems and practice change. The survey report establishes priorities to support a strong and sustainable sector peer workforce.

**Discussion Section:** The discussion on the lived and living experience AOD workforce, will be moderated by peer and lived experience advocate, Chris Gough. Chris will bring his considerable expertise to bear on a conversation that will showcase a broad diversity of projects from the peak bodies of alcohol and other drug services across the states and territories. Despite having very different aims and objectives, these projects are unified by a commitment to standing with and alongside the lived and living experience workforce. This 'standing with', allows the peak bodies to hear from and amplify the voices and perspectives of service users towards new policies and practices, in ways that are specific to their own spheres of influence while also, importantly, being potentially replicable. All the presentations are co-authored by and, where appropriate, presented by, lived and living experience colleagues.

Importantly, the peak bodies already have in place the infrastructure to share learning and expertise amongst themselves. This APSAD Presenter Symposium provides another forum for knowledge exchange, in the context of which APSAD attendees will be invited to ask about the dual experiences of peak bodies and their lived and living experience collaborators.