ATDC

CONSUMER ENGAGEMENT STRATEGY

PRELIMINARY REPORT

CONFERENCE WORKSHOP OUTCOMES

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ATDC

Tasmanian Institute of Law Enforcement Studies (TILES) is committed to excellence in law enforcement research. Collaborative research that links academics with practitioners is a hallmark of that research. The Institute focuses on four strategic priorities namely research, teaching, communication, and professionalism.

TILES Vision | To achieve an international reputation for excellence in law enforcement research.

TILES Mission | To conduct and promote evidence-based research to improve the quality of law enforcement and enhance community safety.

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ACKNOWLEDGEMENT OF COUNTRY

We acknowledge, with deep respect, the traditional owners of the lands on which we work and live.

The Tasmanian Institute of Law Enforcement Studies is sited on *lutruwita* (Tasmania) Aboriginal land, sea and waterways, and our scholars work across the lands of the *muwinina* people of *nipaluna* (Hobart), and the *palawa* peoples of *palanwina lurini kanamaluka* (Launceston) and *pataway* (Cradle Coast).

The muwinina and palawa peoples belong to the oldest continuing cultures in the world. They cared and protected Country for thousands of years. They knew this land, they lived on the land and they died on these lands.

We honour them.

We acknowledge that it is a privilege to stand on Country and walk in the footsteps of those before us. Beneath the mountains, along the river banks, among the gums and waterways that continue to run through the veins of the Tasmanian Aboriginal community.

We pay our respects to elders past and present and to the many Aboriginal people that did not make elder status and to the Tasmanian Aboriginal community that continue to care for Country.

We recognise a history of truth which acknowledges the impacts of invasion and colonisation upon Aboriginal people resulting in the forcible removal from their lands.

Our Island is deeply unique, with spectacular landscapes with our cities and towns surrounded by bushland, wilderness, mountain ranges and beaches.

We stand for a future that profoundly respects and acknowledges Aboriginal perspectives, culture, language and history. And a continued effort to fight for Aboriginal justice and rights paving the way for a strong future.

TABLE OF CONTENTS

ACRONYMS & DEFINITIONS

AOD	Alcohol and Other Drugs
ATDC	Alcohol Tobacco and Other Drugs Council
ATOD	Alcohol, Tobacco and Other Drugs
DEN	Drug Education Network
LE	Lived Experience(s)
LEA	Lived Experience Advocate(s)
LEPH	Law Enforcement and Public Health
NGO	Non-profit Organization
TILES	Tasmanian Institute of Law Enforcement Studies
UTAS	University of Tasmania

EXECUTIVE SUMMARY

Early 2021, the Alcohol, Tobacco and Other Drugs Council contracted the Tasmanian Institute of Law Enforcement Studies to evaluate its consumer projects. It was agreed that one of the first steps in the research was to scope out community expectations and thoughts about what consumer and community engagement should look like in the Tasmanian AOD sector, who should be involved, and the parameters of this involvement. As part of this initial exploration of the broader field and of the aspirations of the local sector, and before engaging in any fieldwork, the research team offered to organise a workshop at the 2021 ATDC conference, and to report on workshop discussions, as a way to provide community insights and advice to our research context and direction. This short report is the first deliverable, as part of this project: it documents and analyses the main themes raised during a preliminary scoping workshop, held at the biennial ATDC conference in 2021.

The workshop was called: "What should consumer and community engagement in the AOD sector look like? Considering better engagement practice with courage and confidence". Its rationale and logistics were to conduct a consultation of the broader AOD community, to identify priorities and areas of concern, as expressed by members of the AOD community themselves.

This short report provides a summary of the main themes raised at the workshop and sets them, as a preliminary and guiding exercise, against international engagement literature in the AOD field. Issues, concerns and recommendations made by those present at the workshop provided insight into the current climate of the AOD sector and which direction it could take. The 55 attendees came from a range of support services that were government funded and government affiliated, and from the broader community sector. The discussions revolved around how actors and stakeholders within the AOD sector had specific desires and requests that needed to be addressed. A running thread of this report is how the voice and representation of those with lived experience are invaluable to the AOD sector and to the ATDC as its peak body. In addition to voice, discussions essentially revolved around the positioning of lived experiences in the articulation of broader strategic directions for the sector, the acknowledgement (formal and informal) of those with lived experience, as well as related issues of organisational status and recognition. Further, barriers and obstacles to the involvement of those with lived experiences in decision making were specifically identified as: stigma; community, media and sector education, recognition, and workforce identity.

In this preliminary report, people with lived experience are presented as core, value-adding consultants for this research, as well as sector strategic direction advisers, and essential drivers for better recovery models, rehabilitation, and policymaking. To attest to this, the consumer representatives voice is woven throughout this document.

INTRODUCTION

Research brief

Early 2021, the ATDC sought to evaluate its consumer projects to:

1) establish a baseline understanding of current activities and achievements,
2) determine the impact of changes in these programs and identify what further changes are required, and
3) map the successes, strengths and opportunities for program innovation
4) explore current international arguments for and practices in the ongoing resourcing of consumer / community engagement, not only for the organisation, but also for across the AOD industry. This exploration will assess best practice world-wide on consumer / community engagement in the AOD sector, with an analysis of transferable elements across all identified models
5) explore what consumer and service providers want to see in an independent organisation dedicated to engagement and contrast this with international literature to determine the best fit for the Tasmanian AOD sector.

In answer to this, the Law Enforcement and Public Health (LEPH) team at the Tasmanian Institute of Law Enforcement Studies (TILES) offered an independent project brief for consideration. This short report is the first deliverable, as part of this project.

REPORT FOCUS

As part of the exploration of the broader field and of the sector, the research team offered to organise a workshop at the 2021 ATDC conference. The workshop was called: "What should consumer and community engagement in the AOD sector look like? Considering better engagement practice with courage and confidence". The rationale and logistics of the workshop were proposed as per the following abstract:

> Consumer and community engagement is broadly acknowledged as a necessary feature of the AOD sector. For the ATDC, consumer and community engagement is a crucial aspect of the sector's activities, which should urgently become 'business as usual'. While recommendations exist and support community engagement in the alcohol and other drugs sector, there is limited consistent framework that considers the specific, logistical and operational pathways to involve consumers and communities in local, organisational or policy decision-making.

This interactive workshop, which is part of a research project financed by the ATDC to improve community and consumer engagement, wants to seek the views from the audience as to how the AOD agencies can consider, with courage, the idea of better involving consumers and communities in all aspects of the sector's activities.

The workshop is held on the first day of the conference, in a room dedicated to this consultation, where conference attendees can come and be part of a structured discussion along the lines of:

- What does engagement currently look like in the AOD?
- What does the AOD sector should aspire to, in terms of engagement?
- What is missing?
- What should be done?
- What are consumers' wishes for engagement?
- What are agencies' wishes for engagement?

The workshops was conducted as a consultation of the broader AOD community, to identify some of the major themes that were to be explored in the research, as part of a community-led priority agenda. There was consideration to organise for 2 or 3 tables to be set up in the room, with a researcher from TILES conducting the discussion (in the same way focus groups would). However, the workshop proved more popular than initially thought, with in excess of 55 attendees. As a prompt reconsideration of logistics, it was agreed that 4 tables would be organised, with the research assistant at one table, the ATDC policy officer at another table, and the chief investigator as a 'floating' discussant across the two remaining tables. Round table discussions were held for 25 minutes, with each table reporting on these discussions to the broader group, followed by a forum brainstorming to conclude the workshop.

This short report provides a summary of the main themes raised at the workshop and sets them, as a preliminary and guiding exercise, against international engagement literature in the field. Issues, concerns and recommendations made by those present at the workshop provide insight into the current climate of the AOD sector and which direction it could take. The 55 attendees came from a range of support services that were government funded and government affiliated. This meant the discussions revolved around how actors and stakeholders within the AOD sector had specific desires and needs that needed to be addressed. A running thread of this literature review is how the voice and representation of those with lived experience are invaluable to the AOD sector and to the ATDC as its peak body. In this preliminary report, people with lived experience are presented as core consultants for not only this research, but also broader sector strategic direction, and essential drivers for better recovery models, rehabilitation, and policymaking. To attest this, the consumer representatives voice is woven throughout this report.

MAJOR THEMES ON CONSUMER ENGAGEMENT

The following will highlight the significant themes which emerged from the workshop discussions. While these were broad in scope and diverse in nature, only the most prominent themes shared across the workshop are discussed in detail. The larger backdrop of international practice and consumer engagement models will be documented and analysed in the literature review, subsequent to this report.

Lived experiences

The value of lived experience

A significant theme presented throughout the workshop from a range of participants was the essential role **people with lived experience** have for the AOD sector. “Lived experience” in this context refers to people who have had long term and temporal use of alcohol and other drugs which have, in varying capacity and times, affected their lives. Problematic substance use can impact daily life such as maintaining stable relationships and employment, access to health services, volatile mental and physical welling and can cause great financial strain (Leis and Rosenbloom, 2009). Recovering from substance use therefore, can interrelate with a number of social welfare issues such as employment, housing, and access to healthcare (Lowe and Gibson, 2011). To have lived experience is to have skills and strengths by which to introduce distinct, relevant knowledge that cannot be replicated through training or formal education alone. People who are at different stages of recovery carry a level of individual trauma, but also a deep sense of shared pain and a desire to support other people on their journey of recovery:

> ‘I've got a lot of experience three decades of, of stuff. So many insights, and so much knowledge and service, and you forget it all. But if you're in in that situation, and sharing and listening to other people, it just brings it all back, and you can help them navigate through their own journey’ (Consumer Rep 1).

Having someone who has lived with the problems agencies are aiming to alleviate can serve as an educational process for all levels of government and non-government organisations who lack reference points (Merritt et al., 2020). Those who have direct experience with these sectors as ‘consumers’ can see the cracks and pitfalls within policy and organizational structures which create hidden barriers to recovery. An absence of advisory body with lived experience representatives can provide reference to policy creators. Lived experience is now considered crucial for seeking feedback on policy implementation, workplace development and research opportunities (Byrne et al., 2013; Chapman et al., 2020; Lancaster et al., 2015). As put by one consumer representative during the workshop:

> ‘I think it's important for people with lived experience to have knowledge of the current services and the way the system runs. Now we're just trying to advocate for better outcomes for services and for the people accessing them’ (Consumer Rep 2).

The diverse wealth of knowledge that lived experiences can bring to the AOD sector is immeasurable, both from an organization standpoint and for the individual. However, the way for this to be structurally implemented and recognised, was a significant theme within the workshop. Many questions were raised during the workshop around how to harness those lived experiences effectively, how to embed people with lived experience within the sector (in something else than ‘customer’, ‘consumer’ or ‘client’ roles), and how services can engage actively with them. While some of these questions remain unanswered at this stage, it is the purpose of our research to bring informed responses from individuals and organisations, and set them against the backdrop of a broad evidence-base, which will be international in scope.

Positioning lived experience at every level of decision making

A suggestion was made to include people with lived experience at every level of the decision making within the AOD sector. Specifically, there was the general feeling that regardless of their position within the sector (paid or unpaid), people with lived experience are not fully considered or listened to, with some significant evidence of scarring by stigma at an individual level (by service providers, both in terms of access or as paid employers) and a societal level (media and stereotypes that affect policy and treatment).

Many workshop participants agreed with the idea that people with lived experience should be **included at every level of the AOD sector**. At every level of decision making, people with lived experience can provide insight into areas of policy, rehabilitation programs, initiatives and NGO-affiliated services that are otherwise, heavily influenced by shifting political and social attitudes towards substance use (Ritter et al., 2018). The inclusion of those with lived experience in every level of the AOD sector holds intrinsic value for the individuals who are able to contribute to ‘the big picture’ and further assist others. To neglect the insight and perspectives of those with lived experience can feel exclusionary and hurtful:

> ‘Why should they be in a separate group? Why aren't they just part of the organisation, on the governance on the staff in any other role? Why? Why are we separated?’ (Consumer Rep 4).

While this quote from the workshop gives a provoking representation of attitudinal (non-)acceptance issues in the sector, it is essential to note an important nuance on that point: the further discussions we had at the conference and with stakeholders indicate that about 50% of the current AOD workforce identify as having some level of lived AOD experience: whether their own, or within the family or close circle of friends. It is important to note that the nature of this exclusion might be about a lack of formal value recognition (rather than presence), and an insistence on acquired workforce skills (as opposed to the lived experience itself), or some reluctance to be too vocal about this experience. There is therefore a cultural element to the valuing of lived experience that warrants attention and analysis.

There was a strong wish to integrate those with lived experience into the AOD sector structures, **through both paid and unpaid volunteer positions.** The discussion broached on the topics of consistency in roles, opportunities for education and skill development and to address underlying stigma within the sector.

Paid employment for those with lived experience includes the discussion of implementation and integration of accredited certification or further education. For example, the Health Issues Centre Course in Consumer Leadership, is well reviewed online, and provides certification to attendees. Also, the Drug Education Network (DEN) have developed a comprehensive peer work program which aims to integrate peer workers into the Tasmanian workforce. The Alcohol Tobacco and Other Drug (ATOD) Peer Workforce Project, aims to equip workers with a range of skills such as active listening, trauma-informed practice, self-care and working with diverse people and teams. As of March 30, this program has had 9 successful graduates (The Drug Education Network, 2021). However, workshop participants were under the impression that this program still relies on volunteer time and dedication to compete the program, and does not lead to guaranteed employment or certification. The views expressed in the workshop suggested that educational programs and skill development must occur alongside paid employment that has a structured, accredited career pathway.

Providing dedicated, structured careers and educational pathways for both volunteer and paid positions needs to coincide with appropriate certification to ensure volunteers receive recognition and paid workers receive appropriate resources to build their career (Chapman et al., 2020). The integration of career pathways alongside the flexibility of volunteer roles can create more choice around the level of access for those with lived experience. Volunteers should be offered the same level of training and support which is given to paid staff, as it strengthens and motivates them (Marshall et al., 2015). The integration of certification provides a ‘safety net’ for workers in the recovery process who have otherwise been paid less for comparable work and who have less access to senior roles than their counterparts (White, 2009).

A representative from the ATDC indicated that their group had a discussion about what paid employment would look like, if positions were created (of note: while the issue of volunteering was acknowledged as relevant to the overall topic of consumer engagement, it was not raised specifically in the workshop). They suggested a number of elements would need to be considered, such as: what an acceptable salary rate would be, how time would be calculated and how this would impact on any other income:

> ‘We had a very interesting discussion on payment. How would consumer reps be paid? When? Why? What for? And how do you go about that? Noting that some people are claiming Centrelink, or other income support – this could cause some hassles for people’ (ATDC representative).

As emphasized by the World Health Organization (2019), deciding what pay rates are appropriate for peer support workers (including in a possible capacity as casual employees) is essential, as these rates must reflect the importance of specialised knowledge. Setting a rate of payment that is lower than other paid staff, for example, can convey the message that peer roles are not considered as valid or as important within the AOD sector (Legere, 2014). Having paid, accredited positions within the AOD sector for people with lived experience to build a career from, can help in rectifying current barriers and discrimination that was referred to in the workshop. More specifically, as one participant explained, when peer workers are discussing their client’s stage in their individual recovery process, their perspective is dismissed by health professionals who ‘pull rank’:

> ‘the [knowledge] consumer or the lived experience brings, tries to level out that authority, there's definitely a reaction of "Oh, actually, I’ve got the degree. Or I’m the practitioner. So yes, your experience is valid, but mine says that I am the professional authority"’ (Consumer Rep 3).

As this quote emphasises, when peer workers enter the workforce, they can find resistance from other healthcare workers. This is either due to ‘pulling rank’. Several workshop participants stated that there were inconsistencies in the sector (and outside the AOD sector) on what is considered ‘best practice’ on how to help those in the recovery process, particularly if an organisation holds a more traditional treatment-orientated model *in lieu* of a recovery-orientated model of care (Blash et al., 2015; Moran et al., 2013). As one workshop participated said, the core issue here, is the underlying stigma around what ‘kinds of knowledge’ are considered ‘valid’ or ‘valuable’ within health-based professions. This same participant framed this divide as discriminatory and patronizing:

> ‘that’s what's got to be addressed. The patronising approach to peer support workers. Peer support workers are just people the same as "clinicians", they just are’ (Consumer Rep, 5).

A solution, suggested by one consumer rep stated was to ‘look at the bigger picture’ which: ‘needs to value peer workers as much as professionals’ (Consumer Rep 2).

The inclusion of people with lived experience into every level of the AOD sector does not mean they are free from **stigma and discrimination** from the organizations they are assisting. However, as peer support workers and people with lived experience become more involved within all aspects of an organisation (i.e.: boards, committees, program development, etc), other staff gain more exposure and experience with people in recovery. Such knowledge exchange by osmosis can help staff overcome and dispel harmful stereotypes and myths about people with substance use issues which are chronically imbedded within how we approach health, policy reform and individuals themselves (Legere, 2014).

Reduction of stigma, greater education and integration and media awareness

Stigma and Discrimination

Stigma and discrimination are at every turn for those as different stages of their recovery process. Social exclusion, judgement and discrimination are experienced on a daily basis, from a range of different sources, ranging from family members, friends to the federal government (Leis and Rosenbloom, 2009). Stigmatization of those who use drugs manifests within communities through pervasive stereotypes, misinformation, and harmful attitudes about the nature of drug use. Stigma is considered a serious public health issue: it perpetuates prejudice and discrimination against individuals and affects structural responses to problematic drug use, such as criminalization, access to housing and appropriate healthcare (Leis and Rosenbloom, 2009; Paquette et al., 2018). It was no surprise that the most powerful theme throughout the workshop was addressing and reducing stigma towards people with lived experience. Possible avenues to achieve this, according to participants, included increasing education around problematic drug use and addressing misinformation or harmful images of those who use drugs within the media. The stories presented at the workshop re-affirm that stigma for those with lived experience starts from the very beginning of their recovery process, and is relived throughout their engagement with service providers.

Stigma, at its core, is comprised of a few interrelated elements: a lack of knowledge on complex health issues and barriers faced by those with lived experience, and expressing unhelpful attitudes that reinforce prejudice, stereotypes, and shame for clients. Stigma is then reinforced and perpetuated by service providers through ignorance of the recovery process, expressing prejudice views about drug use, which leads to discrimination (Thornicroft et al., 2007). We note that one of our participants indicated that there might be a distinction to make between the AOD sector workers, who are largely aware of stigma and seek to eliminate it, and those within other sectors who might still perpetuate this stigma do the factors we noted here. Discrimination that is (sometimes persistently) experienced by those with LE, alongside harmful stereotypes about drug use, can become internalised, evoking feelings of shame and can lead to isolation and relapse (Armstrong, 2017; Corrigan and Watson, 2002; Mohamed et al., 2021; Paquette et al., 2018).

There was string consensus during the workshop that practical strategies and education had to be designed for recognising, preventing and reducing stigma across all community and government sectors (see, also Kostadinov et al., 2018). The aim for such strategies is to reduce stigma for those accessing assistance for recovery, as well as address structural attitudes that reinforce discrimination, which is greatly felt by those working within the sector who are consumer representatives and peer support workers (Merritt et al., 2020). At a community level, AOD sectors and associated services should consider greater education to minimize stigma within their sector and to minimize internalisation of stigma by those seeking help (Mohamed et al., 2021). However, workshop participants emphasised that education needs to be heavily integrated with the media.

Media

The role of the media plays a significant part in reinforcing stereotypes. The portrayal of addiction and drug use are often depicted in media in a negative light, and is a historical direct and by product of the 'War on Drugs' discourse. This has powerful effects on the audiences' representations towards individuals who use drugs and how addiction is experienced in daily life (McGinty et al., 2019). Dramatized videos and images which focus on the harms of drug use alone, without any education on how the complexity of what is essentially a health-based issue, can lead to greater internalised shame and humiliation of people with substance use issues. As one representative emphasised:

> 'this is what is missing in harm reduction is stigma - education, integration, and also the work is being done in media as well, their [use of] language'.

For example, news articles focus on the rates of overdose to emphasise a 'drug crisis' without taking the time to address misconceptions around how or why this occurs, is 'missing the mark'. "Drug scare journalism" just reinforces drug use as a private, shameful problem, and upholds harmful and inaccurate stereotypes that skew public perception on what recovery 'looks like' (Stuart, 2019). This includes media that share stories of hope and success of for those seeking to recover from problematic drug use.

In terms of 'what can be done' about the role of the media, stories which emphasise the steps of recovery in a hopeful light may **reduce stigma, self-blame, potential relapse**. Vignette portrayals of people living with addiction who have accessed support services elicit significantly more positive attitudes towards drug use, reduce social intolerance and discrimination in comparison to without. Not only do these kinds of stories model recovery as a possibility, they provide viewers with hope for people who are living with problematic substance use and for those who treat them (Chan et al., 2019; Engel et al., 2020; Paquette et al., 2018; Stuart, 2019). To widely reduce stigma in the media, journalists and other media producers should consider undertaking some form of cultural awareness training which informs how their influence can influence the public's perception of drug use, stigmatization, and discrimination, including steering away from stereotypes and harmful, stigmatizing language (McGinty et al., 2019). There are already some efforts underway to work with the media more effectively and constructively.

Terminology and Language between clients and lived experience

In the drug and alcohol sector, what is considered 'best practice' for how to refer to people with lived experience is a persistent talking point. There are therapeutic and historically loaded terminology and stigma surrounding **language** and the use of labels. For example, stigma surrounding 'relapse' as being synonymous with 'failure' (Gallagher et al., 2017) and a client's refusal to describe oneself as 'addict' or 'alcoholic' indicated that they were in denial or was resisting treatment (Quinn et al., 2004). Due to the meaning inferred by these labels, language such as this has been considered a tool that reinforces stigma, shame and can contribute to dehumanizing clients (Gallagher et al., 2017).

However, those who engage in treatment services and programs for alcohol and other drugs may refer to themselves as 'addicts' or having an 'addiction', which may feel appropriate for their identity or progress (Patil Vishwanath et al., 2019). When people use terms 'addict', 'problematic use' or 'drug dependence' as a means to describe their relationship with substance use and how they perceive these labels, it can give providers a deeply nuanced perception on how clients view themselves and their motivation for change. To deny all stigmatising language would be to deny critical insight into the nature of client's recovery process (Gray, 2010). Within the workshop, it was made clear that any labels should be self-proscribed if clients feel this is helpful for them. As one community support worker emphasised, 'best practice' was steering away from loaded terminology or labels but: 'sometimes people really identify with the word "addict", and that's really powerful to them' (Consumer Rep 3). We note that since the conference, the ATDC has moved towards the adoption of the expression 'lived experience advocates' (LEAs) to refer to consumer representatives.

The use of language is a highly contested contextual terrain, and a fast moving issue. However, fearing to lessen associated stigma by 'steering away' from terminology that is powerful for those using the label, simply reinforces stigma and judgement from service providers (Gallagher et al., 2017). Similarly as Gray (2010) emphasises, those who work in the AOD sector can reinforce stigma around the recovery process if they apply their own labels to clients, such as positioning them in binary or competing categories, such as 'addicts' or 'sober' clients. These dichotomous labels do not fully capture the recovery process, or the hardships associated by clients.

Recognition

Members of the workshop reiterated that quite often, their lived experience feels in opposition to the general public, politicians, policy makers and service providers. One peer support worker stated:

> 'I know it's a concern of mine that **tokenism** [and] politicians, they…stigmatise that consumer rep and their lived experience. And sometimes they see it as a personal attack' (Consumer Rep 5).

As Ritter et al. (2018) emphasise, the general public and politicians are regularly asked to provide their opinion on drug legislation and regulation, without any firsthand experience. This can skew or mislead government decisions and to make policy responses for the wider community, not those who are most directly affected by drug policies (Stuart, 2019). This further separates people with lived experience from the community, making any involvement within policy to feel inauthentic or tokenistic (Marshall et al., 2015). One participant stated this 'tokenism' can be from hearing but not really 'listening' to peer support workers and their client needs:

> 'Not everybody has felt like [they have] had an influence. So people kind of get weary of doing the consultations and spending more time to give their opinion, but then it has no perceivable impact… What actually happens with those opinions? Do minutes get taken and feedback doesn't get passed up onto the board? Who are the decision makers? – People take time to talk [but] they don't really listen. it's being tokenistic' (Participant, 1)

'Tokenism' was a word used by a few people at the workshop, but one consumer representative used another, more descriptive word to describe their experience: resistance. The AOD sector could integrate a watertight structure in which to authentically include and listen to those with lived experience, but if those with lived experience do not feel supported, more shame and stigma emerges. For example:

> 'It seems that in the AOD sector, the existing staff can see the inclusion of people who have recently been treated by them into the service into the system as possibly more of a challenge - a problem to be to be concerned about - rather than something exciting and new, that's going to add benefits' (Consumer Rep, 1)

Viewing people with lived experience as a potential challenge illustrates how co-workers can feel hesitant about the role of those with lived experience within the sector and how this affects their work (White, 2009). The World Health Organization (2019) emphasises that peer supporters have reliance, stability and a strong commitment to their own recovery. They should be provided with the same benefits and discretion as other employees in managing their health issues, particularly as there is no evidence that employability leads to relapse. It has been suggested that purposeful, stable employment can assist in ongoing recovery, because of the intrinsic value it holds and should not be considered a potential cause for relapse (Chan et al., 2019). Instead of viewing people with lived experience as 'potentially problematic', another participant emphasised that instead, peer support workers just require consistent, ongoing, and specific support that acknowledges and respects their hardships alongside their situated knowledge:

> 'Let's support them as a sector. As a grounding force behind them, to say: you guys, we're gonna champion with you and behind you. But also, we recognise that chaos has been your theme song for a lot of years. Let's help you navigate how that still affects you right now' (Consumer Rep 3).

As discussed here, having people with lived experience involved with the AOD sector is important but needs to be handled with consideration, care and appropriate support to avoid further stigmatization. Without this, people with lived experience can be included in areas of service delivery, policy information, panels and development of new models of care, but they are grounded in fragile foundations and still have some way to go (Byrne et al., 2013). **Visible impact and recognition are required for those with lived experience to feel supported and valued.**

One consumer representative relayed their recent experience working with a program that aims to facilitate recovery from several angles (such as providing housing, reconnecting family relationships and group counselling). To be involved in the process of this program was deeply fulfilling for them: 'being able to bring something to the actual process of developing roles, and being part of a co-design process, it's very meaningful for me, and others I'm sure for those that are involved.' They then continued to explain how the peer support had developed in terms of a collective focus as well as one-on-one supervision:

> We have weekly supervision sessions [at the program], where we were talking about where we're going afterwards. What's been happening as a group, and also with one-on-one supervision. So, you know, we have opportunities to create all sorts of things that we can bring to the peer support role. That's pretty exciting'.

This example illustrates that meaningful action through co-design is possible and can be implemented well if the support networks in place are appropriately integrating peer support roles.

Trauma-informed care and person-centric recovery

Listening, learning, and being guided by people with lived experience was not a single theme, but it extended across multiple levels of care. For example, a number of practitioners and peer support workers discussed how their engagement with those in recovery required a more person-centric approach. Whether recovery was framed as a 'cycle' or a 'journey', the steps to recovery needed to be guided and directed by those seeking help and can be facilitated by support workers:

> I never assume that I know what that person needs or the direction that you think [recovery] should go in. And we always started out by saying: what do you need? What kind of support do you need from me? And that person drives the process entirely from that.

This was echoed by a peer support worker encouraged support services to adapt **trauma-informed care and practices**:

> ‘Through trauma informed care, there's always the questions of: what's your thoughts? What's your current direction? Lets co-create this together’.

Another peer support worker emphasised that this approach to recovery gives people the ability to feel listened to and to engage with support services easier:

> To express what I want or what I need or talk about the shit they’ve been through - people need to understand the impact of giving someone that voice has. Once you've done that, in most cases, we have opened up the front door for them. People want to be heard and it has much more of an impact then people expect [rather than] someone asking a question to simply tick a box.

Person-centric and trauma-informed care include recognising the impact of underlying trauma to develop intuitive and flexible recovery plans that are informed and directed by the people seeking help themselves. A number of participants at the workshop emphasised that recovery needs to be approached from a health-based model. Support should be offered through positive social relationship between those seeking help and peer support workers first and foremost. This is with recognition that each individual accessing support services require a mixture of assistance and may approach their recovery with their own personal goals, unique needs, strengths and barriers (Patil Vishwanath et al., 2019).

However, our review of literature indicates that working with people with lived experience, and engaging them in sustained forms of employment or support work needs to be done carefully, and with knowledge of how such work can re-traumatise, and re-engage them into cycles of use.

Cycles of recovery

There were some deep conversations about the level of accessibility of some services for people who require prompt care, or for those who choose to access a particular type of services as per their individual circumstances. Services should seek to either adapt and fit with **cycles of recovery** or have services that are ready to go, as opposed to long waiting periods (providers need to offer other options in interim treatment periods. I.e.: rehab). Policy development and implementation need to be structured with enough flexibility to provide reliable access to treatment and malleable enough to be consistent with the cycle of recovery. A person with lived experience emphasised:

> When you want to engage with the service and get help, often you will be told, you've got a one or three month wait and we are missing really critical times where we could intervene and help people... Because often by the time the day comes around and rehabs ready, they're on a different stage of that cycle.

Any policy making decisions should reflect this recovery cycle and process which can have variations of readiness and instability. Those who worked within the justice rehabilitation programs emphasised that they were awkwardly positioned between government mandated actions and feeling that they are unable to adapt to the cycle of recovery. This was most evident when one worker in this sector emphasised that their client's specific needs were silenced:

> I feel like to a large degree, the voices of the people that I work with probably are a bit silenced, because the treatment is being done to them in a lot of ways...I would hope is, you know, client-centred and personal focus and all those sorts of thing... but realistically looking at it. The other option [for them, is sobriety] or prison.

The wider social and political climate can also fluctuate accessibility to needs and services, which means policy development should consider strong structural integration between areas such as welfare, health services and housing to breach gaps and cover any interrelated issues (Roberts, 2014). Whilst abstinence from substance use is a significant part of the recovery process, this alone is not sufficient because 'successful' recovery is multidimensional and requires ongoing commitment and external support (Costello et al., 2020).

Independent consumer engagement body

As participants in the workshop started to engage with these ideas more broadly, there was general consensus that perhaps integration into the current AOD structure was not appropriate (note: models will be discussed in the literature review). Whilst most conversations discussed the need for **support services to be more integrated**, an alternative idea was to pull away and create a self-determined, 'grassroots' style **independent body**, which was structured by, and for, people with lived experience. What this may 'look like' was discussed, including highlighting existing barriers for recovery and crisis intervention, ongoing support, and what currently works well.

What was made clear, was that an independent body should be considered a 'central hub' for holistic, health-based programs to originate and be backed by the AOD sector. The 'hub' could provide ongoing evidence, analysis and recommendations on current and emerging issues, and act in an advocacy role towards AOD agencies. This, in turn, would allow those services to change and adapt depending on the needs of those seeking assistance, and new trends in evidence-base practice. A reason for this was the scattered availability of peer support workers and isolated programs across the AOD sector:

> Having a separate organisation as a group of peers in control of that organisation, that other organisations can go to for consumer input. I think it would make a lot more sense than having all these individuals in different organisations and there are peer workers in different organisations… It would be great for an organization such as that to have a role in developing peer support staff. Our aim needs to be for peers to play a greater role.

People in support roles can feel a sense of dispersed responsibility and role confusion, where programs and approaches to recovery appear in different spaces and offered by different organisations. Responses indicated that a body which functions as a referral service which is ran and operated by peer support workers was recommended (it was referred to as a consolidation exercise). Others believed this would run into further barriers and structural issues. One person stated they understood why an independent body is wanted, but did not consider this to be the 'end product' but a service which is integrated within the AOD sector more broadly. Regardless, one representative framed this as a means of creating unity, where community members can feel empowered:

> I think, as we unite, we feel stronger, we feel empowered by each other, and we support each other. And I think that there's a place for [people with lived experience] within every organisation and on all boards and in all types of places [but] an 'independent organisation' would be better suited, especially if other states have this.' (Consumer Rep 2).

Shared empowerment and person-centric care would be foundation of the independent organization. It was clear from the workshop that positive relationships with others was crucial for connecting peer support workers with people seeing help. Supervision, group-work and regular meetings for those with lived experience were all referenced as playing an important role in their recovery. This is reflective in research which suggests that positive relationships with peers, loved ones and co-workers are considered one of the strongest motivations for people to commit to and sustain lives without problematic substance use (Chan et al., 2019). This is with recognition that appropriate security and safety measures for peer support workers need to be in place, such as clear boundaries set between clients and peer support workers, no matter how the independent body is structured (Forchuk et al., 2020). Whilst there were concerns about how a separate organisation would run structurally and how it could be positioned alongside or within the AOD sector, one consumer representative stated whilst we are having these discussions we can hold 'two truths'. One is, that an independent organization should be 'ran by the people, for the people’, but the other truth is that to do this appropriately, they need special support and care:

> What we're speaking about is an independent consumer organisation. And it needs to come from the people, by the people. People with a history of substance use, all that tragedy, trauma and chaos, [still make them] just like everyone else. They're more than capable. They are resilient. [However], sometimes they need special care, special support, special encouragement.

As seen here, there are a number of considerations and concerns raised when discussing the notion of an independent body. Yet, what emerged within these considerations, were equally fascinating and exciting ideas and perspectives that viewed this idea as holding powerful potential. An underlying theme throughout this topic was the important role of relatability and shared understanding about the turbulence of recovery. One consumer representative suggested that for a peak body to work meaningfully, however, it must learn from existing support structures and models that are currently working well in other Australian states and territories. These will be explored throughout our research.

CONCLUSION AND NEXT STEPS

This short report provides a summary of the main themes raised at the 2021 ATDC conference community engagement workshop. The themes were outlined and then set against international engagement literature in the AOD field. Issues, concerns and recommendations made by those present at the workshop provided insight into the current climate of the AOD sector and which direction it could take. There is a clear consensus that people with lived experience are of crucial value to the sector and to shaping out the broader strategic directions that need to be considered by agencies in the future.

However, while the value brought by people with lived experience is acknowledged, there are structural and attitudinal issues that remain obstacles to the positioning of lived experiences in the articulation of broader strategic directions for the sector. The acknowledgement (formal and informal) of those with lived experience requires cultural and attitudinal change for some, and the related issues of organisational status and recognition have some consequence in terms of workplace agreements, as well as for the creation of an independent body that would be solely dedicated to consumer engagement.

Education seems to be an essential component of such cultural change, with strong views being voiced as to how consumer representatives and those with lived experience could be fully integrated within structures that have historically refused them their place.

In addition to a formal literature review on the topic of consumer engagement in the AOD sector, the research team will now proceed with the empirical portion of the research brief[1], which consists of talking to sector representatives and consumers (peer workers, essentially) about consumer engagement policy and practice. The themes that will raised in focus groups and interviews will heavily borrow from literature on the topic, but also on the initial insight received from the community. International models for consumer advocacy will also be documented in the literature review, and discussed in interviews and focus groups, in order to inform a series of recommendations which will be made by the research team at the end of this project.

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[1] Full ethics approval has been sought and granted for this empirical work by the University of Tasmania's Human Research Ethics Committee (**Project ID: 26464**; **Project Title: ATDC Consumer Engagement Strategy**)

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