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Alcohol, Tobacco and other Drugs Council Tasmania Inc.

Submission to the review of the Tasmanian Opioid Pharmacotherapy Program

February 2018

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The Alcohol, Tobacco and other Drugs Council

The Alcohol, Tobacco and other Drugs Council Tas Inc. (ATDC) is the peak body representing the interests of community sector organisations (CSOs) that provide services to people with substance use issues in Tasmania. We are a membership based, independent, not-for-profit and incorporated organisation.

The ATDC is the key body advocating for adequate systemic support and funding for the delivery of evidence based alcohol, tobacco and other drug (ATOD) initiatives. We support workforce development through training, policy and development projects with, and on behalf of, the sector.

We represent a broad range of service providers and individuals working in prevention, promotion, early intervention, treatment, case management, research and harm reduction. We are underpinned by the principle of harm minimisation, which aims to improve public health, social inclusion and co-morbid illness outcomes, for individuals and communities.

We play a vital role in assisting the Tasmanian Government to achieve its aims of preventing and reducing harms associated with the use of alcohol, tobacco and other drugs in the Tasmanian community.

In scope/out of scope of this submission

The ATDC supports the provision of pharmacotherapy as a key harm reduction intervention that seeks to reduce drug related harm in the Tasmanian community.

This submission advances the perspective of Tasmanian Opioid Pharmacotherapy Program (TOPP) service user as well as encompasses the practice wisdom of those who work with people with ATOD issues in the community sector in Tasmania. We are providing feedback on how the TOPP system works as well as how the TOPP service user fares within that system.

Out of scope for this submission is a detailed look at clinical guidelines, apart from those that necessarily include psycho social supports, ethical issues as well as information on how to work with the system. We understand the risk to consumers from opioids but we also understand the risk to consumers if a model of service is not responsive to their health needs.

Submission process

The ATDC extended an invitation to all of its members to contribute to this submission. The ATDC met with the Tasmanian Users Health and Support League (TUHSL) on two occasions, and examined written materials from TOPP service users. A meeting with the Southern Manager of the Alcohol and Drug Service provided context to the conversations with consumers. Information from the consultations was then used in concert with research and evidence to develop the following submission. A draft submission was sent to ATDC members for feedback that was subsequently incorporated in this document. TUHSL supported the material expressed in this submission.

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Our submission

We have three key points:

1. Re-balance the program: the TOPP becomes a person-centred program that is safe, accessible and equitable which enables people to become stable and improve their health.
2. Organisations and workforce: we must address the ongoing challenges.
3. Addressing stigma and discrimination.

1. Re-balance the program: the TOPP becomes a person-centred program that is safe, accessible and equitable which enables people to become stable and improve their health.

The ATDC has heard a range of opinions on the TOPP:

(Currently) it's a 'one-size-fits-all' punishment based system, where everyone is assumed to be guilty of doing the wrong thing within the program[1]

It works in some ways from a risk management point of view - ADS hasn't had someone overdose in a long time[2]

- Person centred care[3] places the users of the service at the centre. It assumes that health care providers will show respect to the person receiving care. It sees people who use the service as having a role to play in planning, developing and monitoring aspects of any health program. Person centred care also requires a holistic approach to care, encompassing family and friends[4] as support as well as recognising the individuality of each client presentation. The ATDC has heard feedback that that the TOPP does not employ a person centred approach currently, with the examples of little flexibility around aspects such as take away dosing alongside the structural workforce issues that mean consumers have restricted choice in health care providers or community dosing points as well as inadequate access to appropriate psycho-social supports. As one worker in the Tasmanian community services sector said:

[1] TOPP service user.
[2] Tasmanian ATOD worker.
[3] "Person-centred care is a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome". Health Innovation Network, *What is person-centred care and why is it important*, accessed from http://www.hin-southlondon.org/system/ckeditor_assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf on 2/8/2017
[4] Social supports affect treatment outcomes. Cooper, S & Neilsen, S., 2016, 'Stigma and Social Support in Pharmaceutical Opioid Treatment Populations: a scoping review', *International Journal of Mental Health Addiction*, November.

TOPP does not treat each person and their particular situation in an individual way. Sometimes a person needs to have greater flexibility or different options but most of the time this is not looked into.[5]

- Consumer input is recognised as a fundamental component of an accountable and effective health system.[6] Engagement with consumers ensures that those with a lived experience are able to influence and participate. The review of the TOPP is a key opportunity to build in meaningful consumer involvement across the span of the program; at the planning, service delivery and continuous reflection levels.

- Ritter et. al. has described five roles of consumer participation and how it can support treatment.[7] These include: creating treatment access and entry points, developing client complaints services, provision of peer-based treatment interventions, advocating for better treatment policies and workforce development (capacity building).

- Meaningful input from consumers will add value to the program and lead to greater responsiveness to consumer need. It is the ATDC's view that this aspect of the program is one of the most urgent areas that must be addressed.

Nothing about us, without us.[8]

- The development of the capacity of the Tasmanian Users Health and Support League (TUHSL) to undertake some of the consumer participation functions should be part of the wider service system reform processes currently occurring. TUHSL has recently undertaken governance training and continues to build capacity and momentum towards representing ATOD service consumers. However the TOPP should include a consumer participation strategy or plan that describes and maps areas of need as well as details a plan of action moving forward which includes measurable outcomes.

- The ATDC supports the idea of examining whether a peer worker model could work within the TOPP. Peer workers put the client at the centre of the program and could act as conduits between TOPP staff and service users as well as provide linkages to the wider health system.

- The ATDC has also heard that the policy around take-away doses requires further flexibility and a person-centred approach. Once a person has demonstrated stability and appropriate use of medication within the guidelines, then access to take-aways beyond what is currently provided should be available. The ability to

[5] Tasmanian ATOD worker.
[6] Duckett, S., & Willcox, S. (2011). *The Australian Health Care System* (4th ed.). South Melbourne: Oxford University Press, Victorian Auditor-General. (2012). *Consumer Participation in the Health System*. Melbourne: Victorian Government.
[7] Ritter, A, et. Al. *New Horizons: the review of alcohol and other drug treatment services in Australia*, p 351, accessed online 21/1/2018, found here: https://ndarc.med.unsw.edu.au/resource/new-horizons-review-alcohol-and-other-drug-treatment-services-australia
[8] This is a slogan used by marginalised groups to communicate the idea that policy should have the direct participation of the member(s) of the group(s) affected by that policy.

travel or engage in employment away from home is currently very limited for consumers because of the inflexibility available with take away doses.

2. Organisations and workforce: we must address the ongoing challenges

> *…short 'script periods (two - four weeks) and endless repetitive appointments with case workers. I had approximately eight case workers in a two to three year period while a client of ADS at St Johns Park. Retelling my story every time. The TOPP goes on about 'treatment care teams" and "holistic care" plus pharmacy members becoming part of your treatment experience. Again, not in my experience.*[9]

- There is up to four organisations/individuals that need to work together in order to ensure that TOPP achieves the desired health outcomes for one consumer. These organisations include: Alcohol and Drug Service (DHHS), Pharmaceutical Services Branch (DHHS), Community Pharmacies and GPs. This means that each part of the TOPP needs to be working effectively; a deficit in one area will put pressure on other areas or has the potential to undermine the program as a whole (e.g a lack of GP prescribers results in consumers travelling distances that are prohibitive to holding down employment which occurs in regular office hours and restricts choice of health care providers).

- A shortage of GPs who are 'AOD friendly' and willing to prescribe pharmacotherapy as well as limited options in community pharmacists dispensing the medication are two areas which require long term strategies. According to stakeholders, GP and Pharmacy shortages are most pronounced in the north west of Tasmania. Such structural issues limit choice of, and access to, health care providers for consumers.

- In the interests of greater provision of holistic care; greater focus on psycho-social supports around the TOPP service user is needed. For example, relapse prevention initiatives should be identified and incorporated within the TOPP. Connections, communication and understanding between Alcohol and Drug Service (ADS) staff and CSO staff could be improved. The ATDC could work in partnership with the ADS to facilitate biennial information sessions for CSOs to learn about how the TOPP works. To provide holistic care, connections within and external to the ATOD service system are vital. CSO staff reports of increasing complexity (ATOD issues in concert with other issues such as mental health, housing, justice, employment etc.) in a portion of ATOD client presentations increases the need for greater knowledge in some areas such as mental health as well as greater connections with other service providers in order to manage the competing issues. If issues, such as housing, are not identified then addressing an ATOD issue becomes harder. This is an area of interest to the CSO sector and one which we can add value and input into the new TOPP. Moreover, there is an opportunity to look at new ways to work together and examine innovative partnerships with community organisations to support clients while engaged with the TOPP.

[9] TOPP service user.

- The current *Policy and Clinical Practice Standards* document could be improved to strengthen the program. We have received feedback that the document was difficult to work with. A new set of information materials, tailored to meet the needs of different stakeholders (e.g consumers and their families and friends, clinicians, pharmacists and GPs) would enable the program to work more effectively. TOPP service consumers need a discrete document that outlines issues around ethics and confidentiality, program guidelines, roles and responsibilities and feedback processes. One example with regard to ethical issues is TOPP service users' need to be clearly informed about monitoring conducted by the Pharmaceutical Branch of DHHS. It is logical that this section of the guidelines is written in consultation with, or even partly by, consumers.

- The ATDC has also heard that there is unmet demand for opioid substitution treatment and would welcome further investment and treatment places for those in the community that need it.

- There are other aspects of the wider service system and how the TOPP interacts within it whereby risk to the TOPP service user could be lessened. For example: better integration between the Alcohol and Drug Service and the Tasmanian Prison Service is warranted, greater follow-up of terminated patients due to the high risk of overdose are two examples. There are opportunities for partnerships with CSOs for face to face support for service users and also providing harm reduction and support information for family and friends and other organisations.

3. <u>Addressing stigma and discrimination.</u>

- Perhaps the underlying issue that needs addressing is the stigma attached to drug use generally and then the discrimination for consumers that results. Discrimination, and subsequently, different treatment of people who use drugs can come from many sources; such as a person's social support network and also from health care providers. The relationship between TOPP service users and health care providers (ADS staff, other health/social support providers, GPs, Pharmacists) is influential in treatment outcomes.[10]

> *Qualitative interviews of people in treatment for opioid dependence in the US found that 30% of respondents reported stigma from family or friends, with parents the most common source. Some participants said their parents saw them as untrustworthy, and believed that people that used drugs were 'irresponsible' and 'liked to party'. Additionally 20% of participants reported stigma from employers or co-workers, again referring to being seen as untrustworthy. Another qualitative study US study found mistrust concerning opioid dependent people by some family physicians, preferring they attended special drug clinics instead.*[11]

[10] Anstice, S., Strike, C., & Brands B., 2009, 'Supervised methadone consumption: client issues and stigma, *Substance Use & Misuse*, 44:6, pp794-808.
[11] Cooper, S & Neilsen, S., 2016, 'Stigma and Social Support in Pharmaceutical Opioid Treatment Populations: a scoping review', *International Journal of Mental Health Addiction*, November

> *Stigma surrounding (pharmaceutical opioid) dependence may present a barrier to pain relief… people dependent on PO who request further pain relief may be seen as drug seeking, leading to mistrust, poor communication and under treatment.*[12]

- Stigma can also be internalised:

> *US qualitative interviews of people in (opioid substitution treatment) for heroin use revealed that drug dependence was seen as a 'moral shortcoming', with clients viewing themselves as, "not quite junkie, not quite conventional".*[13]

- The stigmatisation of people who use alcohol and other drugs is widely recognised as reducing access to, and affecting the efficacy of, health care and treatment seeking. Cooper & Neilsen have noted that *"…stigma is one important barrier to treatment entry…"*.[14]

- While there has been progression in addressing stigma in the mental health sector, stigma towards ATOD consumers continues.

> *We, along with paedophiles and terrorists, are one of the few sections of society it is almost universally acceptable to discriminate against and stigmatise publicly"*[15]

- Meaningful consumer input into the TOPP is one mechanism that could identify and address stigma and discrimination towards TOPP service users.

> *This is something ATOD consumer perspectives play a key role in countering, by supporting engagement with the treatment system and actively representing the interests of their marginalised constituents in health care and policy settings.*[16]

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[12] Esqyuibel, A., & Borkan, J., 2014, 'Doctors and patients in pain: conflict and collaboration in opioid prescription in primary care, *Pain*, 155, pp2575-2582.
[13] Murphy, S., & Irwin, J, 1992, 'Living with the dirty secret": problems of disclosure for methadone maintenance clients, *Journal of Psychoactive Drugs*, 24:3, pp257-264.
[14] Cooper, S & Neilsen, S., 2016, 'Stigma and Social Support in Pharmaceutical Opioid Treatment Populations: a scoping review', *International Journal of Mental Health Addiction*, November.
[15] Crawford, S., 2013, Shouting through the bullet-proof glass: some reflections on pharmacotherapy provision in one Australian clinic, *International Journal of Drug Policy*, 24:6.
[16] Ritter et al, 2014, New Horizons: The review of alcohol and other drug treatment services in Australia, National Drug and Alcohol Research Centre, UNSW, p350. Accessed online on 22/11/2016, found here: https://www.health.gov.au/internet/main/publishing.nsf/Content/699E0778E3450B0ACA257BF0001B7540/$File/The-review-of-alcohol-and-other-drug-treatment-services-in-Australia.pdf

- Studies have shown a link between language and stigma.[17] Language that describes drug use and the consumer in the Clinical Guidelines also needs to be reviewed for contributing to stigma and discrimination.

- Of further concern, is the widespread apathy, reported in one study, of non drug users toward drug users regarding stigma and discrimination with many participants viewing discrimination towards drug users as "not a serious problem" (63%) as opposed to findings for mental illness (38%).

- The ATDC supports the full involvement of consumers in the TOPP review process and into the future. Consumers are the only ones who can tell us how the system operates, if it meets their needs and what could change. Every attempt must be made to garner meaningful input in this review.

[17] Fischer, B., Chin, A., Kuo, I, Kirst, M., & Vlahov, D., 2002, 'Canadian illicit opiate users' views on methadone and other opiate prescription treatment: an exploratory qualitative study', *Substance Use and Misuse*, 37:4, pp495-522, Gidman, W., & Coomber, R., 2014, 'Contested space in pharmacy: public attitudes to pharmacy harm reduction services in the west of Scotland, *Research in Social & Administrative Pharmacy*, 10:3, pp576-587, Harris, J., & McElrath, K., 2012, 'Methadone as social control: institutionalized stigma and the prospect of recovery', *Qualitative Health Research*, 22:6, pp810-826.

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