The Unintended Consequences of Pharmacotherapy Policy in Tasmania

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Your Rights – Your Say

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Background
Advocacy Tasmania Inc. (ATI) is an independent, non-government organisation that provides ‘your say’ advocacy to older persons, people with a disability, people with mental health disorders and people with drug and alcohol issues. ATI acknowledges that people are experts in themselves and that all individuals have an inherent right to autonomy. ATI respects the fact that as a non-drug user organisation it does not hold an authoritative voice on the issues that affect people who use drugs (PWUD). However, in the absence of a funded drug user organisation in Tasmania and in light of the numerous issues raised with us by service users, we are obligated to contribute to the systemic advocacy efforts to improve service user input on these issues. We hope that this paper will assist in the push towards meaningful involvement of people who use drugs (MIPWUD) in service provision in our state.

The language used in this paper is deliberate and considered, and the author offers the following clarifications:

- **Opioid substitution therapy**: There are a number of terms currently being used in the sector including opioid substitution therapy, pharmacotherapy, and medically assisted treatment. The author chose to use opioid substitution therapy when referring to the legal prescribing of opioids for the treatment of dependence as it is a purely descriptive term and eliminates any perceived value-laden assumptions.

- **Service User**: As this paper is discussing a policy document that relates to a particular service the author felt service user was the most accurate term to describe individuals who are using or may potentially use opioid substitution therapy.

- **Patient**: The term patient is used a selected number of times through the document when referring to a clinical relationship that extends beyond the specific service provision being discussed in the paper.

- **People who use drugs** (PWUD): A review of relevant literature highlighted that this term rather than the previously used term ‘drug user’ makes it clear that PWUD are not defined by their drug use, rather it is only one element of who they are as people.

**Introduction**
Since the inception of the Alcohol, Tobacco and Other Drugs program at ATI four years ago, service users have expressed ongoing concern regarding the impact of opioid substitution therapy policy in Tasmania. The Tasmanian Opioid Pharmacotherapy Program Policy and Clinical Practice Standards (TOPP) is unapologetically risk focused and conservative.¹ Justification for this approach has always been the profile and demographic of Tasmanians who use drugs and the way it differs to mainland service users. Tasmania has a very low availability of heroin which has resulted in a significant increase in prescription opioid misuse over the last twelve years. There are also higher levels of opioid related harms in Tasmanians who use drugs when compared to the rest of Australia.²

It is not the intention of this paper to deny the impact of opioid related harm on the Tasmanian community, nor to dispute the clinical validity of the TOPP. Rather, the paper will argue that recognising individuality and providing opportunities for meaningful input of people who use drugs (MIPWUD) into policy, is critical to treatment success. It will explore the development and implementation of the TOPP to date and how it is being experienced by service users. It will draw from a research survey conducted in 2013 by ATIs Consumer Engagement Project. This paper will claim that the negative language of the TOPP, combined with the ambiguity as to its authority, has decreased its effectiveness, irrespective of its clinical validity. It will posit that a proactive approach to integrating service user input into future policy review and development will significantly improve the effectiveness of the TOPP and the experience for Tasmanian service users. It will then make a number of recommendations as to how this can be achieved.

Tasmanian Policy in a National Context

Drug policy is a complex and multifaceted area. It requires a number of factors to be fully considered in order to be truly effective. It is this view that “drug use is influenced by a complex interaction of physical, social and economic factors”³ which underpins the harm minimisation framework used in Australian National policy. This is further explained in the aims of the National Pharmaceutical Drug Misuse Framework for Action which has a stated aim not only to reduce misuse but to “enhance the quality use of pharmaceutical drugs without stigmatisation or limiting their accessibility for therapeutic use”.⁴ As aforementioned, the TOPP, whilst referring to harm minimisation as an underpinning concept, is a particularly conservative document that focuses on risk and harms. However, if the objective of policy is only to mitigate harm it is arguably lacking in vision. As a community we should not aim as low as to merely reduce the harms arising from drug misuse. We should look to also increase the positive contributions people who use drugs (PWUD)

¹ Alcohol and Drug Services Tasmania (ADS), Tasmanian Opioid Pharmacotherapy Program: Policy and Clinical Practice Standards (Hobart: Tasmanian Government Department of Health and Human Services, May 2012), 10
² For more information on the history of opioids in Tasmania and the Tasmanian opioid consumer profile see National Drug and Alcohol Research Centre, Report: A Review of Opioid Prescribing in Tasmania A Blueprint for the Future (Sydney: University of New South Wales, 2012)
are able to make as members of society, increasing overall social, financial and human capital for the individual and the community as a whole.

The language used when writing policy plays a significant role in the nature of its subsequent implementation. A recent review by ATI of the various state and national guidelines for opioid substitution therapy in Australia revealed some significant differences in the language used. Arguably these differences have contributed to the varying experiences reported by Tasmanian service users.\(^5\) This paper is limited in its ability to comment on the implementation of the policies and guidelines of other states and relies on the assumption they are implemented in line with the available documentation.

As aforementioned, whilst there are some clinical variations across states these differences and the evidence surrounding them are not the subject of this paper. This paper concerns itself with the policy documentation and the need for meaningful involvement of people who use drugs when developing and implementing these policies.

All states express clearly in their policy documentation that opioid substitution therapy is evidence based and of benefit to individuals who are opioid dependant. All states outline in their policies and guidelines that opioid substitution therapy should be based on supervised dosing as the default position. There is also agreement that there are significant clinical and social risks involved in providing opioid substitution therapy. It is when you look at the way these risks are presented that significant differences begin to appear.

The majority of states use positive language when discussing both risk and potential service users. The gravity of the risk is acknowledged, but the practical implementation of the program is discussed in terms of increasing and rewarding protective factors. Most jurisdictions focus on how to balance the risk to ensure the program results in increased functioning of service users and the associated increased benefits for the community as a whole. The tone of the TOPP is very different with numerous pages reiterating the clinical risks to patient and community and very little focus on the practical implementation of the program in the context of improved social and community functioning. Service users themselves are often portrayed in such a way that one could be led to believe they are all likely to fail at their treatment should the program introduce elements of flexible delivery.\(^6\)

Conversely, the language of other jurisdictions rightfully humanises potential service users and acknowledges their individuality. Queensland, Victoria and NSW go as far as to discussing the barriers that individuals may face in positively engaging with the program, both psychological and practical, and how these may be addressed to encourage participation. Significant focus is given to the necessity of the therapeutic relationship and the building of mutual trust in order to retain service users in treatment. Take away dosing, for example, is not described as a privilege but as a reinforcement of positive engagement and recognition of increased protective factors. It is equally

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\(^5\) ATI records data on all individual advocacy issues for which support is provided. ATI staff have also collected anecdotal evidence from a broader cohort of consumers and conducted a telephone survey of Tasmanian Pharmacotherapy consumers. Reports from consumers across all three sources have supported and informed the position being taken in this paper.

acknowledged that should the risk be too great or the individual circumstances change, fully supervised dosing should be reinstated immediately. The TOPP acknowledges some barriers faced by Tasmanian service users such as transport and access but does not extend this into program flexibility to address such barriers.

Further to this and in line with the National Pharmacotherapy Policy all states, including Tasmania, claim that the primary aim of opioid substitution therapy is to reduce or cease illicit drug use. Again differences are highlighted in the language that follows. Other states discuss levels of risk associated with polydrug use and acknowledge that polydrug use is likely to occur in a number of service users and is not automatically in and of itself a risk that justifies increased restriction or exit from the program. Acknowledgement is given to the need for consideration of the types of drugs being used and whether the use itself is ‘problematic’. The TOPP uses language and provides direction that suggests any polydrug use, irrespective of the context, will result in exclusion due to associated risk. There is no significant section of the policy that mitigates this hard line approach with ways to support service users to reduce their polydrug use and engage more positively with the treatment. This approach does not foster honesty in the relationship between service user and clinician and is more likely to lead to the perception currently being expressed by service users that the treatment program centres on punishment.

Interpretation by clinicians has done little to dispel this belief as they too often seem unclear as to their authority or ability to manage patients who are opioid dependent or on opioid substitution therapy. As well as the negative language relating to service users and risk used in the TOPP, there is ambiguity as to the level of authority of the document. Again language has played an important role in this area. Despite verbal assurance that the TOPP is meant as a standard and guideline only, the language does not reflect this. Constant use of the term ‘must’ rather than ‘should’ leaves the impression that the instructions which follow are mandatory. This is further reinforced by regular references to the need to consult with Alcohol and Drug Services, often implying that patient management in this area is too high risk for any other practitioner to attempt. Experienced private practitioners are left unsure as to when they are permitted to use their own clinical judgement and those without experience are often fearful to provide any service to patients who require Schedule 8 medication. The widespread confusion over where the TOPPs authority began and ended was raised in a recent review of Pharmaceutical Service Branch decisions by the Tasmanian Ombudsman. This resulted in a recommendation from the Ombudsman’s office that “DHHS takes steps to make sure that ADS runs its pharmacotherapy program in accordance with s 59E, and that consideration also be given to the appropriateness of continuing to administer that program under the current legislation.” This issue was being addressed at the time of writing this paper, however,

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7 ADS, Tasmanian Opioid Pharmacotherapy Program: Policy and Clinical Practice Standards (Hobart: Tasmanian Government Department of Health and Human Services, May 2012), 29
8 Intergovernmental Committee on Drugs, National Pharmacotherapy Policy (Australian Government, January 2007), 12
9 Based on opinions of private practitioners expressed to ATI staff in the course of individual advocacy work since April 2010
10 Ombudsman Tasmania, Investigation into the administration of s59E of the Poisons Act 1971 by the Pharmaceutical Services Branch of the Department of Health and Human Services (Hobart: Ombudsman Tasmania, March 2013)
11 Ibid, 27
it supports the information being provided by service users that the TOPP document has contributed to both the confusion and the culture of fear amongst service users and prescribers alike.

It needs to be acknowledged that it was not the intention of the TOPP to be based on punishment. In fact the Opioid Review states clearly that the Tasmanian approach was not intended to be punitive.\textsuperscript{12} It is also likely that in practice there is evidence of flexibility for some service users. However, the negative language used combined with the ambiguity regarding the level of authority of the document has effected implementation and led to this perception. To date the experiences of a number of Tasmanian service users have been unnecessarily negative.

The National Drug Misuse Framework points to the need to reduce stigma and discrimination for ATOD service users. This begins with the language we use in policy and ultimately ends in the way service users feel about treatment and other services. When the implementation of a policy results in those who are directly affected feeling marginalised and punished it is not likely to be effective in achieving its objectives, nor does it contribute to the ultimate goal of reducing stigma and discrimination experienced by ATOD service users. The use of inclusive and non judgemental language in policy will logically extend to inclusive and non judgemental practice in operation. Service user input into policy would help ensure effective and contemporary language was being utilised.

**The Tasmanian Experience**

It is this aspect of meaningful input of people who use drugs, in the absence of a funded, service user led organisation in Tasmania, which has been arguably lacking. There was a level of consultation prior to the implementation of the TOPP which was contributed to both directly by service users and by ATI based on the experiences shared by its current and past service users.\textsuperscript{13}

The key messages were:

- The language used was too proscriptive and likely to be interpreted by clinicians as mandated, reducing flexibility of practice.
- The lack of a holistic approach and acknowledgement of individual circumstances was likely to lead to increased harms to service users as their involvement in the opioid substitution program could actually reduce their community involvement and overall functionality.

Unfortunately, no apparent changes were made to either the document or the implementation process, and both issues appear to have had the predicted negative impact on service users. The failure to adequately gather, acknowledge and incorporate service user feedback resulted in a tokenistic process that contributed to a feeling of disempowerment and disengagement for service users.

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\textsuperscript{12} National Drug and Alcohol Research Centre, *Report: A Review of Opioid Prescribing in Tasmania A Blueprint for the Future* (Sydney: University of New South Wales, 2012), 79

\textsuperscript{13} ATI were given a short period of time to gather service user feedback on the proposed TOPP document. In this time ATI compiled a report based on interviews with 18 service users. Further information was submitted based on the observations of ATI staff throughout their individual advocacy work over the preceding two years.
This message from services users of a sense of paternalism, that they feel is directly related to Tasmanian Opioid and Pharmacotherapy Policy, has been repeatedly and consistently reinforced to ATI via a number of channels. This has included the content of statewide referrals, the issues raised by service users via the intake process and the information provided by other Community Service Organisations on their clients behalf. The nature and consistency of this concern led to ATI’s Consumer Engagement Project conducting a survey to gather a more coherent picture of the concerns of Tasmanian service users.

A qualitative survey was conducted with current opioid substitution therapy service users on their experience of the TOPP’s implementation. The impacts reported by survey participants included increase in risk taking behaviour, defined as increased poly drug use and illicit use, in attempts to mitigate the impact of prescription changes or take away dose restrictions. Participants also reported negative social, physical and psychological impacts. These included concerns around inadequate pain management and a lack of an individualised treatment approach. A number of participants also raised concerns that the stigma associated with opioid substitution therapy in Tasmania negatively affected their ability to contribute to society through employment and study. These impacts, identified by service users, highlight the potential for opioid substitution therapy to operate in contradiction to its aim of increased functionality for people who use drugs, if the needs of the service user are not adequately considered in implementation. There was little to no direct impact on service delivery noted, with the majority of issues in this area\textsuperscript{14} predating the TOPP.

The additional themes noted in the research were perhaps the most interesting as these centred on the service users perceptions of the TOPP and its implementation. Common themes were the feeling that the system was punitive and lacked incentive for positive behaviour change or engagement in treatment. Service users reported a lack of trust in the therapeutic relationship and a feeling that their service provider saw them as less than human. Fear, stigma and discrimination and a lack of consultation or information provision also featured strongly in participant responses. There were also a number of service users who contacted ATI to explain that they would like to participate in the survey but felt that they could not as their fear of retribution was so strong.

The survey acknowledges a number of limitations, including participant numbers and a lack of ability to draw statistically significant conclusions from the data. However, it does put forward the experiences of a number of individuals and provides further evidence that the service user experience needs to be meaningfully acknowledged in further policy development in this area\textsuperscript{15}.

The Necessity of the Service User Voice

Service user input or consumer engagement can no longer be dismissed as a new concept. It is no longer accepted as best practice to ignore the fact that people are experts in themselves. It is well embedded in numerous areas of health care with the majority of service users not just expecting it

\textsuperscript{14} The key issues here were around staffing, an important aspect that has been openly acknowledged by ADS as a barrier to effective service delivery in the ATOD sector.

but demanding it. Its benefits have shown to extend to the service users, service providers and the community as a whole.

A study conducted by the Development Research Centre on Citizenship, Participation and Accountability (Citizenship DRC) over a period of ten years, looked at citizen participation at a political level on an international scale.\(^{16}\) Whilst this is obviously a significantly larger cohort than the Tasmanian community, many of the findings hold relevance for the improvement of service user input in the ATOD sector. One of the key concepts outlined in the report was the importance of seeing people not in a role prescribed to them by social structures and institutions but as individual actor/agents with the drive and knowledge to shape relevant policy. The research found that meaningful involvement positively impacted service development and increased a sense of inclusion.\(^{17}\) It also found that participation can be equally disempowering if it is tokenistic and disingenuous.\(^{18}\)

These global scale findings are being mirrored in the research being done in the ATOD sector. The Australian Injecting and Illicit Drug Users League (AIVL)’s “Trackmarks” Project detailed the positive impact that drug user organisations have had on Australian Drug Policy.\(^{19}\) The Tasmanian experience was an unfortunate exclusion from this project as Tasmania remains without a funded drug user organisation to support PWUD and contribute to policy development. The recent re-establishment of the Tasmanian Users’ Health and Support League (TUHSL) will hopefully start to address this gap.

Numerous barriers to participation are discussed in Teresa Hinton’s “Voices on Choices” report. These include the diversity of the groups and needs of people who use drugs, the illicit nature of drug use preventing a willingness of service users or potential service users to speak up, the stigma and discrimination associated with identifying as a person who uses drugs and the fear of treatment refusal or withdrawal.\(^{20}\) However, the report goes on to look at numerous successes in the United Kingdom and lessons that can be learnt to further service user input in Tasmania. It is clear from the research to date that whilst service user input is not without its challenges it remains critical to effective and sustainable policy and treatment in the ATOD sector. If nothing else, as stated in “Nothing About Us Without Us”, there is an ethical imperative to meaningfully involve individuals who are going to be affected by policies and treatment practices.\(^{21}\)

**Summary**

The integration of service user input with ATOD policy has been traditionally lacking. Recent implementation of Tasmania’s key policy document, the TOPP, has led to a number of concerns for service users. The language used, combined with the increased restrictions, has reportedly effected...
therapeutic relationships and arguably led to increased risks for service users. Service user input has numerous benefits for service users, service providers and the community as a whole. It has been effective in supporting positive policy development across the health sector an there is no reason to believe it can not have the same impact on the ATOD sector if implemented in a meaningful and comprehensive way.

It is not the belief of ATI that ADS have deliberately excluded service users from policy development. Rather the lack of a drug user organisation, combined with a historically medicalised model of drug treatment, has meant that progress in this area has been slow. However, the recent revival of TUHSL and the formation of a Consumer Reference Group through ATI provide Tasmanian policy makers with an unprecedent opportunity for inclusive policy development in the ATOD sector. As highlighted in the aforementioned Blurring the Boundaries report, if rights based movements were only about maintaining existing rights, they would only service to reinforce the status quo and society would be without the many positive changes we have collectively achieved.  

With a concentrated effort Tasmania can take itself from ‘ground zero’ in consumer engagement to a national leader in meaningful involvement of people who use drugs.

22 Citizenship DRC, Blurring the Boundaries: Citizen Action Across States and Societies (Brighton: Citizenship DRC, 2011), 15
23 Hinton, T, Voices on Choices: working towards consumer-led alcohol and drug treatment (Hobart: Social Action and Research Centre Anglicare Tasmania, 2010), 10
Recommendation 1:
That the scheduled 2014 review of the TOPP include meaningful service user input with an established feedback mechanism to ensure that service users who do contribute are informed on any changes made as a result of the information they provide or, conversely, the reasons for not making recommended changes.

Recommendation 2:
That further service user surveys are conducted with a particular focus on including responses from those groups who were not represented in ATIs most recent survey (ie rural residents and people who inject drugs (PWID)).

Recommendation 3:
That ADS consult with an established drug user organisation on establishing a robust methodology for both gathering and using service user input into the policy and implementation of treatment services for opioid substitution therapy in Tasmania.

Recommendation 4:
That ADS consult with an established drug user organisation to develop an embedded service user input policy that will allow ongoing service user input into policy and service delivery.

Recommendation 5:
That the Tasmanian government provide recurrent funding for a drug user organisation in Tasmania to enable it to effectively support people who use drugs in Tasmania and to contribute to policy and treatment issues that affect the people it represents.
Bibliography


Ombudsman Tasmania. *Investigation into the administration of s59E of the Poisons Act 1971 by the Pharmaceutical Services Branch of the Department of Health and Human Services*. Hobart: Ombudsman Tasmania, March 2013