



Submission to the Royal Commission into Victoria's Mental Health System:

Support for people living with HIV

5 July 2019

Living Positive Victoria

Living Positive Victoria is a not for profit, community-based organisation representing all people living with HIV in Victoria since 1988. It is committed to the advancement of human rights and wellbeing of all people living with HIV. The organisation offers a wide variety of peer led services to both inform and connect people living with HIV. Living Positive Victoria also advocates for the rights of all people living with HIV through law reform as well as challenging stigma and discrimination.

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Thorne Harbour Health

Thorne Harbour Health is one of Australia's largest community-controlled health service providers for people living with HIV and the lesbian, gay, bisexual, trans and gender diverse, and intersex (LGBTI) communities. Its services include general practice, health promotion, counselling, family violence, housing support, and alcohol and other drug rehabilitation and harm reduction programs. Thorne Harbour Health primarily serves the populations of Victoria and South Australia, but also leads national projects. Thorne Harbour Health works to protect and promote the health and human rights of LGBTI people and all people living with HIV.

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Positive Women Victoria

PWV provides support, information and advocacy for women in Victoria living with HIV. For over thirty years PWV has responded to the changing needs of women living with HIV, recognising the impact gender has on the way women experience HIV and addressing the specific needs and emerging issues that affect women living with HIV in Victoria.

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1. Introduction

Living Positive Victoria, Thorne Harbour Health, and Positive Women Victoria welcome the opportunity to contribute to the Royal Commission into Victoria's Mental Health System, and would like to thank the Australian Research Centre in Sex, Health and Society for providing feedback and endorsing this submission.

While this submission deals in detail with mental health concerns for people living with HIV, we would like to begin by putting the submission in context. It is clear that Victoria's mental health system is beset by some significant structural and funding issues that affect service delivery and outcomes, with specific groups within the community more vulnerable to these shortcomings. Key areas of concern include:

- A lack of policy and systems compliance consistency between local, state, and federal levels of government;
- Patchy and inconsistent access and referral pathways to reliable evidence-based drug and alcohol services, including rehabilitation programs, particularly from general practice;
- A need to make mental health services physically and culturally safe and welcoming places for vulnerable and marginalised populations of people, including people living with HIV;
- A need for services that address the health and mental wellbeing of people who may not have access to services because of their immigration, visa or refugee status;
- Coordination of patient pathways and the patient journey; and
- A need to ensure that compliance with privacy legislation does not become a reason for poor coordination of care, by funding and encouraging services to invest in technologies that allow services to share patient information while safeguarding privacy.

A long history of constructive community action and government collaboration has made significant progress in the fight against the human immunodeficiency virus (HIV). Advances in biomedical treatment have made it possible to suppress HIV and prevent its progression to acquired immunodeficiency syndrome (AIDS), indeed they have made it possible for people living with HIV to live a normal lifespan, and to achieve an undetectable viral load, preventing the onward transmission of HIV.

Despite these advances, significant gaps in HIV care continue to exist. In particular, the mental health burden experienced by people living with HIV has a significant impact on individual and public health, as it affects every major aspect of the HIV response.

In 2017, there were an estimated 26,444 people living with HIV in Australia,¹ and that number has increased since then. Many people living with HIV experience poor mental

¹ Australian Federation of Aids Organisations (AFAO), 'HIV in Australia, 2019', AFAO (Web Document) <https://www.afao.org.au/wp-content/uploads/2018/12/HIV-in-Australia-2019_No-Bleed.pdf>

health outcomes, and evidence indicates a complex and bi-directional relationship between poor mental health and living with HIV.²

The Victorian and Commonwealth governments have committed to goals that are consistent with UNAIDS' 90-90-90 goals. Specifically, that by 2020, 90% of all people living with HIV will know their status; 90% of those diagnosed with HIV will be on treatment; and 90% of those on treatment will have an undetectable viral load.

One of the hurdles in achieving and maintaining our current goals is the mental health of people living with HIV. People with mental health issues are at an increased risk of acquiring HIV, and people living with HIV can have poorer mental health outcomes than the general population due to the anxiety and depression that can be associated with the condition itself and/or the stigma and discrimination they experience as a result of their HIV status.

Key to improving the mental health of people living with HIV is combatting HIV-related stigma and discrimination, which are strongly correlated with poor mental health outcomes.³ Also necessary is the appropriate integration of evidence-based interventions and community-controlled HIV mental health and wraparound support services. This will address gaps in the HIV care continuum, and yield positive service delivery outcomes. It is essential that people living with HIV, or those who may be at risk of contracting HIV, are able to access person-centred, respectful and confidential mental health support when required.

Our organisations remain available to provide further evidence, consultation and testimony to support the efforts of the Royal Commission, as required.

² Fiona Leh Hoon Chuah et al, 'Interventions and approaches to integrating HIV and mental health services: a systematic review' (2007) 32 *Health and Policy Planning* 27.

³ Jason Appleby, 'HIV, mental health and stigma: a brief survey of current research' (2013) 11(2) *HIV Australia* 17.

2. Summary of recommendations

1. Invest in population-wide, community-controlled HIV awareness and anti-stigma campaigns to tackle HIV related stigma and discrimination.
2. Build on progress made with the repeal of section 19A of the *Crimes Act 1958 (Vic)*, and end other forms of HIV criminalisation that continue to hinder the HIV response in Victoria and stigmatise Victorians living with HIV.
3. Invest in program support to ensure that all health care workers have the skills to provide culturally safe and competent services for people from diverse communities, including understanding the specific needs of people living with HIV.
4. Develop and implement an intersectionality framework to identify multiple risks and disadvantages experienced by people with poor mental health, HIV status and other intersecting minority positions, and address barriers to inclusion through an integrated policy framework and associated organisational toolkits.
5. Endorse the proven mixed-model of mental health service provision that includes both mainstream and community-controlled HIV mental health and wraparound support services, and prioritise community-controlled services.
6. Increase ongoing funding for wraparound community-controlled HIV support services.
7. Endorse community-controlled vocational service providers that are capable of assisting people living with HIV assess employment-related risks, facilitate pathways and skill development, and address underlying barriers to employment through integrated service provision.
8. Increase funding for HIV peer support and navigation programs to allow for greater capacity, coverage and diversity.
9. Increase ongoing funding for community-controlled HIV organisations to provide alcohol and other drug services.
10. Increase ongoing funding for home care services for people living with HIV.
11. Fund the co-design of new, and expansion of existing, community-controlled family counselling, peer education programs, and other support services for families of people living with HIV to build stronger communication and relationships within families.

3. Mental health experiences of people living with HIV

3.1. Rates of mental health conditions

People living with HIV have higher rates of mental illness than the general population.^{4,5,6} Anxiety and depression are associated with the HIV diagnosis itself, as well as with stigma and discrimination that can occur as a result of one's HIV status. Relationship difficulties, sexual exclusion and violence, issues with self-esteem, and anxiety disorders can present at key moments during the lifetime of someone living with HIV. This includes at the time of diagnosis of an opportunistic infection or AIDS defining illness, a declining CD4 count (cells that are killed by HIV) or transient viral increase ('blip') or any other reminder of ongoing HIV infection.⁷

3.1.1. Suicidal Ideation

The stigma and discrimination experienced by people living with HIV can cause them to become withdrawn and isolate themselves. This is especially true for people living with HIV at vulnerable intersections, such as immigrants, men who have sex with men, people without familial connection and support, people with pre-existing mental health conditions, and people experiencing intimate partner violence.

While it is known that people living with HIV experiencing isolation can lead to suicidal ideation,⁸ there is little available research about suicide rates of people living with HIV. It is possible that these rates have changed over time along with changes in the health and social impacts of HIV. Many risk factors for suicide are factors that are common in the lives of people living with HIV, including social isolation and marginalisation, chronic illness, depression and anxiety, unemployment or financial vulnerability, drug and alcohol use, and social stigma.⁹

⁴ Jennifer Power et al, 'HIV Futures 8: Health and Wellbeing of People Living with HIV' (The Australian Research Centre in Sex, Health & Society, La Trobe University: Melbourne, 2016) <https://www.latrobe.edu.au/_data/assets/pdf_file/0006/766896/HIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf>

⁵ Wendy Heywood and Anthony Lyons, 'HIV and elevated mental health problems: diagnostic, treatment, and risk patterns for symptoms of depression, anxiety, and stress in a national community-based cohort of gay men living with HIV' (2016) 20(8) *AIDS and Behavior* 1632.

⁶ Anthony Lyons et al, 'Factors related to positive mental health in a stigmatized minority: An investigation of older gay men' (2013) 25(7) *Journal of Aging and Health* 1159.

⁷ 'HIV and anxiety fact sheet', *American Psychiatric Association* (Web Page) <www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources>.

⁸ Brian Kelly et al, 'Suicidal ideation, suicide attempts, and HIV infection' (1998) 39(5) *Psychosomatics* 405; Nina A Cooperman & Jane M Simoni, 'Suicidal ideation and attempted suicide among women living with HIV/AIDS' (2005) 28(2) *Journal of Behavioral Medicine* 149.

⁹ Kelly, B., Raphael, B., Judd, F., Perdices, M., Kernutt, G., Burnett, P., ... & Burrows, G. (1998). Suicidal ideation, suicide attempts, and HIV infection. *Psychosomatics*, 39(5), 405-415; Cooperman, N. A., & Simoni, J. M. (2005). Suicidal ideation and attempted suicide among women living with HIV/AIDS. *Journal of Behavioral Medicine*, 28(2), 149-156.

3.2. Psychological side effects of antiretroviral medication

Some medications used to treat HIV can have side effects that cause anxiety, depression and other psychological symptoms.¹⁰ There are potentially severe pharmacokinetic and pharmacodynamic interactions between HIV antiretroviral medication and psychotropic medications. There are specific contraindications to the use of some antipsychotic medications when protease inhibitors are prescribed as treatment for HIV. Drug interactions must be considered and monitored carefully when using psychopharmacotherapy in people living with HIV.¹¹

3.3. Impact of mental health conditions

People living with HIV who also have a serious mental illness are less likely to adhere to antiretroviral medication.¹² Adherence to medication is important for both personal and community health. A low viral load is important for a person living with HIV to keep control of the virus and maintain a healthy immune system. It also affects the cognitive abilities of people living with HIV.¹³ Also, a person with an undetectable viral load is not able to pass on HIV.^{14,15} For these reasons, adherence to medication and suppressing the viral load in people living with HIV increases their mental health and quality of life.¹⁶

A person's health impacts their ability to enter the workforce and engage in sustained work; being asymptomatic or having an undetectable viral load are positively associated with successful labour force participation, and a strong sense of personal identity can also have facilitative effects for employment.¹⁷

¹⁰ American Psychiatric Association (n 7).

¹¹ Ibid.

¹² Buckingham E, Schrage E, Cournos F. 2013. Why the treatment of mental disorders is an important component of HIV prevention among people who inject drugs. *Advances in Preventive Medicine* 2013: 690386; Jeffrey S Gonzalez et al, 'Depression and HIV treatment nonadherence' (2011) *Journal of Acquired Immune Deficiency Syndromes*, online edition. DOI:10.1097/QAI.0bo13e31822d490a

¹³ Chang, L., Ernst, T., Witt, M. D., Ames, N., Gaiefsky, M., & Miller, E. (2002). Relationships among brain metabolites, cognitive function, and viral loads in antiretroviral-naive HIV patients. *Neuroimage*, 17(3), 1638-1648.

¹⁴ Rodger A. *Association between sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy: the PARTNER study*. 21st International AIDS Conference, Durban, abstract TUAC0206, 2016.

¹⁵ Rodger A et al. *Risk of HIV transmission through condomless sex in gay couples with suppressive ART: the PARTNER2 study expanded results in gay men*. 22nd International AIDS Conference, Amsterdam, abstract WEAX0104LB, 2018.

¹⁶ Grace, D., Chown, S. A., Kwag, M., Steinberg, M., Lim, E., & Gilbert, M. (2015). Becoming "undetectable": Longitudinal narratives of gay men's sex lives after a recent HIV diagnosis. *AIDS Education and Prevention*, 27(4), 333-349.

¹⁷ Catherine Worthington et al, 'Enhancing labour force participation for people living with HIV: a multi-perspective summary of the research evidence' (2012) 16 *AIDS and Behavior* 231.

3.4. Neurocognitive comorbidities

It is important to consider neuropsychiatric conditions when assessing anxiety and depression in people living with HIV, particularly HIV-associated neurocognitive disorders.¹⁸ In Australia, an estimated 7% of people living with HIV are affected by HIV-associated dementia (the most severe of the HIV-associated neurocognitive disorders) while 30% are affected by a HIV-associated neurocognitive disorder.¹⁹ Age, co-infection with hepatitis, methamphetamine use and a family history of dementia all increase the risk of people living with HIV developing a neurocognitive disorder.²⁰ Since the advent of highly active anti-retroviral therapy, and with a larger HIV positive population living longer, the incidence of HIV-associated dementia has fallen; however, its prevalence has increased.²¹

3.5. AIDS Survivor Syndrome

While the advent of effective medication for people living with HIV has greatly improved their quality of life, it has also created unique stressors on their mental health. The US-based Multicenter AIDS Cohort Study (MACS)²² has investigated AIDS Survivor Syndrome and how it affects people who have lived through the HIV epidemic, prior to the development of highly effective antiretroviral therapies. As of 2013, the average age of people in the study was 56, and roughly half of the men surveyed (49%) were living with HIV. More than a quarter (27%) of men in the study had lost more than 10 people close to them to AIDS. Thirty-five percent of men reported that they “still grieve” for these lost people, 7% of men reported that they “still deeply grieve,” and 3% reported that they “grieve these losses nearly every day.”²³

3.6. The Lazarus effect

Another side effect to the improved quality of life brought on by effective treatment for HIV is the Lazarus effect. Prior to the development of effective treatment, many people living with HIV lived their lives as if they were about to die; for example, by selling off assets and spending life savings.²⁴ Once effective treatments drastically increased the quality and longevity of the lives of people living with HIV, many who considered themselves terminally ill never fully recovered financially. These financial pressures add to all the other mental pressures which surround living with HIV, leading not only to poverty but also significant anxiety and depression. This has been seen anecdotally through the peer navigator program at Living Positive Victoria.

¹⁸ American Psychiatric Association (n 7); ‘Help Sheet 19: HIV associated dementia’, *Alzheimer’s Australia* (Web Document) <https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia19-HIVAssociatedDementia_english.pdf>

¹⁹ Ibid.

²⁰ ‘HIV and cognitive disorders fact sheet’, *American Psychiatric Association* (Web Page) <www.psychiatry.org/psychiatrists/practice/professional-interests/hiv-psychiatry/resources>

²¹ ‘What once was old is new again: the re-emergence of HIV-associated dementia’ (2009) 7 *HIV Australia* 20.

²² Roger Detels et al, ‘The multicenter AIDS cohort study, 1983 to...’ (2012) 126(3) *Public health* 196.

²³ Emily Land, ‘What is AIDS Survivor Syndrome?’, *San Francisco Aids Foundation* (Web Page) <<https://www.sfaf.org/collections/beta/what-is-aids-survivor-syndrome/>>

²⁴ Stephen Klotz et al, ‘HIV Infection-Associated Frailty: The Solution for Now Is Antiretroviral Drugs: A Perspective’ (2019) 18 *Journal of the International Association of Providers of AIDS Care* 1.

4. Prevention

4.1. Combatting stigma and discrimination

The *Victorian HIV Strategy 2017-2020* commits Victoria to the ambitious goal of eliminating HIV stigma and discrimination by 2030.²⁵

Stigma and discrimination are a large contributor to poor mental health outcomes for people living with HIV.²⁶ Stigma can prevent people from disclosing their HIV status and obtaining the support, treatment and care they need.²⁷

While stigma is external to the individual, stigma becomes internalised and is often deeply diminishing to the person who experiences it.²⁸ Both external and internal stigma influence the mental and physical wellbeing of people living with HIV.²⁹ Stigma merely has to be perceived for it to have a significant impact on a person's mental health,^{30, 31} and has been directly linked to depression.³²

4.1.1. Awareness and anti-stigma campaigns

Educational initiatives and community-controlled anti-stigma campaigns can combat HIV stigma, raise awareness, and build resilience in communities. Thorne Harbour Health's HIV Still Matters and Treat HIV Now, and Living Positive Victoria's U=U campaigns have raised awareness of HIV, contributing to HIV prevention and anti-stigma efforts. However, there exists a need for a dedicated, population-wide, community-controlled HIV anti-stigma campaign if Victoria is to make headway in achieving its ambitious goal of eliminating HIV-related stigma and discrimination. It is essential that any such campaign be based on the principles of the meaningful involvement of people living with and affected by HIV.

²⁵ 'Ending the AIDS Epidemic by 2030', Fast-track Cities, (Web Page) <www.fast-trackcities.org/cities/victoria>

²⁶ Sean Slavin et al, 'The HIV stigma audit: community report' (National Association of People Living With HIV/AIDS, National Centre in HIV Social Research) <http://napwha.org.au/files/napwa_stigma_audit_report.pdf>

²⁷ James Dennis Fortenberry D et al, 'Relationships of stigma and shame to gonorrhoea and HIV screening' (2002) 92(3) *American Journal of Public Health* 378.

²⁸ Elaine Brohan et al, 'Experiences of mental illness stigma, prejudice and discrimination: a review of measures' (2010) *BMC Health Services Research*.

²⁹ Peter Vanable et al, 'Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women' (2006) 10(5) *AIDS and Behavior* 473.

³⁰ 'Beyondblue Information Paper: Stigma and discrimination associated with depression and anxiety', *BeyondBlue* (Web Document) <<https://www.beyondblue.org.au/docs/default-source/policy-submissions/stigma-and-discrimination-associated-with-depression-and-anxiety.pdf>>

³¹ Anthony Lyons et al, 'Psychosocial factors associated with resilience in a national community-based cohort of Australian gay men living with HIV' (2016) 20(8) *AIDS and Behavior* 1658.

³² Mary R Tanney et al, 'Depression and stigma in high risk youth living with HIV (YLH): A Multisite Study' (2012) *Journal of Pediatric Health Care* 26(4) 300; Michael Young et al, 'Interpersonal Discrimination and the Health of Illicit Drug Users' (2005) 31(3) *American Journal of Drug and Alcohol Abuse* 371.

Recommendation 1

Invest in population-wide, community-controlled HIV awareness and anti-stigma campaigns to tackle HIV related stigma and discrimination.

4.1.2. End legislative discrimination

In 2015, Victoria repealed section 19A of the *Crimes Act 19589* (Vic), which specifically criminalised the intentional transmission of HIV, labelling it an “outdated, discriminatory law” that was the only offence of its kind in Australia to single out people living with HIV.³³ However, people living with HIV can still face criminal charges for reckless HIV transmission, as well as reckless endangerment in cases where no such transmission or transmission risk occurs.

These laws do not take into account recent biomedical advances in HIV prevention. There is a need to clarify what constitutes ‘reasonable precautions’ taken to prevent the transmission of HIV, as reasonable precautions are not limited to condom use. Scientific evidence supports that a sustained *undetectable* viral load means HIV is *untransmittable* (U=U), and partners without HIV can protect themselves using pre-exposure prophylaxis (PrEP). Indeed, it has been demonstrated that an undetectable viral load is the most powerful HIV prevention method available.³⁴ It is not reckless for people living with HIV to have sex without a condom if other reasonable precautions (such as adherence to treatment and the maintenance of an undetectable viral load) to reduce the risk of HIV transmission have been taken.

The *Sex Work Act 1994* (Vic) prohibits people living with HIV from working as sex workers.³⁵ This discriminatory law is in breach of the right to non-discrimination, and fails to recognise both that sex workers have high rates of condom use, and that people with a sustained undetectable viral load cannot transmit HIV.

Based on evidence from the national HIV Stigma Indicators Project that many health care workers admit to having treated patients differently based on their HIV status. There is a need to ensure health care workers are adequately trained to provide culturally safe services to people from diverse communities, including people living with HIV and their specific needs.

³³ ‘Another Step Toward Equality for People Living with HIV’, *Premier of Victoria* (Web page) <<https://www.premier.vic.gov.au/another-step-toward-equality-for-people-living-with-hiv-2/>>

³⁴ Alison Rodger et al, ‘Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study’ (2019) 383(10189) *The Lancet* 2428.

³⁵ *Sex Work Act 1994* (Vic), ss 19-20.

Recommendation 2

Build on progress made with the repeal of section 19A of the *Crimes Act 1958 (Vic)*, and end other forms of HIV criminalisation that continue to hinder the HIV response in Victoria and stigmatise Victorians living with HIV.

Recommendation 3

Invest in program support to ensure that all health care workers have the skills to provide culturally safe and competent services for people from diverse communities, including understanding the specific needs of people living with HIV.

4.2. Mental health and HIV risk

Prevalence studies have shown that mental health is a risk factor for HIV acquisition and other blood borne viruses (BBV).^{36,37} Multiple co-occurring conditions, such as substance abuse and depressive symptoms, contribute to an even higher risk.³⁸

A US study of men who have sex with men found that the probability of acquiring HIV increases as the number of comorbid conditions increases,³⁹ and severe mental health problems (for example, disorders that are persistent, disabling, and require specialised psychiatric treatment) contribute an even higher risk.⁴⁰

People living with serious mental illness and/or addictions experience much higher rates of physical ill health than the general population.⁴¹ The mental health burden in this population widens health inequalities and contributes to disability, which affects access to care. This is further exacerbated by insufficient early intervention in primary care to people experiencing symptoms of mental illness, which is critical to reducing future adverse outcomes.⁴²

Of particular relevance to people living with a serious mental illness and HIV is the influence psychiatric illness may have on risk behaviours, medication adherence and disease progression.⁴³ Psychiatrists treating people living with HIV should ensure adequate support is provided either through up-skilling or appropriate referrals.

³⁶ Elizabeth Hughes et al, 'Prevalence of HIV, hepatitis B, and hepatitis C in people with severe mental illness: a systematic review and meta-analysis' (2016) 3(1) *The Lancet* 40.

³⁷ Christina S Meade & Kathleen J Sikkema, 'HIV risk behavior among adults with severe mental illness: a systematic review' (2005) 25(4) *Clinical psychology Review* 433.

³⁸ Ibid.

³⁹ Dale O'Leary, 'The syndemic of AIDS and STDS among MSM' (2014) 81(1) *Linacre Q* 12.

⁴⁰ Ibid.

⁴¹ Royal Australian and New Zealand College of Psychiatrists, 'Keeping body and mind together: Improving the physical health and life expectancy of people with serious mental illness' (RANZCP Melbourne, Australia: 2015)

⁴² Louise Farrer et al, 'Primary care access for mental illness in Australia: Patterns of access to general practice from 2006 to 2016' (2018) 13(6) *PLoS One* e0198400.

⁴³ Kurt Andersson-Noorgard, 'Mental illness and HIV' (2010) 18 *Social research briefs* 1.

Despite a higher incidence of HIV-related risk behaviours (e.g. sex without a condom, trading sex for money and drugs) among people living with mental illness, attention to HIV education and prevention for this group of people has been limited to date.⁴⁴ People with serious mental illness should be identified as a health priority population group. Psychiatrists should consider screening their patients for sexual and drug use risks during routine psychiatric assessments. HIV testing should be offered where indicated by risk histories or other relevant medical findings.

Some of the risk behaviours surrounding exposure to HIV have specific causes. For example, women, and men who have sex with men who experience intimate partner violence are more likely to engage in at risk behaviours for contracting HIV (such as unprotected sex and drug use).⁴⁵ While heterosexual men do not experience the same levels of intimate partner violence, they do also participate in risk behaviours.

4.3. Intersectionality framework

There are some specific communities or groups of people whose risk of HIV transmission, or of a poorer health outcome if diagnosed with HIV is related to cultural and other factors. Therefore, it is necessary to take an intersectional approach, to ensure that these factors, where relevant, are acknowledged.

These risks are related to factors including more general cultural or social isolation, as well as language, cultural differences, or the practising of behaviours that are stigmatised within the broader community. These can increase the vulnerability of people with HIV, including their vulnerability to poor health and mental health outcomes. There may be less support available to these people due to language or cultural barriers, health literacy, or appropriate health services.

One group of people at high risk of poor mental health outcomes from HIV is people who are seeking asylum or who are refugees, people who cannot access services because they do not have Medicare access, or people who may be concerned that seeking testing or treatment for HIV may affect their visa status.

The stigma associated with a HIV diagnosis may be great in certain communities. It is crucial to support the mental health of people living with HIV by supporting peer-led approaches that recognise the diversity of cultural background and life experience of people living with HIV.

⁴⁴ Sandra C Thompson et al, 'HIV risk behaviour and HIV testing of psychiatric patients in Melbourne' (1997) 31 *Australian and New Zealand Journal of Psychiatry* 566; Andersson-Noorgard (n 37).

⁴⁵ Laura Bogart et al, 'The association of partner abuse with risky sexual behaviors among women and men with HIV/AIDS' (2005) 9(3) *AIDS and Behavior* 325.

Recommendation 4

Develop and implement an intersectionality framework to identify multiple risks and disadvantages experienced by people with poor mental health, HIV status and other intersecting minority positions, and address barriers to inclusion through an integrated policy framework and associated organisational toolkits.

5. Community-controlled services

Community-controlled organisations are governed and operated by and for affected communities, which enables them to deliver safe and culturally appropriate services that are trusted by the communities they serve.

Community-controlled health services, such as those provided by Living Positive Victoria, Thorne Harbour Health, and Positive Women Victoria, have a long history of mobilising community-led responses to health issues that are capable of overcoming access barriers posed by privacy concerns, stigma and discrimination experienced by people living with HIV.⁴⁶ Supportive environments facilitate people seeking the care they need, ultimately resulting in better health outcomes.

Peer led programs work best when integrated into the formal structure of the healthcare system. Providing knowledge and skills to the healthcare providers who work with people living with HIV is the best way of ensuring that these people will receive the best care possible. This includes the dissemination of information about available programs to any healthcare provider who may diagnose a person with HIV. All healthcare providers should be aware of issues relating to HIV, know where they might be able to access this information and/or feel confident enough to refer people living with HIV to another healthcare provider who is better equipped to deal with issues relating to HIV. This is especially true for any mental health professional, including acute and emergency responders to mental health (such as suicide helplines, general practitioners and psychologists, psychiatrists, and counsellors).

Recommendation 5

Endorse the proven mixed-model of mental health service provision that includes both mainstream and community-controlled HIV mental health and wraparound support services, and prioritise community-controlled services.

5.1. Overview of services

5.1.1. Living Positive Victoria's services

Living Positive Victoria delivers the following peer-led programs to better the mental health and quality of life for people living with HIV:

- Ongoing contact for people living with HIV with regular Cook and Chats for heterosexual men; Seaside retreats for people living with HIV and their families; and Planet Positive for all people living with HIV.

⁴⁶ Nous Group, 'Demonstrating the value of community control in Australia's HIV response: AFAO and Australia's State and Territory AIDS Councils' (24 June 2016).

- Gen Next, an empowering program which allows young people living with HIV to connect and build knowledge about the social and health issues relating to HIV;
- The Positive Leaders Development Institute, which builds leadership skills in people living with HIV.
- Positive Self-Management program; a capacity building program designed to allow people aging with HIV to maintain their health independently
- Volunteer participation and community events delivery which promote acceptance, validation, visibility and community connection.

5.1.2. Thorne Harbour Health's services

Thorne Harbour Health provides the following services to support the mental health of people living with HIV:

- Counselling Services for people affected by or at risk of HIV
- Alcohol and Drug Counselling, Care Coordination and therapeutic group services
- Family/Intimate Partner Violence programs
- General Practice with specialist care for people living with HIV/Hep C, and specific bulk billing General Practice services to the trans and gender diverse community;
- The Positive Living Centre, a drop-in centre providing practical, social and peer support for people living with HIV;
- The Community Support Program, which provides staff and volunteer support to people living with HIV, including medical transport and group activities, and home care from attendant care workers; and
- Housing Plus, a state-wide program supporting people living with HIV who are homeless or at risk of homelessness to seek appropriate and stable accommodation.

5.1.3. Positive Women Victoria's services

Positive Women Victoria services include:

- Individual support for women and girls living with and affected by HIV;
- Support and referral for women living with HIV from diverse cultural and social backgrounds;
- Peer support leadership and development programs for women to increase the visibility of women living with HIV in the community; and
- Advocacy and peer-led education, including education for health care and other service workers, to increase understanding of the specific health and mental health needs of women living with HIV in the community.

5.2. Wraparound support

In addition to medical treatment, wrap-around HIV support services are essential, because when people's basic needs are met they adhere better to treatment.⁴⁷ Treatment adherence is of fundamental importance because it improves the health of people living with HIV, while also reducing HIV transmission through the maintenance of an undetectable viral load.

Examples of wrap-around support services include low cost meal programs, recreational and physical activities, housing support, home care, and employment services. Home care is of particular importance in the context of an ageing population of people living with HIV; residential aged care can cause many people who had been living openly with HIV to feel they have to hide their HIV status.⁴⁸ As people living with HIV are living longer due to the advancements in treatments they will be needing to access supports through the aged care system and in aged care facilities. There are unique challenges to providing mental health support in an aged care context. Conditions such as HIV-related neurological complications⁴⁹ may add to the already complex care needs associated with ageing. Aged care workers need to have the skills and training to care for PLHIV, stigma in the aged care setting is something many people fear..

Recommendation 6

Increase ongoing funding for wraparound community-controlled HIV support services.

Recommendation 7

Endorse community-controlled vocational service providers that are capable of assisting people living with HIV assess employment-related risks, facilitate pathways and skill development, and address underlying barriers to employment through integrated service provision.

5.2.1. Peer support

Key to the success of peer support is that it is delivered by peers with a shared lived experience with those they support. The empathy and connection to community ensures a safe space for people to work through issues that impact their mental health such as internalised stigma, depression and coping with the diagnosis itself.

⁴⁷ Gonzalez (n 11).

⁴⁸ Catherine Barrett, 'My people: Exploring the experiences of gay, lesbian, bisexual, transgender and intersex seniors in aged care services' (Report, Matrix Guild Victoria Inc and Vintage Men Inc, June 2008).

⁴⁹ Clifford, D. B., & Ances, B. M. (2013). HIV-associated neurocognitive disorder. *The Lancet. Infectious diseases*, 13(11), 976–986. doi:10.1016/S1473-3099(13)70269-X

5.2.1.1. Living Positive Victoria's peer support

Living Positive Victoria's peer navigation program is designed to help people who have been newly diagnosed with HIV and/or are struggling with the day to day realities of living with HIV. This is achieved by connecting them with other people living with HIV who can help them navigate their way through difficult times. The diverse team of peer navigators aims to be able to cater to a wide variety of shared experiences with and around HIV including gender, sexuality and culture.

Living Positive Victoria also runs Phoenix, a peer facilitated workshop designed for people who have yet to come to terms with their HIV diagnosis. This program connects people living with HIV with each other, and provides health literacy around HIV, including treatments, health concerns and strategies to prevent transmission of HIV. There are three different Phoenix workshops which are tailored for different demographics; men who have sex with men, heterosexual men, and women living with HIV.

An evaluation of Phoenix showed statistically significant improvements for participants in social, psychological and health concern indicators at two months follow up.⁵⁰ As the following testimonials make clear, Phoenix provides psychosocial support to people living with HIV at a time when they need it most:

"I went to Phoenix years ago and still have friends I made at these groups. Phoenix is very professionally run, and they pack a lot of good information into the time. It's a good way of learning about the diversity of experience from others in the group, and quietly busting a few self-generated myths. I appreciated just being able to express myself in front of peers."

5.2.1.2. Thorne Harbour Health's peer support

Thorne Harbour provides HIV peer support through the Community Support Program and the Positive Living Centre.

Community Support peer staff work regularly in the ID clinics of major HIV hospitals, with a focus on talking to people who are newly diagnosed and ensuring that they are connected to other appropriate Community Support services. This includes referral for support from peer volunteers, medical transport and on-going support from a volunteer team to combat social isolation and connect clients to their community. Peer staff train and support the peer volunteers, and also facilitate small group social gatherings for peer support.

Peer staff at the Positive Living Centre provide one-on-one peer support for new and existing clients and refer them to other services as required. Trained peer volunteers also facilitate HIV peer support groups that run weekly for up to eight weeks and provide a safe and supportive environment for exploring key topics about living with HIV.

⁵⁰ Graham Brown and James Dunne, 'PozQoL PLHIV Quality of Life implementation and evaluation trial' (Australian Research Centre in Sex, Health and Society, La Trobe University: Melbourne, 2019).

An evaluation of Thorne Harbour Health’s community support at the Positive Living Centre showed statistically significant increases in social, psychological and health concern indicators over two to three months.⁵¹

Thorne Harbour Health and Living Positive Victoria are collaborating on a peer-led, HIV & Ageing Project. The project includes the Positive Self-Management Program for HIV and also a monthly Peer Support Network gathering offering sessions covering a variety of topics relating to HIV & Ageing in a social setting.

Recommendation 8

Increase funding for HIV peer support and navigation programs to allow for greater capacity, coverage and diversity.

5.2.2. Alcohol and other drug treatment services

The concurrence of mental health conditions and substance use is often referred to by people working for Victorian alcohol and other drug treatment services as a ‘dual diagnosis’. The term emerged when the Victorian mental health and drug systems were deinstitutionalised between 1988 and 1998, and in the process re-conceptualised as two separate systems, and large psychiatric hospitals were closed in favour of community-based services.⁵² Victoria differed to other states in that it adopted a less medicalised model and a wholly non-government specialist AOD workforce; one that lacked funding for addiction medicine and psychiatry support.⁵³

Dual diagnosis presents as clients self-medicating to alleviate the symptoms of poor mental health or to help cope with feelings and self-worth that is impacted by stigma and discrimination. This is particularly relevant to people living with HIV who are struggling with their HIV status as well as any other stressors present in their lives.⁵⁴

A 2012 study of Victorian AOD treatment services found that study participants believed, consistent with dual diagnosis program evaluations,⁵⁵ that dual diagnosis discourse has positively influenced AOD service screening, assessment and treatment.⁵⁶ In addition, the study found that notable barriers to quality improvement included high expectations that the

⁵¹ Ibid.

⁵² Bridget Roberts and Rebecca Jones, ‘Dual Diagnosis Narratives and Their Implications for the Alcohol and other Drug Sector in Australia’ (2012) 39(4) *Contemporary Drug Problems* 663, 666.

⁵³ Ibid.

⁵⁴ De Hert, M., Correll, C., Bobes, J., Cetkovich-Bakmas, M., Cohen, D., Asai, I., et. al. (2011). Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. *World Psychiatry* 10(1), 52–77.

⁵⁵ Australian Healthcare Associates, ‘Evaluation of the Victorian Dual Diagnosis Initiative’ (Australian State and Territory Peak Alcohol and Other Drugs (AOD) 2011); National Improved Services Initiative Forum, ‘Outcomes from the National Improved Services Initiative Forum: A Tale of Two Systems’ (Australian State and Territory Peak Alcohol and Other Drugs (AOD) Non-Government Organisations. Adelaide, 2011)

⁵⁶ Roberts and Jones (n 45) 678.

sector provides professional services with specialist expertise, as well as more general support from a low funding base.⁵⁷

Recommendation 9

Increase ongoing funding for community-controlled HIV organisations to provide alcohol and other drug services.

5.2.3. Housing support

Housing Plus is a state-wide Victorian program operated by Thorne Harbour Health that supports people living with HIV who are homeless or at risk of homelessness to seek appropriate and stable accommodation. Homelessness and inappropriate public housing can cause a lot of stress for people living with HIV. These stressors include but not limited to the fear of stigma and discrimination from an unwanted or unplanned disclosure of their HIV status and/or not being able to look after their physical health without an appropriate place to store and take medication.

Housing Plus streamlines client referrals to Thorne Harbour Health's mental health and other health and support services, which improves efficiencies and data integration between services. This emphasises the importance of community-controlled health service delivery and the integration of mental health and wraparound support services.

5.2.4. Home care

Home care supports people living with HIV to continue living independently for longer than would otherwise be possible. Home care provides attendant care workers to assist with cooking, cleaning and shopping, and is targeted at people with complex physical or mental health conditions who may otherwise need to move out of their home into a supported living facility. Home care also assists people recovering from a serious hospital admission in their transition back to independent living and supports palliative clients to stay at home for as long as practicable. Home care complements clinical services, promotes HIV and mental health treatment adherence, and improves the physical and mental health of people living with HIV.

⁵⁷ Ibid 679.

Recommendation 10

Increase ongoing funding for home care services for people living with HIV.

5.2.5. Support for families

Caring for people with mental health conditions can be a burden for families, and a lack of support from family or community can lead to negative impacts for people with poor mental health.⁵⁸ Family support structures can be less accessible to people living with HIV due to the stigma associated with HIV.⁵⁹ As families are a key support structure for people with poor mental health, it is important that families, both biological and chosen, are knowledgeable about the mental health and wellbeing issues that can affect someone living with HIV.⁶⁰

Not only should families of HIV positive people be knowledgeable about what struggles may be experienced by those living with HIV, but they need to be supported to deal with issues that arise for them in caring for those individuals. Community-controlled family counselling, peer education programs and support services will help families reduce the stigma surrounding HIV and create a supportive environment to allow for better mental health outcomes for themselves and those they care for.

Recommendation 11

Fund the co-design of new, and the expansion of existing, community-controlled family counselling, peer education programs, and other support services for families of people living with HIV to build stronger communication and relationships within families.

⁵⁸ Ajit Avasthi, 'Preserve and strengthen family to promote mental health' (2010) 52(2) *Indian journal of psychiatry* 113.

⁵⁹ Tillhalefi Tlhowe et al, 'Strengths of families to limit relapse in mentally ill family members' (2017) 22(3) *Health SA Gesondheid* 28.

⁶⁰ Asha Persson et al, 'Families Living with Blood-Borne Viruses: The Case for Extending the Concept of "Serodiscordance"' (2017) *Interdisciplinary perspectives on infectious diseases* 1.

6. Conclusion

This submission has outlined measures to improve the mental health and wellbeing of Victorians living with HIV, including improved prevention and bolstered community-controlled mental health and wraparound support services.

Key community-controlled HIV organisations have collaborated on this submission to outline a range of recommendations to combat stigma and discrimination, and build on existing funded services and programs.

We must never forget that the HIV response is not just about ending new HIV transmissions and getting people living with HIV on treatment; it is also about ensuring people living with HIV are supported by high quality, culturally safe mainstream and community-controlled mental health and wraparound support services, and can live free of the impact of HIV-related stigma and discrimination. By doing this, and by adopting the recommendations in this submission, we can work towards a Victoria where people living with HIV maintain the good mental health and high quality of life that they deserve.