Submission
No 55

INQUIRY INTO HOMELESSNESS AMONGST OLDER PEOPLE AGED OVER 55 IN NEW SOUTH WALES

Organisation: Positive Life NSW

Date Received: 10 June 2022

Positive Life NSW

The Honourable Scott Barrett MLC
Standing Committee on Social Issues
Legislative Council
Parliament of New South Wales
Submitted via website: www.parliament.nsw.gov.au/committees/inquiries

To the Honourable Scott Barrett MLC,

Re: Inquiry into homelessness amongst older people aged over 55 in New South Wales.

Positive Life NSW (PLNSW) welcomes the opportunity to provide a submission into the Inquiry into homelessness amongst older people aged over 55 in NSW.

Scope of this Submission

PLNSW is the state body representing all people living with HIV (PLHIV) in New South Wales (NSW), representing the largest body of PLHIV jurisdictionally in Australia. We offer information, referral and advice on all relevant issues for PLHIV, with the aim of ensuring the optimum quality of life, care and support for PLHIV in NSW and their friends, family and carers. More information can be found at www.positivelife.org.au.

We thank the NSW Legislative Council for this opportunity to:

1) clarify and quantify specific impacts of homelessness on the quality of life and health of PLHIV over the age of 55 years in NSW, including women living with HIV (WLHIV) and

2) highlight challenges PLHIV over the age of 55 years face when navigating their right to a secure, safe and private home in NSW, free of the risk of homelessness.

Definition of homelessness

Homelessness encompasses a range of states of housing, from sleeping rough on the streets to forms of housing which are below a minimum community standard, such as couch-surfing, living in overcrowded accommodation, or living in unsafe conditions. The Australian Bureau of Statistics (ABS) definition of homelessness incorporates three key elements: adequacy of the dwelling; security of tenure in the dwelling; and control of, and access to space for social relations.[1] The NSW

[1] Australian Bureau of Statistics, '4922.0 – Information Paper – A Statistical Definition of Homelessness, 2012', (2022), accessible at: https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4922.0Main%20Features22012?opendocument&tabn

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Homelessness Strategy 2018-2023 cites three states of homelessness: primary homelessness where an individual has no conventional accommodation or shelter; secondary homelessness where an individual might be living in shelters, emergency accommodation, refuges or 'couch-surfing'; and tertiary homelessness where an individual may be living in substandard accommodation such caravans or boarding houses.[2]

Research

According to a recent report from the City Futures Research Centre, University of New South Wales, 'Managing Access to Social Housing in Australia: Unpacking policy frameworks and service provision outcomes'[3], stress on the New South Wales social housing system is clearly intensifying. The proportion of total lettings to highest priority applicants increased from 41% to 60% in the six years to 2020-21. This means longer wait times for income-eligible but non-priority social housing applicants. NSW and WA priority wait-list criteria are the most restrictive in Australia.

Proportion of PLHIV in NSW over the age of 55 years

NSW is home to over 11,721 PLHIV[4], representing the largest number of PLHIV jurisdictionally in Australia. Approximately 5,861 PLHIV are over 55 years of age, of which 645 are women. Within these proportions there are a smaller number of transgender and non-binary PLHIV.

Positive Life NSW Housing Program

The PLNSW Housing Support program offers support and advocacy to all PLHIV across the NSW metropolitan and regional areas to access, achieve and maintain stable accommodation, including those at risk of homelessness. We support PLHIV to find crisis or temporary accommodation; complete a housing application; apply for a transfer to another property; address any maintenance and/or tenancy issues; lodge a complaint and/or attend a tribunal hearing; and provide appropriate referrals. PLNSW works alongside relevant government, health, and sector agencies and bodies to source and secure the best possible independent living and housing arrangements.

As of May 2022, PLNSW had provided housing support to 941 PLHIV who were homeless or at risk of homelessness. This equates to 8% of the population of PLHIV in NSW. Historically and to an even

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[2] Department of Communities and Justice, (2018), *NSW Homelessness Strategy 2018-2023*, accessible at: https://www.facs.nsw.gov.au/__data/assets/pdf_file/0007/590515/NSW-Homelessness-Strategy-2018-2023.pdf

[3] Pawson, H. and Lilley, D. (2022) *Managing Access to Social Housing in Australia: Unpacking policy frameworks and service provision outcomes; CFRC Working Paper*; Sydney: UNSW City Futures Research Centre

[4] Wilson, D. 2011. *Mapping HIV Outcomes; geographical forecasts of numbers of people living with HIV in Australia,* UNSW Sydney

great extent today, PLHIV face an array of issues with regard to housing insecurity due to ill health, ageing, financial instability and HIV-related stigma and discrimination.

Background

The HIV/AIDS epidemic in Australia has predominantly affected men who have sex with men (MSM).[5] Many of these identify as gay or homosexual men and include bisexual men. While a small proportion of PLHIV diagnosed at this time were women, today in Australia women living with HIV (WLHIV) make up 11% of all HIV diagnoses across Australia.

The first case of HIV was in 1981. Prior to the roll-out of HAART in 1996, a HIV/AIDS diagnosis was a death sentence. At that time, HIV rapidly destroyed the immune system and left the individual at risk of a range of opportunistic infections such as pneumonia, candidiasis, paronychia, molluscum contagiosum and hairy leukoplakia. [6] Medication that was thought to treat HIV was experimental, accessible only in clinical trials, highly toxic and insufficiently suppressed the virus. PLHIV endured debilitating side effects of nausea, nerve pain, hematologic toxic effects as well as muscle wasting, swollen lymph glands, along with disfigurements of Kaposi's sarcoma, lipodystrophy syndrome (body fat distribution), rashes, and skin hyperpigmentation.

Before the advent of HAART, it was not unusual for newly diagnosed PLHIV to be told by their primary care physicians and community to ‘prepare to die’, plan their funerals, and cash in their superannuation and life insurance policies, so as to enjoy the life they had left before the burden of HIV overwhelmed them. Many also lost not only family, friends and partners, but also their employment, community, and housing options. With the introduction of highly effective antiretroviral therapy (HAART) in 1996, PLHIV have been able to take daily HIV antiretroviral medication to halt the replication of HIV in the body, achieve immune reconstruction and regain their health. PLHIV who maintain regular adherence to their medication as prescribed by their HIV specialist, experience life spans similar to their HIV-negative counterparts. Today HIV is regarded as a chronic manageable disease, akin to diabetes or asthma. This changed health reality has led to the emergence of a significant ageing population living with HIV in NSW.

Even as HAART became available, many PLHIV found themselves unemployed or still too ill to resume full time work, without retirement funds, or savings and reliant on social security benefits such as the Disability Support Pension (DSP) and dependent on public or social housing schemes. MSM diagnosed with HIV/AIDS at that time aged in their twenties and thirties are in their sixties and seventies today, still relying on public or social housing, in receipt of social security, living with the

[5] O'Donnell D, Grulich A, Garsia R, Parkhill N, Browne K. HIV in NSW in 2010: sustaining success in an evolving epidemic. *N S W Public Health Bull.* 2010;21(3-4):49-53. doi:10.1071/NB10022

[6] Hawkins T. Appearance-related side effects of HIV-1 treatment. *AIDS Patient Care STDS*. 2006;20(1):6-18. doi:10.1089/apc.2006.20.6

impacts of premature ageing-related health impacts[7,8] and the psychosocial impacts of living long-term with illness.[9, 10, 11]

A complex picture

The impacts and factors for PLHIV who are homeless or at risk of homelessness is complex which includes interlinking factors of time of HIV diagnosis, illness, health, financial security, the experience or threat of HIV stigma and discrimination, and experiences of homophobic threat or violence. Additionally, between 14-28%[12] of PLHIV experience HIV Associated Neurocognitive Disorder (HAND) and HIV Associated Dementia (HAD). HAND describes the spectrum of neurocognitive deficits associated with HIV caused by persistent central nervous system (CNS) HIV infection and inflammation.[13]

It was this significant factor impacting the health and wellbeing of PLHIV in NSW which prompted Positive Life to create the Housing Support program in 2016 to streamline housing pathways for PLHIV living in NSW and maximise the opportunity for PLHIV to be considered and assessed as priority applicants for housing. PLNSW also supports a portion of PLHIV whose needs require a higher level of supports that are unable to be meet or managed well by government, public and social housing departments.

PLHIV who experience homelessness are faced with competing priorities of shelter, safety and food insecurity as compared with those regular engagement with medical and healthcare providers (retained in care), and consistent management of their HIV and health through prescribed HIV

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[7] Rodés B, Cadiñanos J, Esteban-Cantos A, Rodríguez-Centeno J, Arribas JR. Ageing with HIV: Challenges and biomarkers. *EBioMedicine*. 2022;77:103896. doi:10.1016/j.ebiom.2022.103896

[8] Sangarlangkarn A, Yamada Y, Ko FC. HIV and Aging: Overcoming Challenges in Existing HIV Guidelines to Provide Patient-Centered Care for Older People with HIV. *Pathogens*. 2021;10(10):1332. Published 2021 Oct 15. doi:10.3390/pathogens10101332

[9] Iriarte E, Cianelli R, Villegas N, et al. Factors Associated With Psychosocial Illness Impact Among Black/African American and Hispanic Older Women Living With HIV [published online ahead of print, 2021 Nov 19*]. J Am Psychiatr Nurses Assoc.* 2021;10783903211058786. doi:10.1177/10783903211058786

[10] Navarro R, Paredes JL, Echevarria J, et al. HIV and antiretroviral treatment knowledge gaps and psychosocial burden among persons living with HIV in Lima, Peru. *PLoS One.* 2021;16(8):e0256289. Published 2021 Aug 19. doi:10.1371/journal.pone.0256289

[11] Bhochhibhoya A, Harrison S, Yonce S, Friedman DB, Ghimire PS, Li X. A systematic review of psychosocial interventions for older adults living with HIV. *AIDS Care.* 2021;33(8):971-982. doi:10.1080/09540121.2020.1856319

[12] Alford K, Daley S, Banerjee S, Vera JH (2021) Quality of life in people living with HIV-associated neurocognitive disorder: A scoping review study. *PLoS ONE* 16(5): e0251944. https://doi.org/10.1371/journal.pone.0251944

[13] Eggers, C., Arendt, G., Hahn, K., Husstedt, I. W., Maschke, M., Neuen-Jacob, E., Obermann, M., Rosenkranz, T., Schielke, E., Straube, E., & German Association of Neuro-AIDS und Neuro-Infectiology (DGNANI) (2017). HIV-1-associated neurocognitive disorder: epidemiology, pathogenesis, diagnosis, and treatment. *Journal of neurology*, *264*(8), 1715–1727. https://doi.org/10.1007/s00415-017-8503-2

antiretrovirals and viral suppression. Without reliable access to clean, safe facilities, including water, safe storage, money and transport, homeless PLHIV tend to have more missed HIV outpatient appointments[14] to monitor their HIV viral load, lower CD4 counts[15], and find it difficult if not impossible to consistently take their HIV antiretroviral medication (adherence), and store and maintain a continuous supply of antiretrovirals.

> These are illustrated in the following case studies: *'Peter' at 62 years old is a gay man living with HIV who is 'sleeping rough' in the city. After being evicted from his rental accommodation, he attempted to apply for public housing. After a series of staff changes and experiencing HAND-like symptoms of memory loss, and difficulties with attention and concentration, Peter found it increasingly impossible to navigate the public or social housing system. Four months later he 'slipped through the cracks' of the public housing system. He avoids the crisis shelters nearby as he finds them intimidating and feels they are always full. New priorities of safety, shelter and food insecurity have eclipsed his previous priorities of regular medication adherence and medical appointments now that he is homeless.*

For ageing PLHIV, as housing service application processes move ever more online, those with limited digital skills or access to technology are increasingly locked out of a digital housing economy.

> *'Trevor', a 56 year old gay man living with HIV moved from social housing in Sydney to the Northern Rivers of NSW due to threats and acts of homophobic violence, bullying and HIV phobia. These experiences of HIV discrimination and stigma have amplified his anxiety and depression. During his most recent arrival at temporary accommodation in a local hotel, his efforts at socialising in the new community attracted the familiar and unwanted HIV stigma and homophobia. Furthermore, his low digital literacy and limited skills negotiating technology, means he is faced with further barriers to navigate the growing trend of online housing services.*

PLHIV who are homeless have increased risk of illness including Hepatitis C[16], pneumonia, tuberculosis[17], and skin infections[18] impacting an already compromised immune system. Homelessness is a stressful experience, and psychological destress has been shown to increase the

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[14] Sivaraj V, Pittrof R, Davies O, Kulasegaram R. Homelessness among an inpatient HIV-positive cohort at a tertiary care hospital in central London. *Int J STD AIDS.* 2020;31(7):705-707. doi:10.1177/0956462420918682
[15] Sivaraj V, Pittrof R, Davies O, Kulasegaram R. Homelessness among an inpatient HIV-positive cohort at a tertiary care hospital in central London. *Int J STD AIDS.* 2020;31(7):705-707. doi:10.1177/0956462420918682
[16] Sivaraj V, Pittrof R, Davies O, Kulasegaram R. Homelessness among an inpatient HIV-positive cohort at a tertiary care hospital in central London. *Int J STD AIDS*. 2020;31(7):705-707. doi:10.1177/0956462420918682
[17] Aldridge RW, Hayward AC, Hemming S, et al. High prevalence of latent tuberculosis and bloodborne virus infection in a homeless population. *Thorax.* 2018;73(6):557-564. doi:10.1136/thoraxjnl-2016-209579
[18] Rudge Sian, Webster Ian, van Beek Ingrid (2008) Infectious diseases in homeless people. *NSW Public Health Bulletin* 19, 76-77. doi: 10.1071/NB07128

severity of HIV. Mental ill-health conditions such as depression and anxiety can decrease medication adherence[19], which is absolutely crucial to the healthy management of HIV.

'Paul', 54 years old, was a retired secondary school teacher working full-time as a furniture store general manager when he was diagnosed with an aggressive but treatable form of cancer. After eight months of treatment he returned home to find his rental accommodation lease had terminated and he was forced to move in with a friend. After a breakdown of the friendship, he soon found himself homeless living in his car. While Paul socialised within a supportive LGBT community, he was fully aware how vulnerable he was as a gay man living with HIV on the street. Without the support of HIV-specialist accommodation services such as PLNSW, Paul admits his anxiety and spiralling depression could have easily tipped him over, jeopardising his health routines of regular medical appointments, blood tests, and accessing and taking his HIV medication.

It is acknowledged that not only are there high rates of homelessness among PLHIV there are relatively high rates of HIV among the homeless.[20] Without the usual routine and safety of shelter, work and social integration, people who experience homelessness may engage in sexual activity as an alternate way of staying safe or supplementing their income, or are exposed to sexual violence placing them at increased risk of contracting HIV. Self-medication through drug-use and injecting drugs can become an option for people who experience homelessness which increases the risk of HIV especially if needles are shared or reused.

Women living with HIV (WLHIV) are often diagnosed 'late', sometimes five to ten years after contracting HIV. This means WLHIV often miss out on the benefits of starting HIV antiretrovirals earlier and the more immediate immune reconstitution, and live with poorer health outcomes over a longer period of time. This may also impact their employment prospects and for WLHIV with children, precarious housing can further negatively intersect their health and wellbeing.

'Mary' is a 62 year old woman living with HIV. She is separated from husband and homeless. She has been on the public housing priority list for over two years. Mary is living in a very vulnerable situation above a pub (own room) and shares communal living spaces with others who are often men.. Mary spends up to 80% of her limited income on rent.

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[19] Padilla M, Frazier EL, Carree T, Luke Shouse R, Fagan J. Mental health, substance use and HIV risk behaviors among HIV-positive adults who experienced homelessness in the United States - Medical Monitoring Project, 2009-2015. *AIDS Care.* 2020;32(5):594-599. doi:10.1080/09540121.2019.1683808

[20] Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) n.d., *HIV Management for nurses and midwives: People experiencing homelessness.* https://hivmanagement.ashm.org.au/key-affected-populations/people-experiencing-homelessness/

HIV Futures is a longitudinal study of the Australian population of PLHIV that has been running since 1997. The survey is relaunched every couple of years and comprises a range of questions relating to various life domains including housing and financial security. While this is Australian-wide research, it is worth noting that respondent rates were highest in NSW (37.7%, n=317) and therefore figures in HIV Futures 9 are considered indicative of the lived experience of PLHIV in NSW.

HIV Futures 9[21] reported that PLHIV in the 50-64 age group were a particularly vulnerable group, reporting poorer general health and overall poor quality of life. 79.9%[22] of people aged in this 50-64 age group reported living with at least one comorbidity in addition to HIV, such as cardiovascular issues, asthma and arthritis. PLHIV In the 50-64 age group were significantly less likely to own a home outright[23], one in three were in private rental (31.2%) or other forms of accommodation (32.4%) most commonly living in public/community/social housing. Futures 9 also reported that "PLHIV in this age group are often ineligible for services for older people due to their age (under 65)." [24]

HIV Futures 9 also reported that nearly half of the WLHIV respondents were living in private rental (48.6%) and none of the women over the age of 65 years were home-owners.

> *'Sharon' is a 65 year old woman living with HIV renting privately in regional NSW. This was becoming increasingly difficult to manage on her aged care pension, and she also owed additional debts after the death of her husband. Sharon relied on public transport to travel to her nearest HIV services over an hour away from home, which aggravated her multiple medical conditions. With her health in decline, and a landlord unwilling to carry out accessible modifications to the property, Sharon decided it was time to move closer to her daughter who would be able to provide ongoing support. Unfortunately, her public housing application was rejected, and she is battling a second appeal to overturn the original decision.*

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[21] Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019) *HIV Futures 9: Quality of Life Among People Living with HIV in Australia*, monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[22] Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019) *HIV Futures 9: Quality of Life Among People Living with HIV in Australia*, monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[23] Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019) *HIV Futures 9: Quality of Life Among People Living with HIV in Australia*, monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

[24] Power, J., Amir, S., Brown, G., Rule, J., Johnson, J., Lyons, A., Bourne, A. and Carman, M. (2019*) HIV Futures 9: Quality of Life Among People Living with HIV in Australia,* monograph series number 116, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, p.44.

Many ageing MSM have experienced implied or overt homophobia, and WLHIV living with HIV over the age of 55 years of age often experience HIV stigma and discrimination from clinical and allied service providers including housing service personnel.

> *Kim, a 58 year old woman living with HIV has experienced regular HIV stigmatising actions from clinical staff including housing service providers, who upon realising she is living with HIV, assume she is either a sex worker or has a history of sex work, or a practising injecting drug user or has a history of injecting drug use. Kim feels that she is belittled and disadvantaged and that her needs are not addressed adequately because of HIV stigma and discrimination.*

Mainstream housing services, many of which include faith-based services, are ill-equipped to meet the needs of PLHIV which includes MSM and transgender people. This is due to a lack of HIV knowledge, understanding and acceptance of difference. HIV ignorance coupled with fear of transmission often leads to HIV stigma and discrimination from staff and service personnel. By the same token, ageing MSM living with HIV who have experienced or witnessed faith-based homophobic discrimination and vilification by religious institutions in the past, tend to avoid interactions with faith-based institutions and personnel.

Summary:

While housing stability is associated with improved HIV health outcomes, increased likelihood to achieve viral suppression, better long-term health outcomes[25] and reduced risk of HIV transmission[26], HIV and homelessness are intricately related.[27] Ageing PLHIV often experience medical complications, comorbidities, polypharmacy, poorer mental health, social isolation, stigmatisation and discrimination. The intersection of living with HIV, ageing and risk of homeless come together to form a 'a perfect storm of vulnerability'.

Positive Life NSW would like to commend the NSW Upper House Standing Committee on Social Issues in their dedicated and thorough research and consultation process with the Inquiry into homelessness amongst older people aged over 55 in NSW to make it as strong as possible for all NSW residents including those of us living with HIV.

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[25] Crock E. Access to healthcare services for people living with HIV experiencing homelessness – a literature review. *Australian Journal of Advanced Nursing* 2016;34(1):42-51.

[26] Wiewel EW, Singh TP, Zhong Y, et al. Housing Subsidies and Housing Stability are Associated with Better HIV Medical Outcomes Among Persons Who Experienced Homelessness and Live with HIV and Mental Illness or Substance Use Disorder. *AIDS Behav.* 2020;24(11):3252-3263. doi:10.1007/s10461-020-02810-8.

[27] Johnson L, Lewer D, Aldridge RW, Hayward AC, Story A. Protocol for a systematic review of treatment adherence for HIV, hepatitis C and tuberculosis among homeless populations. *Syst Rev.* 2020;9(1):211. Published 2020 Sep 13. doi:10.1186/s13643-020-01470-y

Positive Life NSW

If this submission requires additional information or clarification, I can be contacted at

Yours respectfully,

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Chief Executive Officer

10 June 2022