PositiveLifeNSW
the voice of people with HIV since 1988

Centre for Workforce Futures at Macquarie University and SkillsIQ
Aged Services Industry Reference Committee
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Dear the Aged Services Industry Reference Committee,

Re: Submission into the Reimagined Personal Care Worker Discussion Paper

Positive Life NSW (Positive Life) welcomes the opportunity to provide a submission into the Reimagined Personal Care Worker Discussion Paper Consultation.

Positive Life is the state-wide peer based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

Background:
In April 2020, the Aged Services Industry Reference Committee (IRC) contacted stakeholders to seek input into priority areas relating to training and competencies for the aged care workforce of today and tomorrow. The Discussion Papers, developed through the engagement of expert researchers and specialist content writers, are requesting stakeholder input to shape the content of future training and pathways, to address the skills gaps of the aged care workforce and optimally resource the sector to properly provide for the needs of older Australians into the future.

The second Discussion Paper, 'The Reimagined Personal Care Worker',[1] seeks to define the skills a personal care worker (PCW) needs to have based on current and predicted consumer needs, and the attendant knowledge and skills that will be required to provide quality care now and in the future. Positive Life believes that this consultation is an important opportunity to gather community views and an evidence base from a diverse range of voices who are concerned about the state of the aged care system in Australia for an increasingly ageing population.

Research modelling from the Kirby Institute shows that there were 25,490 Australians living with HIV in 2018 and this will increase to 31,170 in 2025 and 34,990 by 2030.[2] Surveillance data showed that in 2017, 25.51% of PLHIV were 55 years and over (n=6,290) and 10.75% were 65 years and over (n=2,650).[3] By 2025, these proportions will have increased to 33.98% of PLHIV 55 years and over (n=10,940) and 16.98% of PLHIV 65 years and over (n=5,467), and by 2030 there will be 17,670 aged 55 years and older and 11,057 aged 65 years and older.[4] It is worth noting that the proportions of PLHIV in older age brackets will continue to increase, which will lead to an increasing demand on aged care services by this population.

The Australian PLHIV population density varies significantly across Australia. Currently, states with the largest populations of PLHIV in 2017, were New South Wales (9,475), Victoria (6,559) and Queensland (4,865). Western Australia (2,136) and South Australia (1,292) had smaller populations of PLHIV. Tasmania, the Australian Capital Territory, and the Northern Territory have very small populations of PLHIV (less than 370 respectively). Most PLHIV live in major capital cities (Sydney,

[1] The Centre for Workforce Futures at Macquarie University and SkillsIQ Limited on behalf of the Aged Services Industry Reference Committee (ASIRC), 'The Reimagined Personal Care Worker Discussion Paper, (2020).
[2] Gray, R. 2019. Estimates from the current HIV cascade from each jurisdiction. Sydney: Kirby Institute.
[3] Kirby Institute. 2018. HIV, viral hepatitis, and sexually transmissible infections in Australia: annual surveillance report. Sydney: UNSW.
[4] Gray, R. 2019. Estimates from the current HIV cascade from each jurisdiction. Sydney: Kirby Institute.

Melbourne, Brisbane, Perth, and Adelaide - in that order). There are small populations in rural and regional areas (generally less than 20%), except in Queensland where about half of the PLHIV population live in regional, rural, and remote areas.[5] Providing quality aged care to PLHIV with complex care needs in metropolitan areas, will challenge aged care services. However, the provision of aged care to PLHIV with complex care needs in regional, rural, and remote areas of Australia, will be even more difficult. Small populations are spread over large geographic areas and access to HIV specialist clinical care, if often extremely limited.

The Consultation requested submissions address a range of questions centered around three main themes, of which Positive Life's responses are outlined below.

<u>The breadth of care recipients' needs:</u>
We believe that all people who are ageing should be able to maximise their happiness, fulfillment, and healthy living in a self-determined and autonomous way within society. The priority and focus of care delivery needs to be considered from the end user's perspective (the individual), rather than from a government or service provider perspective. Equity, access, cultural safety, stigma and discrimination, quality of life, and quality (rather than merely quantity) of service delivery should be the key outcomes for delivering care services according to recipients' needs. Additionally, striking a balance between 'duty of care' and 'dignity of risk' must be prioritised by both care providers and individual PCWs in collaboration with people who are ageing to achieve these key outcomes. It is vital that PCWs are able to interact with and respond effectively to the unique and oftentimes intersecting needs of people who are ageing in a culturally appropriate and safe way.

The provision of quality non-discriminatory aged care services to PLHIV in home care or residential settings presents a unique health and care challenge for PCWs, and those educating and employing PCWs. PCWs must be able to consider all older people, inclusive of all backgrounds and life experience, while acknowledging and working towards equitable outcomes for those older people more disadvantaged by intersecting and oppressive circumstances. Ageism is only one subset of stigma and discrimination experienced by people who are ageing, and these experiences are compounded depending on intersecting disadvantages held by ageing people. For instance, the provision of non-discriminatory aged care to PLHIV will challenge aged care services who employ staff who may have deeply held fears and prejudices about homosexuality, illicit drug use, sex work, gender dysphoria, and by association, HIV.

When addressing stigma and discrimination, it is also imperative that its impacts on physical and emotional health are considered, particularly for those most vulnerable such as PLHIV, people who identify as LGBTQIA+, people who inject drugs, etc. There are a range of social factors that have negatively impacted on the lives and health of PLHIV. Transmission of HIV in Australia continues to occur primarily between gay, bisexual, and other men who have sex with men (GBMSM), through male-to-male sexual contact. 63% of HIV notifications were attributed to male-to-male sex in 2017, a 7% decrease from 70% in 2016. Heterosexual sex accounted for 25% of notifications, an increase from 21% in 2016.[6] In general, it is broadly agreed that approximately 80% of Australian PLHIV are GBMSM, and 20% identify as heterosexual. The 20% of heterosexual PLHIV are approximately evenly split between men and women. Despite the efficacy of modern HIV treatment to control HIV infection and prevent transmission, HIV remains a highly stigmatised disease requiring lifetime specialist treatment and monitoring.

These social factors are experienced by older PLHIV, who were diagnosed in the pre-ART era and have survived into the current era. Many not only deal with their own health issues but lost multiple

[5] Kirby Institute. 2018. HIV, viral hepatitis, and sexually transmissible infections in Australia: annual surveillance report. Sydney: UNSW.
[6] Ibid.

partners and extensive social networks to AIDS. They were forced to leave employment and became reliant on welfare. Consequently, many now live in poverty, in public housing, and have never had the opportunity to amass savings, superannuation or assets. Issues for older PLHIV who live in social housing include but are not limited to: social isolation; lengthy and confusing processes, and often slow responses to necessary repairs and home modifications; safety considerations in regards to anti-social behaviour of other residents towards PLHIV; and lengthy wait times for housing transfers, such as the need to move to a ground floor apartment due to increased mobility issues. In addition, many older PLHIV live with ongoing HIV-related stigma from the general community with considerable fear and concern about their future, their increasingly poorer health, losing independence, failing cognition, and dealing with loneliness and potential discrimination from people in aged care services who may hold prejudices about homosexuality and/or HIV. The recent media coverage of physical and emotional abuse by aged care service staff has intensified concerns for PLHIV, that they will be treated with less dignity and respect than others who are ageing who have experienced more mainstream conventional social environments.

Through a community consultation conducted in 2019 by Positive Life about experiences of aged care services, which was undertaken by over 400 PLHIV survey respondents, we received a significant number of complaints from ageing PLHIV about PCWs being poorly trained, rude and unhelpful, and in some cases, patronising and disrespectful. There have also been complaints about poor communication skills, the need for better service coordination and the need to reduce long waiting times for services. We have received reports of discriminatory behaviour by PCWs who have no or limited knowledge of HIV. Some feared they would contract this blood-borne virus (BBV). There were also examples reported of discrimination by PCWs who were homophobic. Acts of discrimination ranged from being ignored, shamed and silenced, to outright refusals to provide service. Abuse and neglect primarily resulted from ignorance and fear on the part of PCWs about HIV, HIV treatment, and the negligible risk of transmission to staff or other residents. The potential for abuse by PCWs who hold prejudices is of real concern. Education about HIV will be needed to ensure that aged care services and PCWs maintain respectful and non-discriminatory care. Peer-led organisations such as Positive Life NSW are best placed to provide HIV education to aged care services and need to be resourced to do so. Additionally, specialist HIV services that manage PLHIV with HIV-Associated Neurological Disorder (HAND) and HIV-Associated Dementia (HAD) are well placed provide training to PCWs (and aged care clinical staff) who care for clients with these conditions.

Additionally, the community survey reported an overwhelming majority of ageing PLHIV (95%) wanting to remain living in their home until it became impossible for them to manage any longer. They wanted to receive services from other PLHIV, or carers trained and knowledgeable about HIV and LGBTQIA+ issues. The primary reasons were due to a deep and abiding distrust and dislike of faith-based institutions and their attitudes and actions of marginalisation and discrimination against LGBTQIA+ people, particularly older gay men. Many reported having no confidence they would be cared for in a respectful and dignified way by faith-based services. Some reported they would rather suicide than be cared for by a religious/faith-based organisation.

Aged care services in Australia often assume the responsibility of extending healthy, active years of life is solely that of the individual (the person who is ageing) to take a more proactive approach in. This is not an accurate picture of life for many Australians with intersecting co-morbidities and barriers to access. The socio-economic determinants of health and the structural framework around these systems and services are often constructed in such a way that they deter individual health-seeking behaviours and self-determination. Many of these systems and services are designed so as to exclude some populations of people, whether through being culturally unsafe, inaccessible, expensive, complicated, discriminatory, or otherwise challenging to access. The priority should also be on asking how services and systems can be better established to be patient-centred with the individual in mind rather than the system or service, considering quality over quantity at every stage of co-design.

In addressing a variety of care and support needs there must be an acknowledgement that ageing processes happen at varying timeframes and rates for different individuals and that this impacts on many people's ability including PLHIV to remain living at home longer. As such, those aged 50-64 years should be assessed for aged care services on the basis of clinical indicators, levels of physical functional impairment, and other factors such as living alone and/or without familial support, rather than chronological age being the only factor. This is also particularly important for ageing Aboriginal and Torres Strait Islander people, who even though their qualification for access to aged care services may commence at an earlier chronological age, may require these services prior to this age limit due to a range of intersecting health and social factors. Additionally, ageing Aboriginal and Torres Strait Islander people require culturally appropriate and safe aged care services, as well as potentially earlier access.

It is also important to note that in considering new and emerging trends in dementia and other neurocognitive disorders, ageing and aged care, there are also emerging populations that are ageing. For example, this is the first time in history that people are living with HIV long-term so that they enter the aged care system by virtue of age, require care and support services, and develop age-related neurocognitive disorders such as HAND and HAD. This challenge to care providers should not be minimised or ignored.

<u>The range of skills required:</u>
The Discussion Paper notes that: "Despite high levels of qualification in some areas of the aged care workforce, and the Aged Care Quality Standards calling for 'suitably qualified' workers, no specific qualification is stipulated, and there's no mandated minimum qualification for PCWs. Nor is there any requirement for ongoing continuous professional development (CPD), resulting in the widespread onboarding of unqualified staff. The Australian Nursing and Midwifery Federation (ANMF) and the Australian College of Nursing (ACN) have called for PCWs to be regulated with nationally consistent nomenclature and titles, a code of conduct, professional standards and scope of practice, to ensure nationally consistent minimum educational and CPD requirements."[7]

If appropriate and non-discriminatory care and support is to be provided in community and residential care settings, it will be necessary for PCWs to understand the clinical and other support needs of PLHIV as well as the impacts of stigma and discrimination. We consider it necessary for PCWs to be trained in the following proficiencies, including annual further education requirements, such as participation in an accredited continuing professional development program:

- *The clinical management and treatment of HIV, BBVs, and chronic health conditions;*
- *The management of PLHIV with HAND and HAD;*
- *The transmission risk of HIV and other BBVs in care settings, including an understanding of Treatment as Prevention (TasP) and Undetectable Viral Loads (UVLs);*
- *Universal infection control, prevention procedures, and management (in 2017, there were an estimated 2,899 people [11% of all PLHIV], living with HIV who were unaware of their HIV status [undiagnosed].*[8] *The same report noted that the proportion of undiagnosed PLHIV was estimated to be higher in females [13%], than males [10%], and higher in Aboriginal and Torres Strait Islander people [14%], than in the Australian-born non-indigenous population [10%]. People born in Southeast-Asia had the highest proportion of estimated undiagnosed HIV [27%], compared with people born in sub-Saharan Africa [13%], and other countries [10%]);*
- *HIV privacy and confidentiality legislative and clinical policy requirements;*

[7] The Centre for Workforce Futures at Macquarie University and SkillsIQ Limited on behalf of the Aged Services Industry Reference Committee (ASIRC), 'The Reimagined Personal Care Worker Discussion Paper, (2020).
[8] Kirby Institute. 2018. HIV, viral hepatitis and sexually transmissable infections in Australia: annual surveillance report. Sydney: UNSW.

- *Cultural awareness training on the diversity of HIV populations, sexual identities, gender dysphoria and recreational drug use;*
- *The mental and physical health impacts of HIV-associated stigma and discrimination on the wellbeing of PLHIV;*
- *Service provision focusing on self-determination, dignity, and respect;*
- *A basic level of English language literacy for PCWs where English is a second or additional language, as well as numeracy and effective communication training;*
- *The dangers of polypharmacy, non-adherence to HIV and other medications, misuse of prescribed and non-prescribed medications (including illicit drugs) and their relationship to hospital admissions, disability, and premature death;*
- *Community transport for ageing PLHIV in regional, rural, and remote areas of Australia to be transported to HIV specialist clinical care in regional centres and metropolitan cities, including to city-based centres with multidisciplinary hospitals and experience in the clinical management of PLHIV with comorbidity;*
- *Conducting service delivery sessions via Telehealth and other online communication and health technologies, as well as remote liaison and referral with other service providers and/or members of a multidisciplinary care team;*
- *Home-based and residential aged care practices specific to regional, rural, and remote areas proportional to the challenges that extensive geographical area coverage entails.*

Individual workers vs. multidisciplinary teams:
Positive Life believes that support for multidisciplinary teams of aged care providers are vitally important for appropriate service delivery and must include not-for-profit aged care service providers, for both home-based aged care services and residential aged care services. For-profit providers will be more inclined to operate in an environment where profit margins are maximised at the expense of care recipients. This is a significant barrier to access to care for many and the system needs to adapt in response. For the reasons provided previously, religious-based/backed institutions and for-profit corporations are not always best placed to provide quality aged care services to PLHIV and other ageing Australians. Not-for-profit organisations should be considered on merit and qualitative measures, rather than primarily quantitative measures.

Priority considerations should be given to increasing funding for home-based support services from a range of specialist as well as mainstream providers to increase access and reduce wait times for services, facilitate improved shared-care arrangements, service coordination, continuity and streamlining, as well as recognition of social support as an integral component of aged care service delivery. This includes but is not limited to provision of these support services by not-for-profit organisations.

It is important to note that in conducting aged care services within multidisciplinary teams, that lived experience is vital when working with individuals and communities of PLHIV, particularly in research and service delivery. Community organisations which are peer based (such as Positive Life NSW) are uniquely positioned to offer patient-centred, peer-based support services to ageing PLHIV within a multidisciplinary team, and training to mainstream aged care providers. PLHIV understand the health and social issues faced by other PLHIV and the potential contexts in which stigma and discrimination can occur. Additionally, not-for-profit organisations such as the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) provide face-to-face and online training offerings relating to HIV management and service delivery, for example, HIV in Ageing for Aged Care and Community Nurses Online Learning Module.

Furthermore, the clinical management of HIV can only be conducted by accredited practitioners (s100 prescribers), who are specialists trained in the clinical management of HIV. Aged care services with

PLHIV in residential care must initiate and maintain shared clinical care arrangements between the residential aged care facility doctor and an HIV specialist doctor (s100 practitioner) to ensure appropriate clinical management and treatment of HIV and other chronic health conditions. Unfortunately, the availability of s100 prescribers outside major metropolitan areas is extremely limited. The provision of HIV specialist clinical care for PLHIV in facilities located in rural or regional areas may be difficult to facilitate and may require services such as the organisation of fly-in/fly-out specialist clinical care.

In addressing the needs of ageing PLHIV with HIV-related dementias, including HAND and HAD, aged care provision should be conducted in coordination with HIV specialist neurology services at Centres of Excellence (such as St Vincent's Hospital, Sydney), with appropriate additional resource allocation for the increased workload this will generate for these specialist services in working within a multidisciplinary framework of aged care.

Multidisciplinary shared care arrangements will also be necessary for the clinical management of other chronic health conditions in PLHIV. All PLHIV experience comorbidity at higher rates than the general population. For example, HIV positive gay men experience comorbidity at two to three times the rate of HIV-negative gay men and at substantially higher rates than the general population. They also experience a significantly increased number of comorbidities.

Positive Life believes that the role of a PCW is integral to the safe, effective, and quality delivery of aged care services to all ageing people in Australia, including PLHIV. We believe that PCWs should be trained to an accredited high standard, and remunerated accordingly, rather than the current reality of "an entry level worker paid minimum wage and with at best an entry-level qualification or none at all".[9] *It is unrealistic to expect PWCs to have a complex and wide ranging knowledge base, skills, capabilities, and responsibilities in an individual care provision setting, or indeed even in a multidisciplinary care team setting, given these and other funding-related constraints. Positive Life will continue to advocate to Australian governments for increased funding for adequate, safe, and accessible provision of emotional, social, and physical aged care services for all ageing Australians, including PLHIV.*

Summary:
Positive Life would like to commend the Aged Services Industry Reference Committee in their dedicated and thorough research and consultation process with the aim of reforming the Personal Care Workforce and aged care service delivery systems, to make them as strong as possible for all Australians including those of us living with HIV.

If this submission requires additional information or clarification, I can be contacted at janec@positivelife.org.au or on 02 9206 2177.

Yours respectfully,

Jane Costello
Chief Executive Officer

27 July 2020

[9] The Centre for Workforce Futures at Macquarie University and SkillsIQ Limited on behalf of the Aged Services Industry Reference Committee (ASIRC), 'The Reimagined Personal Care Worker Discussion Paper, (2020).