Australian Federation of AIDS Organisations

napwha national association of people with HIV australia

Australian Federation of AIDS Organisations and National Association of People with HIV Australia comments regarding

Senate Community Affairs References Committee: The future of Australia's aged care sector workforce

29 February 2016

About AFAO & NAPWHA

AFAO is the national federation for the HIV community response. AFAO's members are the AIDS Councils in each state and territory; the National Association of People with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe National HIV Alliance; and Scarlet Alliance, Australian Sex Workers Association. AFAO advocates for its member organisations, promotes medical and social research into HIV and its effects, develops and formulates policy on HIV issues, and provides HIV policy advice to Commonwealth, state and territory governments. AFAO develops targeted HIV prevention and health promotion programs to people living with HIV and communities most affected by HIV, namely gay men, sex workers, injecting drug users, Aboriginal and Torres Strait Islander people, and people from or who travel to countries with high prevalence of HIV.

NAPWHA is the peak organisation representing people living with HIV (PLHIV) at the national level. NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community. NAPWHA promotes the meaningful involvement, visibility and centrality of all people living with HIV (PLHIV) in all aspects of Australia's response.

Overview

AFAO and NAPWHA are pleased to make this submission, which focuses on item j. of the Terms of Reference, namely:

- challenges of creating a culturally competent and inclusive aged care workforce to cater for the different care needs of Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse groups and lesbian, gay, bisexual, transgender and intersex people;

HIV is both a chronic and complex health condition at every level - in terms of its natural history, transmission risks, treatment regimens, the impact of co-morbidities, and issues relating to ageing with HIV. People ageing with HIV can have a wider range of health conditions than their HIV-negative peers, with associated treatment and care needs. Especially for older people who have lived long-term with HIV, this can mean multiple treatment regimens that should ideally be coordinated centrally.

HIV-related stigma and discrimination is a further all-pervasive issue for people ageing with HIV, affecting access to care and the quality of the care provided by health, disability and aged-care workforces.

With 75% of people living with HIV being gay men, this cohort can face particular challenges in terms of living comfortably in an accepting aged-care facility. Experiences of stigma associated with HIV *and* homosexuality can be quite profound. This intersection of characteristics, each of which can be heavily stigmatised, is useful to bear in mind when considering how to best create a more culturally competent and inclusive workforce; the design of any workforce training to develop a more culturally competent and inclusive workforce must address the intersection of identities. If properly addressed, a gay HIV-positive man from a non-English speaking background – as the proverbial canary in the coalmine – should feel comfortable and supported in any aged-care facility. The creation of such a welcoming environment would indicate that one of the aims of this inquiry – "creating a culturally competent and inclusive aged care workforce to cater for the different care needs" has been well addressed.

HIV and Australia's health system

Australia has sought to address the complexities of HIV prevention and treatment since the beginning of the epidemic, developing seven national HIV strategies over the years, each underpinned by a partnership of governments, HIV community organisations representing people living with HIV and people from affected communities, researchers, and clinicians – including GPs and specialists working in primary care.

Australia continues to have one of the lowest HIV prevalence rates globally. This success in responding to HIV is attributed to the strength of Australia's public health system, and the role played by the HIV partnership in identifying and addressing new and emerging issues. Treatment uptake rates are now estimated to be above 75% for people with HIV who are linked to care, and HIV testing rates are strong. Nationally, gay men continue to account for over 75% of diagnoses.

All stages of the health/disability/aged care service continuum apply in respect of people with HIV. Over the 30 years of the HIV response the health system has adapted, with the HIV partnership ensuring that ongoing issues affecting the quality of care and support provided for PLHIV have been identified and in many cases addressed.

Ageing with HIV and the health system

At least in capital cities, coordination of care and support for people ageing with HIV works well, especially for people with the capacity to self-manage and for people with doctors and ancillary health providers engaged in relevant professional networks and partnerships with community. HIV community organisations have worked with GPs and hospital specialists to improve and better 'problem-solve' patient pathways, and provide access to primary and secondary/tertiary services. Community input over the years, often in partnership with HIV clinicians – via various structures, including Medicare Local collaborations - has resulted in reforms which address structural, workforce and policy issues, thereby enhancing quality and accessibility of health care for PLHIV. Primary health clinicians have also been involved in the development of policy guidelines regarding HIV testing and infection control that have addressed actual and potential HIV-related discrimination in the health system.

Ageing with HIV and the NDIS

Community care most frequently accessed by people with HIV has, until recently, been delivered through the Home and Community Care (HACC) service network, including for example, community transport, Meals on Wheels, Home Care, community options and Neighbouraid.

The move to the NDIS has failed to articulate a clear transition for PLHIV as they age, particularly for those who may have episodic rather than ongoing or regular support needs. The preventative role of HACC services has been well established, with research clearly showing that HACC support assisted people to live well at home. Issues relating to the transition from home to aged services need to be identified to ensure that people transitioning from disability services in the community to aged care, whether at home or in an aged care service, receive a similarly high quality well-coordinated care and support.

Ageing with HIV and the aged care system – the gaps

Any aged care model needs to be able to address both the structural and social determinants of health for people with chronic and complex heath conditions. There is generally a lack of knowledge

and expertise in the aged care workforce regarding the complexities relevant to treating particular chronic/complex conditions. There is a need to enhance training and professional development regarding these complexities, so that the care needs of people with chronic and complex heath conditions are met. There is also a need for training and professional development regarding the stigma and discrimination issues faced by people with HIV, including stigma and discrimination related to sexuality, ethnicity and race, and/or injecting drug use – taking into account that HIV is in and of itself an infectious and still stigmatised condition.

Research shows that the prevalence of depression among HIV-positive people is higher than in the general population, and that mania, hypomania and psychosis occur more frequently.[1] The report needs to address the prevalence of dementia, depression and other mental illnesses among people living with HIV, and the particular care issues that will emerge given this prevalence. It needs to be acknowledged that overlaying issues of sexuality can complicate HIV-positive people's access to appropriate treatment, care and support services, and that catering for such needs is part and parcel of catering for diversity.

Serious gaps in respect of HIV literacy for the aged care workforce that affect the quality of care for PLHIV include:

- Lack of knowledge of the care needs of PLHIV, particularly people with co-morbidities and/or age-related conditions that complicate treatment and care – such as depression and mania as mentioned above
- Lack of understanding of the importance of HIV-related privacy and confidentiality[2]
- Ongoing discrimination in the health workforce against PLHIV, either due to misunderstandings regarding infection risk for staff, homophobia, or prejudicial attitudes relating to injecting drug use and sex workers
- Inadequate infrastructure/technology to facilitate information flow, including My Health Record/PCEHR (see below)
- Treatment access issues persist for PLHIV outside metropolitan areas
- Poor referral pathways for people outside metropolitan areas
- Poor linkages between health, disability and aged-care services.

Need for health care networks to include aged care service providers

There is a need for network building to enhance understanding of the needs of communities with high prevalence of particular chronic and complex conditions and/or with high risk factors associated with that condition. HIV is a case in point; enhancing the capacity of the aged care workforce to provide high quality care that addresses the specific needs of people from these particular communities, or with certain health conditions, will necessarily enhance the quality of care

[1] Newman, C., Mao, L., Kidd, M., Saltman, D., & Kippax, S. (2009). Primary health care project on HIV and depression: Key findings. Sydney: National Centre in HIV Social Research, The University of New South Wales.

[2] The HIV Futures studies conducted by the Australian Research Centre in Sex, Health and Society have consistently found that approximately one third of people living with HIV surveyed had experienced discrimination from health care services. Confidentiality of patient information has been among the most common breaches reported. Citation: J Grierson, M Pitts, R Koelmeyer (2013) HIV Futures Seven: The Health and Wellbeing of HIV Positive People in Australia, monograph series number 88, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

generally. Community engagement and building networks and partnerships with HIV community organisations is the key to addressing these issues.

Primary Health Networks are ideally placed to better integrate services for people in aged care who live with HIV, including between primary health care, hospital, disability, aged and community sectors.

Need to address sexual expression

The ability of residents in aged-care facilities to express themselves can be limited due to an array of issues. According to the Sexuality Assessment Tool (SexAT) for residential aged care facilities, these issues include:

> "negative or judgemental staff attitudes towards sexuality (including cultural beliefs), lack of staff education, lack of privacy, lack of time to ascertain and respond to the older person's needs, and the prioritisation of other aspects of their wellbeing over sexuality.
>
> Furthermore, staff may be unaware of other sexualities and the needs of older people who identify as gay, lesbian, bisexual, transgender or intersex (GLBTI). Some facility staff may have good intentions, but be unsure of how to change practice, or how to make the facility environment conducive to sexual expression."

AFAO commends to this Inquiry the "Sexuality Assessment Tool (SexAT) for residential aged care facilities", an Australian Government Initiative, produced by the Australian Centre for Evidence Based Aged Care (ACEBAC), LaTrobe University[3]. It provides check-lists with practical steps for aged-care facilities to take to support expression of sexuality, recognising that "intimacy and the expression of sexuality are fundamental aspects of a person's wellbeing that continue to be important as we age."

A key aspect of "creating a culturally competent and inclusive aged care workforce to cater for the different care needs" is ensuring that residents – of all types – are respected and supported in the appropriate expression of their sexual health needs.

Stigma & discrimination: need for specialised training and professional development

People living with HIV include gay men (predominantly), people who have used injecting drugs, and sex-workers. People among these populations can experience discrimination in mainstream aged care settings and may thus fail to disclose critical information because of mistrust. Aged care workforce training and professional development programs should seek to improve awareness of the social determinants of health among the workforce, including strategies to improve access to health care and services for people from these populations.

Community Advisory Committees should be established, with membership including representative organisations best placed to provide input regarding the development of aged care workforce

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[3]Bauer, M., Fetherstonhaugh, D., Nay, R., Tarzia, L. & Beattie, E (2013). *Sexuality Assessment Tool (SexAT) for residential aged care facilities.* (Available from the Australian Centre for Evidence Based Aged Care, La Trobe University, Melbourne VIC 3086). Available at: http://www.agedcare.org.au/publications/agendas-docs-images/sexuality-assessment-tool-sexat-for-residential-aged-care-facilities

training and professional development programs to enhance understanding of the particular issues faced by people living long-term with infectious BBVs, including PLHIV. The focus of these committees should include interconnected issues relating to culture and ethnicity, and racism – particularly highlighting issues for LGBTI people, Aboriginal and Torres Strait Islander communities and CALD communities that include people from countries with high prevalence of HIV or other BBVS. Such community input would help ensure that any new models are resident/patient-centred and enhance the quality of care for all people in aged care.

Current scope and focus of aged care workforce development

The Department of Social Services website, at https://www.dss.gov.au/ageing-and-aged-care/workforce-development-programs, sets out current initiatives designed to "boost education, training and professional development for the workforce involved in caring for older Australians", including a range of programs to develop the workforce in respect of the needs of Aboriginal and Torres Strait Islander, and CALD communities. As outlined above, there is a need for workforce development to enhance understanding and address stigma and discrimination related to particular conditions of high prevalence among particular communities, including and particularly for LGBTI, A&TSI and CALD communities. The Commonwealth-funded resource Positive Caring Handbook[4] (produced by Living Positive Victoria in partnership with the Royal District Nursing Service), is an excellent Victorian resource that should ideally be expanded to cover all States and Territories, for use as a primary resource for aged-care workforce training and professional development programs.

AFAO and NAPWHA propose that:

- Training and professional development programs be developed for the aged care workforce, at all levels (professional through to ancillary heath care workers), that seeks to enhance knowledge and understanding of HIV and other BBVs, and of HIV/BBV-related stigma and discrimination, especially issues faced by people among high-prevalence populations
- Appropriate training and professional development resources be developed for implementation of this training/professional development, in partnership with community organisations representing people with HIV/other BBVs. N.B. Training and professional development resources must addressing intersecting identities
- Community Advisory Committees, including PLHIV, be established, with membership including representative organisations best placed to provide input regarding the development of aged care workforce training and professional development programs to enhance understanding of the particular issues faced by people living long-term with infectious BBVs, including PLHIV
- The Commonwealth-funded resource Positive Caring Handbook[5] be expanded to cover all States and Territories, for use as a primary resource for aged-care workforce training and professional development programs
- Promotion and use of the federally-funded Sexuality Assessment Tool (SexAT)[6] by aged-care facilities, both at an organisational level, and for staff training/development.

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[4] Available at: www.livingpositivevictoria.org.au/_literature_206859/Positive_Caring_Handbook

[5] Available at: www.livingpositivevictoria.org.au/_literature_206859/Positive_Caring_Handbook

[6] Available at: http://www.agedcare.org.au/publications/agendas-docs-images/sexuality-assessment-tool-sexat-for-residential-aged-care-facilities