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Joint AFAO/NAPWA Submission to: Inquiry into access to planning options and services for people with a disability

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About AFAO

The Australian Federation of AIDS Organisations (AFAO) is the peak body for Australia's community sector response to the HIV/AIDS epidemic.

AFAO is charged with representing the views of our members: the AIDS Councils in each state and territory, the National Association of People Living with HIV/AIDS, the Australian Illicit and Injecting Drug Users' League, the Anwernekenhe Aboriginal and Torres Strait Islander HIV/AIDS Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO advocates for its member organisations, promotes medical and social research into HIV/AIDS and its effects, develops and formulates policy on HIV/AIDS issues, and provides HIV policy advice to Commonwealth, State and Territory Governments.

About NAPWA

NAPWA is the national organisation providing advocacy, policy, education and outreach for people living with HIV. NAPWA membership includes organisations for people living with HIV (PLHIV) in each state and territory and the following affiliate members: Positive Heterosexuals (Pozhets); Positive Women (Victoria); Straight Arrows; and the Positive Aboriginal and Torres Strait Islander Network (PAT SIN). NAPWA works across a range of health care and HIV-positive education initiatives to promote the highest quality standards of care and to encourage appropriate clinical and social research into the causes and prevention of HIV. NAPWA is a founding member of the Australian Federation of Disability Organisations (AFDO) and is funded by the Commonwealth to provide advocacy and policy advice to Government and other agencies on national issues affecting people with HIV.

Our perspective on this Inquiry

AFAO and NAPWA are particularly pleased to be given the opportunity to make submissions regarding issues faced by people ageing with HIV, especially given the recent launching of the Sixth National HIV Strategy 2010-2013.¹ We are keen that Inquiries such as this focus on issues highlighted in the Strategy that facilitate its implementation as part of broad reform of Australia's health and aged care systems.

¹ Sixth National HIV Strategy 2010-2013, Commonwealth of Australia 2010

Social model of disability

Recognition of past and ongoing barriers to social participation that relate to stigma and discrimination associated with conditions such as HIV, is essential for people ageing with disability to have a good quality of life.

We note that Article 1 of the United Nations Convention on the Rights of Persons with Disabilities utilises a social model of disability, defining persons with disability as including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.² Accordingly, a person living with HIV may be defined as disabled under the CRPD. Likewise HIV is a disability for the purposes of the Disability Discrimination Act (DDA), 'disability' being defined as including 'the presence in the body of organisms causing (or capable of causing) disease or illness'.³

Australia's response to HIV

Australia responded to the HIV/AIDS epidemic in the 1980's by developing and delivering bold initiatives to limit and harness the spread of HIV, ameliorate its impact on affected communities, and limit AIDS-related deaths. Nurturing collaborative partnerships between people living with HIV, affected communities (primarily the gay community), health care professionals, researchers and government was pivotal to the development of effective HIV prevention programs, as was recognition of the need to build in the meaningful participation of people living with HIV and affected communities. Australia's HIV response continues to be recognised globally as a sophisticated, systematic and successful partnership approach. There is widespread acknowledgement that it is due to the effectiveness of Australia's partnership response that the prevalence of HIV remains lower in Australia than in other comparable high income countries. Australian gay communities, sex workers, and people who inject drugs - including from within Aboriginal and Torres Strait Islander communities - have responded to emerging issues in the epidemic and have been instrumental to the development of the five National HIV Strategies implemented to date.

The Sixth National HIV Strategy

Development of the Sixth National HIV Strategy represents the continued involvement of all partners in developing strategies to respond to significant current and emerging issues, including issues relevant to a growing cohort of HIV-positive people who are now over fifty and subject to premature ageing.

While the Commonwealth recognised the importance of ageing issues in the Fifth National HIV Strategy, noting the need to 'develop long-term support for HIV-positive people who are ageing or have chronic disabilities', limited progress has been made to date. The Sixth National Strategy has re-stated the Commonwealth's commitment to ageing issues and we anticipate that the Implementation Plan for the new Strategy will be focused and responsive to these matters.

The Sixth National HIV Strategy identifies ageing as a key issue for the development of priority actions in respect of the 'treatment, health and wellbeing' of PLHIV. In common with this Inquiry, the stated objective is to 'improve the quality of life' of

² United Nations Convention on the Rights of Persons with Disabilities, available at <http://www.un.org/disabilities/convention/conventionfull.shtml>

³ *Disability Discrimination Act 1992*, The Office of Legislative Drafting and Publishing, Attorney-General's Department, Canberra

older people, including by having regard to the ‘increasing diversity among people living with HIV’:

‘Avenues for improving access (to services) for people living with HIV and determining the best practice models for service delivery across HIV specific and mainstream long-term support services, including aged care services require consideration and should be progressed in consultation with people living with HIV, through advocacy and workforce development initiatives in partnership with the relevant commonwealth, state and territory departments.’⁴

There is a risk that the Sixth National HIV Strategy is not perceived as relevant to planning for people with disability. However, HIV is both a disease and a disability, and the psycho-social issues facing people living with HIV are directly relevant to this Inquiry. We propose that the National HIV Strategy Implementation Plan being developed by the Department of Health and Ageing is of direct relevance to this Inquiry and that it should be taken into account in the Committee’s deliberations and recommendations. As noted by Professor Michael Kidd, Chair of the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections, at the launch of the HIV Strategy in May,

‘While we may not see all our governments agreeing on all aspects of our national health reform agenda, it is significant that every single health minister was willing to sign up to this new set of strategies and, in so doing, commit their health services to meet the targets for prevention, treatment and care set in each strategy.’⁵

HIV prevalence in Australia

At the end of 2008 there were an estimated 17 444 people living with HIV in Australia, 995 of whom were diagnosed in the previous year.⁶

New HIV infections continue to be predominantly among men who have sex with men (69% in 2008) but while the Australian epidemic remains concentrated in the gay community, there are indications of smaller but significant epidemics occurring in other communities. For example, there are emerging epidemics among ATSI injecting drug users and their sexual partners, and among populations of certain other culturally and linguistically diverse (CALD) communities.

It is crucial to consider these epidemiological factors when planning to meet the needs of an ageing HIV- positive population.

Ageing and HIV

With the improvements in highly active antiretroviral treatment (HAART) since 1996, HIV-positive Australians are surviving longer and are generally not developing AIDS-defining illnesses - in sharp contrast to the high mortality rates which characterised the epidemic in the early stages of the epidemic. This and an increase in the median age of people diagnosed with HIV, has resulted in a marked change to the age distribution of the HIV-positive population. While less than 15% of Australians

⁴ Sixth National HIV Strategy 2010-2013, op cit

⁵ Professor Michael Kidd AM, speech at launch of Sixth National HIV Strategy

⁶ National Centre in HIV Epidemiology and Clinical Research, 2009, HIV/AIDS, viral hepatitis and sexually transmitted infections in Australia, Annual Surveillance Report 2009, National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales, Sydney

living with HIV were over 50 in 1996, 33% of people living with HIV are now over 50 (over 6 000 people)⁷.

Middle-aged people with HIV are susceptible to an array of chronic co-morbidities normally associated with ageing - due both to the effects of the virus itself and due to effects of long-term antiretroviral treatment. Common co-morbidities for people with HIV include:

- cardiovascular disease
- diabetes
- arthritis
- osteoporoses
- neurological impairment (e.g., Alzheimer's, Korsakov's dementia)
- vascular dementia
- mental health issues
- cancers (anal, bowel, breast, cervical and lymphoma).⁸

These co-morbidities are present at a younger age in the HIV-positive population than in the general population; they are wider in range; and they are more severe in effect. While the average 75 year old without HIV is on drug treatment for two co-morbidities, the average 55 year old living with HIV is on drug treatment for three co-morbidities. People who have lived with HIV for many years are thus effectively ageing prematurely.

The mortality rate among Australian people living with HIV due to these co-morbidities is approximately five times higher than among the uninfected general population of a similar age.⁹ Deaths directly attributable to AIDS-defining illnesses are now less common than deaths attributed to these co-morbidities, the most significant being liver failure, suicide/drug overdose, cardiovascular disease, lung cancer, and non-AIDS cancers¹⁰. Bone mineral density loss, neuro-cognitive impairment and frailty are also associated with increased risk of morbidity and mortality.

Accelerated ageing due to the virus itself

The premature ageing of people with HIV appears to be substantially attributable to the virus itself. Emerging research suggests that senescence, the process whereby the capacity of cells to divide and grow is lost with ageing, starts earlier for a person with HIV. Current understanding is that accelerated ageing may begin from day one of acquiring the virus, and even with antiretroviral treatment, inflammatory hormones remain elevated. It seems that HIV infection compresses the ageing process, perhaps accelerating the effects of co-morbid conditions, including frailty.

⁷ Falster K et al. Trends in antiretroviral treatment use and treatment response in three Australian states in the first decade of combination antiretroviral treatment. *Sexual Health*. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2742671/>

⁸ , K., Law, M.G. (2006). Risk factors and causes of death in the Australian HIV Observational Database. *Sexual Health* 3, 103-112.

⁹ Petoumenos K et al. *Rates of cardiovascular disease following smoking cessation in patients with HIV infection: results from the D:A:D study*. Seventeenth Conference on Retroviruses and Opportunistic Infections, abstract 124, San Francisco, 2010. Available at: <http://www.aidsmap.com/en/news/7CD6E027-9B7D-411B-9D98-A45E587EDCB7.asp>

¹⁰ Petoumenos, K et al, *ibid*

Lifestyle risk factors and persistent immune dysfunction and inflammation also compound the effects of HIV on the ageing process. One study showed that HIV infection alone is as significant a risk factor for developing atherosclerosis as risk factors like smoking¹¹.

There are gender differences in the accelerated ageing effects associated with HIV. HIV-positive women are developing similar co-morbidities to men with HIV, but there appear to be additional metabolic complications associated with early menopause due to both HIV itself and to the effects of HAART.¹²

Effects of long-term highly active antiretroviral treatment (HAART)

While premature ageing effects are caused by HIV infection itself, other secondary conditions can be associated with antiretroviral drug toxicities. Although it may be known that particular antiretroviral drugs are affecting a patient's organ functioning, there may be no alternative to the person continuing treatment with the drugs that are producing the adverse effects. Alternative medications may be less effective and changing the HAART combination may place person at increased risk of developing further HIV-related co-morbidities, such as neuro-cognitive disorder.

National and international HIV studies are currently investigating the impact of long-term anti-retroviral therapy on the ageing process, such as increased susceptibility to cardio-vascular disease, hypertension, osteopenia, diabetes, arthritis, metabolic disorders, and some mental illnesses. Most drug trials testing for side-effects are conducted on people in their thirties or forties, however, with the result that people in older age groups may be prescribed HAART drugs despite lack of knowledge of side-effects for older age groups. Side-effects of long-term antiretroviral treatments (including HAART) and the development of co-morbidities need to be better understood to improve the quality of life of older people living with HIV.

Dementia

Risk factors for developing dementia are complex for people with HIV. Not only is HIV infection a risk factor for developing dementia in itself, but co-morbidities such as diabetes can multiply that risk.¹³

AIDS Dementia Complex (ADC), caused by deterioration of the central nervous system, is the most common cause of dementia in people under 40. Although ADC normally occurs in the late stages of HIV infection, it may occur within a few years of contracting the virus. ADC may involve severe depression, personality changes, psychosis and, less commonly, mania.¹⁴ As the life expectancy for people with HIV increases, so too will the incidence of ADC.

Frailty

Frailty is a recognised clinical syndrome associated with risk of injury and incapacity. Recent studies have found that HIV-positive men were three to eight times more likely to have a combination of conditions that together constitute frailty syndrome.

¹¹ Simone MJ and Appelbaum J, HIV in older adults. *Geriatrics*. 2008 Dec; 63: 6–12.

¹² Conde, DM et al., Menopause: The Journal of The North American Menopause Society, Vol. 16, No. 1, pp. 199/213

¹³ Cysique, L.A., P. Maruff, and B.J. Brew, Prevalence and Pattern of neuropsychological impairment in HIV Epidemiology and Clinical Research, NSW. Australian Institute of Health and Welfare, Canberra, ACT. 2009.

¹⁴ www.projectinform.org/info/adc/adc.pdf

The prevalence of frailty among 55 year old men who had been diagnosed with HIV less than four years previously was similar to that of uninfected men over 65 years.¹⁵

◆ **Recommendations:**

That the Commonwealth fund further research regarding the effect of HIV and HAART on the ageing process, so as to better understand:

- *the causes of accelerated ageing in HIV-positive people, and that research include investigation of gender-specific factors, including effects for transsexual people;*
- *the side-effects of HAART and other medical combinations for people over forty years; and*
- *emerging trends and projections in the HIV-positive population, and the implications for service planning and delivery.*

Need for coordinated primary health care

People aging with HIV who have a range of chronic conditions may need the advice of four or five specialists – with no single doctor having expertise across all the conditions. Difficulties arise for patients dealing with increasingly regular medical appointments, and for doctors managing cross-referrals. Most importantly, unless the patient is an expert in self-care management and is forthright in dealing with doctors, contraindicated medications can be prescribed.

These challenges are highlighted in the Sixth National HIV Strategy which states that:

‘Changes in the morbidity profile of HIV require a focus on the aged care system and on mental health and well-being ... (and) demand adjustments to HIV clinical services and research.

‘Avenues for improving access for people living with HIV and determining best practice models for service delivery across HIV specific and mainstream long-term support services, including aged care services require consideration and should be progressed in consultation with people living with HIV, through advocacy and workforce development initiatives in partnership with the relevant commonwealth, state and territory departments.’¹⁶

The Strategy further states that providing quality, well coordinated care to HIV-positive people with multiple chronic conditions requires a team-based, interdisciplinary approach, including GPs, specialists, nurses, Aboriginal Health Workers, pharmacists and other primary care providers.¹⁷

Interplay of the Sixth National HIV Strategy and proposed health reforms

In presenting its proposed health and hospitals reforms, the Federal Government argued that the reformed health and hospitals infrastructure will,

¹⁵ Desquilbet, L., et al., Frailty in older adults: evidence for a phenotype. *J Gerontol A Biol Sci Med Sci*, 2001.

Available at: <http://biomedgerontology.oxfordjournals.org/content/62/11/1279.abstract>

¹⁶ Sixth National HIV Strategy, op cit, 6.3.1

¹⁷ Sixth National HIV Strategy, op cit, 6.3.3

‘... bring together GPs, nurses, visiting medical specialists, allied health professionals and other health care providers to provide integrated, multidisciplinary care ... (which) will particularly benefit Australians with chronic and complex diseases.’¹⁸

The Federal Government’s planned adoption of responsibility for the funding of all health services provided outside hospitals, including GPs and community health clinics, could facilitate the development of best practice models of care for people with HIV. These initiatives, we believe, have great potential for creating coordinated models of care for people ageing with multiple HIV-related chronic health conditions, especially for those people whose ability to juggle appointments may be affected by frailty, financial constraints and social disadvantage.

The proposed National Network of Medicare Locals would ideally serve to better connect, not only primary health services involved in patient care, but also allied health services. Implementation of Commonwealth Budget and health reform initiatives must also address the care and support of people ageing with chronic illness, including HIV. There must be clear linkages between the Implementation Plan for the 6th National HIV Strategy and those developed in respect of recent Federal Government health reform initiatives.

GP workforce issues

In the eighties and nineties caring for patients with HIV presented clinical challenges for medical students and GPs. Debilitating illness and high mortality rates among young people with HIV created and sustained strong and passionate commitment among medical professionals. This led to the establishment of networks of GPs with high caseloads of HIV-positive patients, and the gradual development of competencies around HIV medicine and health management; Australia led the way with patient engagement and treatment.

These pools of GP expertise are shrinking. In Sydney, for example, of the current cohort of 25 to 30 GPs with HIV expertise, 15 are approaching retirement age and GPs are now generally less engaged regarding HIV. It is perhaps understandable that responding to the needs of older people with HIV, who require gerontology care and management of a complex array of HIV-related symptoms and co-morbidities, does not produce the passion and commitment elicited by the unfolding epidemic of HIV/AIDS in the eighties and early nineties. There is also a misconception that the care of people living with HIV is solely about managing HAART prescriptions.

Responding to the issues of premature ageing among Australians with HIV requires the development of targeted GP training and education resources that enhance an understanding of the impact of HIV on the natural ageing process, the associated co-morbidities of the illness and the psycho-social issues faced by older people living with HIV. It is particularly crucial that front-line clinicians better understand the challenges posed by the prevalence of neurological conditions affecting people living with HIV, especially AIDS dementia complex. Case management of people living with HIV must include periodical neuro-cognitive assessments.

¹⁸ A National Health and Hospitals Network for Australia’s Future (the Report), available at: <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhhrc-report-toc>

Health care workers need easily accessible information regarding the co-morbidities associated with HIV, the specific health implications and what actions can be taken to provide HIV-positive people with clear self-management information rather.

◆ Recommendations:

In addition to the general recommendations made above:

- *that as part of the initiatives announced in the May 2010 Budget, the Commonwealth develop guidelines for the management of chronic conditions for the use of GPs and GP practice nurses, which facilitate team-based coordinated care;*
- *that the recommendations of the Models of Access and Clinical Service Delivery for HIV-Positive People Living in Australia¹⁹ be implemented;*
- *that the needs of people ageing with HIV be considered as part of the Commonwealth's review of models of care, with a focus on identifying systemic barriers and loss of follow-up issues in specific populations;²⁰ and*
- *that models of care for GPs include access and equity principles that acknowledge the need for patient-centred, coordinated and integrated care; self-management; and continuum of care.*

Ageing with HIV: discrimination, stigma and psycho-social issues

As for any person ageing with disability, maximising the opportunity for an HIV-positive person to maintain quality of life into old age means understanding and responding not only to their health care needs, but also to the cultural and socio-cultural context that has defined their life and their experience of disability.

Sexuality

Ageing can bring with it with ever-increasing scrutiny of personal life by family, doctors and community services, along with the need to deal with a plethora of government bureaucracies and healthcare professionals. These challenges are acknowledged in a general sense in the policy strategies under development by the Commonwealth, states and territories, however, the particular issues faced by gay, lesbian, transgender and intersex (GLBTI) people as they age is given scant attention.

Most people ageing with HIV in Australia are, and will continue to be, gay men. For those who have avoided disclosing their sexuality throughout their lives, or who have limited disclosure to a small circle, the fear of exposure of private life and facing discrimination by health and aged care providers is very real and the prospect of entering into an aged care facility or service is daunting for people who have led contained and isolated personal lives due to the fear of exposure. Further research into this issue would support strategies to address this predicament, and enhance the quality of life of older LGBT people.

Although the steady development of strong anti-discrimination laws over the years has resulted in substantial progress toward eradicating discrimination on the grounds of sexuality, these broad social advancements can be peripheral to older people's personal lives. Many older gay men diagnosed with HIV in the eighties or nineties

¹⁹ Available at: <http://napwa.org.au/files/MACSD%20-%20Final%20Report.pdf>

²⁰ Sixth National HIV Strategy, op cit, 6.3.3

experienced stigma and discrimination due to their diagnosis and its close association in the Australian community with homosexuality, promiscuity and illicit drug use. This can create fear of dealing with bureaucracies – including health bureaucracies.

Mental health and dementia

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, and recent surveys of HIV-positive people show significantly higher use of mental health services than people in the general population²¹.

Much thought is being given to the rising incidence of dementia across the Australian community. Strategies are being developed regarding emerging home-care and institutional care needs for the general population, however, there is a clear need to focus on the complex issues faced by specific populations. HIV-positive people constitute one such population given the prevalence of dementia, depression, other mental illnesses and the overlaying issues of sexuality complicating access to appropriate treatment, care and support services.

Cultural diversity

While there has been strategic planning regarding cultural diversity in Australia's ageing population, there has been little recognition of the particular vulnerabilities of HIV-positive ATSI people and people from CALD backgrounds as they age. The stigmatisation of people with HIV and of gay men within some ATSI and CALD communities means that many HIV-positive people are estranged from their cultural community. This can complicate the assessment of individual needs for service access, as estrangement from cultural community may mean that a person's association is with the gay community or that they are socially isolated. The nature of these vulnerabilities and the diversity within cultural communities needs to be explored so that strategies can be developed that ensure that older HIV-positive people receive quality, culturally sensitive, care, community support.

The Sixth National HIV Strategy expressly acknowledges that ATSI communities have limited access to culturally appropriate HIV services, including primary health care services. With a higher prevalence of HIV infection among ATSI women than the general population²², there is a need to explore these emerging issues for aged-care and community service planning.

Privacy and confidentiality issues

Despite the introduction of anti-discrimination laws in Australia over recent decades, and the introduction of laws in most states- and territories protecting people living with HIV against non-consensual disclosure of their status, HIV positive people continue to face overt and covert discrimination in daily life. This discrimination extends to provision of health care and aged care services. 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

²¹ M. Carman et al., Trends in the location of the HIV-positive population in Australia: Implications for access to healthcare services and delivery. Australian Research Centre in Sex, Health and Society, LaTrobe University. Available at: <http://www.publish.csiro.au/paper/SH09063.htm>

²² Sixth National HIV Strategy, op cit

had experienced discrimination from health care services. Confidentiality of patient information has been among the most common breach reported.²³

HIV-positive people can be intensive users of the healthcare system – especially as co-morbidities associated with ageing emerge. People with HIV have much to gain from the introduction of e-health identifiers and electronic storage of health records, in terms of ensuring that treating health professionals are fully aware of co-morbidities and treatment histories. However, they may also have reason to fear such initiatives given the potential for a wider pool of health and aged care professionals to have access to comprehensive health records indicating their HIV-positive status - both within and beyond the healthcare system.

◆ **Recommendations**

- *that the Commonwealth fund research to enhance understanding of the psycho-social issues faced by people living with HIV as they age, particularly those associated with stigma and discrimination and the relationship to sexuality, cultural background and injecting drug use;*
- *that the Commonwealth initiate consultations, as part of its implementation of the Sixth National HIV Strategy, regarding workforce sensitivity training and professional development on stigma and discrimination issues faced by people living with HIV, LGBTI people, injecting drug users and sex workers; and*
- *that national guidelines be developed for service providers to ensure that practitioners have ready access to comprehensive information regarding the design and delivery of socially inclusive services²⁴.*

Home and community care issues

Disability/aged care program gaps

As discussed above, HIV-positive people age prematurely. This can pose problems for people requiring ‘premature’ access to aged-care services where the definition of ‘aged’ is routinely set at 65 years of age.

This service gap is derived from arbitrary eligibility criteria for services provided by the disability support system, and Home and Community Care (HACC) services. Not only does this pose access barriers for people newly requiring care and support, but age-based eligibility criteria can also mean that people who have been served well by disability services find the transition to aged services both difficult to negotiate and emotionally distressing – including people with HIV-related dementia, who have complex psycho-social needs, and who have formed close bonds with community organisations

²³ J Grierson, R Thorpe, and M Pitts (2006). HIV Futures 5: Life as we know it, monograph series no. 60, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, p. 68. Available at: <http://www.latrobe.edu.au/hiv-futures/HIV%20Futures%205%20Report.pdf>

²⁴ The Department of Health in the UK has developed a comprehensive guide for the National Health Service along these lines, entitled Sexual Orientation. It can be found at: http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_095635.pdf

HACC program issues

Another area of need identified nationally by HIV-positive people is housing support. There is a critical need for emergency and respite accommodation for HIV-positive people. There is also a clear need for improved access to supported accommodation, and to subsidised accommodation for HIV-positive people living on low incomes.

Access to secure and affordable housing, including emergency accommodation, is a well-known and extensively documented factor affecting peoples' health and wellbeing. Although some community health services have identified the need to develop access strategies in delivering HACC and disability programs to people living with HIV, these programs are piece-meal and ad hoc. The lack of affordable and appropriate housing is a source of great anxiety among HIV-positive people in most states and territories. There is considerable ongoing uncertainty about these arrangements and to what degree current programs will continue to be funded – particularly given current health reform proposals

Care Packages

As discussed above, the coordination of care services for people ageing with HIV requires a model of service delivery that links patient care to a range of health care services. Currently HIV home care services are coordinated for HIV-positive people by a diverse range of medical and community sector personnel. These include both high and low caseload general practitioners, sexual health doctors and a range of allied health professionals. There is an urgent need to for coordinated case management, both in the HIV-specific and mainstream health services. It is important to engage HIV-positive people in the development of service delivery models which favour a case management approach to the provision of care which is person-centred, culturally appropriate, socially inclusive and sensitive to individual circumstances and potential issues relating to HIV-related stigma – past and ongoing.

◆ Recommendations

- *that DoHA fund a comprehensive review of Commonwealth and state/territory legislation to identify programs and services for which eligibility is prescribed by age, disability support pension and/or age pension entitlement, to identify gaps in access and to integrate specialist and primary care services;*
- *that the transition between disability and age-care services be streamlined, and that transition to aged-care services not be mandatory. Transitional issues must be addressed in individual care package funding and should specify maintenance of links to specialist services, such as HIV and GLBT services; and*
- *that the Commonwealth develop, in collaboration with community organisations, training and advocacy programs for the disability and aged care workforce.*

Residential care issues

Younger people in aged-care

The recently release of the Mid-Term Review of the Younger People in Residential Aged Care (YPIRAC) Program²⁵ highlights the ongoing need for residential care

²⁵ Available at: http://www.facs.gov.au/sa/disability/pubs/policy/ypirac/Pages/mid_term.aspx

facilities for young people with severe disability who are living in or at risk of admission to residential aged care. We note, however, that very few young people have been moved to more appropriate residential care under this program to date, and that as the program targets people who are under 50, the cohort of people ageing with HIV-related dementia are not generally covered by the initiative.

The rising prevalence of dementia constitutes one of the most challenging issues associated with health and aged care planning. The fact that the prevalence of dementia among people living with HIV is significantly higher than in the general population and that it affects people at a younger age must be taken into account in health and aged care planning.

People with dementia unable to be placed

Professor Bruce Brew, Professor of Neurology and Medicine at the University of New South Wales, is well aware of the range of issues associated with placing people with HIV-related dementia in residential care:

'Nursing homes just will not accept these sorts of patients for a whole host of reasons. It's a common theme amongst young neurologically impaired patients that there are very few, if any, facilities prepared to take them on. It shouldn't be the case but unfortunately it is the case and then you have the extra problem of their being HIV infected, and even in this day and age some still misplaced fear, misunderstanding, of how to deal with HIV infected patients.

'There's a lot of homophobia that goes with that inevitably because most of the people with HIV in Australia are gay men, so we do hear stories about people where the staff are double-gloved just for simple things like coming in and, you know, delivering their breakfast. You know people are treated like they're in barrier nursing, dinner trays being brought in and left on the table by the door rather than brought to your bed because the attendant won't come that close to you. Unfortunately in the aged care sector there are a lot of people working in aged care who have limited literacy around these things, it's semi-skilled work a lot of it and it's a relatively low paid work too, for what aged care workers have to deal with. So without trying to excuse that level of misunderstanding I think there are reasons for it.

'There are patients who are unfortunately left in a variety of hospital settings, sometimes in palliative care settings. There are other patients who are essentially managed at home with extreme carer fatigue and burden. And there are some patients who simply can't be placed and essentially remain in hospital and then one complication develops after another and they pass on.²⁶

Discrimination in aged-care

*My People: A project exploring the experiences of GLBTI seniors in aged care services*²⁷ provides deep insights into the issues faced by GLBTI people entering

²⁶ ABC Radio National, All in the Mind, *Ageing Positive: HIV, dementia and the brain*. Available at: <http://www.abc.net.au/rn/allinthemind/stories/2010/2896016.htm>

²⁷ C Barrett, *My People - A Project Exploring the Experiences of Gay, Lesbian, Bisexual, Transgender and Intersex Seniors in Aged-Care Services*. Available at: <http://www.matrixguildvic.org.au/MyPeopleReport2008.pdf>

residential aged care. Her interview with 'Tom' keenly portrays the isolation felt by a gay HIV positive man in care, and highlights the pressing need for workforce sensitivity training – regarding both the psycho-social impacts of living with HIV and also regarding sexuality. Tom's account of his experiences in care speaks for itself:

Tom's story:

My name is Tom and I've been in a nursing home since I had a stroke four years ago. I had the stroke because I've got HIV. I've got two brothers and one sister but we don't talk because I'm gay and I've got HIV and they disapprove. I've got no one in my life now that loves me, except the old girl, she loves me. When mum goes I'm done. Because I'm gay, I'm a lonely man. Oscar Wilde said 'City life, millions of people living lonesome together.

When I came here I told the staff that I was married and they started asking to see the pictures of my wife. Of course I didn't have any and because they knew I had HIV they worked out that I'm gay. I can't talk to the staff about being gay because I'm worried my care will be worse. I'm not able to live a gay man's life here because there is no privacy and there are rules and some people think that gay is disgusting. I keep my mouth shut. I have to be careful how I act and careful of what I say. I'm only sixty-four but I'm an old man.

The HIV makes me feel old and this place makes me feel old. I've got no one to talk to here because the residents sleep all day and they have dementia. My mind is still good but I have no conversation. I talk to Lizzy; she's my Community Worker from the Victorian Aids Council. I talk to her about how much I miss sex, touch and intimacy, but I can't talk to the staff in here about that. When I realised there was nothing for me in here; that I had to forget about a sexual relationship with a male, my libido was extinguished. For years I rallied against this place, and then I got depressed and succumbed to it. I need to meet interesting people to make me feel alive again for a while and then back to this deadness. What else is there, I can't talk to them. I'm a reasonably intelligent man. It's depressing being in here so I started on anti-depressants. They're called happy pills. I had to go on them when I came here. It's depressing.

I've got extra services because of the HIV. People who know about HIV come here to help the staff look after me. I have Lizzy who organises volunteers to take me out for a latte, or a beer or a drag show. They've helped with my HIV and they've changed the way staff treat me. See they are used to gay men and I can be a gay man when I'm with them. They've educated the staff about how to care for me, so I get better care. They check that I'm getting the right care. The staff here know that there are people who are interested in what happens to me. That makes a difference.

The services that come in for my HIV have made some staff take an interest in gay culture. One Nurse wants to come to a drag show with me. That's good because a lot of straight people don't understand gay people. The other benefit is that the services understand gay men, so it's my chance to be with my kind of people. When I'm with them, I come alive. We can talk about the old times and I can be myself. Lizzy says there are more gay men with HIV like

me who are going to need aged care. Can you tell them my story so that they get looked after as well and don't get lonely like me?' ²⁸

Tom's experience graphically highlights the pressing need for sensitivity training for the aged-care workforce, focussing on the particular needs and vulnerabilities of people who have been socially marginalised.

◆ **Recommendations:**

- *that the need to provide suitable, age-appropriate residential care for young people with disability, including severe cognitive disability, be a primary focus of the Commonwealth's health reform agenda, and that the particular needs of the growing population of HIV-positive people in this cohort be taken into account in service planning;*
- *that the Commonwealth fund the development of training and educational resources to sensitise doctors, health care, disability and aged care workers to issues faced by GLBTI people, people living with HIV, injecting drug users and sex workers. The resources should be developed in partnership with specialist community sector organisations and should cover cultural diversity, sexual diversity, stigma and discrimination; and*
- *that strategies be developed to improve access to aged care complaint systems and community organisations that provide advocacy in complaints (Sixth Strategy -6.4)*

Daily life ageing with HIV ...

The following case studies, drawn from recent interviews by NAPWA staff of Bobby Goldsmith Foundation clients, highlight some of the health and psycho-social issues that people living with HIV confront as they age. The clients' names have been changed to protect their privacy.

Mark

Mark is 44 years old and was diagnosed HIV-positive almost 20 years ago. Mark lives in supported accommodation in central Melbourne having spent many years being "shuffled through a number of rehabilitation centres" as he "struggled to come to terms with drug and alcohol problems". Mark was referred to the supported accommodation service following major health deterioration and has been living there for almost 10 years. Mark is supported by a number of HIV-specialist services and professionals including his local HIV clinic, psychologist, HIV Community Team, community nurse and social worker. Mark also has an occupational therapist who is working with him on his severe Peripheral Neuropathy (a nervous system condition believed to be related to HIV and treatments) causing extreme pain, and in Mark's case, severely reduced mobility, with Mark dependent upon a motorised wheelchair.

Mark is socially isolated, with his only immediate contact coming from fellow residents and staff at the accommodation centre - he does enjoy the support of his parents and two siblings – who all live in other states. Mark's lack of mobility, social isolation and the degree to which his supported accommodation provides "a safe haven" for him has resulted in a degree of

²⁸ Ibid, p.51

dependency on these services and he says he “doesn’t know where I would be without them”. Mark’s mobility is affected to such an extent, that a visit to the doctor, or a cup of coffee at the local café (both no more than 200 metres away) constitutes a major undertaking requiring considerable planning and support.

Thinking of the future, Mark says that for him to live at all independently he would require specific and specialised case management and a high degree of community support, including those that he receives at the moment. For Mark, the risk of losing any of these “is just too much to contemplate”.

Mark has been in receipt of DSP since becoming diagnosed and, as such, has no life savings and no superannuation accrual and subsequently no retirement plans or financial backing. And, although Mark’s parents are independently wealthy, as an adult, estranged from his family for some time in the past, Mark does not see that financial support from that quarter is “expected or anticipated”.

Clive

Clive is a 59-year-old man living in the St George area of metropolitan Sydney and diagnosed with HIV 25 years ago. Clive has been on the Disability Support Pension (DSP) for almost as long as he has been diagnosed and describes his financial situation as “pretty dire – I’m behind about \$100.00 every fortnight” – and sometimes he has to “cut corners [...] including “going without food”. In the past, Clive has borrowed from family and Centrelink “to make ends meet”.

Until four years ago, Clive had been renting in the private market and his ‘snowballing debts’ had required that he move home “many times” – he now lives in secure supported accommodation with other adults living with drug and alcohol issues.

Clive has been hospitalised a number of times since his diagnosis and now has a threatening heart condition and describes his overall health as “pretty poor”. Clive is socially isolated, and like others living long-term with HIV, he has lost a significant number of close friends and acquaintances. When asked to describe his emotional wellbeing Clive says he “gets very depressed and often feels down”. Clive sees a psychiatrist, a psychologist and his regular HIV doctor and is currently prescribed anti-depressants.

Clive is estranged from his family – except his younger sister who is his closest support but who also lives in another state and “we don’t see each other often – about once or twice year – but she does call occasionally”.

When asked about his future plans, Clive says that at 59 years of age he does not see any single man, Clive has no immediate guardian, or support network should he become ill and require hospitalisation and this is “a real problem for me”. From previous experience, Clive is concerned that there is “no one to manage the rent and pay the [utility] bills” and he worries “about becoming homeless again”. Clive has used the Office of the Protective Commissioner

and the HIV/AIDS Legal Centre (HALC) in the past who have resolved some of these problems on his behalf. However, when it comes to the future Clive prefers to “put it all in the too hard basket” because Clive’s particular experience of living with HIV to date has been “so difficult and unpredictable”.

Greg

Greg is 61 years old and lives alone in public housing in rural NSW, he was diagnosed HIV-positive in 1992 and has been on the DSP since 1993. Greg has a ‘female companion’ who lives independently from him, as do his two adult children. Greg says that financially he “lives day-to-day and week-to-week” and he is a regular client with an HIV Clients Service organisation which provides him with limited financial support – to assist with meeting essential utility bills.

Despite Greg’s long-term diagnosis, he says that HIV is not his most pressing health concern. Rather, Greg has survived two heart attacks, has three Stents in his heart and his compromised general health means that his heart condition, in particular, requires ongoing professional monitoring and personal attention to things like diet and exercise. Greg says that he is “not consciously thinking about the future” he struggles with relationships and friends and says he has “come to the point where [he doesn’t] need anyone”. For Greg, HIV has been like “carrying a big secret” and his experiences of disclosure of his status in the past “has not paid off” and he says that “is why I have become withdrawn”.

When asked of his closest support, Greg identified his ageing mother. He went on to muse that his mother’s health is deteriorating “she is in her 80’s you know” and he is “no longer certain who is looking after who”. For Greg at 61 years of age, any thought of the future is for him “the end – I mean we’re talking end game and I’d rather not think about that really”.