

21 March 2011

Inquiry into Caring for Older Australians
Productivity Commission

Email: agedcare@pc.gov.au

Dear Sir/Madam,

Re: Productivity Commission Draft Report, *Caring for Older Australians*

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.

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 (PATSIN). 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.

While AFAO and NAPWA congratulate the Productivity Commission for the breadth and detail of its draft report *Caring for Older Australians*, we are dismayed that the particular needs of people ageing with HIV have been overlooked.

As outlined in the **attached submission** to the Senate Inquiry into Access to Planning Options and Services for People with a Disability, people who have lived long-term with HIV have often faced a complex interplay of cultural and sexual identity issues. This interplay of issues does not evaporate with age. There is ongoing stigma associated with HIV within the broad community and within sub-populations – including among aged care service providers - and there is a pressing need for mainstream aged care workforce development by way of sensitivity training around HIV. The draft report certainly addresses the need for broad-based sensitivity training covering issues around disability, cultural background and sexuality; however, there is no reference in the report to workforce issues regarding HIV-related stigma and discrimination in particular. This is despite the fact that stigma has long been recognised as a serious and debilitating feature of the HIV epidemic. Commitment to reducing stigma and addressing issues relating to ageing with HIV are both priorities under the Sixth National HIV Strategy. NAPWA is currently conducting an audit of the experience of HIV stigma among people living with HIV in Australia. Formative evaluation undertaken on behalf of AFAO and by NAPWA has indicated that HIV stigma remains a salient issue among people living with HIV. Findings from the audit will also address important national social inclusion principles.

AFAO and NAPWA request that the Commission's report be revised to address these omissions, particularly **Chapter 9 Catering for diversity – caring for special needs groups**. We ask that a new section be included in Chapter 9 that identifies people with HIV as a special needs group. In particular we ask that the Commission address issues regarding:

Privacy and confidentiality

Despite the introduction of anti-discrimination laws in Australia over recent decades, and the introduction of laws in most states/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 the 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 had experienced discrimination from health care services. Confidentiality of patient information has been among the most common breach reported.¹

Content regarding HIV-related privacy and confidentiality issues should be a mandatory component of course curricula, training and continuing education for the health, disability and aged care workforces.

Cultural diversity

While the report recognises the need for strategic planning regarding cultural diversity in Australia's ageing population, there is no recognition of the particular vulnerabilities of HIV-positive people from Aboriginal and Torres Strait and other culturally and linguistically diverse communities. The stigmatisation of people with HIV and of gay men within some communities can mean that many HIV-positive people are estranged from their family and

¹J 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>

cultural community and the support that their community would otherwise provide with ageing.

This estrangement and isolation can complicate the assessment of individual needs for service access, and create substantial access barriers. The nature of these vulnerabilities and the diversity that exists within cultural communities needs to be recognised in the report, so that appropriate responses may be developed.

Mental health and dementia

Much thought is being given to the rising prevalence of dementia across the Australian community. Strategies are being developed regarding emerging home-care and institutional care needs for the general population and for specific populations such as people from culturally and linguistically diverse populations.

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. 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.

Research developments

We also draw the Commission's attention to important recent research conducted by NAPWA and the National Centre in HIV Epidemiology and Clinical Research regarding the age distribution and survival rates/forecasts for Australians living with HIV. The study found that the population of people living with HIV is ageing: in 2010 the proportion of the HIV-positive population over 55 years was 25.7% and by 2020 it is expected to be 44.3%.

Thank you for this further opportunity to provide input to this Inquiry.

Yours sincerely

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