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13 May 2011

Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428 Canberra City ACT 2601

Email: disability-support@pc.gov.au

Dear Sir/Madam,

Please find following the joint submission of the Australian Federation of AIDS Organisations (AFAO) and the National Association of People Living with HIV/AIDS (NAPWA) to the Productivity Commission's Disability Care and Support Draft report.

The Australian Federation of AIDS Organisations (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 Living with HIV/AIDS (NAPWA); the Australian Injecting and Illicit Drug Users League (AIVL); 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 and its effects, develops and formulates policy on HIV issues, and provides HIV policy advice to Commonwealth, state and territory governments.

The National Association of People Living with HIV/AIDS (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.

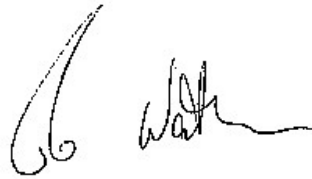
Accordingly, we submit this document as AFAO's and NAPWA's joint submission to this Inquiry. We

would like to take this opportunity to congratulate the Government for its timely decision to undertake this Inquiry, and are very pleased to contribute comment.

Yours sincerely,



Don Baxter
Executive Director
Australian Federation of AIDS Organisations



Jo Watson
Executive Director
National Association of People Living With HIV/AIDS

AFAO and NAPWA joint submission to the Productivity Commission's Disability Care and Support Draft report

Our perspective on this Inquiry

AFAO and NAPWA are pleased to be given the opportunity to make a submission in response to the Productivity Commission's recently released draft Disability Care and Support Inquiry report (the Report).

AFAO and NAPWA agree with the Commission that the current disability support system is underfunded, unfair, fragmented, and inefficient - giving people with disability associated with impairment arising from a medical condition or illness little choice and no certainty that they will get the support they require. We welcome the key proposal to create the National Disability Insurance Scheme (NDIS). AFAO and NAPWA believe that the NDIS Scheme would go some way to providing long-term care and support to people who develop a significant disability as a result of a medical condition or illness, including people living with HIV.

AFAO and NAPWA are concerned that the proposed NDIS addresses the needs of people with disability who live with HIV. We believe that people with disability should be treated equitably regardless of the nature and determinants of their disability. While we believe that the NDIS should be broadly consistent in its eligibility, assessment and appeals processes, it should also be sufficiently flexible to take into account all impairments which fall within the definition of a social model of disability, whether those impairments are directly attributable to a condition or related to co-morbidities.

We believe also that it is crucial that people with lived experience of disability have a key role in governing and administering the NDIS.

HIV and Disability

HIV meets the definition of 'disability' under the Disability Discrimination Act (DDA), 'disability' under the Act being defined as including 'the presence in the body of organisms causing (or capable of causing) disease or illness'.¹

For any consideration of what disability means in terms of a person's capacity to participate in community and economic life to their full potential, the social model of disability provides the most

¹ *Disability Discrimination Act 1992*, The Office of Legislative Drafting and Publishing, Attorney-General's Department. Australian Government, Canberra.

appropriate approach. The model ensures that past and ongoing barriers to social participation are acknowledged and addressed in policy and strategy development. Indeed, 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 having a disability under both the DDA and under the CRPD. This social model approach means that the physical impairments associated with HIV are taken into account when assessing a person's support requirements, as are any psycho-social barriers to their social and economic participation in community life. Such barriers may stem from the pervasive impact of HIV-related stigma and discrimination – past and ongoing. This impact may be exacerbated by other social factors including levels of educational attainment and access to employment and housing. Due regard to such psycho-social barriers is essential if people with significant disability associated with living long-term with HIV are to have equitable access the NDIS.

Assessing NDIS eligibility

The Productivity Commission states that NDIS eligibility should be determined by functional measures, condition-based measures, or a hybrid approach where appropriate.

AFAO and NAPWA are concerned that the selective use of functional, clinical measures fails to reflect the social model of disability. We believe that the use of a framework such as the International Classification of Functioning, Disability and Health (ICF) to assess eligibility of support may be appropriate - provided that it is used in conjunction with a broad set of goals that foster full social and economic participation and inclusion. The ICF tool in fact incorporates a range of such measures, to assess the extent to which people with disability engage in social and civic life, and the availability of support technologies.

Criterion 1 - comments

Where a person's functional physical or cognitive impairment is sufficiently severe, the person would seem to be eligible for the NDIS under criterion 1. AFAO and NAPWA understand that HIV-positive people who have significant physical and/or cognitive impairments which unequivocally result in severe disability would fall under the 1st NDIS eligibility criterion³, i.e., by virtue of experiencing 'significant limitations in communication, mobility and self-care'.

Assessment of the support requirements of individuals with severe functional impairments should take into account any psycho-social issues that may affect communication, mobility and self-care, so that the person's needs can be assessed and properly tailored support provided. AFAO and NAPWA propose that NDIS assessor training should incorporate an understanding of the impact of psycho-social issues faced by HIV-positive people with disability. Where an individual's medical evidence on

³ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, 13.

which assessments are based includes information regarding their HIV-positive status, eligibility and assessments should take into account potential psycho-social issues the person may face in accessing support services.

AFAO and NAPWA also believe that people with disability require avenues to negotiate and appeal across all levels of the assessment process. Appeal mechanisms should allow for proactive advocacy; for some people an independent advocate may mean the difference between obtaining an accurate assessment or not. It is important that adequate funding is provided to ensure access to independent advocates.

Criterion 3 - comments

The Report indicates that for 'Tier 3 – individually tailored funded supports', eligibility for funding is predicated on individuals having a 'permanent disability'⁴, and attention is drawn to the terms of reference stating that the NDIS should address the long-term care and supports needs of individuals with a 'severe and profound' disability.⁵

AFAO and NAPWA recognise that given the efficacy of anti-retroviral treatment, many people living with HIV have no or minimal impairments associated with HIV. Accordingly, many HIV-positive people will maintain relatively good health, without significant disability, well into old age and will require no assistance from the disability system.

However, as the Australian population generally ages there will be a disproportionate number of people living with HIV who acquire disability, physical and cognitive, associated with HIV as they age⁶. People who have lived long-term with HIV are susceptible to an array of HIV-related co-morbidities which are normally associated with ageing - due both to the effects of the virus itself and due to effects of long-term antiretroviral treatment. Common HIV-related co-morbidities include⁷:

- cardiovascular disease
- diabetes
- arthritis
- osteoporosis and other bone conditions
- neurological impairment (e.g., Alzheimer's, Korsakov's dementia)
- HIV-related dementia
- mental illness

⁴ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.15.

⁵ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.10.

⁶ National Centre for HIV Epidemiology and Clinical Research (NCHECR) and National Association of People Living With HIV/AIDS (NAPWA). (2010). *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*. University of New South Wales (UNSW), Sydney.

⁷ Petoumenos, K., Law, M. (2006). Risk factors and causes of death in the Australian HIV Observational Database. *Sexual Health* 3(2),103–112. doi:10.1071/SH05045.

- cancers (anal, bowel, breast, cervical and lymphoma).

People living with HIV may thus experience impairments at an earlier age than the general population, and these may be 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 may thus experience develop a disability earlier than those who do not have HIV. It is also important to note that people who acquire HIV over the age of 50 tend to experience a more rapid deterioration in health compared to those who acquire HIV under 50 years of age.⁸

AFAO and NAPWA are concerned that NDIS eligibility criteria may preclude people with disability associated with living long-term with HIV, as these impairments may be ascribed to the 'normal' or 'natural' ageing process. For people who have lived many years with HIV, the debilitating impact of the disease in conjunction with a range of co-morbidities may mean that they effectively age prematurely, while for people who acquire HIV later in life, the disabling impact of the disease will be more severe. It is important that NDIS assessment guidelines acknowledge the effect of age-related impairments for people living with HIV in planning service and support options. When an individual's requirements change, assistance should also change, thereby providing certainty and adequate support to maximise the person's participation in community and economic life.

Many chronic illnesses result in functional limitation. AFAO and NAPWA support the view, as expressed by the NSW Government, that coverage under the NDIS should include people with chronic illness where their condition requires long-term support for daily living.⁹ AFAO and NAPWA agree with the Productivity Commission's proposal that the NDIS form a common memorandum of understanding (MOU) with the health sectors in each state and territory to ensure that the health, and support requirements of individuals with chronic and progressive health conditions are met in an integrated and equitable fashion.

The fact that middle-aged people living with HIV are more likely to develop disability, and be challenged by the difficulty of managing a complex array of co-morbidities, should be recognised in the development of NDIS eligibility criteria and assessment processes.

Use of the terms 'permanent', 'severe' and 'profound' may mean that people with disability associated with a range of impairments arising from multiple, chronic conditions may have difficulty establishing NDIS eligibility. This may include HIV-positive people whose physical impairments and psycho-social barriers together mean that they may require a range of supports. As outlined above, in the interests of equity and greater inclusion, AFAO and NAPWA support the social model of disability. We contend that clinical measures of impairments and disability should be assessed with consideration to any social barriers that exclude full inclusion and participation, including attitudinal

⁸ NCHECR and NAPWA. (2010). *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*. UNSW, Sydney.

⁹ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.22.

and environmental barriers.

Aboriginal and Torres Strait Islander Australians and the NDIS

As discussed in the Report, Aboriginal and Torres Strait Islander Australians experience disability on average at an earlier age than other Australians. AFAO and NAPWA believe that it is essential for there to be equitable access to quality care for Indigenous Australians living with HIV who may experience a range of access barriers, including well documented psycho-social health issues.

In its report *Australia's Health 2010* the Australian Institute of Health and Welfare, focused on the socio-economic gradient of health, concluding that those with advanced socio-economic status tend to be healthier than those individuals located at the lower socio-economic status. The Report concluded that disability and lower socio-economic status go hand-in-hand: 'severe disability was more common in those suburban areas where residents had relatively few economic resources than in areas whose residents had more.'¹⁰ The gap between the health of Aboriginal and Torres Strait islander communities and that of the wider population is significant, and the compounding nature of disability means that ATSI people with disabilities have greater care and support needs. NDIS eligibility criteria, procedural guidelines and assessment processes must fully recognise these needs.

It is crucial that the planning and implementation of NDIS draw on the expertise of Aboriginal and Torres Strait Islander communities' expertise. We endorse the comments made by the Australian Federation of Disability Organisations regarding the importance of capturing local knowledge about planning of the NDIS.¹¹ Local knowledge should help establish priorities regarding infrastructure, disability support staff training needs including culturally appropriate service provision.

Payment options

AFAO and NAPWA are pleased that the Productivity Commission has called for assessment of NDIS support requirements to be self-directed in many instances. We are concerned however that these payments be sufficiently flexible to accommodate individual needs. HIV-positive people in receipt of pensions and fortnightly payments may find it convenient to roster their budgets fortnightly, while others may prefer options that accommodate their support requirements over a monthly cycle.

AFAO and NAPWA are also of the view that people living with episodic, chronic illness (as is often the case for people living with HIV), may have extended periods of time without requiring support. For these people, we propose that the notion of a 'support bank' be considered, whereby funds are accumulated until needed, or where access to support funds (also self-directed) is allocated in lump sums on long-term regular basis.

Complaints and monitoring

¹⁰ Australian Institute of Health and Welfare (AIHW). *Australia's Health 2010*. AIHW, Canberra, p. 254.

¹¹ Australian Federation of Disability Organisations. (2011). Submission to Productivity Commission's Aged Care Inquiry Draft Report, p. 22.

AFAO and NAPWA believe that there should be a robust monitoring framework and complaints handling mechanism to ensure that the NDIS is administered fairly and consistently, and that it reflects the intended high-level purposes behind introducing the Scheme.

We support the views expressed by the Deafness Forum that the Administrative Appeals Tribunal is not the appropriate vehicle for process-based review. We agree with the Deafness Forum's recommendation that the Government establish an independent Office of the Disability Ombudsman, with suitable powers to protect the most vulnerable in our community, including the power to refer cases to the Australian Human Rights Commission and undertake independent monitoring of trends/issues and regular reporting on these to the Parliament.

Aged Care

AFAO and NAPWA support the Report's first funding option as we believe this best ensures the integration between the NDIS and aged care services from an individual/end-user viewpoint.¹² The first option is that regardless of when or how people acquired their disability, and irrespective of which system they elected to be in:

- the NDIS would fund the care and support needs of people aged up to the pension age, including for disability arising from age-related conditions like strokes and early onset dementia (thus potentially covering people with severe disability associated with HIV-related conditions); and
- the aged care system would fund the care and support needs of all people over the pension age. If a person elected to stay in the NDIS, the assessment tools from that system would be used to determine their funding. This would ensure that people who acquired a disability before the pension age would have the assurance that they would not get a different level of care and support.

Mental health

AFAO and NAPWA recognise that while there is overlap between mental health and disability services, there are also significant differences. The current lack of integration between the two sectors disadvantages people with multiple disabilities, including people living with HIV.

It is also essential that the NDIS incorporates recognition of particular vulnerabilities of certain populations – including people among Aboriginal and Torres Strait Islander communities; refugees; lesbian, gay, bisexual, transgender and intersex communities – all of whom are known to have higher than average rates of mental illness. Adoption/use of the social model of disability for determining NDIS eligibility and assessment would best facilitate appropriate responses to the needs of people among these vulnerable groups.

¹² Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.20.

AFAO and NAPWA support the Report's proposal that allocation of responsibility for service provision be according to the principle that each sector should focus on their area of comparative expertise.¹³ So for example, the mental health sector would be responsible for:

- specialised services such as psychology, psychiatry (which would include early intervention), acute and inpatient services and pharmaceuticals for all types of mental illness; and
- provision of all services to people with non-permanent mental illnesses (such as many affective disorders).

Palliative care

AFAO and NAPWA support the Report's recommendations that where an individual with an advanced terminal illness seeks NDIS support, they should be referred to the palliative care sector; and where an individual is in receipt of individually funded support and their condition subsequently deteriorates such that they are in the final stages of their life, they would continue to have their care and support requirements met by the NDIS.¹⁴

Implementation Issues

According to the Report, while current users of National Disability Administrators (NDA) services will overwhelmingly receive funded support under the NDIS, the same may not be true of all Home and Community Care (HACC) users.¹⁵ HACC services currently cover a wider range of individuals than the target populations that would be eligible for funded supports under the NDIS, and AFAO and NAPWA are concerned that current 'low-level' HACC users may not get the same level of services using the NDIS assessment criteria.¹⁶

The Report raises the question of whether a so-called 'no-disadvantage' test should therefore apply, but ultimately argues against it in favour of comprehensive and objective assessments of the nature, frequency and intensity of a person's current support needs. It proposes that the assessment process be person-centred and forward looking, and consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do.

¹³ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.25.

¹⁴ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.30.

¹⁵ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.25.

¹⁶ Productivity Commission. (2011). *Disability Care and Support*, Draft Inquiry Report. Australian Government, Canberra, p. 3.32 - 3.33.

AFAO and NAPWA are supportive of this approach in principle. However, if there is any gap between assessment and receiving the assessed benefit, the individual should be at no disadvantage with the support they receive in the interim.

Conclusion

The introduction of the National Disability Insurance Scheme (NDIS) provides a transformative opportunity to provide long-term care and support for individuals who acquire a significant disability as a result of a medical condition or illness.

The Report argues for the integration of the NDIS with existing service delivery, such as aged care, mental health, palliative care and HAC C services. We support the Productivity Commission's proposal that the NDIS should include a common memorandum of understanding (MoU) with the physical health, mental health, palliative and aged care sectors, so no individual is disadvantaged by the introduction of the NDIS.

In its Report, the Productivity Commission stresses that in its view NDIS eligibility should be determined by functional measures, condition-based measures, or a hybrid approach where appropriate. Such an approach is inadequate in respect of HIV and other chronic illness which, by their nature and progression, often include a range of disabling co-morbidities. AFAO and NAPWA firmly believe that NDIS assessments should be based on the social model of disability. Such a view ensures that all people with a long-term disability resulting from a medical condition or illness, including those whose disabilities result from HIV, receive appropriate care and support.