



**Australian Federation
of AIDS Organisations**



Comments on

***A New System for Better Employment and Social
Outcomes
Interim Report of the Reference Group on Welfare
Reform to the Minister for Social Services***

August 2014

About AFAO & NAPWHA

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 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 the Commonwealth, state and territory governments.

The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV. NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community. NAPWHA provides advocacy, policy, health promotion, effective representation, and outreach on a national level. NAPWHA also contributes to clinical and social research into the incidence, impact and management of HIV.

AFAO & NAPWHA have had the opportunity to read the National Welfare Rights Network and ACOSS submissions on the Interim Report. AFAO endorses the comments and recommendations made in these submissions – particularly given that these views are informed by their detailed understanding of past and present welfare frameworks.

AFAO and NAPWHA appreciate that many of the proposals set out in the Interim Report are undeveloped and are included to generate discussion among stakeholders. Our particular interest regarding the welfare reform proposals primarily relate to the potential impact of the proposed changes to DSP eligibility criteria on people with chronic conditions such as HIV, and regarding the proposed alternative framework for providing income support to people with intermittent or partial incapacity to work due to medical or psychiatric disability.

Although HIV is now generally a manageable health condition, people living with HIV can be severely debilitated or generally frail due to the compound effect of managing multiple chronic conditions and HIV treatment regimes. This is especially the case for people ageing with HIV, many of whom having lived with HIV for decades. Some people in this category are now on DSP, and some are on NSA. Others are still in work – full or part time – but approaching the point where they cannot reasonably sustain ongoing employment. These people are effectively forced into early partial or full retirement and we are concerned that any restructure of the social support system represents an improvement in terms of enhancing social and economic engagement.

Historical background: HIV and social security entitlements

From the mid-eighties to the late nineties, people who had been diagnosed with AIDS were often considered to be “manifestly” eligible for DSP. Assessment guidelines had regard to AIDS “stages”, and medical evidence indicating that a person had a low CD4 count and ongoing HIV-related infections generally meant that they DSP was granted. People recently diagnosed with HIV who had episodically debilitating symptoms were also fairly routinely granted DSP. Not only was the impairment rating system for DSP more flexible than it is now, but the work test was 30 hours a week and the DSP eligibility criteria in the Social Security Act could take into account socio-economic factors affecting a person’s work capacity and capacity to retrain. This meant that people with AIDS who were severely ill and had no work capacity were fast-tracked to DSP; and that people with HIV who experienced episodic HIV-related infections and ongoing depression, for example, could either work part-time and receive part-pension or do periods of full-time casual work with breaks during which they would claim and receive pension.

The Modern Context of HIV

Modern antiretroviral treatment means that a person diagnosed with HIV now has a work capacity and life expectancy equivalent to their HIV-negative peers. However, the cost of HIV treatment and care in Australia is expensive. PLHIV already spend an average of 30% of their income on medications¹. Proposed changes contained in the 2014 Federal Budget have the potential to significantly raise costs for Australians living with HIV, with increases in the PBS co-payment, an increase in the level at which the PBS safety net becomes effective, and the proposed introduction of a copayment for health services.

Historically, the debilitating effects on health of living with HIV mean that as a group people living with HIV are proportionately more reliant on welfare. In 2010 there were 21,000 people diagnosed and living with HIV in Australia². 40% of these were reliant on a government benefits and a further 30% were living below the poverty line³. Changes to the welfare system therefore have the potential to be amplified within the HIV-positive community. It is crucial that payments to people with HIV are adequate and take into account the increasing cost of HIV treatment and care.

People ageing with HIV

While disability and chronic ill health may not be major issues for young people with HIV

¹ Menadue, David (2011) *Forced to the Margins: Australian HIV population and the burden of poverty* at http://www.acoss.org.au/images/uploads/David_Menadue-Dimensions_of_poverty.pdf

² Ibid.

³ Ibid.

given early diagnosis and optimal treatment, this is not the case for the older cohort of Australians living with HIV.

Research conducted by NAPWHA and the National Centre in HIV Epidemiology and Clinical Research (now the Kirby Institute) regarding the age distribution and survival rates/forecasts for Australians living with HIV showed 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%; by 2020 it is expected to be 44.3%⁴.

People who have lived with HIV for many years and who are now ageing may experience impairments generally associated with ageing at an earlier age than the general population, and these may be more severe in effect. This is due both to the effects of the virus itself and due to effects of long-term antiretroviral treatment. Common HIV-related co-morbidities include⁵:

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

For people in this situation who now claim DSP, impairment levels are generally assessed in relation to chronic co-morbidities, under a number of Impairment Tables. If capacity for work is significantly affected by these comorbidities they can qualify for DSP.

HIV and stigma

In addition to managing a range of co-morbidities, people who have lived long-term with HIV have often faced a complex interplay of cultural and sexual identity issues. There is ongoing stigma associated with HIV within the broad community. The *HIV Futures 7 Report* demonstrates that stigma is a significant issue for people with HIV, with over two thirds agreeing with the statement that "Few people would want a relationship with someone

⁴ Jansson, J. Wilson, D. & Watson, J. (2008) *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*, National Centre in HIV Epidemiology and Clinical Research (UNSW) & The National Association of People Living With HIV/AIDS, Sydney, p.49
<https://kirby.unsw.edu.au/sites/default/files/hiv/attachment/FinalModHIVoutcomesAusRep.pdf>

⁵ 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.

who has HIV”⁶. Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic and commitment to reducing stigma and addressing issues relating to ageing is a priority under the new *Seventh National HIV Strategy 2014-2017*⁷.

Proposed changes to DSP eligibility criteria

The Interim Report states that under the new system:

“Disability Support Pension would be reserved only for people with a permanent impairment and no capacity to work. This would recognise that people who can never work need pension-level assistance. People with disability who have capacity to work could be assisted through the tiered working age payment. This would recognise their current or future capacity to work. In setting eligibility rules it would be important to strike the right balance between investing in those with capacity to work and providing a pension for those who cannot work now or in the future.”

As noted elsewhere in the Report, for people with an ongoing partial capacity for work or intermittent capacity for work due to disability or chronic ill health, DSP is an attractive alternative to Newstart Allowance: DSP provides a higher rate of payment, as well as more generous income and assets tests, and more concessions. If people in this group could not access DSP and instead could only access the working age payment, policies and processes would need to ensure that the impact of particular impairments were understood by assessors and taken into account in developing obligations and activity plans and taken into account in imposing penalties for non-compliance with activity test obligations. Social factors such as HIV-related stigma would also need to be understood and taken into account in assessments of work capacity, obligations and in considering non-compliance penalties. Developing such policies would potentially further complicate payment regimes, not streamline them.

The proposal that only people with no capacity for work would qualify for DSP would mean that many people with significant impairments affecting work capacity – ongoing reduced capacity and/or episodic total incapacity – would be exposed to unrealistic obligations and harsh penalties associated with maintaining eligibility for the new working age payment. We propose that people with ongoing partial capacity for work and people with intermittent incapacity for work should retain pension-level assistance under the new system and that moving these groups to the “tiered working age payment” would complicate rather than

⁶ 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.

⁷ Commonwealth of Australia. (2014). *Sixth National HIV Strategy: 2014–2017*. Commonwealth Department of Health and Ageing, Canberra.

simplify the system. Assessment processes under the new system would need to be sufficiently flexible to take into account the severe frailty that can be associated with management of chronic co-morbidities, for example those experienced by people living long-term with HIV.

People with episodic psychiatric disability/mental illness

There are particular issues for people ageing with HIV who along with managing physical co-morbidities have severe symptoms associated with intermittent psychiatric conditions. Such symptoms may 'wax and wane'. A person with severe episodic mental illness needs certainty of income support, such certainty enhancing work capacity and prospects when they are asymptomatic. Casual work for short bursts can be possible for people with severe mental illness due to ongoing psychiatric disability but periods of employment can be short-lived. Expecting sustained, ongoing part-time work at regular hours for people meeting these indicators is unrealistic and counter-productive, placing added stress on people attempting to work while struggling to live with periodic mental illness.

DSP is currently the best form of income support for people in this position: it is not activity tested and the security offered by suspension policies to cover periods of return to work serves to enhance employment participation.

People with cognitive impairment

Given the rising prevalence of dementia in the general population and the particular cognitive issues, including HIV-related dementia, that can affect people ageing with HIV, there is a need to ensure that reframed eligibility criteria for DSP incorporate meaningful assessment of dementia-related impairment. Particular reference should be made to early-onset HIV-related dementia and the issues faced by people who must effectively retire from the workforce early. DSP is currently an appropriate payment for people in this situation pending reaching Age Pension age. For people with cognitive impairments, particular issues in meeting obligations regarding job-seeking and other activities, need to take into account physical and psycho-social barriers to engaging with employers and support providers.

Select submission template questions

Simpler architecture: What is the preferred architecture of the payment system?

- DSP should continue to be targeted to people with a reduced capacity for work due to disability or chronic ill health. Reform is needed to ensure that DSP recipients with

partial capacity to work with support are provided with job seeking assistance and support to enter/re-enter the workforce.

- We fully support the notion that the social security system should facilitate getting people with partial capacity to work into employment but cannot agree that the means to this end is moving people with partial and/or intermittent capacity to work due to disability/chronic illness off DSP and onto a working age payment.
- Reforms to address the cumbersome complexity of the current social security payment system could be made without fundamental structural changes. DSP provides for a higher rate of payment, a less stringent income test and more generous concessions – this is appropriate for people whose disability/chronic health conditions significantly affects their work capacity, whether the effect is that they cannot work at all, permanently, or whether the effect is partial and ongoing or intermittent.
- There is a particular need to ensure that in developing any the new income support system the particular needs of people with psychiatric, cognitive and intellectual disabilities are taken into account.

Fair rate structure: How should rates be set, taking into account circumstances such as age, capacity to work?

- The new system should include a disability allowance, payable to all income support recipients, to meet the cost of disability – payable to people with ongoing limitations to work capacity due to disability/chronic illness who incur significant costs associated with their condition.