Submission on the Interim Report of the Reference Group undertaking the

Welfare Review

(August 2014)

Introduction

Positive Life South Australia Inc. is a community-driven organisation which works alongside the HIV-positive community in South Australia. Many of the changes proposed or discussed in the Interim Report of this Welfare Review can be expected to have a significant impact on people living with HIV – particularly those on low incomes, including Centrelink payments.

Unfortunately, Positive Life SA does not have the resources to produce a detailed submission in response to all aspects of this Interim Report. This submission focuses on those areas with a unique impact on HIV-positive people with complex health needs – which, in many cases, similarly affect people living with other chronic illnesses and/or deteriorating capacity to work.

People living with HIV essentially fall into 2 groups:

1. Those who contracted HIV prior to the advent of effective HIV treatments (in 1996) and commonly face complex health issues.
2. Those who had access to effective HIV treatments (post 1996), many of whom live *close to normal* lives.

This submission mainly relates to the first group. Many members of this group are aged in their 40's, 50's and 60's, but have a health profile more typical of someone in their 70's, 80's or 90's. (This *premature ageing* is a result of the long term effect of the HIV virus on people's bodies, in the absence of HIV treatment which reduces viral load.)

The Wider Context

Positive Life SA believes that it is critical that Interim Report recommendations be seen in the context of the 2014 Federal Budget – particularly anticipated changes which would increase the cost of living for HIV-positive people and reduced income for those who rely on income support from Centrelink. This includes proposed significant increases in the cost of health services, including:

- Increases in PBS co-payment.
- Increases in the PBS Safety Net, including the expectation that Concession Card holders will gradually be expected to pay for more prescriptions each year.
- Introduction of $7 health service co-payment, including visits not under *Chronic Disease Management* items.
- Preclusion of the $7 co-payment from the Medicare Safety Net and private health insurance rebates.

Changes to Centrelink will impact many people living with HIV. People applying for DSP or Age Pension will progressively need to be poorer, in real terms, to qualify for pensions (due to the 3 year freeze on assets test and income test thresholds). Stricter health and age eligibility criteria for pensions will have a disproportionate impact on HIV-positive people facing deteriorating health, compared with the general public. Similarly, the emphasis on more punitive measures for people on Newstart Allowance who fail to meet *participation requirements* will leave people facing periodic illness vulnerable to penalties, or at the very least, breaks in their income payments. And, cuts to the Seniors Supplement will affect HIV-positive people with a Seniors Health Card from 2015 onwards.

Further, as a result of cuts to funding for seniors concessions to State and Territory Governments, we have already seen cuts in South Australia. For example, from July 2015, the SA Government will no longer fund reduced local council rates (currently $190 per year for concession card holders).

Economic Realities of HIV

Approximately 21,000 people were living with HIV in Australia in 2010. Of these, 40% (approximately 8,400) of relied on a government benefit with a further 30% (approximately 6,300) living below the poverty line[1]. Even before the changes outlined above, HIV-positive people were, collectively, under significant financial stress.

HIV-positive people spend up to an average of 30% of their income on medications - including both prescribed and non-prescribed; HIV and non-HIV medication[2]. A NSW survey found that 46% of HIV-positive people are struggling to afford HIV medications and 60% are struggling to afford other prescribed medications – and that hardship forces people to make choices between health care and basic living expenses[3]. A 2012 St Vincent's Hospital study found that, over a 6 month period alone, 14% of patients reported that they had interrupted HIV treatment, and 9% reported that they had stopped their HIV treatment, because of pharmacy costs[4]. Discontinuing HIV medication has long term individual and economic implications: the health and wellbeing of HIV-positive people will be severely compromised, reducing their capacity to work and increasing their cost to the health system.

In South Australia, assuming their expenses were consistent with the average cost of living[5], HIV-positive people on DSP spend their entire pension on housing, utilities and medication – with (literally) nothing left for other medical expenses, food, vitamins, transport, communication, clothing, complementary health treatments, personal care and household items. Ironically, some HIV medications must be taken in conjunction with food in order to be effective. With the cost of healthy food having increased much faster than fast food, a poor diet becomes an economic imperative rather than a choice – which can have particularly dire health consequences for people living with HIV. For example, a recent Canadian study, found double the mortality rate over a 13 year period amongst one group of HIV-positive people with inadequate nutrition, compared with a similar group of HIV-positive people with adequate nutrition[6].

It is simply expensive to live with HIV[7]. To place HIV-positive people under further financial pressure would have very negative individual, social and economic consequences.

The Current Situation

An HIV diagnosis alone has not been sufficient grounds to qualify for a Disability Support Pension (DSP) for several years. In order to receive DSP, HIV-positive people must demonstrate that they will be unable to work for more than 15 hours per week in the foreseeable future (at least the next 2 years) due to their *disability*.

Since the introduction of *Welfare to Work* reforms in 2006, many people living with HIV have unsuccessfully applied for the DSP. This is due to tightening of the medical criteria and introduction of work capacity testing. The number of people accessing DSP was further tightened in 2011 (when all *Job Capacity Assessments* were conducted by Department of Human Services) and 2012 (when revised *Impairment Tables* were introduced). A significant proportion of HIV-positive people who would previously have been eligible for the DSP, are now forced to try to survive on Newstart.

HIV-positive people who currently qualify for DSP generally have multiple co-morbidities – most commonly heart disease, hepatitis C, cancer, peripheral neuropathy, diabetes, osteoporosis, kidney disease, mental health conditions and/or AIDS.

The Big Picture – Quick Comments on Specific Proposals

Adequacy of Newstart payments

The Interim Report cites both a Productivity Commission report and the Henry Tax Review, which talk about reducing the difference in payment rates between people who can only ever be expected to do part time work, and those who will never be able to work. Positive Life SA applauds the report's recognition of the inadequacy of the rates paid to some people with a disability who are not on DSP. We strongly support

payment of higher rates to people *who are likely to remain on income support for a longer period, such as … people with disability and a partial capacity to work*, and reviewing single rates for non-pensioners.

Supplementary payments

The proposed withdrawal of a variety of supplementary payments is a matter of great concern. It is difficult to support the proposal that they be *built into* the 4 types of pensions/payments, rather than being separate *add-ons*, given the emphasis throughout recent government announcements on reducing expenditure on social support. The Interim Report fails to quantify the discrete additional amount that would be added to base pensions or payments to accommodate these supplements. In the absence of these details, it is impossible not to draw the conclusion that this strategy (however logical the rationale) will simply function as another cost-cutting measure which will further erode the real value of income support for the most disadvantaged members of our community.

Indexation of payments

Whilst accepting that *there is no simple formula for determining an appropriate level of assistance*, Positive Life SA is deeply concerned about the possibility that CPI could be used as the basis for indexing Centrelink pensions and/or payments. We support the 3 principles outlined in the Interim Report – that payment should be adjusted to maintain:

1. The real value of payments,
2. The relative value of payments, and
3. A coherent system.

The evidence is clear on the viability of CPI as the means for maintaining either the real, or the relative, value of payments – to reflect either *basic adequacy* or *community living standards*. Whilst pensions have maintained their real value over time, over the 10 years leading up to release of the 2009 Harmer Pension Review, the single Age Pension rose by 20% in real terms, compared to a rise of less than 0.5% for Newstart[8] – due to use of CPI to index Newstart, compared with a more sophisticated indexing system for pensions. Clearly use of CPI for indexation will not maintain the *real* or *relative* value of payments.

Penalties for working

Positive Life SA notes that too often, HIV-positive people are effectively penalised for working under the current Newstart system, due to the system's inability to adjust weekly payments in a seamless way. Too often, undertaking periodic work results in delayed payment and/or under or over payment. This disruption to income can have profound effects on people living on, or below, the poverty line. In reality, it functions as an active disincentive to undertake paid work.

Positive Life SA supports the idea of addressing some of the current problems with *double penalties* for people who undertake part time work – both the Centrelink income test (losing income support payments according to how much recipients earn) and being taxed on this income. This is a far greater disincentive to work than the current disparity between DSP and Newstart payments!

Incentive to work

Positive Life SA questions the assumption that the current disparity in payments between the DSP and Newstart acts as a disincentive for people on DSP to explore their work capacity, even if they will never be able to work full time. In our experience, the financial stresses associated with ongoing poverty on either payment provide more than adequate incentive for HIV-positive people to improve their income wherever possible. Given the structural problems with continuity of payments for people on Newstart, in practice, the DSP system provides greater incentive to work than Newstart.

Systemic flexibility

Positive Life SA is concerned about the assumption that a Working Age Payment could be sufficiently *flexible* and *nimble* to accommodate the (sometimes rapidly) changing circumstances of HIV-positive people. In light of Centrelink's long history of inefficiency in responding to people in periodic employment, it is essential that the final report of the Reference Group address the fundamental question: *What would it take for the social*

services system to be able to accommodate significant, ongoing, unpredictable variations in the number of hours worked each week by people with chronic illness?

- How could this notoriously inflexible, inaccessible system be made responsive and agile?
- How could Centrelink manage day-to-day, week-to-week or month-to-month changes in the capacity of chronically ill people to participate in work?
- How could Centrelink assess HIV-positive people's capacity to seek and/or accept work, when this may constantly vary for some recipients?
- How could the system ensure seamless continuation of payments, in a context of varied work capacity?
- How might the system require people to participate in activities which would make them *work ready* – including training focused on *the skills employers want* or treatments support? (e.g. would Centrelink pay the costs of HIV treatment for those who cannot afford the PBS co-payment?)

Our Primary Concern – People with Episodic Illness & Deteriorating Capacity to Work

Positive Life SA recognises the Government's overriding priority – that *work is better than welfare.* According to the Federal Minister for Social Services:

> *… the system should help people build the capacity they need to participate economically and socially, to the extent they are able.*[9]

We understand that the government primarily sees social security benefits as an *investment* in people, helping them to get work before they become entrenched on welfare.[10] However, we are concerned that the Welfare Review does not take sufficient account of those people currently on DSP who live with the threat of significant, extended periods of episodic illness and/or deteriorating capacity to work.

The Minister has said that DSP recipients suffering *episodic* illnesses (*e.g. depression*) would be better off being given monthly or quarterly medical certificates rather than getting *set and forget* pensions[11]. It is interesting that he uses a mental health example of an episodic illness, rather than a physical example such as a chronic illness.

The Interim Report proposes that people with significant, extended periods of episodic illness and/or deteriorating capacity to work should be moved from permanent/secure income support (DSP) to temporary/insecure payments (Working Age Payment). The report gives 2 examples of why new criteria should be applied to the DSP:

- A plan designed to prepare someone for work could be developed for longer than 2 years (e.g. people with intellectual disability may need support to develop capacity for work over a longer period, or someone may need extended medical/psychological treatment before they can return to work).
- Many mental health conditions are episodic in nature and people with these disabilities can be supported in ways that help them to gain and maintain ongoing employment.

Throughout the Interim Report, people are described as *looking for work* or *job seekers* – the word *unemployed* rarely appears. In other words, if people are not looking for work, they should not qualify for payments. This fails to recognise the *workload* associated with multiple chronic illnesses – the time required for appointments with medical specialists, often requiring long periods in waiting rooms; the time spent waiting to fill scripts in public hospital pharmacies (in most states and territories, the only dispensers of HIV medicines); and the fact that these services are generally only available within standard working hours. It is not uncommon for someone with HIV and other co-morbidities to have 4 – 6 medical specialists, and to spend a day per week focused on addressing their health needs.

The entire Interim Report is predicated on 3 key assumptions about anyone with a disability who is not permanently disabled:

Report Assumptions	The Realities for HIV-Positive People
An inability to find work reflects individual weakness, lack of willingness to work, *lack of preparedness*, the need to develop skills and/or the need to undergo treatment.	HIV-positive people come from all walks of life and professional backgrounds. They are teachers, childcare workers, doctors, dentists, nurses … They are truck drivers, construction workers, sales people, plumbers, builders … They are mothers, fathers, parents and grandparents. Many have had highly successful careers - cut short by illness associated with HIV and/or discrimination in the workplace. Too many are resistant to *being on welfare*, and have depleted their life savings (even, their superannuation) in an attempt retain their independence. Far from being *welfare-dependent*, many HIV-positive people would love to be able to work! Too many are completely ill-prepared for a life of poverty – the skills they lack relate to living on Centrelink payments, rather than work skills. They continue to prioritise medical treatment over other life priorities in the hope that they will return to good health. Too many continue to hope that, at some time, they may be able to return to work. This sometimes unrealistic hope is further fanned by social messages which serve to demonise people with disabilities, suggesting that it is their fault that they are unemployed, and pressuring them to undertake a level of employment beyond the best medical indicators.
People with disabilities are on an upward trajectory toward improved work capacity.	
Episodic illness is restricted to mental health conditions.	

The interim report makes little comment on chronic illnesses and episodic ill-health, other than mental health conditions. It reinforces the idea that the key barriers to undertaking paid work are individuals' attitudes and welfare-dependence. It implies that mental health conditions are somehow less legitimate than physical health conditions. The reality is that some people with HIV face reduced capacity to work over time, and some will experience enforced breaks in employment due to episodic illness.

Many HIV-positive people, particularly those who have lived with HIV for many years and those with multiple chronic conditions, have already lost any opportunity to build or maintain a career path. As a result of this and their inevitable *unreliability* due to episodic ill-health and/or medical demands, any part time employment opportunities are likely to be in casual, low paid work. HIV-positive people can also find it difficult to explain gaps in their work life to a prospective employer, without feeling compelled to disclose their HIV status. Ultimately, this group of HIV-positive people is unlikely to be able to build assets, and can be expected to have to rely on the income support system into the foreseeable future.

The *dignity of work* is already available to people on DSP. Recipients can undertake up to 15 hours of paid work per week. They can also contribute through voluntary work and/or undertake education or training (if they can manage the prohibitive cost on a low income). The incentive to undertake paid work is clear in terms of both its emotional and financial benefits, and many positive people on DSP already undertake some part time work commensurate with their capacity at the time. The difference is that the person (rather than Centrelink) manages the flexibility required in response to variations in their health and *medical workload*.

Stigma and discrimination in the workplace are very real experience for PLHIV in 2014. A fundamental flaw in the Interim Report is its failure to address the existing structural, cultural and practical barriers to employment for people with disability, including people living with HIV. It provides little detail on how barriers to the employment of HIV-positive people, and others being moved from DSP to Working Age Payment would be addressed:

- What extra resources would be available to incentivise employers to employ people with complex health needs?

- And, particularly for people who are ageing, living with HIV and/or living with mental health issues – what strategies and resources will be implemented to address adverse employer attitudes, stigma and discrimination?
- What is the evidence that employers will be willing to maintain the employment of people experiencing mental health episodes?
- What is the evidence that employers will knowingly employ HIV-positive people and maintain their employment through (potentially lengthy) episodes of ill-health?
- Will employers will be required to build in additional personal leave for HIV-positive employees who are more likely to face frequent/extended illness and must attend multiple medical appointments?

Conclusion

It is essential that the Final Report of the Welfare Review Reference Group proposes a realistic $ starting amount for basic income support and a more viable mechanism for ensuring that income support payments keep pace with the real cost of living for recipients. The Interim Report appears to recognise that current Newstart payments are inadequate to provide recipients (particularly long term recipients) with a *basic acceptable standard of living*. Given the current and increasing cost of health services, even current pension payments (including DSP) are inadequate to provide a basic acceptable standard of living for people with complex, chronic health issues (given their additional and growing health costs). The new *more consistent* rates must be more similar to the current DSP rate than the current Newstart rate. This would need to vary according to participants' health status – and the high and increasing cost of meeting their direct and indirect health needs. It should also vary according to whether recipients have any prospect of building a career, or engaging in well-paid work. The evidence clearly demonstrates that indexing according to the CPI has led to a significant loss of the real value of Newstart Allowance and other benefits over time. If supplements were discontinued, their joint quantified value should be added to this base benefit and should, too, be indexed over time in a manner that retains their real and relative value.

It is also critical that the Group's Final Report propose an incentive-based, rather than penalty-driven, system for encouraging workforce participation amongst people with a disability who have no realistic prospect of ever working full time. At the very least, this should include a secure base pension, payable at a rate commensurate with the DSP, with the capacity to work for up to 15 hours per week without having earnings *double taxed* by both Centrelink and the ATO.

Endnotes & References

[1] Menadue, David (2011) *Forced to the Margins: Australian HIV population and the burden of poverty* at http://acoss.org.au/images/uploads/David_Menadue-Dimensions_of_poverty.pdf
[2] ibid
[3] ibid
[4] McAllister J et al. *Financial stress is associated with reduced treatment adherence in HIV-infected adults in a resource-rich setting*. HIV Med, online edition. DOI: 10. 1111/j.1468-1293.2012.01034.x, 2012.
[5] Figures produced by SACOSS, and detailed in Positive Life SA (2013) *Economic Realities of Living with HIV*. Contact us (executiveofficer@hivsa.org.au) for a copy of this paper.
[6] From *Food insecurity linked to HIV-treated drug users' deaths*, June 2013 at http://www.aidsmeds.com/articles/food_insecurity_1667_24057.shtml
[7] For a more comprehensive account of the health costs of HIV see: Menadue, David (2011) *op cit.* Contact us (executiveofficer@hivsa.org.au) for a more detailed account of the wider economic realities of living with HIV.
[8] Carers Australia (13 May 2014) *Media Release: Carers Face a Tougher Future under Budget Changes* at: http://www.carersaustralia.com.au/media-centre/media-releases/
[9] *Pension whittled away, but super untouched,* John Collett, Sydney Morning Herald, May 14, 2014 at http://www.smh.com.au/business/federal-budget/pension-whittled-away-but-super-untouched-20140513-388bs.html
[10] *Budget: $7 GP fee brings end to free doctors visits,* Daniel Hurst, The Guardian, 13 May 2014 at http://www.theguardian.com/world/2014/may/13/budget-7-gp-fee-brings-end-to-free-doctors-visits
[11] ibid