



NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS

PO BOX 917 Newtown NSW 2042 **TELEPHONE** 02 8568 0300

EMAIL admin@napwa.org.au **WEBSITE** WWW.napwa.org.au

PENSION REVIEW

Submission to Dr Jeff Harmer
the Secretary of the Department of Families,
Housing, Community Services and Indigenous Affairs

Robert Mitchell
President, NAPWA

26 September 2008

Summary

1. Based on the success of combination antiretroviral medications, HIV infection has taken on the form of a chronic, episodic illness or disability. Given the variable nature of the course of HIV illness and the direct and indirect side effects of current treatments, people with HIV may have to move in and out of paid employment and the welfare system as the state of their health demands. Many people living with HIV/AIDS (PLWH/A) are dealing with the effects not only of HIV infection but also of ageing. The design and functioning of Australia's social security system has a direct impact upon a significant proportion of PLWH/A, and the National Association of People Living With HIV/AIDS (NAPWA) supports any moves that might be taken to strengthen the financial security of seniors, carers and people with disability.
2. The ability of people with chronic illnesses such as HIV/AIDS to maintain their health and well-being is severely compromised by financial hardship and the stresses associated with an ongoing struggle to make ends meet. Costs associated with increases to the base rate of pensions need to be weighed at the health and social policy level with the costs associated with treatment of, and rehabilitation following, morbidity exacerbated by the substandard living conditions and stresses of the many citizens living with chronic illness. Since PLWH/A are amongst these, NAPWA is in support of any moves by government to increase the base rate of pensions.
3. Consideration could be given to making the single rate of pension closer to 70 per cent of the combined couple rate.
4. Any improvements to public health, public housing and public transport would represent concrete benefits to people reliant upon income support.
5. Australia provides a wide range of supplementary payments and concessions to people reliant upon income support, which NAPWA strongly supports. Consideration could be given to ensuring greater uptake of such entitlements through the provision of public information and easing of the administrative burden associated with concessions such as the PBS Safety Net.
6. Any moves that might be adopted by policy makers to make it easier for people with chronic illnesses such as HIV/AIDS to find and keep work in the open labour market, and hence reduce their dependency upon the income support system, are welcomed and supported by NAPWA. The health care benefits implicit in receiving the DSP could possibly be retained for those engaging in work, but on low incomes, by the introduction of a 'Chronic Illness Concession Card' focused on alleviating costs associated with maintaining well-being in the face of chronic illness.

The Pension Review

The Minister for Families, Community Services and Indigenous Affairs (FaHCSIA) has asked the Secretary of FaHCSIA, Dr Jeff Harmer, to complete an investigation into measures that might be adopted to strengthen the financial security of seniors, carers and people with disability, and to report by 28 February 2009 on the:

- appropriate levels of income support and allowances, including the base rate of the pension, with reference to the stated purpose of the payment
- frequency of payments, including the efficacy of lump sum versus ongoing support
- structure and payment of concessions or other entitlements that would improve the financial circumstances and security of carers and older Australians.

This investigation (the Pension Review) will inform the Inquiry into Australia's Future Tax System through Dr Harmer's membership of the tax review panel. The Inquiry has the broader role of reporting on 'improvements to the tax and transfer system for individuals and working families, including those for retirees' (Pension Review Background Paper: 1).

The National Association of People Living With HIV/AIDS (NAPWA) recognises the importance of Australia's income support system to many of the people living with HIV/AIDS (PLWH/A) in the country, and puts forward the following submission to the Pension Review. This is in keeping with its function as the national advocacy body for people living with HIV/AIDS, as evidenced by its record in contributing to national discussions relating to disability, income support and Australia's welfare system in general.

NAPWA

The National Association of People Living With HIV/AIDS was established following a recommendation put by HIV positive people attending the National AIDS Conference in Hobart in 1988. As the peak National body, NAPWA is identified as representing the issues and concern of people living with HIV/AIDS in Australia at the interface between government, medical and other community stakeholders. NAPWA was the forerunner to many state PLWH/A groups, and part of its brief was to support State and Territory groups in setting up advocacy organisations and networks. Its membership is drawn from these State and Territory organisations and groups, who have the responsibility to communicate the issues, concerns and approaches of their respective groups to NAPWA. They comprise:

- Australian Capital Territory - PLWHA (ACT)
- New South Wales – Positive Life NSW
- Northern Territory – PLWHA (NT)
- Queensland – Queensland Positive People (QPP)
- South Australia – PLWHA (SA) Inc
- Tasmania – Positive Services, TasCAHRD
- Victoria – PLWHA Victoria
- Western Australia – HIV/AIDS Peer Advisory Network (HAPAN)

NAPWA associate members comprise:

- Body Positive NZ (Peak HIV positive advocacy organisation in New Zealand)
- PATSIN (Positive Aboriginal and Torres Strait Islander Network)
- Positive Women (VIC) – support service for HIV positive women in Victoria
- POZHETS (NSW) – support service for HIV positive heterosexuals in NSW
- Straight Arrows (VIC) – support service for HIV positive heterosexuals in Victoria

Key NAPWA activities include lobbying government to improve current programs that support PLWH/A, lobbying government departments for adequate funding for PLWH/A, lobbying service providers to ensure the current needs of PLWH/A are being met, participating in community based education programs for PLWH/A, developing capacity within PLWH/A organisations to undertake work especially in relation to advocacy, representation on committees covering issues such as treatments access, disability coalitions and education

strategies, and the supporting and encouraging of volunteer participation in the delivery of key NAPWA activity.

NAPWA also provides organisational support for the operation of the HIV Living Today Network (HLTN), a nationwide grouping of concerned PLWH/A focused on social justice and social policy advocacy for fellow PLWH/A. The HLTN has functioned as NAPWA's Reference Group in the preparation of this submission to the Pension Review.

Previous participation of NAPWA in national discussions and submissions processes include:

- Submission to the Reference Group on Welfare Reform – the McClure Report in 2000
- Responding to the Australians Working Together – Better Assessment and Early Intervention discussion paper from the then Department of Family and Community Services in 2001
- Presenting information to the Senate Community Affairs Reference Committee Inquiry into Poverty and Financial Hardship in 2003
- Submission to the Senate Select Committee on Medicare and Committee on the Health Legislation Amendment (Medicare and Private Health Insurance) Bill 2003
- Contributing to the development of the 5th National HIV/AIDS Strategy 2005 – 2008.

Context: People Living with HIV/AIDS and Income Security

HIV infection and AIDS in Australia

The Human Immunodeficiency Virus (HIV) attacks the human immune system, leaving infected individuals vulnerable to chronic progressive illness, opportunistic infections and cancers. Once those infected with HIV cross a certain medically defined threshold, they are described as having Acquired Immunodeficiency Syndrome (AIDS). AIDS is a notifiable condition in all states and territories in Australia. Since the mid-1990s, the clinical manifestations of chronic HIV infection have changed dramatically amongst people with access to combination antiretroviral therapy, which is available in Australia under the Highly Specialised Drugs program in keeping with Section 100 of the National Health Act, 1953. The introduction of these treatments has reshaped the HIV epidemic, leading, for example, to substantial increases in survival following an AIDS diagnosis – median survival among people diagnosed with AIDS increased from 19 months prior to 1997 to 34 months among cases diagnosed with AIDS in 2003.

The signs and symptoms of chronic HIV disease can be described as follows:

- Immune activation symptoms consequent upon primary infection with HIV, including fever, night sweats, myalgia, arthralgia and lymphadenopathy
- Mild immunodeficiency, including shingles, herpes simplex, and oral conditions such as candidiasis
- Immune reconstitution disease, in situations after people with advanced HIV infection have started with HIV treatments, with agents of infection including cytomegalovirus (CMV) and *Mycobacterium avium*
- Severe immunodeficiency, with more serious and life-threatening opportunistic infections including *Pneumocystis jirovecii* pneumonia (PCP), Kaposi's sarcoma, Non-Hodgkin's lymphoma and neurological conditions

(Australasian Society for HIV Medicine, 2001; NSW Health, 2005; National Centre in HIV Epidemiology and Clinical Research, 2007).

By the end of 2006 there were cumulatively 26,267 diagnoses of HIV infection, 10,125 diagnoses of AIDS, and 6,723 deaths following AIDS in Australia. The average age of people diagnosed with HIV was 37 years, and 89.2 per cent were male (National Centre in HIV Epidemiology and Clinical Research, 2007). Based on the latest figures released by Professor John Kaldor of the National Centre in HIV Epidemiology and Clinical Research (*Sydney Morning Herald*, September 17 2008) there are altogether 16,692 people currently living with HIV infection in Australia.

HIV infection and AIDS, including asymptomatic HIV infection, is recognised as a disability under the Commonwealth Disability Discrimination Act, 1992.

Financial security of PLWH/A in Australia

There are no exact descriptions of the financial situations of all PLWH/A in Australia, but the most comprehensive data available, based on a cross-sectional study of a sample of HIV positive Australian residents (N = 982) carried out in 2006 (Grierson, J., Thorpe, R. & Pitts, M. 2006) indicate the following of relevance to this submission.

Employment status of respondents to the survey is 34.1 per cent in full-time work, 19.8 per cent retired, 17.1 per cent working part-time, 10.7 per cent unemployed, 4.2 per cent studying and 3.3 per cent involved in home duties.

The primary source of income of the respondents is a government pension or benefit (45.7%), salary (43.5%), superannuation/annuity/savings (4.8%) or the financial support of a partner (2.2%).

Those who are not working stopped work between 1984 and 2005 (median = 2000), with a large proportion (19.6%) indicating that their career ended at their time of diagnosis. Many people diagnosed with HIV were urged to move from employment into income support via the Disability Support Pension in the years prior to 1996 (when combination antiretroviral treatments became accessible) and have experienced many years of continuous unemployment, despite improvements in health.

Of those who have worked, 51.6 per cent had stopped work for reasons related to their HIV at some point, with interruptions to employment being caused most commonly by poor health (48.3%), stress, depression and anxiety (47.4%) and low energy levels (46.5%). The most common source of income during the most recent interruption to employment was a government benefit of some sort (71.6%).

Using the measure of the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research, over one quarter (28.3%) of PLWH/A are living below the poverty line, and this figure has remained consistent in previous surveys of PLWH/A carried out by the same research institute.

Over half of those on a government benefit (58.0%) are living in poverty. Whereas the survey suggests that there is no gender difference in the proportions of people living below the poverty line, those respondents who shared financial resources with a partner were significantly less likely to be below the poverty line than those who did not.

The current debt burden of the PLWH/A surveyed averaged at \$40,395, with those who owned their home having a median debt of \$2,000, those currently paying of their home with a median debt of \$50, 293, those in private rental accommodation with a median debt of \$5,000 and those in public rental accommodation with a median debt of \$908.

The items most respondents rated as very difficult to pay for were quality of life costs (travel, going out, entertainment) and those items most likely to be rated as not at all difficult were support services, medical services and medication. Substantial proportions rated food, clothing, utilities and rent as very difficult. Slightly less than one-fifth (18.8%) had used the services of a financial counsellor in the last two years.

Primary data – current financial situation of a sample of PLWH/A

Although not presented as findings that could be construed as representative of all PLWH/A in Australia, primary data was gathered for the purposes of this submission via interviews carried out with HIV positive Australian citizens who are reliant upon income support. The interviews were conducted in August and September 2008 in three states by members of the HIV Living Today Network who are part of NAPWA's Reference Group for this submission (see above). It was explained to the interviewees, whose anonymity is protected by the use of

pseudonyms, that their participation would assist NAPWA to 'strengthen its submission by drawing on the lived experiences of people living with HIV'. These interviews have formed the basis for the writing of the six case studies presented in the Appendix to this submission. Relevant insights gained from the six interviewees regarding their income security are summarised in Table 1 below.

Table 1: Current financial situation of a sample of PLWH/A

Sex	Age	Residence	Income security
M	66	Metropolitan; lives alone in public housing	HIV positive since 1986; received DSP from 2000 following cardiovascular illness, now on Age Pension; co-morbidity of HIV illness and cardiovascular disease exacerbates his living costs; he makes use of meals on wheels; his energy bills are difficult to afford; he requires a car due to mobility difficulties - upkeep of car represents great financial stress; he has no savings or credit card; <i>'he feels the current costs of food and other essentials have gone up quicker than the pension and that the quality of his life has slipped over the past few years'</i>
M	69	Outer metropolitan; lives with three pets in privately-owned home	HIV positive since 1988; received DSP from 1994, currently receiving Age Pension; numerous medical problems due to HIV illness, and to problems associated with ageing; requires a car because of lack of public transport; three dogs contribute greatly to his quality of life, but food and vet bills pose a significant expense for him; <i>'he notes that food bills have skyrocketed in the past year with meat and vegetables much dearer than the pension can allow for'</i>
F	Mid-30s	Regional centre; lives with 12 year old son in private rental	Diagnosed HIV positive in 2004; many HIV-associated illnesses, also toxic reaction to antiretrovirals, which have prevented her from taking them; she experiences significant weight loss, rash, low energy levels; unable to work; cares for 12 year old son, father doesn't provide child support payments; \$3000 in arrears on private rental – close to half her pension goes on rent each fortnight; current financial state in a critical situation; <i>'HIV has added a huge burden and stress onto her life and she currently feels considerable despair about her situation'</i>
M	58	Regional centre; lives in private rental share house	HIV positive for twenty years; in receipt of DSP for ten years and receives Utility, Rental and Telephone Allowances; although in reasonable health, unable to work regularly, due to HIV illness; has expenses related to needing to have a car; he raised the issue of <i>'the higher cost of living associated with living in a regional area, particularly lack of adequate public transport and access to affordable fresh foods'</i>
M	34	Inner-metropolitan; lives with partner in private rental	HIV positive since 2001; receives the DSP, Rental Assistance, Telephone and Utilities Allowances; medical expenses include complementary treatments such as dietary supplements and massage; diagnosed with anxiety and depression and receives psychiatric treatment; painful ingrown toenails require regular treatment by podiatrist; his partner is also HIV positive, but employed, and he <i>'acknowledges that the quality of his life is largely dependent upon his partner'</i>
F	40	Outer metropolitan; lives with 3 dependent children in family-owned home	Diagnosed with HIV in 1999; married for 21 years, now separated, has three dependent children, two of whom have behavioural problems requiring regular treatment; was receiving the Carer Payment until 2006 because her husband is severely visually impaired; now that the marriage has disintegrated, the Carer Payment was terminated, but she still cares for her chronically-ill mother; she receives Newstart and the Single Parenting Payment and is registered with the PSP; deals with toxicity linked to anti-HIV medication, osteoporosis, depression and anxiety; has a current debt of \$15,000; unable to keep up with house repairs; relies heavily upon non-government services including financial assistance; her <i>'ability to maintain her own health and the health of her children is significantly compromised by financial hardship and stress'</i>

Context Summary

Antiretroviral treatment has extended the lives of many people living with HIV/AIDS, allowing HIV positive people to re-enter the workplace, education and the social and economic fabric of the nation. However the treatments raise a number of increasingly complex health management issues, some of which may require at any time short-term or ongoing hospitalisation, drug treatment or other medical interventions. These issues include:

- Neurological, psychological and psychosocial effects of living with HIV - these may require interventions including drug treatment, counselling and psychiatric assessment and support
- Ageing with HIV and the co-morbidities that arise from this

- Acute toxicities – admissions to acute care in HIV are now most notably associated not with opportunistic illness, but with antiviral toxicities which require hospitalisation, such as reactions to treatments
- Chronic side effects of therapy – many of these side effects may require a person to seek additional professional health care advice, which may range from specialist medical advice to ancillary health support, such as seeing a dietician or massage therapist
- Long-term toxicities – in some people these can lead to chronic health problems such as lipodystrophy, elevated cholesterol and triglycerides factors for heart disease, diabetes and organ problems such as chronic inflammation of the liver.

HIV infection in the age of antiretroviral therapy has therefore taken on the form of a chronic, episodic illness or disability. Co-morbidity with other health conditions is common, and this is particularly true for those who have been infected with HIV for many years and who are ageing. Given the variable nature of the course of HIV illness and the direct and indirect side effects of current treatments, people with HIV may have to move in and out of paid employment and the welfare system as the state of their health demands. Available data suggest that approximately half of HIV infected people in Australia could be financially dependent upon the income support system, and that more than half of these could be living below the poverty line.

NAPWA's Responses to the Terms of Reference of the Pension Review

Appropriate Levels of Income Support and Allowances

As background to the debate on the adequacy of levels of income support and allowances, NAPWA would like to draw attention to the relationship between disability and poverty, and particularly the attempts to estimate the **cost of disability**, represented by 'the income required to offset the negative impact of disability at a given standard of living' (Saunders, 2006: 6), and its impact on the incidence of poverty. Based on data gathered in 2007 in the General Household Survey (GHS), a multi-purpose continuous survey carried out in the UK, disabled adults were found to be twice as likely to live in low income household as non-disabled adults (30 per cent to 15 per cent), and the gap is bigger than a decade ago. The main reason given for this is their high levels of worklessness. A graduate with a work-limiting disability is more likely to be lacking but wanting work than an unqualified person with no disability (see <http://www.poverty.org.uk/summary/key%20facts.shtml>).

In a paper reviewing evidence linking the presence of disability to the risk of poverty using data from the 1998-99 Household Expenditure Survey (HES) in Australia, Saunders (2006: 11) suggests that 'there is clear evidence of an 'income penalty' associated with the presence of a disability within the household...using the 50 per cent of median income benchmark, the poverty rate for households with a disability is 1.6 percentage points above that of households unaffected by disability, corresponding to a 21.6 per cent higher risk of poverty'. He concludes that 'there are major differences in the income levels, and hence poverty risks facing households with and without a disability, whatever the composition of the household...Broadly speaking, having an adult member of the household with a disability is estimated to add about the same to the household budget as the cost of the second adult in couples that do not have a disability...In income terms, the costs of disability are estimated to average around 29 per cent of (equalised) household income, rising to between 40 per cent and 49 per cent of income for those with a severe or profound restriction' (Saunders, 2006: 22).

NAPWA is broadly in support of the principles underpinning the design of the Australian social security system¹, but questions whether the current rates and the benchmarking of pension

¹ According to the Pension Review Background Paper (Commonwealth of Australia, 2008: 4 – 5) five key principles underpin the design of the Australian social security system:

payments adequately meet the objectives of the system when the cost of disability (briefly discussed above) is taken into account. A common theme raised by stakeholders, including the people interviewed in order to obtain primary data for this submission, is that higher costs of living have been making it more and more difficult for people who are reliant upon income support to make ends meet. In addition to the rise in general living expenses that affects all citizens, many PLWH/A have additional health costs not covered by Medicare or the PBS, for example the need for dietary supplements, complementary medicines and counselling. These, together with a greater incidence of worklessness, as indicated in the discussion above, can be described as aspects of the cost of disability for people living with HIV/AIDS.

While it is accepted that any increases in the base rates for pensions would be costly to the public purse, NAPWA recommends that consideration be given to raising the rate of pension payments by up to \$100 per fortnight in order to help people get on top of food, accommodation, transport and health care costs, energy bills and other increasing costs of living. This would reduce the risk that people with chronic illness experience standards of living that make everyday management of the chronic illness a constant struggle – ‘consigned to a life of poverty’, as expressed by Keith, Case Study 5.

An issue of concern relates to the situation of individuals living alone. The single rate of pension payments is currently 60 per cent of the combined couple rate, with the maximum rate of pension at \$546.80 per fortnight for a single person and \$456.80 for each member of a couple (Commonwealth of Australia, 2008: 6). A large number of PLWH/A live alone, and would benefit from the single rate being closer to 70 per cent of the combined couple rate, especially since many live in metropolitan areas and regional centres, which is advantageous due to the proximity of health and support services, but where costs of necessities such as accommodation and food are high for single people.

Frequency of Payments

NAPWA is broadly in support of the current situation regarding the frequency of payments², but notes that emergency funds are hard to come by for many people, and questions whether PLWH/A on income support, many of whom are understandably reluctant to take on the costs and risks associated with having a credit card, have the flexibility within current arrangements to balance different types of expenditure. Areas of difficulty include optician expenses (Stephen, Case Study 1), house repairs (Kate, Case Study 6), vet bills (Barry, Case Study 2) and school fees (Lisa, Case Study 3). There is community support available from institutions

-
- Support of a basic acceptable standard of living, accounting for prevailing community standards.
 - Treating people in similar circumstances similarly. Those with additional costs are given greater assistance, either through transfer payments or the provision of services, to help them achieve a similar standard of living.
 - Targeting of payments to those not able to fully support themselves. Income and assets tests are used to reduce payments for people with private resources.
 - Promoting participation and self-provision through a combination of services and assistance to help people deal with disadvantage, including disability and caring, incentives to work to provide for current needs and for retirement, and obligations to work and to seek suitable work for those who are expected to.
 - Sustainability, with the broad community accepting that those who receive social security payments are in genuine need, and that the overall system is affordable across the economic cycle and in the long run.

² The Pension Review Background Paper notes that most Australian income support payments are paid on a fortnightly basis in order to provide people with the money they need for their day-to-day living costs. Some payments, such as the Utilities Allowance, are made quarterly, and regular bonuses are intended to help with larger lump sum costs. People can use Centrepay to make regular payments to cover expenses such as utility bills and can use electronic banking to make direct payments from their accounts to help manage their finances. Most income support-reliant households have relatively few assets, including cash savings, and 52.7 per cent of people who are mainly reliant upon transfers as their main source of income do not have a credit card (Commonwealth of Australia, 2008: 24 – 26).

such as the David Williams Fund in Victoria and the Bobby Goldsmith Foundation in NSW, but there are caps to the help that can be acquired in any given year.

Any measures by government that might be adopted to make it easier for people on income security to secure funds in emergencies would be welcomed by PLWH/A and their advocacy organisations. One example of this might be a government scheme to help pensioners who own their own home to secure reverse mortgage arrangements with a minimum of risk. The current arrangements are described as 'exploitative' in the sense that banks are exploiting people on pensions who have managed to buy their houses, but cannot afford the upkeep costs (as noted, for example, by Barry, Case Study 2).

A common theme amongst the case study respondents is that of the need to have private means of transport, with the associated expenses of running and maintaining a car. As noted by Stephen (Case Study 1) his 'greatest stress is not knowing when something will go wrong with the car and inability to budget for this'. Lisa (Case Study 3) often has to make use of taxis to buy groceries or attend hospital visits, with public transport being difficult for her due to her appearance (rash, low body weight). The need to have private means of transport is common to many PLWH/A living in suburban, regional and rural areas due to the fact that HIV medical services are generally provided in specialist facilities – for example, antiretroviral medications can only be prescribed by specialist physicians and obtained at a limited number of public hospital pharmacies. The current system makes it difficult for people to have the flexibility to meet transport costs, and the Mobility Allowance is only available to people who are working, studying, training or doing voluntary work for more than 32 hours per four weeks.

Structure and payment of concessions and other entitlements

NAPWA acknowledges the safety net provided by the wide range of concessions and entitlements³ available to citizens, and notes that the case study interviewees in this submission have taken advantage of supplementary payments such as the Utilities Allowance, Telephone Allowance and Rent Assistance (see Appendix). The organisation strongly encourages the government to continue making such payments available to all people reliant on income support, amongst whom are a large proportion of PLWH/A.

While public health care and initiatives such as Enhanced Primary Care for chronic care management are welcome forms of non-cash assistance, the current long public hospital waiting lists are forcing many pensioners to take out costly private health insurance. Private health insurance for PLWH/A is itself not as straightforward as it might be for other citizens – people with HIV do not get an automatic right to private health care and many need to wait for 12 months before being able to draw on such insurance. A strengthening of the public health system would be of great benefit to especially those people who are dealing with the chronic illnesses associated with both HIV infection and ageing, and prevent the financial burden that could mean additional expenses of around \$70 per fortnight (as indicated by Barry, Case Study 2).

The PBS Safety Net is a valuable entitlement to pensioners with high medical bills, but there is a question about its uptake and accessibility, and about the administrative burden it imposes upon those who wish to take advantage of it. Any moves to improve the accessibility and ease of use of the Safety Net would be welcomed. These might include:

- a centralised tracking system for HIV and other medications

³ The Pension Review Background Paper notes that transfer payments work best when the costs of different groups are clustered tightly around the average and work less well if used to address costs that are borne unevenly in the population. Hence these payments operate in conjunction with other concessions (Pensioner Concession Card, Health Care Card etc) and other subsidised forms of non-cash assistance (accommodation support, health services, disability related services, home and community care etc) to meet the needs of people who face high costs because of factors relating to especially disability (Commonwealth of Australia, 2008: 27 – 32). An issue for social policy is whether the direct provision of services will meet an individual's needs more efficiently and effectively than cash transfers.

- linking of the PBS Safety Net to Medicare bulk-billing.

Related Issues

As is likely to be the case for other chronic conditions, and particularly those which are episodic and intermittent in their impacts, HIV illness has not been adequately catered for in the current welfare to work arrangements. NAPWA strongly supports the recent changes, which make it easier for people on the DSP to consider returning to work. Following an announcement by the Hon Brendan O'Connor, Minister for Employment Participation, DSP recipients looking for employment from 8th September 2008 will undertake a simpler assessment process in the form of a new 'service referral' Job Capacity Assessment (JCA). The assessment will collect information required for determining the most appropriate employment service for the job seeker, and will not collect information for determining income support, nor will it review the person's pension entitlement.

NAPWA looks forward to seeing what impacts this change might have on voluntary re-engagement of PLWH/A - many of whom have valuable skills - into Australia's workforce. The change could provide encouragement to 34 year old Keith (Case Study 5) who at the time of the interview stated: 'I can't live on the money I get and I can't go out to get a job, because I'm afraid I'll lose my DSP and Health Care Card benefits and then where will I be... I'd like to utilise my science degree before I forget everything I learned and just get on with life like other people'.

As a further means of encouraging PLWH/A currently in receipt of Newstart to re-engage with the world of work, the government could consider weakening the link between receipt of income support and access to the Health Care Card for people with chronic illness. This could take the form of a 'Chronic Illness Concession Card' for people who have returned to the workforce on a full-time or part-time capacity, particularly focused on alleviating the health care costs of those on low incomes.

References

Australasian Society for HIV Medicine, 2001. **HIV/AIDS and Viral Hepatitis: a guide for primary care**. Australasian Society for HIV Medicine, Sydney

Commonwealth of Australia, 2008. **Pension Review Background Paper**. Department of Families, Housing, Community Services and Indigenous Affairs, Canberra

Grierson, J., Thorpe, R. & Pitts, M. 2006. **HIV Futures 5: Life as we know it**. Monograph series number 60, The Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne.

National Centre in HIV Epidemiology and Clinical Research, 2007. **HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2007**. National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales, Sydney.

NSW Health, 2005. **HIV/AIDS care and treatment services needs assessment**. NSW Department of Health, Sydney

Saunders, P. 2006. **The costs of disability and the incidence of poverty (SPRC Discussion Paper No. 147)**. Social Policy Research Centre, University of New South Wales, Sydney

Appendix – Case Studies

Case Study 1 – Stephen

Stephen is 66 years old and has been HIV-positive since 1986. He has recently been placed on the Age Pension but was previously on the Disability Support Pension from 2000 when he suffered 3 strokes in the one year followed by a heart attack in 2001. His doctors suggested that the HIV antiretroviral medications he has been taking since 1993 and HIV itself may have played a role in the strokes and heart attack he suffered. Stephen has limited mobility now and apart from regular trips to the doctor, spends a lot of his time at home in his Office of Housing flat.

Stephen finds living on the Age Pension at its current rate a struggle. 'The last three days before pension pay day are the hardest,' he says. 'I have to scrimp to make it through those days. I don't go out much or have many indulgences, so for me to find it difficult suggests others must be doing it hard as well'. The added costs of medicines for his cardiovascular disease and HIV (approximately \$50 per month), the petrol for his trips to the doctors as well as energy bills are the biggest cost issues that Stephen has to deal with.

As Stephen cannot walk far, given his limited mobility caused by the strokes, he finds it easier to drive a car. A friend helped to purchase it but the costs of maintaining it are a constant headache as the car is over fifteen years old. He spends about \$60 per month on petrol and other costs associated with the car, not including maintenance. His greatest stress is not knowing when something will go wrong with the car and his inability to budget for this. He says he would be very isolated without it.

Stephen's gross fortnightly pension is \$416.92 after his Office of Housing fortnightly payment (\$135.68) and another small deduction is taken out. His electricity bills amount to \$47 per fortnight and gas is \$28 per fortnight. Taking out medicines (\$25 per fortnight) and car expenses (\$30 per fortnight), he is left with \$286 per fortnight.

As he lives alone, and has some difficulty both cooking and shopping for himself, he has arranged for Meals in a Moment, a once daily meal to be delivered at a cost of \$120 per fortnight.

Stephen cannot afford to go to the optician for new glasses that he says would cost \$500.

He has no savings or credit card and has accessed the Centrelink Emergency Grants of \$500 three times so far (you can only do this once every three years), and has paid these debts off over months.

He has not used any disability services except for the Positive Living Centre run by the Victorian AIDS Council – largely for a cheap meal once a week. He receives regular free visits from the Royal District Nursing Service and uses the free Dental Plus service for HIV-positive people in Prahran.

Stephen feels an extra \$50 a fortnight in his pension would make an enormous difference to his life. He feels the current costs of food and other essentials have gone up quicker than the pension and that the quality of his life has slipped over the past few years.

Case Study 2 – Barry

Barry is 69 years old, on the Age Pension, and has been HIV positive since 1988. He was placed on the DSP in 1994. Barry has had numerous medical problems over the last ten years, including skin cancers, complications caused by the surgical removal of a 'buffalo hump' from his back (a side-effect of HIV antiretrovirals), calcification and injury requiring surgery to his shoulder, prostate problems and arthritis. He acknowledges that some of these conditions could have come with age—without HIV – but believes strongly that ready access to hospital-based services is a serious problem for HIV positive people and that his experiences of lengthy waiting lists over recent years has made it necessary for him to take out private health insurance to protect his well-being into the future.

Taking out private health insurance has added a major financial burden to Barry (\$70 a fortnight), but it gives him some peace of mind about his health. He took the step after he waited for 14 months in severe pain before a shoulder injury was operated on. He has the usual expenses (energy bills \$50 per fortnight, car expenses \$75 per month, pharmaceuticals \$55 per month), and says he requires a car because public transport is not accessible where he lives. He attends medical appointments at the Alfred Hospital on average twice a month and travels over 40 km to get to this major specialty service for people with HIV in the state.

Barry also acknowledges that he has the 'advantage' of owning his own home – his only asset. However three years ago his inability to live on the DSP whilst owning a home forced him to take out a reverse mortgage on his home—whilst he was given 20 per cent of the value of the house at the time, if he were to sell or to pass away, the bank would take 40 per cent of the sale price. He thinks this is a 'rip-off' which he has to live with, and thinks the government could help aged pensioners like himself to obtain reverse mortgage arrangements which were less exploitative.

Barry has three dogs (one was left to him to care for by a friend who died from AIDS) and, whilst this is a significant expense both for food and vet bills (these have averaged \$100 a month for the past year) he couldn't live without his pets—they mean everything to him for their company and their contribution to his quality of life. He also notes that food bills have skyrocketed in the past year with meat and vegetables much dearer than the pension can allow for.

He is unable to make much use of the Victorian AIDS Council's services due to their distance from his residence, but does get free dental treatment from Dental Plus in Prahran.

Barry's recommendations are:

1. There should be a review of access to hospital care or HIV positive people due to their likelihood to have more health problems than the general population.
2. There should be an investigation into a Government scheme to help pensioners who own their own home with reverse mortgage arrangements.
3. Public transport costs for pensioners in Victoria are dearer than other states and should be reduced.
4. The DSP and Age pensions should be increased by as much as \$200 per fortnight to bring them into line with other countries around the world and to acknowledge the true costs of living at the moment.

Case Study 3 – Lisa

Lisa is in her early thirties and was diagnosed HIV positive in 2004. She has had an extremely difficult time trying to get on top of her HIV-associated illnesses, having had several episodes of pneumonia, Gullain-Barre syndrome (which led to severe neuropathy), and recently having the AIDS-defining illness, *Mycobacterium avium* Complex (MAC) infection, which has left her with significant weight loss, an unsightly rash, very low energy levels and an inability to take on any kind of employment. Lisa has had problems with taking HIV antiretrovirals due to their severe side-effects, which may have contributed to her developing an AIDS-defining illness, and she currently is not taking any until she recovers from the MAC infection.

As well as these serious health problems, Lisa's current financial state is also in a critical situation. She lives in the provincial Victorian city of Geelong where it has been impossible to find an Office of Housing public rental property due to very long waiting lists. She currently pays \$200 per fortnight out of her DSP for private rental but has become so far behind in payments (\$3000 in arrears) due to her other costs, that a further \$50 comes out. It means that close to half her pension goes on rent each fortnight.

Lisa has a 12 year old son whose food bills are high and she struggles to keep up with school fees (\$465 per year) and expenses, relying heavily on the generosity of the school as she often can't pay. Lisa has no family supports where she lives, her son's father lives in the United Kingdom and he doesn't provide any child support payments. She gets a Family Allowance Payment but even allowing for this, after rent is taken out she has to survive on \$330 per fortnight. She has not been able to meet her energy bills and is \$1000 behind in arrears—another \$20 comes out of her pension towards these arrears.

The only emergency help Lisa has been able to access has been a monthly \$40 food voucher from Positive Women, a support organisation for HIV-positive women in Melbourne.

A major problem for Lisa at the moment is her lack of transport. She feels embarrassed to get on public transport with her appearance, as she has lost huge amounts of weight and has a rash covering much of her body. To buy groceries or attend hospital visits, she often feels the need to take taxis. She also has little energy to carry groceries long distances herself. While she acknowledges it is an expense she can't afford she is currently spending about \$50 per week on taxis for these purposes.

Lisa feels that \$100 extra a fortnight in her DSP would help her to get on top of things, decrease her current levels of stress and help to support her teenage son. When she is able to take HIV antiretrovirals she knows this will add a further expense on top of her current medications. HIV has added a huge burden and stress onto her life and she currently feels considerable despair about her situation.

Case Study 4 – Eric

Eric is 58 years old and has been HIV positive for twenty years. He has been in receipt of the Disability Support Pension for the last ten years. In addition to the DSP, Eric receives a Utility Allowance, Rental Allowance and Telephone Allowance, totalling approximately \$650 per fortnight. Eric says he is in reasonable health, although unable to work regularly due to his HIV. He moved from central Queensland to a midsized regional city in Queensland.

Eric finds making ends meet on the pension difficult despite living in a private rental share house. He would be unable to raise funds in an emergency, for which he gives the example of an unscheduled or short notice visit to a sick relative. He does not have a credit card or savings. He feels that an extra \$200 per fortnight would ease his financial burden and provide a small level of security.

His weekly budget is:	Rent	\$125.00
	Electricity	\$10.00
	Food	\$70.00
	Telephone	\$10.00
	TOTAL	\$215.00

In addition to the basics, Eric also has vehicle expenses including vehicle registration and insurance, medication at \$15.00 per month, clothing etc. He expressed concerns that a suboptimal diet has led to a poorer state of general health: 'I often have to go without breakfast. I just can't afford to eat three meals a day'. Eric raised the issue of the higher cost of living associated with living in a regional area, particularly the lack of adequate public transport and access to affordable fresh foods.

Health issues other than HIV can be problematic due to expense surrounding GPs, dental and optical needs. Eric has accessed the Positive Directions Client Care Fund for dental care and optical needs – spectacles. The Client Care Fund is Queensland Government sponsored to provide grants for private medical treatments specifically for HIV positive people.

Case Study 5 – Keith

Keith is 34 years old and has been HIV positive since 2001. He was also diagnosed with Hepatitis C in 2007, but fortunately his immune system has cleared the Hepatitis C infection, which is generally more difficult for people with HIV. He receives a Disability Support Pension, Rental Assistance, and Telephone and Utilities Allowance, totalling \$659-60 per fortnight.

Keith is currently prescribed the anti-HIV medications Atazanavir, Didanosine (ddI) and Lamivudine (3TC) at a cost of \$15 per month. Despite his age, anti-HIV medications have contributed to a significant rise in his blood fats (triglycerides) and blood pressure. His doctor prescribed lipid lowering and hypertensive medication as well as a regular exercise routine. These prescribed medications cost an additional \$15 per month. A gym membership costs \$600 per year (a good deal according to Keith) as well as gym clothing and occasional consultations with a professional exercise physiologist who adjusts his routine to meet his fluctuating health and physical capacity.

Keith has been advised by his GP and dietician to take dietary supplementation including a multivitamin and Astragalus, to improve digestion and absorption of medication and food. The cost is approximately \$40 per month. He currently receives a free massage from his local AIDS Council (ACON) whenever possible. The therapy improves circulation, reduces stress, and improves his mental health. If there are no appointments available due to high demand for the free service, he pays \$60 for a private therapist.

As a result of his HIV diagnosis, Keith has also been diagnosed with anxiety and depression, which contributed to him relinquishing a successful career and going onto the DSP. He is being treated with anti-depression/anxiety medication costing \$5 per month. He regularly consults a Psychiatrist to manage his mental health. The Psychiatrist does not bulk bill and requires an up-front payment of \$175. After claiming the Medicare rebate, the gap payment for each session is \$35. Keith also has a leg length difference which requires regular consultation with a chiropractor, and he also gets extremely painful ingrown toenails requiring regular treatment by a podiatrist every six to eight weeks, at which time the nail has to be partially removed. The toenail condition reduces his mobility and is a side-effect resulting from a previous anti-retroviral combination, which included Indinivir.

Keith lives with his partner of 14 years. They have recently moved to an apartment in inner-Sydney to be closer to experienced HIV clinicians and support services. His partner is also HIV positive and is currently employed. Their apartment rental costs \$350 per week of which Keith pays \$170. Kevin acknowledges that his quality of life is largely dependent upon his partner who subsidises the cost of food, utilities and other living expenses.

He states: 'I've been constrained and consigned to a life of poverty' - a welfare trap which he describes as a 'double disincentive'. He feels strongly that the inflexibility of the DSP, particularly the 15 hour rule and the punitive reduction in pension payments for people who do work, has stymied him from looking for work, and will ultimately lead to his increased reliance upon welfare. He feels 'stuck between a rock and a hard place.....with no clear path to opportunity'. He says: 'the future looks very empty'n and he is not optimistic about his quality of life improving greatly under the present system.

'I can't live on the money I get and I can't go out and get a job, because I'm afraid I'll lose my DSP and Health Care Card benefits and then where will I be? Maybe on the street...I'd like to utilise my science degree before I forget everything I learned and just get on with life like other people'.

Case Study 6 – Kate

Kate is a 40 year old woman who was married for 21 years (now separated) with three children – Chris 20, Lachlan 14 and Kaitlyn 12. They live with their mother, who was diagnosed with HIV in 1999.

Kate and her children live in a modest suburban Sydney house. The house is 50 per cent owned by her sister, with the remaining 50 per cent being equally owned by Kate and her ex-husband. Her ex-husband is HIV positive and pays a total of \$12.76 per fortnight to support the two youngest children, aged less than 16 yrs.

Until 2006, Kate was receiving a Carers Payment. Her husband receives a full Blind Pension, having been severely visually impaired for 25 years. Kate was his carer. Their marriage disintegrated after Kate's HIV diagnosis, and her husband lodged an application for separation in 2006 and informed Centrelink. Kate's Carers Payment was terminated. During this time, Kate had to cease treatment for HIV because she was unable to pay for HIV medication. Kate has subsequently been placed on Newstart, has registered with the Personal Support Program (PSP), and in 2007 she was granted a Single Parenting Payment of \$580 per week.

Kate is prescribed the anti-HIV medications Combivir (AZT/Lamivudine) and Tenofovir, costing \$10 per month. The medication has side-effects including elevated blood pressure, requiring hypertensive medication costing \$5 per month and lipodystrophic enlargement of Kate's breasts, which required surgical intervention and a lengthy recovery in hospital, together with home care for her children. She has also been diagnosed with depression and anxiety requiring treatment costing \$10 per month. Her age, gender, HIV, and treatment profile, has contributed to an osteoporosis diagnosis, requiring calcium supplementation of \$5 per month. Vitamin and food supplements have also been prescribed by her GP, costing a further \$26 per month.

Kate's two eldest children have been diagnosed with Attention Deficit and Hyperactivity Disorder, and both require regular treatment. The eldest is prescribed Linux - \$26 per month and Ritalin \$64 per month. The middle child is prescribed Ritalin costing \$5 per month. Until six months ago the cost was \$64 per month. The two boys also require twice yearly monitoring by a paediatric specialist, costing 4 X \$285, of which \$49 is rebated by Medicare.

House repairs have not been possible and there is an ongoing problem with leaks in the roof, damp and termites. After a recent burst water pipe, and because no money was available for a plumber, the water had to be turned off for two weeks until an advance could be arranged from Centrelink to pay a plumber.

Kate has no savings and has been paying her council rates and other expenses on a credit card. Her current debt is around \$15,000. She also has an elderly mother with a chronic mental health condition requiring care and supervision.

Kate's ability to maintain her own health and the health of her children is significantly compromised by financial hardship and stress. She relies heavily upon non-government services including financial assistance from the Bobby Goldsmith Foundation and support services from ACON as well as other community services.

Kate believes \$70 – 80 per week would significantly improve the quality of life for all the family and her own physical and mental health.