

# NAPWA

## Submission to the National Human Rights Inquiry Into Employment and Disability

2005

### About NAPWA

The National Association of People Living with HIV/ AIDS is the peak non-government organisation representing PLWHA (People Living with HIV/ AIDS) community-based groups in Australia. NAPWA is overseen by a Board of Directors, nominated by the membership of PLWHA groups and organizations from around the country. NAPWA's goal is to advance the human rights and dignity of people living with HIV/ AIDS in the Australian community, so that PLWHA can live free from discrimination, and enjoy their rights to appropriate treatment, employment, education, accommodation, care and support. NAPWA provides advocacy, policy, education and outreach for people living with HIV/ AIDS. There are over 14,000 Australians currently living with HIV/ AIDS.

NAPWA works in partnership with the Australian Federation of AIDS Organisations (AFAO), NAPWA works to ensure a national continuum of community-based advocacy and service delivery, from prevention, to care and support. It is understood that AFAO will be providing a supporting statement for this submission prepared by NAPWA.

NAPWA has contributed to national discussions relating to employment and disability including;

- Responding to the Australians Working Together – Better Assessment and Early Intervention discussion paper from the Department of Family and Community Services in 2001.
- Participating as a member of the Centrelink National Disability Customer Reference Group since 2001.
- Presenting information to the Senate Community Affairs Reference Committee Inquiry into Poverty and Financial Hardship, in May 2003.
- Submitting information for the Productivity Commission Inquiry into the Disability Discrimination Act, during 2003.
- Contributing to the development of the 5<sup>th</sup> National HIV/AIDS Strategy 2005 – 2008 and in doing so has continuing to draw attention to the changing care and support needs of PLWHA, the complexities of disease management and the cost burdens of living with HIV/AIDS.
- Engaging in recent forums organised by the Department of Education and Workplace Relations on workforce participation for people with disabilities.

The perspectives that NAPWA has presented in these forums and previous submissions are gathered from NAPWA members and People Living with HIV/AIDS through a range of mechanisms, including twice yearly general meetings of members. Principally, the perspectives presented in this Inquiry Submission come from the NAPWA Care and Support Portfolio Working Group who provide high level advice and advocacy on major issues impacting on PLWHA from palliative care to pensions and welfare, from disability legislation to re-training and employment.

It is noted that the Inquiry's methodology includes public submissions as well as consultations with community groups. NAPWA would be more than willing to attend any further consultations that are part of the inquiry, or

present direct personal testimony to the Human Rights Commissioner and the Acting Disability Discrimination Commissioner.

## Background

The Inquiry being conducted by HREOC is welcomed by NAPWA at a time when many of its members have stated their deep concerns about the future of welfare support services such as the Disability Support Pension. Through participation in government-initiated inquiries, discussions and consultations, NAPWA has shown a great deal of willingness, as directed by its members, to describe what support arrangements are essential if HIV positive people who are not currently engaged in workforce participation are to engage, or re-engage. Throughout these discussions NAPWA has pointed out that for a certain group of people, because of illness and disability there is no possibility of engaging in the workforce and this is not about personal will, but about the reality of HIV disease, illness and disability<sup>1</sup>. In addition, a profile has emerged in the era of antiviral therapies for HIV disease where the nature of disease progression is seeing the emergence of episodic illnesses and co-morbidities that complicate simplistic assumptions of working or not working. The reality for many with advanced HIV disease progression and treatment is that patterns of ability to work and illness have become 'episodic' and this offers a particular set of challenges.

NAPWA is concerned that speculation about the current social service arrangements are adding to stigma and discrimination<sup>2</sup> for a group of people

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<sup>1</sup> This submission will draw heavily upon Futures 4, a national survey report on the lives of HIV. Positive Australians produced by the Australian Research Centre in Sex, Health and Society, La-Trobe University. J. Greirson, R. Thorpe, M Saunders and M Pitts (2004) *HIV Futures 4: state of the [positive] nation*, monograph series number 48. This report contains important details on the employment, finance and poverty experiences of many PLWHA.

<sup>2</sup> The experiences of stigma and discrimination in Australia have been well documented see for example; *Discrimination – The Other Epidemic* NSW Anti-Discrimination Board, Sydney, 1992; S Kippax, G Tillett, J Crawford & J Cregan *Discrimination in the Context of AIDS: Disease and Deviance* Dept. Human Services & Health, Canberra, 1992; *HIV/AIDS Related Discrimination: PLWHA Project Report; Research into HIV/AIDS Related Discrimination*; both, Dept. Human Services

who are already experiencing this in many ways. Not only may this have an effect in individual decisions about engagement in the workforce but also makes NAPWA determined to state again that this vulnerable group, who are not able to participate in the workforce, need guaranteed and appropriate social welfare support. We welcome the opportunity afforded by this Inquiry to describe some of the systemic barriers and disincentives to workplace participation that exist for people with HIV, and to explore how some of those disincentives may be addressed. The hope is that work to redress the stigma and discrimination experienced by PLWHA can continue, so that for PLWHA who are able, there are some options for workplace participation.

There are now about 14,000 Australians living with HIV and AIDS (more than ever before, due to advances in treatment). Many of these people have complicated care and support needs, including the availability of Commonwealth Government assistance. Through our contact not only with HIV positive people, but also with general practitioners and other clinicians involved with HIV, we believe it is more important than ever that Commonwealth assistance schemes like the DSP are able to support and reflect best practice in the clinical management of HIV infection. Contact with these primary care providers indicates that there are number of PLWHA with high-level support needs (such as housing, complicated and expensive treatments and psychosocial support) for whom a welfare safety net is essential to support best clinical practice.

#### How this submission is structured.

The submission includes direct responses made to the Issues Papers circulated by HREOC. There is a response to some of the broad debates about employment and disability (Issues Paper 1) and then attention is given to the central themes of the Inquiry as they relate to PLWHA including:

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& Health, Canberra, 1994; and also *Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV* [www.ancahrd.org/pubs/index.htm#papers](http://www.ancahrd.org/pubs/index.htm#papers)

- structural and systemic barriers facing people with HIV/AIDS in relation to employment and workplaces (Paper 2);
- the factors which might impact on employers willingness to recruit, hire and retrain people living with HIV/AIDS (Paper 3);
- the nature of government assistance which is available to ensure equality of opportunity for PLWHA in employment arrangements (Paper 4).

### **Issues Paper 1: Employment and Disability – The Statistics**

The use of statistics is often fraught. Many people in the Australian community are suspicious of their collection, and suspicious statistics can be manipulated or used to ‘make them say anything’. The appropriate collection and use of statistics, however, is vital to policy development. Based on the understanding that strong policy must be based on careful consideration of **all** available data, the following comments relate to the practice of using (or not using) statistics to create ‘spin’.

The Commonwealth collects useful data, particularly relating to Disability Support Pension entitlement. This data is publicly available on the JobAble website, which is in itself a commendable practice. Reference to the full range of data is not evident, however, in recent arguments for changes to Disability Support Pension.

The Commonwealth government has repeatedly drawn attention to what it says is an unprecedented and unsustainable increase in the number of people receiving the Disability Support Pension. It appears that many, including large sections of the media, inferred that this increase is the result of people becoming lazier, or that significant numbers of people are receiving government support to which they are not entitled. There have been suggestions that the pension is being ‘rorted’ by people who don’t have ‘genuine’ disabilities and that the average taxpayer is shouldering this burden.

Yet to date, no evidence has been presented to suggest that it has become easier to access the DSP, or that people are routinely manipulating eligibility criteria. Recipients must pass strict medical tests that are determined by the

Commonwealth, and controlled by medical practitioners employed by the Commonwealth. In fact, more than 1/3 of applications for DSP are rejected.<sup>3</sup>

The JobAble website lists several factors which are thought likely to have caused the increases in the DSP customer numbers in the last decade:

- loss of access to other, often more appropriate, forms of support such as Veterans' Affairs Service Pension, Widow B and Wife Pension;
- increases in the Age Pension qualifying age for females;
- demographic effects such as the ageing of the population; and
- changes in the labour market which have resulted in a reduced capacity for people with disabilities to find or retain work.<sup>4</sup>

This last issue is particularly important, as community perceptions about DSP recipients have a direct impact on individuals. People should be able to openly and honestly apply for DSP without having a sense of having to 'prove themselves deserving'. Many people living with HIV/ AIDS already experience discrimination and stigma, and we believe this should not be compounded by their experience of accessing government services to which they are fully entitled.

It is extensively documented that participation in the workforce has psychosocial as well as economic benefits, and any assistance for people with a disability to enter the workforce is to be applauded. The reality is that this is not a simple task. Proposed changes to the social security system, which are likely to include potentially punitive economic penalties and disadvantage, are cause for alarm, as they seem to be at odds with recent data relating to the real employment opportunities for people with disability.

The Australian Council of Social Services (ACOSS) suggests that less than 20 percent of DSP applicants who participate in employment programs are likely to obtain 'substantial employment'<sup>5</sup> within 12 months, citing a number of government trials

- 1. Assessment and contestability trial (2000-2002)** After 1 year on the trial, with labour market assistance, only 10% of participants were in open employment for more than 20 hours per week. One quarter of participants were employed after 1 year, but most were employed for less than 20 hours a week. (Participation was voluntary.)

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<sup>3</sup> During the period 13 June 2003 to 11 June 2004, 36.7% of new claims were rejected. "Characteristics of Disability Support Pension Customers – June 2004, Australian Government at [www.jobable.gov.au/DSPcharacteristics/2004/sec1.asp](http://www.jobable.gov.au/DSPcharacteristics/2004/sec1.asp).

<sup>4</sup> "Characteristics of Disability Support Pension Customers – June 2004, Australian Government at [www.jobable.gov.au/DSPcharacteristics/2004/sec1.asp](http://www.jobable.gov.au/DSPcharacteristics/2004/sec1.asp).

<sup>5</sup> defining 'substantial employment' as a 'mainstream' job of at least 20 hours' employment for at least 13 weeks

**2. Case based funding trial (2001)**

After 18 months of assistance from an open employment assistance provider, less than 20% of participants were in full time mainstream employment for more than 6 months, and most were employed as casuals. Half those in the trial were on DSP, and they achieved lower outcomes. (Participation was voluntary.)

**3. CRS (2002-03)**

In 2002-03, of DSP recipients in CRS over about a 12 month period, 23% obtained a mainstream job for 13 weeks or more, but an unknown proportion of the jobs were casual, or less than 20 hours.

**4. Job Network DSP pilot (2003-04)**

After 10 months of Intensive Support from Job Network providers, less than 10% of those participating in the pilot secured employment of more than 15 hours a week for at least 13 weeks. Participation in this project was on a voluntary basis

NAPWA suggests that the results of these government trials have not been as encouraging, especially in the last case, as has been claimed. Participating in the workforce for people with a disability is complicated and in the next sections of the submission NAPWA points out how that works for People with HIV/ AIDS.

**Issues Paper 2: Structural and Systemic Barriers faced by PLWHA in relation to employment and workforce participation.**

As a background to this section it is important to understand the employment and finances of PLWHA. This information is drawn from *HIV Futures 4: State of the Positive Nation*, a project of the Australian Research Centre in Sex, Health and Society. Of the 1,059 HIV positive Australians from all states and territories who responded to this national survey

- slightly less than one half of the respondents (43%) were current in paid employment;
- most respondents said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis;

- 58% reported that they have stopped work at some time in the past for reasons relating to having HIV/AIDS - low energy level was the most commonly cited reason for this, followed by stress, depression or anxiety and poor health;
- just over half of those respondents working (approx. 20%) said that HIV has had a major impact on their capacity to perform their work duties. Most commonly respondents reported that they tired more quickly, that they had difficulty concentrating and that they have had to reduce their work hours or stop working altogether;
- 16.5 percent of people said they had stopped work as a direct result of the effects of antiviral treatment.

The above figures on labour force participation are similar to another research report, produced by the National Centre in HIV Social Research<sup>6</sup>. This study showed, from a longitudinal study of 425 HIV positive people, that less than half the participants were employed and the most recent survey results showing that only 30% of the cohort were in full-time employment.<sup>7</sup> In the latter survey, whilst some participants' rating of their own health improved as a result of the availability of antiretroviral treatments, most participants in the previous 12 months had experienced symptoms or side effects which they attributed to the medication used to manage their HIV infection or to HIV itself. Nearly 60% had reported diarrhoea and lethargy. As well feelings of anxiety, depression, or fear were experienced by 55.7% of PLWHA in the previous 12 months. Two-thirds of the cohort also reported symptoms of the body-shape changes known as lipodystrophy, which can include severe fat wasting from the face, buttocks or legs, increased abdominal girth, and prominent veins on arms and legs. Of those who had experienced such

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<sup>6</sup> see pH positive HEALTH, method and sampling, Monograph 9/2000. National Centre in HIV Social Research. Faculty of Arts and Social Sciences, University of NSW.

<sup>7</sup> See Positive Health, Then and now...following HIV-positive people's lives over time, Monograph 9/2003. National Centre in HIV Social Research, Faculty of Arts and Social Sciences, University of NSW.

symptoms in the past year, 20% rated these changes in their appearance as “severe”.

From these studies it can be seen that there are is a significant range of health, treatment, and psychosocial factors affecting the ability of HIV positive people to enter or re-enter the workforce. In a paper presented at the Australasian Society for HIV Medicine Conference in 2004, the Vice-President of NAPWA David Menadue, described a ‘myth’ he argued needs to be countered.

“There seems to be a myth circulating that, with improved health outcomes from HAART (Highly Active Antiretroviral Therapy), the needs of plwha have miraculously gone away. They may have changed in severity for a number of people but AIDS councils still report that they are dealing with increasingly complex client needs and that their staff and care teams are overstretched dealing with them. They report high levels of depression and other mental health problems which require sophisticated mental health interventions including drug and alcohol counselling. They are in many cases unable to cope with clients with HIV related cognitive impairment – people who really require attendant care support to live independently or in some cases nursing home level care to meet their needs . . . There are specific needs to be addressed for the Indigenous community and for positive women for example. Issues such as self-esteem, quality of life, reducing social isolation and the management of depression, anxiety and other co-morbidities of HIV need to be understood.”

In this paper, Mr Menadue also spoke about the side effects and toxicities associated with HIV antiviral treatment. These included lipodystrophy and other metabolic changes, such an increasing prevalence of diabetes in people with HIV, and elevated risk factors for coronary artery disease.

Adding to this complex dynamic of living with HIV/AIDS for some PLWHA, are other, often substantive barriers to return to work, some of which we believe can be direct disincentives.

- The loss of the health care concession card within two years of returning to work on a full time basis can mean that for many people, financial gains from returning to work may well be consumed by

increased co-payments for prescription drugs and other medical services. NAPWA has presented detailed case studies, for example, which show that the cost of prescription medications and gap fees, may cost HIV positive people between \$300 and \$400 per month, compared to costs of less than \$100 for health care concession card holders.<sup>8</sup> This is particularly likely to be felt by people returning to part-time or lower income work, a common scenario for people who have been out of work for some time.

- There are often 'hidden' costs associated with looking for work, which may include, transport costs in the city, in country<sup>9</sup> areas might include the costs of buying a car, appropriate clothing, and, the escalating costs of child care on return to work.
- HIV is increasingly experienced as an 'episodic illness', with often unpredictable factors. HIV treatments may work for periods, but then begin to 'fail' (bringing attendant health problems). Side effects can be severe, ongoing, debilitating, and even life threatening. This seriously affects peoples' capacity for regular and fulltime work.
- For those individuals with co-morbidities such as depression, hepatitis C, diabetes or coronary diseases, 'return to work' can usually be best regarded as 'provisional'.
- The disclosure of HIV status in the workplace presents particular problematics and barriers. This is a real fear for PLWHA, based on past experiences. *HIV Futures 4* reports that 43.3% of PLWHA currently in work had not disclosed their HIV status to anyone at their workplace with the most common difficulties for those who do want maintain confidentiality at work being gossip and explaining absences

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<sup>8</sup> National Association of People Living with HIV/AIDS, Submission to the Senate Select Committee on Medicare and Committee on the Health Legislation Amendment (Medicare and Private Health Insurance) Bill 2003.

<sup>9</sup> Regional differences in the ability to find suitable forms of employment, and attendant costs has been discussed in a report called *Northern Exposure, HIV in the Northern Rivers region*, National Centre in HIV Social Research, 2005 p. 58

from work, for doctors appointments and other treatment related matters.

- Some PLWHA talk about ‘the burden of secrecy’ that extends to hiding the fact that they are taking HIV medications, they avoid socialising in the workplace and there are cases known to NAPWA where people have lost their jobs because of their HIV status.<sup>10</sup>.
- There is a lack of knowledge and misunderstanding of the occupational health and safety as it relates to HIV<sup>11</sup>, and that current changes in industrial relations practices which are seeing the casualization of the labour force are eroding the knowledge base of occupational, health and safety issues.
- There is very little education around disability issues generally but specifically community awareness and community campaigns about what it means to have HIV/AIDS have not been developed in recent years. NAPWA has recently received reports of workplace bullying of HIV positive workers in the building and hospitality industries. Those who are working in the casual labour force (and according to current figures this is an increasing number) are particularly vulnerable to discrimination which can take the form of losing casual hours.
- NAPWA members talk about the importance of psycho-social safety in the workplace but feel that the current moment when HIV/AIDS stigma and discrimination is becoming more apparent prevents a feeling of ‘safety’ in many workplaces.

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<sup>10</sup> One of the first cases taken under the *Disability Discrimination Act* when it was introduced was against a Commonwealth government employer, the Commonwealth Employment Service, who had issued guidelines requiring the disclosure of applicant’s HIV status to prospective employers for a range of jobs, including hospital laundry and cleaning staff, police and prison officers, beauty therapist who perform electrolysis, tattooers, sanitation workers and fire-fighters. After a complaint was lodged the guidelines were withdrawn, and replaced by a non-discriminatory policy. This was in 1994, however many PLWHA remember those times when people living with HIV/AIDS were directly discriminated against in workplace environments.

<sup>11</sup> As an example of this, NAPWA was recently asked to provide policy advice to a large health care service who did not understand that current guidelines sit within each State and Territory Health Department jurisdictions. NAPWA advised that best current practice in jurisdictions would suggest that the establishment and maintenance of an environment in which Health care workers (HCWs) know that their confidentiality will be protected, and that they will not suffer unlawful discrimination is essential. Many employer’s and health care facility requirements would not recommend requiring evidence of HIV, HBV, or HCV status, but aim to achieve voluntary compliance and self-disclosure.

- NAPWA is aware of a number of HIV-positive people who want to return to work and set up their own businesses but who have been denied sickness and accident cover by insurance companies -- solely on the grounds of their HIV status, and with no examination of the individual's relative health and likelihood of illness (considerably less in the current treatments environment -- provable by any actuarial examination of the issues). Equally we have numerous HIV-positive people who are denied superannuation cover on the grounds of being HIV- positive -- despite actuarial data which shows that people with HIV are now likely to live relatively normal lifespans if only recently infected and diagnosed with HIV, and clinically managed appropriately.

### **Issues Paper 3: What factors impact on whether an employer will recruit, hire and retain people with disabilities?**

The McLure Report published in July 2000 suggested a re-introduction of case management for people on social security, with an increase in individualized service delivery to be provided by a gateway service (Centrelink) and a referral to other agencies for more intensive assistance if it is needed. NAPWA was pleased with the directions of these recommendations, (although many of the report recommendations have not so far been pursued). From the beginning of the welfare reform debate NAPWA has also highlighted that if people are to think of returning to the workforce or engaging in some retraining to do so, there must be confidence that the efforts of those seeking employment will be met in a productive way by employers who are willing to employ people who have HIV/ AIDS.

There have been a number of articles in the HIV sector press that document the fears spoken of by HIV positive people of judgemental reactions from

potential employers<sup>12</sup>. A common theme is that without investment in workplace training about disability matters such as HIV there will never be a situation where people with HIV/ AIDS can think that returning to work without these fears. Experience has proven that tailored best practice training around HIV awareness and policy development within the workplace is essential to address some of the social exclusions and uncertainties<sup>13</sup> encountered by people living with HIV.

Again in relation to issues for employers and barriers that arise, for people with HIV/ AIDS there are many misconceptions about HIV transmission. Earlier in the submission there was mention of this misunderstandings still existing in some health care worker settings where there are clear guidelines about standard infection control, policy and procedures. In other industry settings; myths, misconceptions combined with stereotyping and lack of information still present problems. At a recent general meeting of NAPWA members a delegate raised their knowledge of a case where a rehabilitation service was recommending to a HIV positive client, that, because they were HIV positive they should not pursue a career in hairdressing because it involved the use of scissors. This story is unfortunately symptomatic of some of the misconceptions about HIV transmission that abound in workplace environments and present a significant barrier in terms of the attitudes of employers and their willingness to employ HIV positive people who disclose their status. This meeting was also told, anecdotally, of a HIV positive person working in food catering who was not given any further casual work after his HIV positive status became known to his employer, again apparently, a decision made on misconceptions held by the employer.

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<sup>12</sup> See *National Aids Bulletin*, Vol 14, No. 1, 2000 'Welfare Wrangling' , David Menadue; PLWHA *NSW Talkabout*, No 105 February 2000 and *HIV Herald*, July 2003 ' Welfare reform – or back to the workhouse' David Edler.

<sup>13</sup> In Futures 4 study, despite the fact that the study showed that for a large number of people advancements in treatments of HIV had opened up the possibility of living more fulfilling and engaging lives, uncertainly was still a condition of living with HIV as 22% of the survey respondents planned only one day at a time, while 51% said that they only planned one year ahead.

The transition or return to work might also involve referral through job network agencies. It seems highly unlikely that specialist job network agencies are going to be revived, given recent directions and discussions at meetings organized by the Department of Education and Workplace Relations (which NAPWA attended throughout Australia) and the trend whereby religious and charitable organizations are granted many of the contracts to run the job network agencies has added an additional level of concern for positive people. NAPWA members have talked about their fears in relation to the culture of these organisations and that they may not be a sympathetic approach to the particular issues of PLWHA. Whilst NAPWA recognises that it is not always practical to have a proliferation of condition-specific job network service providers, it is important that those using these systems feel certain that they will not experience discrimination; whether that is about their HIV status, assumptions about their sexual orientations or other kinds of unhelpful assumptions frequently reported by people who are HIV positive.

#### **Issues Paper 4: Commonwealth Government Assistance**

As an introduction to this section, it is important to provide a picture of the economic realities for PLWHA. *HIV Futures 4* research reveals two salient points that need to frame the importance of sustained and comprehensive forms of government provided social and welfare support for PLWHA.

- Over 50% of the surveyed positive population identified their main source of income as a government benefit or pension. As well, more than one half of PLWHA reported experiencing at least some difficulty with meeting the cost of daily living: 68% had difficulty paying for clothing; 68% for utilities; 64% for housing; 56% for food; and 53% for transport.
- 27% of PLWHA are living below the poverty line and half of those on government benefits are living in poverty.

While increased workforce participation would provide economic and psychological benefit for many people with a disability, including some of those living with HIV/AIDS, it needs to be pointed out that social security income support is the very foundation upon which a significant number of HIV positive people rely. For that reason, our comments largely relate to the proposed changes to DSP to be announced in the upcoming Budget.

It is not possible to gain full detail of the proposed welfare changes but it is our understanding that they are to be based on changes proposed in 2002 which outlined that DSP would not be available to applicants who:

- have a capacity to work part time for 15 hours or more per week (currently 30 hours);
- are assessed as able to benefit from prevocational training or activity such as resume writing or job search (currently only those able to undertake and benefit from vocational training and rehabilitation are excluded);
- currently benefit from the special concession for applicants over 55 years, that the availability of suitable jobs in their local area is taken into account as well as their disability.

This will mean that some HIV positive people who become eligible for DSP under current law, will have to wait until their disabling illness progresses, reducing their ability to work from 30 to 15 hours (for example, 2 days at 7 ½ hours or 4 mornings at less than 4 hours). NAPWA questions the rationale of insisting that an HIV positive person who is unwell, apply for or remain on Newstart Allowance (including Newstart Allowance incapacitated) because they are able to work 15 hours (only) a week.

In 2002, the Government indicated that existing recipients would not be affected by the proposed changes. Current DSP recipients would continue to receive payments under the existing rules. However, if they went off the

pension entirely, they would face the new, tighter eligibility requirements when they reapplied later.<sup>14</sup> For people with HIV experiencing sporadic illnesses, the above changes are of great concern. Given the variable nature of the course of HIV illness and the direct and indirect side effects of current HIV/AIDS 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.

If a person living with HIV/AIDS is to avoid periods of financial hardship or privation the welfare system must be sufficiently flexible to enable this movement to occur seamlessly and without unnecessary distress for the person concerned. In order to be flexible the system must possess an understanding of the fluctuating degrees of wellness and illness that is experienced due to chronic health conditions, such as HIV/AIDS.

Consequently, it is vital that wherever possible DSP be suspended rather than cancelled as currently outlined in section 3.6.1.100 of the *Guide to the Social Security Act*:

The intention of SS(Admin)Act section 96 is to allow customers the advantage of having DSP suspended for 2 years rather than being cancelled, where customers lose qualification because they obtain paid work of at least 30 hours per week at award wages or above, or earn sufficient income to make DSP not payable. Section 96 is intended to cover customers who are likely to go off DSP on a long term basis because of employment. Section 96 is not intended to cover situations where customers work 30 hours a week, or earn higher income, on a one-off basis or only occasionally, but cannot sustain this

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<sup>14</sup> Note that DSP recipients can work for up to 2 years without going off the pension. If they subsequently lose their job as a result of their disability, they can go back on the pension without reapplying. However, they may have to reapply for the pension if they are considered to have left or lost the job for other reasons.

work over a longer period because of their disability. In this situation, DSP should be continued and the earnings assessed under the income test.

While this section of the *Guide* instructs staff to suspend DSP if a client contacts Centrelink within 14 days, unfortunately it also contains the instruction to cancel DSP if a client “fails to notify Centrelink of the commencement of that work within 14 days”. It is absurd that failure to notify within such a short time frame should have such onerous consequences for Centrelink clients. NAPWA argues that the 14 day notification rule should be relaxed. This change is necessary to satisfy the recommendation of the Interim Review of the DSP Pilot (2004) that “streamline administrative systems and processes associated with servicing DSP recipients”, otherwise people are forced to apply for Newstart Allowance, Newstart Allowance Incapacitated or reapply for Disability Support Pension, with all the paperwork, interviews and associated stress concerned.

If enacted, the government’s proposals would shift some HIV positive people from DSP to Newstart Allowance resulting in:

- a reduced basic payment;
- a harsher income test;
- loss of a range of other benefits and concessions necessary to sustain even the most basic quality of life.

For some, this loss of income and entitlements would be catastrophic.

**Reduction in income from DSP to Newstart Allowance <sup>15</sup>**

<b>Earnings (per wk)</b>	<b>Single adult</b> (worse off per wk)	<b>Partnered</b> (worse off per wk)
<b>Nil</b>	\$40	\$20
<b>\$100</b>	\$64	\$61
<b>\$184.50</b> <b>(15 hrs @ min. wage)</b>	\$90	\$104
<b>\$300</b>	\$124	\$162

Clearly the potential for a shift from DSP to Newstart Allowance and the resulting reduction in basic payment, harsher income test, and loss of other benefits and concessions, will act as a disincentive for many to consider work in the context of ongoing, chronic illness, particularly in circumstances where starting a new job may add to a person’s psychological and physical stress, which may in turn affect their condition. This is obviously contrary to the alleged spirit of proposed welfare reforms and the recommendation of the *Interim Review of the DSP Pilot* that disincentives to participation for DSP recipients be removed.

NAPWA does not support the reduction of assistance for this group who are on forms of social welfare support because they require it, in fact NAPWA suggests that these forms of support need to be increased not decreased. Various concessions available to those on the DSP such as the Health Concession Card are so vital to PLWHA being able to meet the costs of medicines that the possibility of loosing this Concession Card acts as a disincentive for returning to work. For this reason NAPWA argues that at least this two year entitlement after return to work must remain if people are to be encouraged to make a transition to work.

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<sup>15</sup> Figures as calculated by ACOSS from Centrelink data at December 2004. Calculation includes maximum basic payment, maximum Rent Assistance and Pharmaceutical Allowance for both DSP and Newstart. Includes Telephone Allowance for DSP recipients.

There is a great deal of concern that the definitions about ability to return to work will include those who are able to, and in fact may already be participating in some forms of voluntary work. NAPWA points out that there are a different set of obligations, expectations and flexibility in regards to volunteer work and further, that voluntary work allows PLWHA to meet health needs and appointments and carry out the 'self care' that is necessary when living with HIV/ AIDS. Voluntary work allows a space for this self-care to continue whereas paid employment would not. There is also a great deal of concern that if volunteer work is seen as signaling work readiness then HIV sector and other community care sectors will lose valuable volunteer contributions which ultimately would have to be met in other, and perhaps less cost effective ways by Government.

Whilst DSP provides the recipient with financial resources to obtain the basic requirements of food and shelter it is only when combined with a number of other benefits and concessions that the person living with HIV/ AIDS may adequately cover all their basic life and health requirements. These concessions and benefits include:

- Pharmaceutical Benefit Scheme (PBS).
- Travel concessions.
- Housing and rental assistance.
- Concessions on rates and other local and state payments.
- Reduced rates for telephone and other utilities.
- Mortgage relief.
- Discounted food and groceries through private, charitable and state run services.
- Pensioner discounts on social participation opportunities.
- Emergency cash relief, bill and rent payments, provision of nursing and household equipment by charitable and other non-government organisations and services.

It is obvious from research cited that the current rate of DSP, along with whatever concessions available is not enough to meet daily costs of living with HIV/AIDS. For many PLWHA returning to work is a period when it becomes possible to pay off accumulated debt from previous bouts of illness and during this period access to concessions such as the Health Care Card remain even more important.

The McClure Report recommended “a move towards a significant change in the framework of employment services to people with a disability including a greater focus on outcomes, earlier intervention, better case monitoring and support for job seekers with a disability”. The focus of disability reform should shift from a narrow emphasis on reducing the number people on DSP towards a broad focus on engaging people with disabilities with employment, regardless of which payment they receive. Further, it is a false logic that links the development of employment services with a reduction in DSP eligibility: punishment is not the appropriate means to ‘encourage’ disabled people into employment programs. A guarantee of social security protection is needed and system which has flexibilities for those who may be shifting in and out of work due to the nature of their illness and disability.

NAPWA argues that a chronic illness card should be available for those people living with HIV/AIDS who are assessed as having a chronic manageable illness and NAPWA has consistently argued that Category 4 AIDS should always be considered a manifest condition and that some conditions which have resulted from HIV treatments side-effects such as heart attack and stroke, should also be considered manifest for the DSP. It is important to appreciate that there isn’t a criteria, in relation to HIV/AIDS that fits all cases; dual diagnosis with mental health conditions, co-infection with hepatitis C, treatments side effects that have had long term consequences, dealing with the effects of cognitive impairments as well as managing other

co-morbidities complicate any assessment. For these reasons NAPWA has also consistently argued that the reports of treating GPs, who are experienced in HIV should be given recognition in the assessment process. Where independent medical assessment is required, and this is now often carried out by Health Services Australia, these doctors should at least be making decisions based on some awareness training of the dynamics and complications of living with HIV/AIDS.

The Inquiry has also sought feedback on innovative ways of working with particular groups. For PLWHA the programmes that have assisted in returning to work at those that have intensive, tailored support. Experience has also shown that before returning to work placements within organisations where people feel safe and not exposed in terms of having to disclose their HIV status, or if disclosing it are not in fear of how that information will be used. Experience has also shown that peer support and peer mentoring has also been helpful in these environments. There have been a number projects along these lines that have been tried in NSW and Victoria and feedback from NAPWA members in other states suggests that more of these kinds of projects would help to negotiate the transitions to work.

As an example, The Positive Decisions Project was a work experience program in which participants worked two days a week for three months in a community based organisation which was supportive of the needs of PLWHA. It included access to external training courses and vocational counselling sessions. The aim of the project was for people to test their skills, make choices regarding study, volunteering, and see whether they could manage part time or full time work through practical experience. It was designed to give positive people the chance to gauge their work readiness, update their skills and receive some training in a supportive environment.

Experience have shown that PLWHA 'returning to work' is an intensive experience requiring,

- Assistance with setting appropriate and achievable goals
- Vocational assessment and guidance
- Career counselling and identification of meaningful employment opportunities
- Maintaining medical and other social support systems
- Information and support around disclosure.

Feedback from NAPWA membership indicates that this range of complicated issues, including that of managing treatment regimes in the workplace is not understood by generalist Job Network providers. NAPWA argues that there needs to be more direct investment from government to set up and maintain projects like 'Positive Decisions'.

### Summary

It is hoped that the submission has provided enough background and evidence for the Commissioners to appreciate that for People Living with HIV/AIDS negotiating workplace participation remains a complicated matter. There is no doubt that a significant percentage of people have benefited from new HIV therapies and have been able to make the decision to return to work as a result. However, in some instances this is provisional and the profile, from research, shows that this group of people need employment arrangements that take account of the fact that there is still HIV disease progression and that illness, disability and the side effects of treatments still play a big part in decisions about participating in the workplace. NAPWA would like to conclude the submission with a few summary points.

- There needs to be a commitment to an income support system for people with a disability.
- There needs to be some form of chronic illness card and participation allowances for those who are seeking work, or who are working, but are still having to meet the additional costs of living with illness and disability.
- There needs to be a recognition that illness and disability does sometimes, prevent people from participating in the workforce and that there should be some guaranteed form of support for this group.
- There needs to be entry level employment opportunities especially within local, state and federal government agencies.
- There needs to be training for Centrelink staff, assessing Doctors, work capacity assessors and job network providers regarding specific disability impacts and population groups.
- There needs to be more government/business and community partnerships to promote flexible work practices, especially those which will accommodate people living with episodic and chronic manageable illnesses.