



NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS
PO BOX 917 NEWTOWN NSW 2042 AUSTRALIA
TELE: + 61 2 8568 0300 **FAX:** + 61 2 9565 4860
EMAIL admin@napwa.org.au

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SENATOR THE HON JOE LUDWIG
Minister for Human Services
Parliament House, Canberra ACT 2600

Thank you for the opportunity to comment on the Job Capacity Assessment Program and assistance for people with barriers to work. The National Association of People Living with HIV/AIDS would like to provide the following information for your consideration.

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 organisations from around the country. NAPWA provides advocacy, policy, education and outreach for people living with HIV/AIDS.

NAPWA has a long record of contributing 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 5th National HIV/AIDS Strategy 2005 – 2008 and in doing so has continued 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 forums organised by the Department of Education and Workplace Relations on workforce participation for people with disabilities.

Through participation in government initiated inquiries, discussions and consultations NAPWA has shown a great deal of willingness 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 carefully 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. In addition, a profile has emerged in the era of ARV 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 what is currently described as 'episodic' and this offers a particular set of challenges.

NAPWA is concerned that the current social service arrangements are adding to feelings of stigma and discrimination for a group of people who are already experiencing this in many ways. Not only may this have an effect on 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 social welfare support.

Contact with these primary care providers indicates that there are numbers of PLWHA with high-level support needs for whom a welfare safety net is essential and that it would not be supportive of good health practice if this were not available.

From the beginning of the welfare reform debate NAPWA has 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.

The barriers and disincentive for returning to work also include;

- The loss of the health care concession card within two years of returning to work on a full time basis.
- Costs of looking for work which may include, transport costs in the city, in country areas might include the costs of buying a car and the escalating costs of child care on return to work.

- Despite advancement in treatment of HIV over recent years there is an emerging pattern of HIV as an 'episodic illness' which has a substantial impact on capacity to work, at least for (often unpredictable) periods of time.
- For those individuals with dual diagnosis such as depression, Hepatitis C or co-morbidities such as diabetes or coronary diseases any sense of return to work can usually be best regarded as 'provisional'.
- The disclosure of HIV status in the workplace presents particular problems and barriers.
- Some PLWHA talk about 'the burden of secrecy' that extends to hiding the fact that they are taking HIV medications, they avoid socializing in the workplace and there are cases known to NAPWA where there has been a loss of work because of HIV status
- There is a lack of knowledge and misunderstanding of the occupational health and safety as it relates to HIV and that current changes in industrial relations practices which are seeing the casualisation of the labor 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.
- 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 at this time when HIV/AIDS stigma and discrimination is becoming more apparent, this prevents a feeling of 'safety' in many workplaces.
- 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 a relatively normal lifespan if only recently infected and diagnosed with HIV, and clinically managed appropriately.

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.

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.

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.

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 losing 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.

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 the 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.

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 important.

It is important to appreciate that there isn't a criterion, 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 these doctors should at least be making decisions based on some awareness training of the dynamics and complications of living with HIV/AIDS.

For HIV-positive people the programs that have assisted in returning to work are those that have intensive, tailored support and that peer support and peer mentoring has also been helpful in these environments. There have been a number of 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.

Experience has 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 and Job capacity Assessors. NAPWA understands that the capacity of assessors to consider circumstances for people with episodic conditions may be limited, as assessments occur at a point in time around which circumstances may change radically. NAPWA is concerned that threats of breaching which are used in correspondence has a negative impact on those who are attending for assessments and creates unnecessary anxiety. There are also concerns about potential discrimination by service providers, based on lack of understanding, and, as well being referred to a Job Capacity Assessor requires yet another point of disclosure with associated concerns for HIV-positive people.

Summary

NAPWA would like to conclude with a few summary points.

- There needs to be a commitment to an income support system for people with HIV/AIDS who require such income support.
- 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, chronic disease and disability.
- There needs to be a recognition that illness, chronic disease 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 illnesses.



Mr Robert Mitchell
President. NAPWA.