



Senate Community Affairs References Committee Inquiry into Poverty in Australia

The Secretary
Senate Community Affairs References Committee

13.3.03

Dear Sir/Madam

Please accept this submission to the Inquiry into Poverty in Australia being undertaken by the Senate Community Affairs References Committee.

This submission has been produced by the Australian Federation of AIDS Organisations (AFAO) on behalf of its member organisations and reflects the general concerns and opinions of those organisations in relation to HIV/AIDS and poverty.

AFAO member organisations are

- State and Territory based AIDS Councils
- The Scarlet Alliance, the national sex worker organisation
- Australian Intravenous League, national body of intravenous drug use organisations
- National Association of People Living with HIV/AIDS

Particular member organisations may of course have specific issues or concerns in relation to this issue and may make individual submissions to the committee.

Within this submission AFAO will specifically address items 1.c and 1.d of the terms of reference as being of most relevance to our members and their constituents, we include a number of case studies to illustrate this submission' assertions.

AFAO also supports and endorses the submission made by the Australian Council of Social Services (ACOSS) regarding the broader issues of poverty and its impacts in Australia.

AFAO is eager to participate in any consultative process undertaken by the committee in the execution of this inquiry.

Yours sincerely
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AFAO Submission to Senate Community Affairs References Committee Inquiry into Poverty in Australia

Terms of Reference

1.c the effectiveness of income-support payments in protecting individuals and households from poverty.

Up to the 30th of June 2002, 22,107 Australians have been diagnosed as having HIV infection. In September of 2002 15,923 of these people were living with HIV/AIDS.

30% of people living with HIV and AIDS live below the poverty line, of which 50% are not in paid employment. However, 55% of in receipt of a government benefit still live below the poverty line. Of particular concern, particularly in light of proposed changes to the lone parent pension, 45.7% of HIV positive women live below the poverty line, compared to 28.7% of men.^{1[1]}

This alarming reality has a number of equally alarming consequences.

56.8% of people living with HIV/AIDS find it very difficult to meet the costs of housing, be that rent or mortgage. 54.4% of people living with HIV/AIDS find it very difficult to meet the costs of food, 51% find it very difficult to meet the costs of transport, and 43.9% find it very difficult to meet the costs of medical services.^{2[2]} There must be a basic level of support for disadvantaged people by raising social security payment rates above the poverty line.

People experiencing significant physical or psychological impairment as a result of HIV infection are dependent upon the Disability Support Pension (DSP), and its associated concessions, in order to maintain an adequate standard of living.

These statistics quoted from the HIV Futures 2 study reinforce the position that whatever changes are made to the Australian Welfare system any diminishment of the current level of income support to those receiving the DSP and other welfare payments is unacceptable.

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

^{1[1]} HIV Futures II Report by the Australian Research Centre in Sex, Health and Society, LaTrobe University, p100-102

^{2[2]} Ibid., p103

of paid employment and the welfare system as the state of their health demands. This situation also applies to people living with a range of other conditions and disabilities.

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.

Whilst the 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.

Recent proposals by the Government to change the structure and nature of Welfare payments, which would have the effect of removing a percentage of people currently receiving the DSP to Newstart and other jobseeker payments alarms AFAO and other disability groups to react with alarm.

If enacted such proposals would:

- Shift welfare recipients from DSP to Newstart resulting in a reduced basic payment.
- Make people with HIV/AIDS and other disabilities ineligible for the range of other benefits and concessions necessary to sustain even the most basic quality of life.

The predictable results would be:

- More people with HIV/AIDS living in poverty.
- Poorer health outcomes arising from the increased anxiety and stress for people already living with a life threatening condition.

Any future changes that are to occur as part of the Welfare Reform agenda must incorporate these considerations

1.d The effectiveness of other programs and supports in reducing cost pressures on individual and household budgets, and building their capacity to be financially self-sufficient

For a significant percentage of people living with HIV/AIDS in Australia, as for people living with other chronic health conditions, the financial and material support of non-government, community based organisations has been key to their ability to maintain an acceptable standard of living and health. These organisations have bridged the gap between government income support payments and what is required in order to do more than to just exist.

Community based organisations, which carry out fundraising in order to provide a range of financial support services to their clients have been in existence since the earliest days of the HIV epidemic in Australia. These organisations may be specialist HIV services or be a subsidiary of mainstream community support services and charities.

An example of a HIV specific, community based organisation is the Bobby Goldsmith Foundation (BGF). Founded in Sydney by members of the gay community it has been providing a range of practical support services to people living with HIV/AIDS across NSW since the first cases of AIDS were diagnosed in Sydney.

To be eligible for services from BGF a person has to be receiving or eligible to receive the DSP or other government benefit.

In 2001 –2003 1 in 6 HIV+ people in NSW used a BGF service, as did half of all people in NSW with an AIDS diagnosis.

BGF service to clients included:

- Providing at least one financial assistance cheque to 961 individual clients.
- Conducted 726 Financial Counselling sessions
- Provided supported housing to 35 people who were homeless or facing homelessness
- Making 36 grants for training and development of small businesses to assist people with HIV/AIDS build a future.

While BGF now receives government funding for specific projects such as provision of supported accommodation, the majority of its funding is still derived from community fundraising. Similar support is offered in other states and territories by AIDS Councils and PLWHA groups..

In any future changes planned for the Australian Welfare system consideration must be given to the role carried out by non-government support services that in many cases allow people receiving welfare payments to do more than survive.

Case Studies

In order to more fully illustrate the impact of possible changes to the Welfare System on people living with HIV/AIDS the following case studies have been compiled. All case studies are derived from the lives of actual people living with HIV/AIDS. Names and some localities have been changed.

1. Clarke

Clarke is 32 years old and tested positive for HIV 8 years ago. He has been taking Combination Therapy to treat HIV for 4 years.

He lives alone in an inner city suburb of Melbourne in Government Housing accommodation.

He has been a recipient of the DSP for 3.5 years. He had to give up work after a series of serious infections as well as a diagnosis of depression left him weak and lacking the required physical and psychological energy to maintain consistent attendance. After commencing combination therapy Clark experienced as side effects chronic Diarrhoea, Nausea and Peripheral Neuropathy.

Clark has managed to survive on the DSP supplemented by periodic recourse to charitable organisations that have assisted him with payment of essential, overdue bills, replacement or repair of household equipment and purchase of food.

He receives a rental subsidy and purchases his prescription treatments under the Pharmaceutical Benefits Scheme.

Income per fortnight:

DSP: \$311.50

Expenses per fortnight:

Rent: \$97.40

Electricity: \$22

Phone: \$30

Food: \$200

Transport: \$14.40

Funeral Fund: \$11.70

Treatments: \$14.00

Credit Card payments: \$12.50

Impact on Clark:

Clark generally manages to survive, although at a very basic manner, on the DSP with periodic assistance from charitable institutions. However, if he were to lose concessions on the cost of his essential HIV drugs, travel and utility bills he would be unable to maintain himself financially.

2. Stefan

Stefan is 41 years old and tested positive for HIV 5 years ago. He has been taking combination therapy to treat HIV for 3 years.

He lives alone in the inner western suburbs of Sydney.

He is employed by a community organization for 3 days a week. He is also in receipt of the Disability Support Pension. He finds with the combination of these two sources of income he can live a satisfactory if frugal life.

Currently as a result of being on the DSP his treatments are covered by the PBS and cost him \$10 a month.

As a result of the side effects from the drugs he has been taking to control HIV disease such as Lipodystrophy and bouts of Constipation alternated with Diarrhoea he finds it difficult to sustain the energy levels required for the 3 days of paid work he currently carries out, frequently having to take sick leave or otherwise reorganise the days he works.

Income per fortnight:

Income: \$850 gross

DSP: \$200

NSW Department of Housing Special Rental Subsidy: \$150

Expenses per fortnight:

Rent: \$280

Electricity: \$32

Phone: \$40

Food: \$150

Fares to and from work: \$6.60

Personal care: \$13

Non-prescription health products: \$16

Health Maintenance costs (yoga class, massage) \$44

Treatments: \$5

Pet care: \$25

Newspapers, Internet: \$52

Clothing: \$25

Incidentals: \$50
Entertainment: \$50

Total: \$788.60

Impact on Stefan:

As well as relying on paid employment to provide financial independence Stefan receives enormous psychological benefit from being able to participate in society and interact with people on a regular basis through his job for a community organization. Whilst the organization that employs him is able to accommodate Stefan's requirements around hours worked, the recently proposed changes to DSP eligibility would see Stefan inappropriately moved from the DSP to a NewStart scheme or forced to give up paid employment altogether in order to remain eligible for the DSP and its accompanying essential concessions.

3. Amanda

Amanda is 32 years old and tested positive for HIV 5 years ago. She has a 12-month-old baby. She is originally from Perth and now lives in a house in the Western Suburbs of Sydney with her partner who is HIV negative and employed on a full time basis.

She had been on combination therapy for 3 years but suspended treatment during her pregnancy. She is about to recommence combination therapy.

Amanda carries out voluntary work for a HIV advocacy organization when her health and child care arrangements allow.

Due to the lack of any public transport infrastructure where Amanda and her family live they have to maintain and run a car. Amanda's family and other social support networks are largely still located in Perth resulting in a lack of unpaid childcare being available to Amanda.

Whilst Amanda is registered as having been approved for the DSP she currently receives no payments due to the income derived from her partners full time employment.

Impact on Amanda and her family:

The expenses for the family would increase to an untenable level in the event of Amanda being removed from the DSP and its associated PBS concession and with the projected price rise in drugs currently listed on the PBS.

4. Ken

Ken is 29 years old and tested positive for HIV 7 years ago. He lives with friends in a house in the hinterland of the Sunshine Coast in QLD. He is in receipt of the DSP and has semi regular casual work in a friend's gift shop, when his health allows.

Due to the fact that Ken lives on a rural property several kilometres from the nearest small town and several hours drive from the nearest large regional centre he has found it necessary to continue to maintain and run a car. Unforeseen expenses such as major car repairs may seriously impact Ken's ability to meet other necessary expenditures.

Ken is not currently taking antiretroviral HIV treatments however he is utilising a number of complementary therapies along with conventional medicines to treat a number of minor infections and conditions.

Available employment opportunities in the region in which Ken lives are generally low and combined with the fact that Ken's HIV diagnosis has become well known in the area even if his health allowed any chance for greater employment would be limited by discrimination.

Income per fortnight:

DSP: \$260.00
Wages: \$50.00

Expenses per fortnight:

Rent: \$25.00
Utilities: \$20.00
Food: \$70.00
Complimentary therapies: \$150.00
Non-PBS pharmaceuticals: \$50
Petrol and other car maintenance: \$137.00
Personal care: \$20.00

Total: \$472.00

5. Mario

Mario is 43 years old and lives with his partner with whom he is paying off the mortgage on a house. Both he and his partner are HIV positive and are using combination therapy.

Mario after suffering major debilitation due to treatment side effects, had been assessed as eligible and been approved for the DSP. He is not receiving payments, as he has been well enough to be working 38 hours a week for the past 3 months. His approval for the DSP however also qualifies him for a concession on the cost of his prescribed treatments under the PBS. Being on the DSP also makes him eligible for concessions on council rates, phone bill, electricity costs, and fares.

Recently proposed changes to his eligibility for the DSP which most concern Mario and his partner are, with the rise in the cost of prescribed medication, which is currently covered under the PBS, if Mario is removed from the DSP he will no

longer be eligible for the concession rate of payment and will find it impossible to afford these essential drugs.

Income per fortnight:

Salary: \$845.00

DSP: Nil

Expenditure per fortnight:

Mortgage: \$316.00

Electricity: \$12.00

Gas: \$10.00

Treatments: \$15.00

Food \$200.00

Phone \$35.00

Total: \$588.00

Impact on Mario:

Whilst Mario and his partner are both in reasonably good health and able to maintain full time employment a positive prognosis for people with long term HIV infection is by no means assured. Aside from the long-term, serious side-effects of many HIV antiretroviral drug treatments, such as liver damage, it remains the case that resistance over time to the positive effects of these treatments is inevitable. With the proposed increase in the cost of HIV treatments and the possibility of no longer being eligible for the DSP and its associated concessions Mario would be faced with a choice of using his limited finances to pay for either his HIV treatments or other life essentials such as food, shelter etc.

Conclusion

In terms of sound economic management AFAO sees an obvious choice confronting the government.

On the one hand an expenditure of funding to provide adequate welfare payments, to people with disabilities and chronic illness, enabling them to maintain their health. On the other the expenditure of larger amounts through the public health system to provide care and treatment for these people when their health has been compromised by the rigors of living in poverty.

For clarification of any issues raised by this submission please contact

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