

# Positive Education Part 1 – Defining the Constituency

*This is part 1 of a 3-part document about positive education in 2002*

## Background Data

### 1. AIDS diagnoses, deaths, HIV diagnoses and diagnosis of newly acquired HIV infection 1991-2000<sup>1</sup>

Year	AIDS diagnoses	Deaths	HIV diagnoses	Cumulative Number of People Living With HIV/AIDS	Cumulative Number of People Living with AIDS
Prior to 1991	3428	2142	10506	8364	1286
1992	791	597	1140	8907	1480
1993	845	689	1018	9236	1636
1994	955	732	917	9421	1859
1995	807	648	896	9669	2018
1996	664	505	897	10061	2177
1997	376	235	748	10574	2318
1998	311	155	693	11122	2474
1999	184	122	702	11692	2536
2000	255	157	639	12174	2634

- a. For the detailed qualifications attached to the interpretation of these data refer to the *Annual Surveillance Report, 2001 HIV/AIDS, viral hepatitis & sexually transmissible infections in Australia* Edited by National Centre in HIV Epidemiology and Clinical Research.
- b. Some tentative observations based on these data are:
- i) *The numbers of people living with HIV and living with AIDS continue to increase - the number of people living with HIV/AIDS increased by 45.6% from 1991 to 2000 and the number of people living with AIDS increased by 204.8% in 2000.*
  - ii) *The Australian epidemic is still predominantly characterised by people living with HIV (as compared to AIDS), although the proportion of people living with AIDS grew from 15.4% to 21.6%.*
  - iii) *There were 3679 new diagnoses of HIV infection from 1996-2000 (i.e. since the advent of HAART). Assuming most of these people are still living as at 2000 they represent 30.2% of people living with HIV.*

2. Estimates of the number of people living with HIV infection by HIV disease stage, 2000-2004<sup>1</sup>

Year	Living with HIV	CD4>500	CD4<500 without AIDS	Living with AIDS
2000	12440	2080	7770	2600
2001	12730	2050	7990	2700
2002	13030	2040	8190	2800
2003	13320	2030	8400	2890
2004	13610	2030	8600	2990

Tentative observations based on these data are:

- i) *without significant changes in infection patterns, the number of both people living with AIDS and HIV in Australia will continue to slowly rise.*
- ii) *people with HIV with CD4<500 without AIDS will continue to constitute between 60 – 65% of people living with HIV.*

### Recommendation arising from this section

- a. That NAPWA and AFAO lobby for the development of appropriate social research projects that focus on people with HIV diagnosed since 1996.

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1. Annual Surveillance Report, 2001 HIV/AIDS, viral hepatitis & sexually transmissible infections in Australia Edited by National Centre in HIV Epidemiology and Clinical Research.

# Health Promotion? Positive Education?

One common problem encountered in the development of this paper was any common understanding of what these terms mean and how they may apply to people with HIV. Very often when people hear these terms their assumption is that it is education and information about treatments or occasionally peer support groups.

A net search on [www.google.com](http://www.google.com) using the search terms 'HIV positive education' reveals over 20000 hits. Of the first 1000 of these 98% are about treatments education, and the remainder are either about positive people educating others about prevention or discrimination or very rarely about peer support groups. There are no discursive articles defining 'health promotion' for people with HIV. A search on 'gay men's HIV education', however, reveals a totally different picture, where the terms 'education' and 'health promotion' - whatever the problems in their application - are applied to the overall living and social contexts in gay men's lives.

AFAO's initial Positive Information and Education Strategy<sup>2</sup> defined its core terms 'information' as 'the product, fact or data which is being provided' and 'education' as 'the process by which information is conveyed in a way which allows the asker to develop an understanding or skill.' There is a widespread perception amongst people I talked to in writing this paper that 'positive education' in Australia consisted of large amounts of information provision and very little 'education'.

Yet 'education' itself constitutes only a part of 'health promotion'. The review of gay and other homosexually active men's HIV/AIDS education in Australia<sup>3</sup> noted the tendency to collapse 'education' and 'health promotion' and commented that "education is a necessary, but not sufficient, strategy to bring about improvements in health outcomes." This review then proposed a framework for health promotion that is summarised below

<b>Health and social Outcomes</b>	Improved quality of life, independence, equity...		
	Reduced mortality, morbidity, disability		
<b>Intermediate health outcomes</b>	Healthy lifestyles	Effective health services	Healthy environments
<b>Health promotion outcomes</b>	Health literacy	Social action, and social influence	Healthy public policy and organisational practice
<b>Health promotion actions</b>	Education	Social mobilisation	Advocacy

In considering what's in scope of this paper, this framework of health promotion has been used.

### Recommendations arising from this section

- a. That the ANET steering group use this framework of health promotion as part of the annual review of ANET's program of activities
- b. That ANET and NAPWA investigate the feasibility of a social mobilisation project specifically targeted at people with HIV diagnosed since 1996, and aimed at articulating both their experience and their service needs

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2. Positive Information and Education Strategic Plan, Australian Federation of AIDS Organisations. National Association of People Living With HIV/AIDS. June 1998. Prepared by Levinia Crooks.

3. Building on success 1. A Review of Gay and Other Homosexually Active Men's HIV/AIDS Education in Australia. Commonwealth Department of Health and Family Services, Commonwealth of Australia. 1998.

# Background Discussion on People Living With HIV/AIDS

*"Plus ce change, plus ce la meme chose"*

[the more things change, the more they stay the same]

**Montaigne**

The arrival of highly active antiretroviral therapy was announced with huge headlines in gay community newspapers after results were given publicly at the XIth International Conference on AIDS held in Vancouver in 1996.

While the impact of this event is probably overstated, it marked a huge turning point in the ability to treat HIV disease, a change – at least while the existing drugs continue to work for most people – in HIV disease from an inevitably fatal infection to a chronic (somewhat) manageable illness.

Paradoxically, individual people often experienced this change in dramatically improved health prospects with HIV as a personal crisis.

Since 1996 there have been a number of identifiable changes in common social contexts for people with HIV/AIDS, the way in which 'AIDS' is experienced culturally has totally changed, and there are a number of identifiable common themes or discourses about people with HIV and AIDS.

Some of these changes include: -

- i) diminished real visibility of people with HIV/AIDS (i.e. less visibly ill people, less death notices) – although the gradual increase in the prevalence of lipodystrophy is changing this
- ii) a decreased priority and cultural space given to AIDS in gay communities – often now described as 'post-crisis' (ref. Murphy)
- iii) a growing world wide epidemic of depression (ref WHO report) – which, while it has particular consequences and contexts for people with HIV/AIDS, is not particular to people with HIV/AIDS alone.
- iv) a huge increase in time spent on, and access to, the internet
- v) the containment of the lived experience of HIV/AIDS inside medical discourses
- vi) an expansion in the role of most AIDS community based organisations that include gay men's prevention education programs to move these programs from a single disease focus to more generic gay and lesbian health programs

There are three common themes in the discourses used to try and aid understanding of the changed HIV lived experience.

These include

- i) the 'post-modern' - the only way PLWHA experience can be understood is by diversity and difference
- ii) the 'medical' (or old fashioned modernist) based on the 'spectrum of illness' - PLWA are by characterised by a set of people with complex needs (usually read as the poorer sicker people with HIV/AIDS), a set of

- people who are doing well and 'have little need for services' and a group of recent seroconverters who temporarily need services but will quickly move on in the context of improved treatments
- iii) the 'social context' – as described by a number of different pieces of social research (cf Race, Davis, Eddy) there has been a change from 'communal' response to HIV to 'individualised' and 'privatised' responses.

The 'diversity and difference' discourse became established to challenge the notion of a universalising HIV lived experience. Before the advent of treatments the natural history of HIV disease was somewhat universalising, and the experience of HIV disease post-treatments is more diverse. However, the lived experience of HIV disease has always been characterised by diversity and difference. The utility of the 'diversity and difference' discourse is that it challenges attempts to label issues like 'depression' or the need for 'return to work programs' as part of any universal or constant experience of living with HIV. As an example of how these universalising discourses can distort, when the issues of people with HIV and mental illness became prominent, it was quite common for HIV community sector workers to estimate that well over 75% of people with HIV "were depressed" at the current time (ref Duffin), when the available data suggests a figure between 5-10% at the current time, with some 35-40% on anti-depressant medication. However, like much of post-modern discourses, the 'diversity and difference' discourse often gets misunderstood as 'understand (and do) nothing' and it does not mean you cannot seek to understand and describe the lived experience HIV within appropriate frameworks and contexts

The more dominant 'medical' framework seeks to understand and describe the lived experience in terms of illness stage. In particular, it tends to ascribe to people with more advanced disease a set of complex issues and describes them as having 'complex needs'. It then tends to describe a large group of people with HIV/AIDS who are well beyond their seroconversion illness whose primary need is seen as effective treatments to maintain their health and who generally are considered to have no service needs beyond their primary health care physicians, and, finally, a group of people with HIV who are close in time to their positive diagnosis who have some time-limited support needs.

There are a number of problems that arise from the 'medical' framework. The first is the way 'complex needs' is understood. It is the case that as a result of improvements in treatments and increased life expectancy, there is increased complexity of medical management of HIV and an increased number of medical issues to deal with. However, "complex needs" is usually used not to describe the medical issues, but to describe the set of psychosocial needs associated with people with HIV/AIDS. Often "complex needs" is a euphemism for "difficult" or "awkward". Sometimes its use leads to a belief that people with HIV/AIDS are more 'complex' than in the past. While increased life expectancy may lead to a set of issues that are more commonly expressed and experienced, and also some issues having different importance, such as financial support, this does not mean that people with advanced HIV/AIDS now constitute a markedly different, more complex (and "difficult") population than in the past.

Service use statistics from the two largest community based organisations in NSW, the Bobby Goldsmith Foundation and the AIDS Council of NSW, show that their services are used by about 15% of the HIV population who would mostly be classified as people with advanced HIV disease often with "complex needs". Thus the coalface experience of the community sector with its HIV+ constituency is characterised by advanced disease and "complex" needs. This often results in these organisations seeking to develop new programs or services for this group of people with HIV/AIDS. This is said to be one factor in what a number of people with HIV spoken to in the

writing of this paper have described as the “re-stigmatisation” of people with HIV/AIDS and increasing tendency to use medical terminology and discourses to describe people living with HIV and AIDS.

One person described the way the medical discourse gets understood and “misused” this way – “People who are seroconverting are said to have temporary support needs, yet unlike 5-10 years ago there is no accessible information for seroconverters particularly addressing the difficult and urgent treatments decision and participation in clinical trials. People who are doing well are said to have no needs and are addressed through generic gay men’s health programs – except so far participation in these programs is very low, and knowledge of this “doing well” group is very limited and has been concluded without appropriate research or rigorous needs assessment. If we had used lack of demand in the mid to late 1980s as a marker of “doing well” then HIV Support programs would not have been established.”

The need to shift from a disease focus where people with advanced disease and “complex needs” both dominate service use and consequently how HIV/AIDS gets characterised and understood led the joint AFAO/NAPWA Positive Education Workshop to articulate the need for a new paradigm which it chose to describe as the ‘wellness model’. This is further described at the end of this section.

There are a number of pieces of recent qualitative research on the lived experience of HIV<sup>4,5,6</sup>. A number of them in their analyses talk on the adoption of ‘individualised’ responses by people with HIV. For example, the “Touch Wood, Everything will be OK” report<sup>4</sup> documents the individual positions adopted by positive men in relation to sexual practice and risk assessment and concludes ‘the effect of medical technologies now shaping individual practices and the new questions they raise about risk will require new or revised messages to cater to this change.’ A UK report<sup>5</sup> notes how people with HIV have adopted individualised stances to the management of treatments, with respondents valuing autonomy and using terms like “self-discipline” . The trend towards individualisation presents a number of problems for health promotion and has implications for practice.

The articulation of the need to move to a new paradigm summarised as the “wellness model” by the AFAO positive education workshop held in 2001 is partly a response to these discourses. It seeks to do three things in particular

- i) to highlight that 80% of people with HIV do not access community based services and that ‘complex needs’ does not characterise the Australian HIV population;
- ii) that in order to think about needs, services and programs for the “eighty percent” of people with HIV/AIDS who do not currently access services, the medical model and an illness focus are not useful starting points to frame the questions that need to be posed in relation to services, and that ‘wellness’ and ‘self-autonomy’ may offer a more useful framework;

and

- iii) that it cannot be assumed that not currently accessing services represents having no service needs or programs.

## Recommendations arising from this section

- a. AFAO/NAPWA consider an audit and review of current community based services for people with HIV/AIDS which maps current services against the changed set of service needs as identified from social research and through appropriate consultations with PLWHA
- b. That ANET look at different models to identify and document the lived experience and needs of people with HIV who constitute the so-called "eighty percent". This may be through a "needs assessment" and would be ideal as part of the work for another "researcher in residence" project that is under consideration.
- c. That given "individualisation" and the changes in social patterns, ANET look at funding a national project evaluating the use of the internet to provide information, education and support to and for people with HIV. Again this project would ideally suit part of a "researcher in residence" project.
- d. A number of local projects are currently underway or completed that seek to document (or assist in the development of individual self-documentation skills) the current lived experience of people with HIV/AIDS. That ANET look at providing funding for the national implementation of the best of these local projects.

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4. "touch wood, everything will be ok". Gay men's understandings of clinical markers in sexual practice NCHSR Monograph 7/2000.

5. Anderson, W., Weatherburn P., Keogh, P. Henderson (2000). Proceeding with care: phase 3 of an on-going study of the impact of combination therapies on the needs of people with HIV. (London, Sigma Research).

6. Ezzy, Douglas, Illness narratives: time, hope and HIV. *Social Science & Medicine* 50 (2000). Pp 605-617

# Changes in Organisational Structures Delivering Positive Education

When the initial Gay Education Strategies project report and the Positive Information and Education Project report <sup>7,8</sup> (the two projects that led to the formation of the ANET team within AFAO) were done, there was a large amount of structural change around the delivery and integration of gay men's prevention education and positive education. The ANET team is a reflection of that integration.

In the last five years there have been a number of other changes in organisational structures as a result of funding changes, improvements in treatments, and the changed spectrum of needs and illness patterns of people with HIV and AIDS. Some of the organisational changes include: (and these are not necessarily typical or national)

- A changed emphasis and/or a decreased role for care and support programs focussed on practical home care for people with HIV/AIDS
- The development of new programs targeted at meeting identified common complex needs, often in partnership with existing state health department programs
- A diminished participation in HIV Support programs
- Reported difficulty in recruiting HIV-positive people to work in HIV-positive education positions in some states
- The development of new programs co-located with the 'clinic' – as this is seen as the pivotal and common service access point for people with HIV
- An expansion into gay and lesbian health, often with a desire to use this as the "agency" (rather than HIV) to target gay men with HIV (though there is so far little evidence of this working in terms of participation of people with HIV) – sometimes this change has resulted in less direct gay men's HIV prevention and HIV-positive health promotion programs
- The organisational separation of PLWHA organisations and AIDS Councils, with more 'education' resources located in PLWHA organisations
- An increased inclusion of issues related to Hepatitis C

Often these changes have been accompanied with new frameworks that reflect changed thinking about the most appropriate ways to respond to the epidemic.

With the changes in structures and roles, the location of positive education within gay men's prevention education programs may no longer be the most effective solution. Care and support programs have had to dramatically change their role, and just as 'individualisation' effects health promotion and education programs, so many (though not all) care and support programs have moved to individual mentoring and friendship programs. Additionally, with the range of 'complex' issues now associated with living with HIV, many care and support programs do a lot of information provision and education. The current national 'education' conferences tend to (although not explicitly) exclude care and support programs and workers and positive education may now have as much interface with care and support as with gay men's education.

## Recommendation arising from this section

- a. That NAPWA and ANET/AFAO co-host a national community care and support conference inclusive of positive education and support workers