

# Positive Education Part 3 – Psychosocial Issues

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

# “Psychosocial” Issues

*“And while for some the Roller Coaster shows some signs of being a smoother and longer ride, for many it continues to lurch around corners, catapult down vertical precipices and loop the loop. In the midst of such turbulence, it seems more critical than ever that all those infected and affected by the pandemic stay on board and work together to better respond to the enormous complexity of HIV/AIDS”<sup>21</sup>*

The immense implications of improved treatments are a constant subtext through this whole paper. Tony Keenan observed “treatment advances can mean a cruel change in expectations, adjusting from a retirement with a very short life expectancy to a longer life with a serious disability and little income”.<sup>22</sup> Six years after the arrival of HAART ways of thinking about, describing and characterising the experience of living with HIV are still often spoken of as being deficient due to large areas of lack of knowledge. There are also perceptions that current understandings may have been distorted by the dominance and privileging of medical frameworks and because the majority of contact with people with HIV/AIDS for many community based organisations has been for people with “complex needs”.

As a result it is difficult to map the range of psychosocial issues that currently characterise living with HIV in some priority order. The issues on the list have been determined from a scan of recent social research (although the issues described are often a reflection of the way the questions were framed), from a review of PLWHA and HIV community sector literature over the last few years and from talking to current positive educators.

## Psychosocial Issue 1: HIV positive Visibility

The visibility of people living with HIV and AIDS is often described as having diminished over the last six years. There are less death notices in gay newspapers, there are less visibly ill people with AIDS (although the increasing incidence and recognition of lipodystrophy and Lipo atrophy may be altering that perception), the importance of HIV identity to individuals has changed so that frequency of disclosure may have changed, experience, knowledge and visibility of people diagnosed in the last six years is often described as very limited, and there has been a noticeable decrease in the use of personal narrative in PLWHA community media. These perceptions, taken together with an impression that medical and treatments issues such as adherence, have been privileged above ‘living’ issues, have led to calls to document and describe the current lived experience of people with HIV/AIDS.

There are often two objectives behind these calls for increased visibility:

- as part of HIV prevention efforts targeted particularly to gay men;
- as part of education strategies to people with HIV with objectives relating to health maintenance and coping.

Sometimes, these two objectives are perceived to be in conflict – what you want to say to HIV-negative gay men about the current realities of living with HIV may be quite different than what you want to convey to HIV-positive gay men.

A number of community-based organisations across Australia are currently embarked on project aimed at documenting the lived experience of HIV. A previous recommendation addresses making the best of these projects available for national distribution. Some of these projects also involve the provision of skills for self-

documentation such as writer's workshops. Additionally ANET is currently working on a 'HIV survival guide' that uses oral history taking to explore the current lived experience of a group of people with HIV.

Recommendations on HIV positive visibility not previously included

- a. That ANET produce a discussion paper on the utility of documenting the 'current lived experience of people with HIV', on methods of self-documentation and the facilitation of the production of documentation of the lived experience of people with HIV.
- b. That ANET explore collaborative opportunities with both the NHRSC and ARCSHS who are doing qualitative research interviews with people with HIV around both access to interview material and interview design to meet joint objectives
- c. That the current ANET 'HIV Survival Guide' project be considered a pilot for on-going work documenting the lived experience of people with HIV

## Psychosocial Issue 2: HIV-positive and Ageing

Discourses about ageing amongst gay men are often described as having been 'interrupted' by the HIV/AIDS epidemic. There is now a tendency to give more priority to issues of ageing for lesbians and gay men – particularly as the 'baby boomers' who are more likely to have 'come out' as gay or lesbian reach an age where there are more likely to begin to interact with aged care services.

In a paper on ageing, Jo Harrison comments "As a researcher in gerontology, with a background in education, advocacy and policy development, it has been apparent to me that gay, lesbian, bisexual, transgender and intersex (glbti) older people almost never rate a mention in aged care in Australia"<sup>23</sup>. In the emerging literature on lesbian and gay men and ageing, people with HIV do not often get mentioned – except in relation to documented examples of discrimination in aged care services based on assumed (rather than actual) positive HIV-status. Partly this is because until recently it was assumed that HIV infection inevitably led to significantly decreased life expectancy, and even with the arrival of HAART, there is still no certainty about the magnitude of the increase in life expectancy.

There is an existing set of discourses and issues attached to so-called "long term survivors". However, older people with HIV are not necessarily long term survivors. In the United States there is a National Association on HIV Over Fifty (NAHOF). A look at the abstracts for their most recent conference<sup>24</sup> gives a map of some of the many HIV medical and social contexts where older age may be an important factor to consider, and demonstrates that older people with HIV can be quite a significant resource for advocacy and education. People with HIV who are both older and "long term survivors" may be a significant resource in terms of the history of the epidemic and have experienced significant personal epidemic impact.

Recommendations on HIV-positive and Ageing

- a. AFAO produce a policy paper that documents the current age profile of Australians with HIV, the changes in life expectancy and the current preparedness of the aged care sector to deal with issues related to both HIV and sexual identity.
- b. That as part of a 'research into practice' project (see work practices section of this report) ANET look at a state based project targeted at developing an intervention for both long-term survivors and older people with HIV.

### Psychosocial issue 3: Mental health issues for people with HIV

The Futures II<sup>25</sup> survey states 'there is growing evidence that depression, anxiety, dementia and other general psychological issues are critical factors in the well-being of positive people'. 29.7% of PLWHA in this sample had been taking medication prescribed for depression in the last 6 months and 26.5% had taken medication for anxiety. Using the Beck Depression Inventory (BDI), 6.7% of the sample agreed with 4 items on the assessment instrument, which is suggestive of clinical depression. Agreement with a number of the items on the BDI was significantly related to being on anti-depressants, having a poorer self-rating of general health, having less social support, current use of Efavirenz and working for or doing volunteer work for an AIDS organisation. It was unrelated to viral load, CD4 count, having had an AIDS defining illness, use of any antiretrovirals except Efavirenz, length of infection, gender or sexuality.

Both the data from Futures II and a number of anecdotal reports from organisations providing care, support and/or counselling services led to perceptions of an increased incidence of the expression of mental health problems amongst PLWHA. However, a close examination of available data does not provide evidence for either an increased incidence of any mental illness amongst PLWHA when compared to a decade ago (though there is not much available data) or that rates of any particular mental illness (except AIDS related dementia) are higher in PLWHA than in people with comparable life threatening illnesses.

A number of workshops have been recently held amongst HIV community sector workers on mental health issues as part of discussing issues of mental health and HIV. It was common for workers in these sessions to estimate that over 75% of people with HIV were currently 'depressed'<sup>26</sup>. This is considered by the author of this paper to both represent how people with 'complex needs' can come to characterise 'living with HIV' and the dangers of a 'HIV and mental illness' discourse having the unintended consequence of restigmatising people with HIV. So while care might be exercised in a 'gay men and depression' project or a 'lesbians and depression' project because the risk of unintended consequences and possible stigmatisation is easily understood, there seems to be less care about attaching mental illness to people with HIV.

The World Health Organisation<sup>27</sup> Global Burden of Disease 2000 analysis shows that unipolar depressive disorders are the leading cause of years lived with a disability (YLD) accounting for 11.9% of the total YLDs. This is expected to rise to 16.4% by the year 2020, making depression the illness causing the highest burden of disease in developed countries. In other words, there is a global epidemic of depression, the reasons for which are not totally understood. Whatever factors are causing this rise in depression globally are likely to be affecting particular sub-populations and depression in these sub-populations may be equally about '21<sup>st</sup> century living' as well as factors relating to the particular contexts of 'gay' or 'HIV-positive'.

However this note of caution does not mean that there are not significant mental health issues for people with HIV. Increased survival times inevitably mean that over time a greater number of PLWHA will experience mental health problems and many PLWHA stories of 'long term' survival highlight how increased survival means that many psychological issues such as unresolved grief and loss, which would have been avoided by death, often now have to be dealt with.

The policy and programmatic response of state-based mental health systems to the challenge of HIV has been very variable. Given increased survival times then it is more likely that existing mental health systems will have to provide services for people with HIV more often.

## Recommendation of HIV and mental health

- a. That AFAO produce a best practice document in relation to people with HIV and their mental health needs
- b. That ANET produce a discussion document on health promotion and mental health in relation to people with HIV and gay men and lesbians which canvasses a range of strategies that may be appropriately conducted by the HIV community sector and identifies any potential role for ANET.

## Psychosocial Issue 4: Peer and social support for people with HIV

There is a volume of research in both HIV/AIDS literature and literature related to other life threatening illnesses confirming the importance of social support and social networks in terms of health maintenance behaviours, coping skills, mood and improved health outcomes.

There is limited data on social support in Australia with Futures II<sup>25</sup> data showing that for the categories of support most likely to be rated as giving 'a lot of support' were parents, pets and close friends, but that over 53.4% of the sample did not rate any source as giving a lot of support, 4.5% got a lot from one source, 4.8% two sources, 10.1% three, 9.1% four, 7.6% five, 9.7% six and 0.8% seven sources gave a lot of support. Of those that had HIV positive friends, 38.2% received a lot of support from them.

The types of "support" programs run now or previously by the community sector in Australia include:

### One-on one

- Professional Counselling
- Peer counselling
- Outreach
- Buddy systems and mentoring

### Practical Home care

### Groups

- Peer support groups
- Social groups and events
- Drop-in groups
- Specifically targeted groups (for recently diagnosed or young and positive)

These support strategies usually include health promotion objectives and have historically been a core strategy for positive education.

The changes in social patterns, HIV identity and community referred to previously in this document have often resulted in a decline in the number participating in programs and the trial of different strategies. In general, the trend in large centres is away from formal group work to drop-in, social groups and one-to-one mentoring type activities. These have always been the typical strategies in smaller centres.

While some states have had some success in programs for people with recently diagnosed HIV infection, most programs are characterised by a lack of participation by people with HIV diagnosed in the last six years. This lack of participation often feeds into the lack of "community knowing" about the lived experience of HIV for people diagnosed since 1996 and possibly uninformed speculation about this groups lack of need for support services.

The Internet is often mentioned as a possible technology to be used in the provision of support. One of the interleukin trials has been experimenting with providing "online" support to remote trial participants and has had limited participation.

Recommendation relating to peer and social support

- a. ANET explore the feasibility, perhaps in partnership with existing online positive groups, of a national Internet support and education web site for people with HIV
- b. ANET commission the documentation of previous and current successful peer support and education projects for national distribution

## Psychosocial Issue 5: Recent seroconverters

The experience of getting a positive diagnosis post-1996 has obviously changed due to the impact of improved treatments. The availability of treatments for people with recent infection as well as clinical trials designed to answer particular questions in relation to treatment for this group has moved the question of treatments from one that can be dealt with in the future to one of immediate import, and means that people identified with recent infection may need to deal with questions of informed consent in terms of trial participation at a time of possible considerable psychological stress.

A couple of AIDS Councils have been running successful programs for people with recently diagnosed HIV infection. However, there is little documentation of the experience of, and the issues faced by, the participants in these programs. The AIDS Council of NSW has been conducting a "research into practice" project designed to look at the development of educational interventions appropriate to enhance individuals decision making about going on HIV treatments close to the time of diagnosis of HIV infection.

Recommendations relating to recent seroconverters

- a. That ANET document existing support programs for recent seroconverters and explore the possibility of providing resources to these programs to additionally document the experiences of participants in these groups
- b. That as part of a 'research into practice' project (see work practices section of this report) ANET look at a state based project targeted at developing an intervention for people recently diagnosed with HIV infection.

## Psychosocial Issue 6: Lipodystrophy / lipoatrophy

Kirsty Machon of NAPWA has written a recent detailed discussion paper<sup>28</sup> on the psychosocial impact of HIV-treatment associated body changes. For a more detailed discussion readers are referred to this paper and recommendations.

If visible and recognisable body changes become more prevalent then their impact is likely to go extend more broadly and have an impact on treatment uptakes and decisions about taking structured (or unstructured) treatments breaks. The impact of over dosing with AZT and the resultant experience of drug related toxicity has been extensively described and its future impact on treatments-related decisions well documented. Lipodystrophy and lipoatrophy have exactly the same potential impacts and there is currently increasing circulation of anecdotal reports about

PLWHA choosing not to treat or to defer treatments because of fears related to the possible development of lipodystrophy.

Recommendations on lipoatrophy/lipodystrophy

- a. That ANET circulate the NAPWA discussion paper to AIDS Councils
- b. That lipoatrophy/lipodystrophy be considered as a priority issue if a 'researcher in residence' project is established at AFAO.

## Psychosocial Issue 7: Psychosocial research agenda for PLWHA

In discussions with key informants in relation to these issues a common perception existed that Australian social research processes in relation to PLWHA were not well 'consumer driven' and that the current methods of determining research priorities and questions in relation to PLWHA were not well known or understood.

Recommendation

- a. That as part of its annual planning cycle ANET develop and consult about a research agenda for gay men's prevention education and ANET and NAPWA do the same in relation to PLWHA and related social research

21. Riding the Roller Coaster: Experiencing Transitions from HIV to AIDS. Geoffrey Woolcock, David Stephens, Susie McLean, Bill O'Loughlin & Beverly Raphael from [www.undp.org/hiv/publications](http://www.undp.org/hiv/publications)
22. Tony Keenan (1997) "New Hope...New Agendas", National AIDS Bulletin, 11:1. 20-21, 36.
23. What are you really afraid of? Gay, lesbian, bisexual, transgender and intersex ageing, ageism, and activism in word is out e-journal, no. 2, March 2002. ([www.wordisout.info](http://www.wordisout.info))
24. Abstracts of the NAHOF 4<sup>th</sup> National Conference on HIV/AIDS and Aging at [www.hivoverfifty.org/nahofabstracts01.htm](http://www.hivoverfifty.org/nahofabstracts01.htm)
25. HIV Futures II. The health and Well-Being of People with HIV / AIDS in Australia. Jeffrey Grierson, Michael Bartos, Richard de Visser and Karalyn McDonald. March 2000. Monograph Series Number 17. The Australian Research Centre in Sex, health and Society.
26. Personal experience (R. Duffin)
27. World Health Report 2001 : Mental health: New Hope, New Understanding. World health Organisation, 2001.
28. **Face value** - On the psychosocial effects of HIV treatment-associated body shape changes. A discussion paper by Kirsty Machon, HIV Health Policy Analyst, National Association of People Living with HIV/AIDS, March 2002.

## Issues of “work practice”

Leadership around educational practice is one of the strategies of the ANET. The most recent review of gay men’s education commented on the lack of documentation to provide evidence of effectiveness.<sup>29</sup>

The high overturn of staff in the community sector makes documentation a vital but often neglected task because of seemingly more important priorities. There is now over 16 years of professional experience and education projects, and it remains the case that much that has been done is undocumented.

### Recommendations :

- a. That ANET compile a manual of existing documents on current core methods of work practice and where the practices have been developed or refined by work in the HIV community sector write discussion documents to explain these
- b. That ANET commission histories of what are seen as some of the most successful projects in both gay men’s education and positive education

29. 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.

## Where to next?

This document will be circulated widely to individuals and organisations for feedback. A workshop at the forthcoming HARD social research and educators' conference in May will provide opportunity for further discussion and feedback. After that time a final version of this document will be produced and circulated.