

Benchmarks Towards a Better Place

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Executive Summary

"It's like visualising that some . . . are facing an approaching crest of a wave in leaky boats without life jackets whilst the rest have life jackets and safe boats to face the viral waves . . . and even those with the life jackets and safe boats need some guarantee they will always have that support . . ."

NAPWA has conducted an 'audit' to capture positive peoples' experiences of the services they use, and to gain a deeper understanding of how HIV affects peoples' quality of life today. The Audit represents new and important work for NAPWA. It addresses a number of questions about service needs, constituency and representation, geography and the policy and advocacy work of NAPWA.

The Audit included a survey which was mailed out to approximately 100 HIV positive conference delegates in December 2005. Completed surveys were accepted until the closing date of January 27, 2006. A total of 64 surveys were completed and returned by mail to NAPWA. In addition to the survey, interviews were conducted with 24 people working in community-based HIV services provision (See consultation schedule attached). Community partners were asked to talk about their experiences of service delivery, and to comment on a number of issues including barriers to effective service provision, the impact of change on their current practice and the needs of clients, and its implications for future service delivery.

The comments and issues raised spoke to a number of concerns positive people wanted to communicate about what life is like for them and their HIV positive friends. This report directly names problems and in some cases proposes solutions, around issues relating to:

- stigma and discrimination;
- the 'burden' of illness;
- access to services;
- financial pressures;
- employment issues;
- access to services for people in rural and regional areas; and
- peer support.

There were also a number of themes that emerged in relation to service planning and delivery, including the complexity of HIV today, coordination of care and support services, mainstreaming, workforce development issues, HIV prevention, funding and leadership.

Our research suggests that there are a series of 'transitions' that HIV positive people are managing as they make changes to their personal circumstances and continue to move towards improved health outcomes. Some people are able to benefit from opportunities as a result of the [effectiveness](#) [1] (Of a drug or treatment). The maximum ability of a drug or treatment to produce a result regardless of dosage. A drug passes efficacy trials if it is effective at the dose tested and against the illness for which it is prescribed. In the standard procedure, Phase II clinical trials gauge efficacy, and Phase III trials confirm it. of treatments and improved health monitoring and management.


However, it is important to understand that for others, having their HIV "controlled" by treatments does not necessarily equate with chronic manageable illness, as there is still no cure for HIV and chronic manageable illness is a reference to a medical outcome rather than quality of life or standard of living. Emerging from these interviews, it is possible to describe increasing 'pressure points' on services. These 'pressure points' relate to pressures placed on existing services due to the changing needs of positive people as well as gaps in service provision or coordination of services.

The changing needs of people living with HIV have implications for both HIV-specific and, increasingly, mainstream services. Moreover, the interface between mainstream and specialist HIV services is often fraught in itself. It is at

these client and service 'pressure points' that successful transitions are threatened. This report demonstrates that there are still significant areas requiring targeted ongoing advocacy and policy responses.

Summary of recommendations

1. That organisations across the HIV sector work to increase opportunities for the participation of HIV positive sub-populations, including CALD communities and indigenous people, in social policy and service planning.
2. That Department of Health and Ageing fund the NAPWA biennial conference at a level adequate to support an enhanced scholarship program for positive people to participate, with specific targets set for sub-populations and those who are financially disadvantaged.
3. That [MACASHH](#) [2] Ministerial Advisory Committee on AIDS, Sexual Health and Hepatides. The Australian Government Department of Health and Ageing's high level expert committee, providing advice on issues relevant to HIV/AIDS, sexually transmissible infections and hepatitis C. seek to initiate work to renew HIV sensitisation and training for healthcare providers.
4. That further research be undertaken to determine the true cost of living with HIV/AIDS.
5. That the Department of Health and Ageing and the Department of Family and Community Services and Indigenous Affairs work together to address shortages in affordable and appropriate housing for people living with HIV/AIDS. Coordination of care arrangements necessarily include housing, respite and emergency shelter programs for positive people.
6. That further research should be conducted into the effects of HIV on identity, including the relationship between HIV positive identity and participation in the national or state HIV responses, and the effects of HIV-related stigma on participation.
7. That further research be conducted into the HIV positive volunteer workforce, with the aim of understanding how best to support the health and wellbeing of volunteers.
8. That the Department of Health and Ageing work to improve referral pathways and access to mainstream health services, particularly mental health and housing, cooperating with other agencies where necessary to achieve this objective.
9. That planning for HIV care and support services take into account the role and availability of dental and oral hygiene programs for positive people nationally.
10. That the Department of Health and Ageing fund research to increase understanding of the various ways in which HIV affects people's mental and psychosocial health, with a view to improved planning and targeting of support services for positive people with mental health issues.

Attachment	Size	Type
Full report [3]	1.08 MB	 PDF

- [living with HIV](#)
- [report](#)
- [Social and emotional support](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/486>

[2] <http://www.napwa.org.au/glossary/term/379>

[3] http://www.napwa.org.au/files/01_benchmarks_main.pdf