

SPECIAL REPORT

# benchmarks towards a better place

HIV Living Unit

December 2007





## ACKNOWLEDGMENTS

This report was developed by the HIV Living Unit at NAPWA. Peter Canavan, HIV Living Program Coordinator, conducted the research, analysed the data and is the principal author. John Rule, Manager of the HIV Living Unit, was also closely involved, and editing for this version of the report was carried out by Abi Groves.

NAPWA would also like to acknowledge the work of the project's Critical Reference Group, who oversaw development of this report. The membership of the group is detailed on page 47 of the Appendix.

Significant assistance in preparing the report was also received from the Australian Research Centre in Sex, Health and Society (ARCSHS), especially Jeffrey Grierson and Rachel Thorpe. Jo Watson, the Executive Officer of NAPWA, was also instrumental in shaping the report.

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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 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 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.

11. That the Department of Health and Ageing re-affirm its commitment to funded peer support programs for people living with HIV/AIDS in the next National HIV/AIDS Strategy.
12. That State and Territory health authorities increase investment in the development of "Healthy HIV Living" support programs for newly diagnosed and "Living Well with Chronic Illness" support programs for people who are living long-term with HIV/AIDS.
13. That MACASSH advise the Minister to direct the Commonwealth Department of Health and Ageing (DoHA) to undertake an assessment of the adequacy of current models of HIV care to meet the current and future needs of HIV positive people. This assessment should include analysis of service utilisation and quality of life issues for positive people to address any gaps within models of care.
14. That funding be made available to support the formation of a small cohort of HIV positive people to enable further qualitative research into the patient journeys and experience of positive people in Australia.
15. That the Department of Health and Ageing and State and Territory health authorities undertake meaningful consultation with HIV positive people and service providers regarding any proposals to direct resources to 'mainstream' care and support services.
16. That MACASHH prioritise workforce development issues in relation to HIV care and support, including the shortage of Section 100 prescribing general practitioners.
17. That systemic and individual advocacy for people living with, and communities affected by, HIV remains a priority, and that specific funding for these functions be maintained.
18. That the Department of Health and Ageing fund further research to assess changing care and support needs and map changes in patterns of service provision.
19. That MACASHH be reviewed with the aim of strengthening national leadership on policy relating to HIV/AIDS.

# Introduction

This report represents work carried out through the NAPWA HIV Living Unit, and includes data drawn from consultations with HIV positive people and a range of community sector partners and organisations involved in the delivery of HIV services.

The NAPWA Care and Support Services Audit was funded through the Commonwealth Department of Health and Ageing (DoHA). NAPWA argued for this project on the basis that there have been significant changes, for example in treatments, which have affected positive peoples' health and wellbeing — and we need to be sure that services are equipped to respond most effectively to these changes.

NAPWA hopes, through this document, to provide some insight into how HIV positive people currently view the care and support services available to them. The intention is that this information can be used by funding bodies, policy-makers, researchers, service-providers and others responsible for the development and delivery of HIV programs. This report sits alongside a range of current projects and initiatives within the community and research sectors which share a common theme and goal: to assess the methods and assumptions which underpin services for HIV positive people in Australia, and to ensure future care services capitalise on the successes of the past, and take into account the major changes in the lives of many people living with HIV.

In addition, NAPWA is working with a range of people and organisations involved in the clinical care of HIV positive people to explicitly consider clinical care models and the future of the HIV clinical workforce, in the context of the dramatic changes in HIV medicine and patient outcomes. For this reason, clinical care is not the major focus of this report rather; this document addresses the broader care and support framework.

The audit comprised surveys and qualitative research interviews and makes some projections as to the likely level of HIV care and support needs in ten years' time. An additional component, utilising health economics modelling, is also underway.

This report does not specifically catalogue jurisdictional differences in care services, or individual differences based on geographic or demographic difference. It is not a report which considers individual sub-populations in specific detail. The 5th National HIV/AIDS Strategy gives particular consideration to the concerns of specific sub-populations: the needs of women, Indigenous people and culturally and linguistically diverse (CALD) communities are all explicitly discussed in the Strategy document. NAPWA has chosen to reflect the needs of the HIV population through general themes, as this is more inclusive for the purposes of policy development.

Similarly, the survey of people living with HIV that underpins this report was never intended to comprehensively represent Australia's HIV population. It was conducted among a group of positive people attending the NAPWA conference, a forum that draws together HIV positive people from around the nation. The results from this analysis should be seen as a starting point for discussion and may be indicative of issues warranting further exploration through a variety of means including research, case studies or HIV sector discussion.

# Methodology

The methodology for the study comprised two principal components: a survey of HIV positive people, and interviews with HIV service providers.

## 1. THE SURVEY INSTRUMENT

The survey instrument asked 13 questions around four survey sections as follows:

### SECTION 1: WHO ARE WE?

**Where we're from** – gender, age, place of residence (state or territory), region as defined by capital city/inner or outer suburban, regional centre or rural, Aboriginal and Torres Strait Islander (ATSI) background, nature and level of involvement in plwha and other HIV organisations.

**Who we represent** – in what representative capacity (if any) the respondent was attending the conference.

**How we identify** – 12 options were offered seeking information on the group that the respondent feels most strongly connected to, or the group whose concerns they are most likely to speak on behalf of.

**Who we connect with** – the degree to which people felt connected with six different groups (other positive people, their state plwha organisation, NAPWA, AIDS organisations, AIDS Councils, AFAO) was canvassed.

### SECTION 2: CARE AND SUPPORT SERVICE ISSUES

In this section five questions were asked about the significance of a range of care and support service issues for the respondent, their friends, their organisation, their region and their constituency. Space was provided for comments.

Service issues were grouped under the headings of 'HIV Health' and 'HIV Living' as follows:

**'HIV Health'** – services provided by general practitioners (GPs), hospitals and clinics, including specialist and ambulatory services, counselling, dental care and health management and monitoring.

**'HIV Living'** – housing, community support services (transport, food networks, and financial management), personal needs such as peer support and opportunities for social participation, and employment and income support (pre-employment and ongoing employment support, accessibility of Job Network services and services to support people returning to work or study.)

Respondents were asked to rate their own need for each service, as well as the needs of their HIV positive peers is currently for each group (e.g. 'you personally' or 'your friends who are HIV positive') from six options ranging from 'very well' to 'not at all' or 'not applicable'.

## SECTION 3: **POLICY AND ADVOCACY**

Respondents were asked about six current areas of policy and advocacy work undertaken by NAPWA, and asked to rate how relevant these were to needs in 'their region' or 'for their constituency'. The areas of work were:

1. Improving access to health services
2. Addressing discrimination in the insurance industry
3. Achieving affordable long term and supported housing
4. Improving the range and quality of plwha return-to-work services
5. Arriving at a 'true' cost of living with HIV
6. Ensuring the implementation of the 5th National HIV/AIDS Strategy at state level.

This section aimed to explore respondents' views about the effectiveness of NAPWA in addressing care and support issues in its policy and advocacy work. Respondents were asked to rate each area on a seven point scale ranging from 'very' to 'not at all', 'not applicable' or 'don't know'. Space was also provided for comments on each question.

## SECTION 4: **PEER EXPERIENCES**

This section asked two open-ended questions:

1. Respondents were invited to freely express anything else they wanted to note in relation to care and support needs or their particular experiences.
2. Respondents were invited to talk about their own lives and the lives of their friends and invited to make any final comments on their care and support needs and experiences.

## 2. INTERVIEWS WITH SERVICE PROVIDERS

In preparing this report NAPWA also consulted extensively with stakeholders around Australia. The principal researcher for the project, Peter Canavan, conducted interviews with 24 people in NSW, Victoria and Queensland (the three states with largest numbers of people living with HIV/AIDS). These were in-depth, semi-structured interviews with representatives of organisations that provide care and support services to people living with HIV/AIDS (many of these representatives are themselves positive).

Group consultations were also conducted with:

- NAPWA membership
- NAPWA Board and Convenor workshops
- NAPWA AGM workshops
- NAPWA women's forum
- AFAO Annual General Meeting workshop
- Consultation with AFAO Board
- Consultation with WA AIDS Council (HIV positive representatives)

(A complete Schedule of Consultations is on page 52 of the Appendix.)

Themes were extracted by examining the data from these interviews and workshops. In analysing the data, the Project Officer worked closely with the project's Critical Reference Group (CRG), which included representatives from NAPWA, AFAO, and PLWHA organisations, including those which represent positive women and positive heterosexual men. Assistance was also provided by the Australian Research Centre in Sex, Health and Society (ARCSHS), particularly Jeffrey Grierson and Rachel Thorpe.

# Survey results

## WHO ARE WE?

- Of the 64 respondents, 49 (76.5%) identified as male and 14 (21.8%) as female.
- Age of participants ranged from 27 to 67 years with a mean of 47 years.

**Table 1: STATE OR TERRITORY: RESPONDENTS' RESIDENCE**

STATE/TERRITORY	FREQUENCY	PERCENTAGE %
ACT	6	10.5
NSW	13	22.0
NT	1	2.0
QLD	5	9.0
SA	11	19.0
TAS	3	5.0
VIC	13	22.0
WA	6	10.5
TOTAL	<b>58</b>	<b>100</b>

**Table 2: RESPONDENTS' REGION<sup>1</sup>**

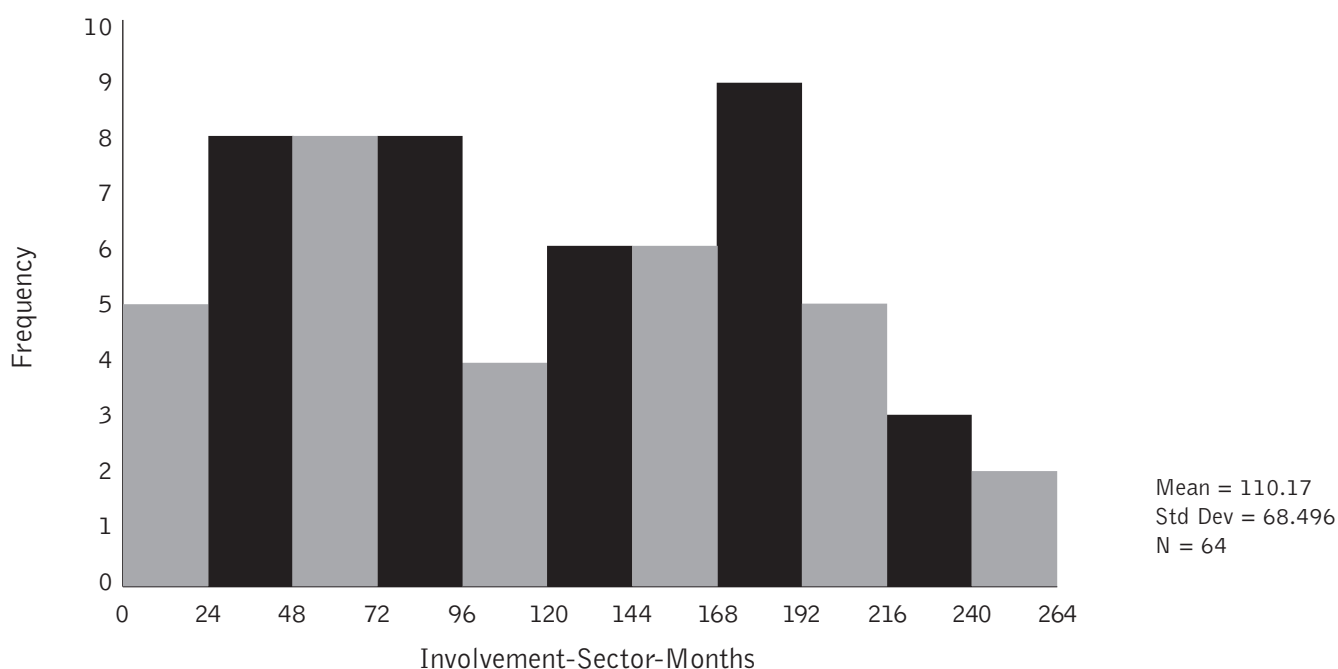
REGION	FREQUENCY	PERCENTAGE %
Capital city	38	67
Outer suburbs	8	14
Regional centre	8	14
Rural	3	5
TOTAL	<b>57</b>	<b>100</b>

- ATSI background – three respondents identified as being from Aboriginal or Torres Strait Islander backgrounds.
- More people cited volunteer work with their local plwha organisation than their AIDS Council.
- Of the 65 respondents, 34 (53.1%) undertook volunteer work within plwha organisations and 25 (39.1%) identified as a client of these organisations, while six (9.4%) held a staff position. Eleven (17.2%) indicated that they had no contact with plwha organisations.
- Of the 65 respondents, 26 (40.6%) received services from an AIDS Council as a client, 20 (31.1%) undertook volunteer work within their AIDS Council and nine (14.1%) held a staff position. Twenty (31.3%) indicated that they had no contact with their AIDS Council.
- Respondents had been involved in the HIV/AIDS sector for some time – though the length of time that respondents indicated they had been involved varied from nil to 240 months (20 years), the mean period was 110.17 months or 9.16 years.

## ■ RECOMMENDATION 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.

**Figure 1: LENGTH OF TIME INVOLVED IN HIV SECTOR**



## WHO WE REPRESENT

Respondents were asked in what representative capacity (if any) they were attending the conference. Twenty options were provided and respondents could tick as many as they felt applied.

As this was the biennial NAPWA conference, it was expected that this group would include people who attended in some representative capacity linked to NAPWA processes of governance and representation.

Apart from representatives linked directly (e.g. Representative Committee, working group members, Indigenous Positive Network (IPN+) members) and indirectly to NAPWA (e.g. through local plwha organisations), scholarships were provided to more than 50 people from around Australia to attend the conference. Some 23 respondents indicated that they were attending in a scholarship capacity, and many of these people were not linked into NAPWA processes of governance or representation.

Respondents reported attending the NAPWA conference in the following capacities:

**Table 3: WHO WE REPRESENT**

REPRESENTATION	FREQUENCY	PERCENTAGE %
Local PLWHA organisation	24	38
Local AIDS council	9	14
NAPWA Representative Committee	6	9
NAPWA Board of Directors	3	5
National portfolio convenors	4	6
NAPWA working group	2	3
National women's meeting	5	8
Indigenous Positive Network IPN+	3	5
Private individual	16	25
Positive womens' organisation	6	9
Scholarship recipient	23	36
NAPWA staff	0	0
AIDS council staff	5	8
Positive Living Centre	8	13
Positive heterosexuals organisation	1	2
Multicultural CALD (culturally and linguistically diverse) organisation	1	2
Indigenous organisation e.g., IPON	2	3
Health worker	4	6
Government sector/AFAO Board or staff	1	2
Other	7	11

## HOW WE IDENTIFY

The survey results indicate that respondents identified as HIV positive in the first instance, followed by identifications based on their sexuality, gender, race or work. Thirty-six (56.3%) respondents indicated that their primary "constituency" when thinking of the group that they most strongly belong to or speak on behalf of was people living with HIV/AIDS generally, followed by both gay and heterosexual HIV positive men (20 people or 31.3%) and HIV positive women (12 people or 21.9%). Thirteen respondents (20.3%) considered their primary constituency as being gay men.

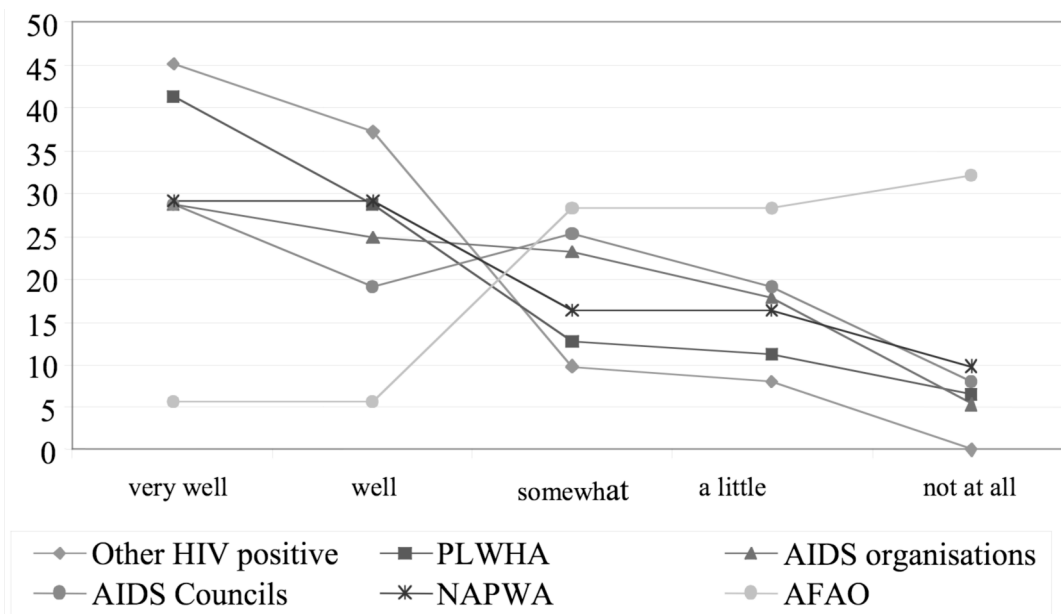
**Table 4: WHO WE IDENTIFY WITH**

CONSTITUENCY	FREQUENCY	PERCENTAGE %
Plwha generally	36	56
Positive gay men	17	27
Positive women	9	14
Indigenous	2	3
Positive female heterosexual	5	8
Positive male heterosexual	3	5
Gay men	13	20
General community	9	14
Health consumers	3	5
Allied health	1	2
Medical community	1	2
Community health	2	3

## WHO WE CONNECT WITH

The connection or identity association with six groups was canvassed rating connection from six options ranging from 'very well' to 'not at all' or 'not applicable'. Overall, as can be seen by the connectedness graph (Figure 2), respondents stated that in order of connectedness, they felt most connected to other positive people, followed by local plwha organisations, then NAPWA and other AIDS organisations.

Figure 2: WHO WE CONNECT WITH



## IS THIS THE SAME FOR ALL OF US?

**State differences** – an analysis by state needs to be treated with caution due to the small numbers of respondents from some states. While respondents were consistently more connected to NAPWA than AFAO, analysis of connectedness to AIDS Councils and plwha organisations by state shows that in NSW there is a more moderate and even sense of connectedness to PLWHA organisations (53.9%) and AIDS Councils (38.5%). In contrast, results from Victoria and South Australia show that in South Australia there is a very high sense of connectedness to both plwha organisations and AIDS Councils (91.6% versus 72.8%), while in Victoria there appears to be a disconnect (91.6% versus 25%).

Of interest is the moderately high level of connectedness to NAPWA in NSW (69.3%), compared with the state plwha organisation (53.9%) and AIDS Council (38.5%). This relatively strong sense of connectedness could be related to the location of the NAPWA secretariat within NSW. (See appendix for cross-tabulations of state results.)

**Regional differences** – Once again, looking at connectedness and engagement with groups and organisations in South Australia, Victoria and NSW, in both capital city and regional locations respondents indicate a greater connection with NAPWA (66 % versus 15%) than AFAO (15% versus 7%) and again with plwha organisations (75% versus 58%). However, the connection appears to be more even with AIDS Council engagement (46% versus 47%) between capital and regional centres. (See appendix for cross-tabulations of regional results.)

It is NAPWA's role to have a national reach, so the above results are not surprising in this context. On the other hand, NAPWA is not charged with a service delivery role so it is possible that the physical presence of ACON outside of Sydney, together with its statewide charter for service delivery, has a role in this result.

The sense of engagement with and connection to NAPWA reported by respondents living in regional areas is important. This provides a useful insight into a difference between NAPWA and the PLWHA state based organisations: NAPWA's reach into regional areas on advocacy and policy briefs is possibly greater than that of state-based plwha organisations which, in the main, do not have the resources to effect a state-wide reach.

**Differences for gay men and women** – Different groups also show different modes of engagement. For instance, women and gay men (including those who identified as 'gay' and 'positive gay men') both followed the national trend in terms of connection to NAPWA (52% versus 41.6%) rather than AFAO (0% versus 9.1%), and to plwha organisations (65.4% versus 66.6%) rather than AIDS Councils (38.5% versus 50%).

The relatively strong connection expressed by women to NAPWA is of interest, and when considered along with the strong level of state connection to NAPWA, it appears that there may be a different mode and frequency of engagement by women than men. One possible reading of this is that women have a different process of engagement with organisations and the politics of HIV than gay men.

Importantly, the sense of engagement and connection by women to the NAPWA process says that structural access and governance arrangements for women within NAPWA, where there is a dedicated national women's network and other key director or portfolio engagement by women, are seen as useful to women. The establishment of a National Women's Network by NAPWA has occurred in spite of a critical mass of women in all states and speaks to the importance and power of a national organisation assisting women by providing a national voice, peer support and education opportunities for women under the NAPWA umbrella.

## ■ RECOMMENDATION 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.

# Living with HIV

This section focuses on some themes in experiences of living with HIV, drawing on comments made by respondents.

## STIGMA AND DISCRIMINATION

*"Discrimination is very much out there."*

The message from respondents who participated in the research is that stigma relating to HIV and discrimination against people living with HIV are still very much present. The *HIV Futures Five* report found that 27.2% of people living with HIV experienced less favourable treatment because of HIV in relation to health services, 10.1% in the last two years. Another 6.8% of respondents had experienced less favourable treatment in relation to accommodation, 3.5% in the last two years.

It is still common for people with HIV to report experiences of discrimination or inappropriate treatment within services; sometimes this discrimination is based on prejudices about sexuality and misunderstandings about HIV and its transmission. Experiences of discrimination have been reported in both HIV-specific and mainstream services, as well as in government departments, and was reflected by those interviewed for this report.

People have also talked about the effects of this — facing an unfriendly receptionist, for example, or to a doctor who suggests you go to the end of the queue — and report it as affecting their overall sense of health and wellbeing, including the process of re-adjusting to work, life and play. For example, one respondent says,

*"Staff in hospitals are not discreet and openly make you feel bad by their behaviour."*

Other examples of discrimination reported by respondents included: some dentists in Victoria refusing to manage HIV positive people, heterosexual HIV positive men from countries in the Horn of Africa experience considerable anxieties about accessing HIV services, disclosure of HIV status and sexuality after seeking care in country Victoria, Home and Community Care providers who would not work with people with HIV, and reports of positive people being harassed and bashed in public housing estates.

Undoubtedly, these experiences are less widespread as treatments have improved, community attitudes to sexuality have begun to change, and there is a generally better understanding of HIV in the community. Nonetheless, fear of discrimination, disclosure, or poor or inappropriate care remain significant factors for many positive people as they access care services.

Stigma arising from the side effects of treatments was also an issue for some respondents. One says:

*"For most it is one big struggle due to stigma and drug side effects."*

While not specifically naming the source of stigma as treatments, it is known from existing research<sup>2</sup> that lipodystrophy experiences can and do accompany feelings of poor self esteem and people speak of feeling unattractive, visible or obvious. Whether stigma is arises from having HIV or treating it, it is a real and worrying experience for many positive people.

Naming stigma in this context highlights the need for appropriate care and support strategies to sit alongside treatment management strategies and provide emotional support and assist people to develop personal coping strategies for living with HIV and treatments side effects.

The issue that continuing stigma and discrimination raises for services providers is: are all staff adequately trained to recognise, understand and be sensitive towards the needs of HIV positive people? Experiences of discrimination have been reported across different health and community services, including in HIV-specific services. Appropriate training for staff therefore includes not only ensuring that staff understand the complex and potentially fluctuating state of peoples' health (e.g. in employment programs or the social security system), but also making sure they are equipped to deal with specific populations such as gay and bisexual men, injecting drug users, or people from diverse cultural backgrounds.

## HIV AWARENESS

*"While the general community are getting better educated – still lots of work to be done."*

Positive people also spoke of areas where they have identified issues or problems and the need for more HIV education work to be done, particularly in health and medical services areas.

*"More education for medical persons e.g. doctors/nurses, etc., around who are asking: "how did you get it?" when it has no medical relevance at that time."*

*"More education needed in some medical areas."*

*"We need more education of health services on HIV."*

*"Need more in the way of making holistic healthcare more affordable and access to practitioners who are HIV aware."*

While the landscape of stigma relating to HIV/AIDS has clearly changed since the 1980s, there is still considerable work to be done in improving awareness and building capacity of services to respond to the needs of people living with HIV.

### ■ RECOMMENDATION 3:

That MACASHH seek to initiate work to renew HIV sensitisation and training for healthcare providers.

## THE 'BURDEN' OF ILLNESS

*"Life is alright, however there is the constant worry . . ."*

Respondents talked about life experienced as a 'burden', 'it's hard', 'it's a struggle', 'there are many worries' and 'it's not easy'. This speaks to the range of complex medical, psychological and social challenges many positive people face in living with HIV or AIDS. These challenges affect people differently, often changing over time as well. As one participant puts it:

*"All people living with HIV and AIDS face considerable psycho-medico-social challenges. However, individuals have different challenge mixes and they change over time."*

As a result of effective treatments and improved health outcomes for positive people, HIV is increasingly being experienced as a chronic manageable illness for many people. Positive people acknowledge there is change and are grateful for their improved prospects. However, sitting alongside this new-found hope is genuine unease about a range of "disease burdens" related to living with HIV and treatments. This was often closely related to financial pressures associated with HIV, with increased medical expenses and reduced capacity to work; financial pressures are discussed in more detail in a following section. For example, one respondent says,

*"Budgeting for my health, living alone, eating properly and educating myself has made my life hard."*

Those in employment also talked about the burden of HIV:

*"The extra burden that living with HIV puts onto our existence must be noted and addressed."*

*"Whether we are working or not, HIV has placed a burden on our lives . . ."*

The issues for people in employment may differ, with problems accessing services during working hours or maintaining employment when life is punctuated by periods of illness.

Yet even for people who are currently well, living with a chronic illness is frequently experienced as a burden and a source of anxiety. HIV adds a dimension of uncertainty about the future, with the knowledge that health can deteriorate at any time. One participant noted,

*"I don't have many positive friends but certainly the ones that I do have, have needed to spend time in hospital this year."*

In talking of the future, one participant captured the uncertainty of living with HIV:

*"Although my own care and support needs are not high, I do worry about the future and what my care and support needs might look like in 10 or 20 years."*

Living longer brings its own set of problems. Recent research from *Futures IV*<sup>3</sup> provides evidence and insight into the additional burden of illness that plw has carry as they age and live longer with HIV and treatments. One respondent says,

*"Life is alright. However there is the constant worry of new ARVs (antiretrovirals) to fight chronic resistance. The long-term effects of HIV or ARVs on health is also a worry. Perhaps the worst part is the physical changes that HIV brings about to body shape. Not at all sure that care and support can address these, but there may be implications as we get older."*

This respondent speaks of being worried about developing resistance to treatments and gaining access to newer improved treatments in time to keep the virus controlled and his health stabilised, as well as worrying about longer-term treatment side effects. In an almost melancholic way, he muses that he's not sure what difference care and support can or will make to living with the physical changes he experiences to his body shape and that he is worried about the implications of continuously treating into the future and ageing with HIV and treatments.

## ACCESS TO SERVICES

All of the broad areas of need (including GPs, hospitals, allied health, housing, income support, community services, employment and personal needs) identified in the survey were rated as very important by respondents. Needs for GP and hospital care rated most highly, closely followed by needs related to allied health, income support, housing and employment. 'Personal' needs, which referred to notions of closeness and connection through peer support and social participation opportunities, rated least highly.

Importantly, all the needs rated highly. Differences between GP care, which was rated most highly, and personal needs, which rated lowest, was just above 10%, for example. There were no significant regional differences and differences between women and gay men were also relatively slight. Results are detailed below.

### By region, using ratings of 'very well' and 'well'

GP	91.1%
Hospital	91.1%
Allied health	88.6%
Housing	87.4%
Income support	87.3%
Community services	87.1%
Employment	81.0%
Personal needs	80.5%

### For gay men, using the ratings of 'very well' and 'well'

GP	91.6%
Hospital	91.7%
Income support	87.5%
Personal needs	83.4%
Community services	82.6%
Allied health	82.6%
Housing	79.1%
Employment	77.3%

### For women, using the rating of 'very well'

GP	90.0%
Hospital	90.0%
Income support	90.0%
Personal needs	80.0%
Community services	80.0%
Allied health	80.0%
Housing	80.0%
Employment	80.0%

The consistency in responses suggests that the needs of people living with HIV were accurately identified by the survey instrument. Whilst key priorities were identified, all service needs rated very highly and it is clear that the eight service needs are all seen by respondents as important to providing effective care and support services.

### Perceptions of need

Interestingly, respondents frequently rated their own need differently to that of their positive friends. This raises an issue about the *perception* of need. The ratings given to the significance of need for "the other" is in every instance higher than the perception of personal need, i.e. respondents considered their friends' needs for services greater than their own.

The significance of this result is not entirely clear. Research from the *Futures<sup>4</sup>* studies suggests that people generally see themselves as being more resilient than the "anonymous other". One interpretation is that respondents tend to under-rate their own need. It is also possible that the volunteer advocacy role performed by many of the survey respondents influences their perceptions of their own needs, as opposed to the needs of other positive people. It is possible that advocates 'hold back' when speaking of personal needs and focus instead on 'arguing the case' for others living with HIV. It may be useful to further explore the influence of the participation of volunteer advocates on their perceptions about their own personal needs.

### GP AND HOSPITAL CARE

*"For all it is health services (accessibility and survival) and cost of living."*

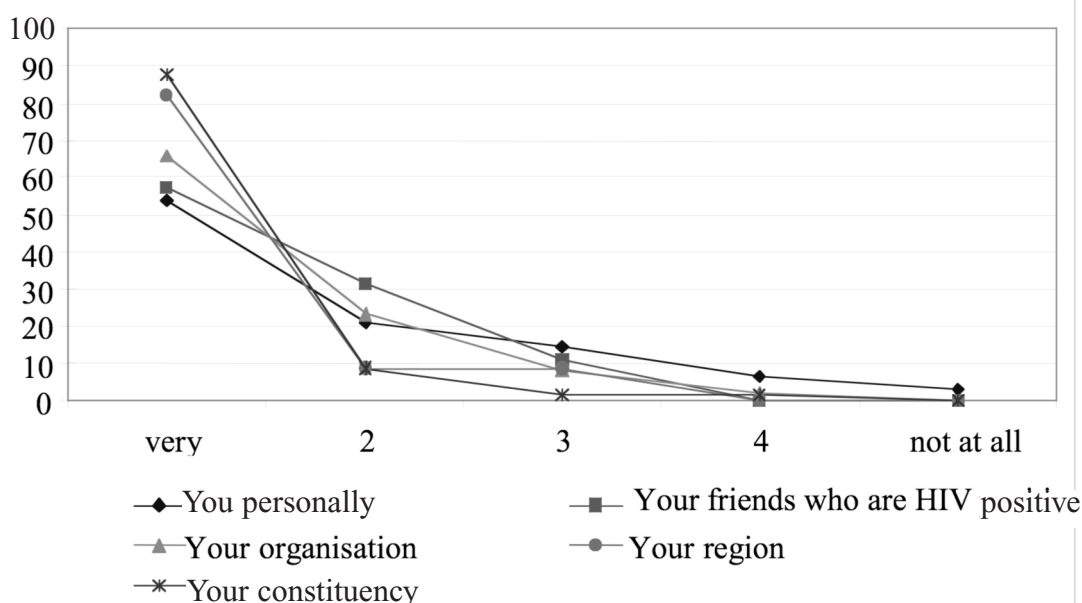
In a hierarchical list of service needs, respondents rated GP care (including health management and monitoring) and hospital services (including specialist and ambulatory services and counselling) consistently the highest of all service needs. This was consistent for all groups (e.g. gay men, women) and across different locations.

NAPWA is not surprised by these priorities as the clinical response to HIV is, for the most part, managed through these settings. This includes a range of clinics, often based in hospitals. Access to general practitioners and hospitals are essential for people living with chronic illness.

Significantly, GP care, hospital services and income support were rated as consistently high needs, regardless of where the respondents lived or to which constituency group they belonged. This was further articulated in the peer dialogues about essential services and the cost of living.

Among a larger sample of men, there was more differentiation, but with all services rating in the top quartile.

Figure 3: SIGNIFICANCE OF GP NEEDS



In this context, it is not surprising that issues around access to GPs and hospitals also featured prominently in comments made by both individual respondents and service providers. Access issues take on a particular dimension for positive people, because of the complexity of HIV treatment and the Section 100 prescribing system. The lack of Section 100 prescribers in many areas was keenly felt. One participant noted that,

*"Many comment on the difficulty finding appropriate GPs, experienced HIV GPs and Section 100 prescribers."*

The lack of appropriately skilled and qualified GPs is a particular issue in regional and rural areas, and places an extra burden on people living with HIV in these areas. Comments such as these were made frequently:

*"Only three S100 prescribing doctors in all of Cairns, Cooktown, Tablelands, Mission Beach region with over 150 positive clients."*

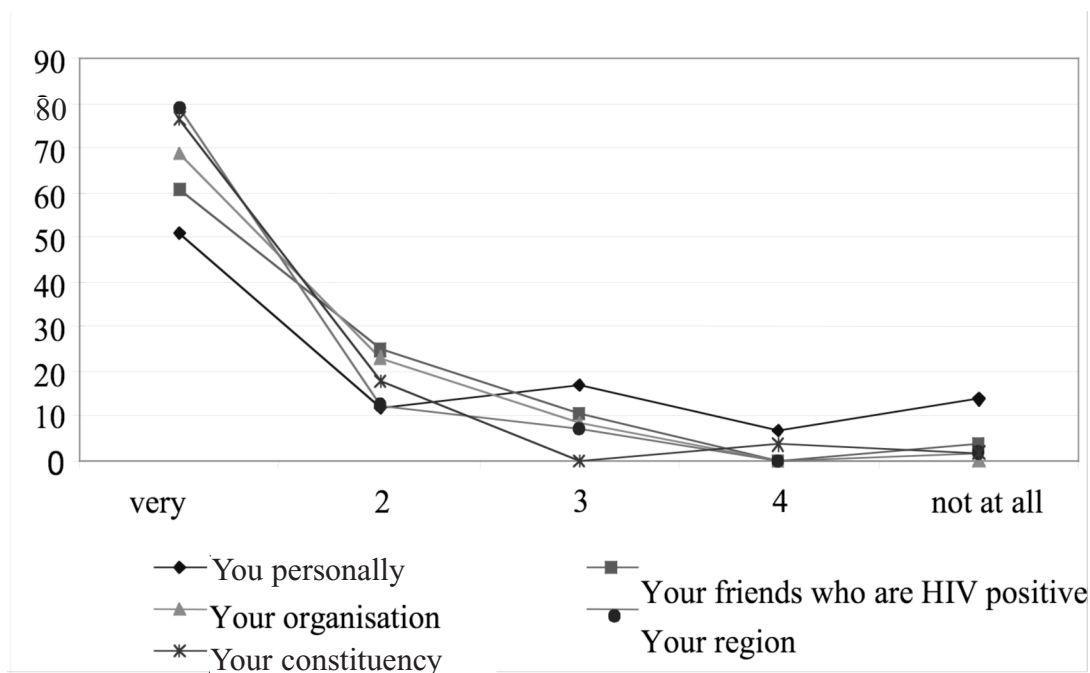
*"Rural Victoria needs more GPs up skilled around HIV."*

It is revealing that many of these comments were made by people living in areas that are by no means remote. For example, another respondent noted that,

*"Having the one area to deal with, Canberra, if things go wrong, turning to other services can be a bit tricky. There's not a lot of choice as there are only two centres to go for a Section 100 prescribing doctor."*

It appears that access to appropriate GP care is an issue in most areas outside the larger capital cities. This points to an important workforce development issue, in relation to the maintenance of an adequate numbers of GPs qualified in the treatment and care of people with HIV; workforce issues are discussed in more detail in another section.

Figure 4: SIGNIFICANCE OF HOSPITAL NEEDS



Needs for hospital care were also rated very highly by respondents, even for those who did not access hospital care themselves. Access for people outside major metropolitan areas was similarly an issue in relation to hospitals. For example, a respondent from the Illawarra explained that,

*"In the Bulli community there is limited care available. In Wollongong there are limited services but I found GPs to access through ACON. It's easier to go to St Vincent's for bloods etc."*

Issues such as this place the extra burden of needing to travel in order to access services on people living with HIV in regional areas.

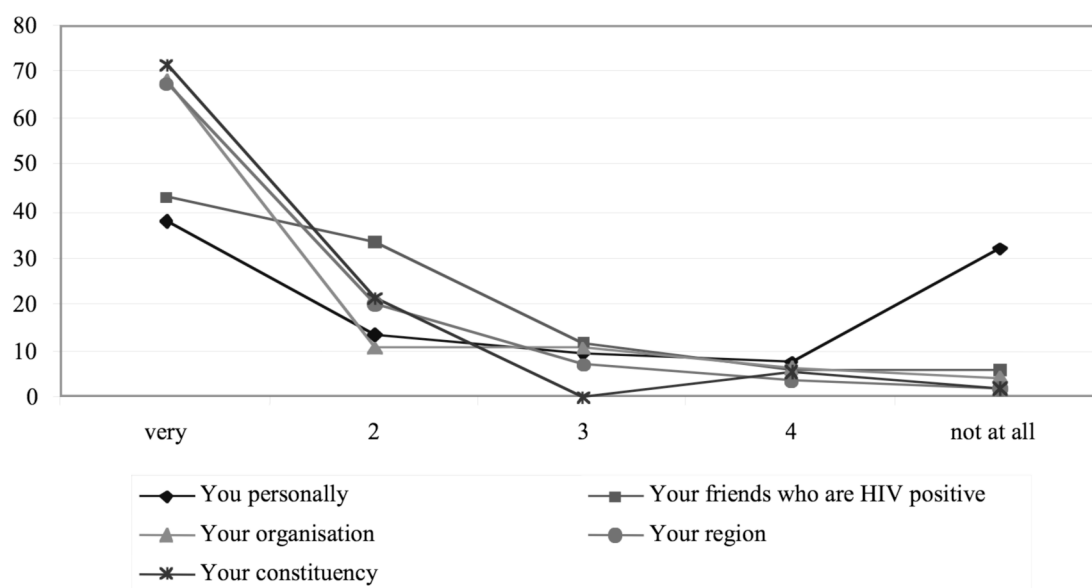
In terms of policy and advocacy issues, the continuing importance of GP and hospital care for positive people underscores the importance of providing best practice care which complies with HIV models of clinical care for positive people, now and into the future. In many respects positive people in Australia have been well-served by the health system. However, maintaining effective HIV care is contingent upon maintaining adequate funding, as well as ensuring that appropriate accountability mechanisms for clinical practice are in place.

## FINANCIAL PRESSURES

*"Life is poor – financially it's a struggle to keep things afloat."*

Income support needs rated very highly in the survey, as can be seen in the Table below.

Figure 5: Significance of income support needs



More generally, financial pressures were a continuing theme in people's responses. Discussion of financial issues was often imbricated with other themes such as health, employment and access to services, as the impact of financial problems was felt in other areas.

*"But the financial hassle has impacted on my health, both mental and physical."*

Moreover, financial issues often affected other needs in a circular manner: financial stress has a negative impact on health, which impacts on employment, creating further financial stress, and so on.

The word "costs", in terms of the costs of living and expenses was frequently used by respondents. 'Affordability', 'costs', the 'extra burden', 'financial hassle' and 'just scraping through' were among the comments made. Here is another example:

*"Cost of living with HIV is a major issue for me. I have to work to pay for my health care regime e.g. gym, vitamins, naturopath, but in doing so have no energy to live life. Do I work less, not affording treatments and get sick?"*

What is clear is that the cost of living associated with HIV is an issue that is felt by a substantial number of positive people across a wide range of social determinants associated with health and well being outcomes.

The results show that income support and other benefits from Government are necessary and important. Many respondents were reliant on government benefits, and often in severe financial stress:

*"Positive people constantly share their struggles managing on DSP (disability support pension) or low incomes. Access to food store (HIVE) has seen an increasing need – stock is limited but demand and need continue to grow."*

*"Life is poor – financially it's a struggle to keep everything afloat."*

*"Income support – most are just scraping by particularly as single parents or single people with little family support."*

*"Friends live in constant poverty and in the endless round of hospital and doctors queues."*

*"Moving into a new house as I have just done is very expensive with phone, power, food, etc . . . then there is medication on top. It would help if there where some sort of help with new house moves to help to get on your feet. Although my HIV/AIDS organisation has helped heaps, it's just not enough."*

Some people made specific mention of the costs of medication. The cost of medication can be a real burden, even for those with access to a low-income Health Care Card. Having to pay for multiple prescriptions – even at a subsidised price – creates significant financial stress for those on low incomes.

*"I just think it would be good if all medication was paid for as it might only be almost \$5 with a concession, but it can add up when you have about four others as well."*

However, it is important to recognise that paid employment does not necessarily resolve financial difficulties. Many respondents in low income generating employment – particularly those in part-time work – spoke of the financial burden of HIV.

*"I personally do not have significant unmet care and support needs. However many people I know do have. They relate to a very decreased financial and material level of comfort compared to what the situation would be if they were not positive. Part of this is to do with having sustained well-paid employment. Part of it is to do with the cost of HIV if you are in the workforce."*

Social security arrangements are an issue here, with many respondents in receipt of the Disability Support Pension. High effective marginal tax rates for people leaving the pension create a real disincentive to move off the pension, even for those who are able to. These examples are typical:

*"My life is hard even though I have a job."*

*"I am trying to raise my capacity to cope with the cost of living with HIV by education and work but sometimes I wish I had stayed on the pension in the bush!"*

Community sources supplement and assist in relieving the financial burden of living with chronic illness. One person noted:

*"My needs are mainly in the cost of pharmaceuticals — I would appreciate a chronic illness card to offset the price of my monthly chemist bill for antiretrovirals and PBS items (increasing every month due to side-effects). I am not entitled to a Healthcare Card but have a low income. My friends on a Healthcare Card have trouble existing and need pantry services, food vouchers, help with costs from David Williams Fund, etc., to survive each week. Cost of HIV is a major problem for them".*

What is clear is that many survey respondents clearly experience financial difficulty in meeting the costs of living with HIV and are worried about their financial survival and future options.

Over time, the financial and social capacity of some positive people may be affected and there may be additional financial challenges directly related to their illness and disease including the cost of medications and supportive health care options and difficulty in meeting the costs for essential items such as food, transport, accommodation and utilities.

It is clear that attention needs to be given to assessing the real cost of living with HIV, both for people in the workforce and out of it.

*"I would support some sort of national benchmarks so we can work out if we are achieving "quality of life". Perhaps "No PLWHA should live below the Henderson poverty line" might be a starting point!"*

#### ■ RECOMMENDATION 4:

That further research be undertaken to determine the true cost of living with HIV/AIDS.

## HOUSING ISSUES

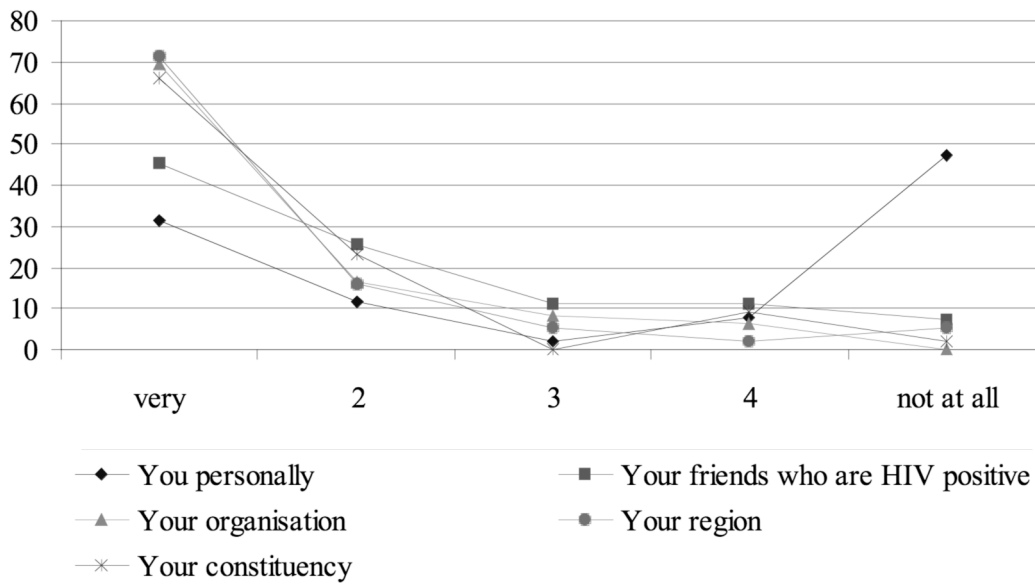
*"I am lucky to have supported accommodation. Without it I don't know what I would have done."*

The other area of need identified nationally by positive people is housing support. The lack of affordable and appropriate housing is a source of great frustration among positive people in most states of Australia.

Emergency and respite accommodation for HIV positive people is a critical area of need. There is also a clear need for improved access to supported accommodation, and to subsidised accommodation for positive people living on low incomes or disability support pensions. There is considerable ongoing uncertainty about public housing, in particular, whether and to what extent public housing programs will continue to be funded in the future.

The importance of secure and affordable housing in people's health and wellbeing is well-known and extensively documented. Appropriate housing – including where necessary emergency and supported accommodation – is an essential component of coordinated care for people living with HIV. The Department of Health and Ageing (DoHA) and the Department of Family and Community Services and Indigenous Affairs (FaCSIA) need to work together urgently to establish a system which will support, rather than undermine, the health and social wellbeing of HIV positive people.

Figure 6: SIGNIFICANCE OF HOUSING NEEDS



**RECOMMENDATION 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.

**EMPLOYMENT ISSUES**

*"My main concern is returning to work and getting little reward for part-time work."*

Welfare reforms have placed greater emphasis on the individual's capacity for work, and there is increased pressure on those in receipt of income support to move into employment. However, in its current form welfare reform does not take into account the episodic nature of HIV illness and the resultant need for flexibility in workforce participation requirements, and make it harder to move into employment.

No-one in the sample talked about working full-time, though many were engaged in part-time work. Many were engaged in part-time work. Although part-time work may be the most suitable option for people living with chronic illness, the structure of income support payments, which are reduced as recipients earn more, creates a disincentive to seek work that is less than full-time. One respondent noted:

*"Working part-time is no reward. Only punishment."*

Many respondents were not working at all:

*"Few of my positive friends are in a position where they can contemplate returning to work."*

Eligibility requirements for income support and a lack of ongoing supports in the workplace may make it harder to re-enter employment. Some people who have been out of the workforce for long periods or who have lost either functionality or confidence to participate in employment require support, training and re-skilling.

*"In South Australia a better coordinated approach to return to work is needed. By this I mean that state plwaha organisations need to be better resourced to pick up. As Centrelink criteria tightens, plwaha organisations need to be strong advocates for the concerns and voice of positive people."*

## Volunteering

However, volunteer work was a strong theme, with many respondents engaged in some form of volunteer work. More than half of the survey respondents were engaged in the HIV/AIDS sector in a volunteer capacity.

*"I am disabled [and] unable to work but volunteer my time."*

Volunteers have made an important contribution to the HIV/AIDS sector over a long period, and positive people form a large part of this contribution. Volunteering has a range of benefits, both to the organisation which receives voluntary participation and the individual volunteer. Volunteering has the capacity to increase personal resilience and enhance work-readiness. It is worth thinking about this group as being part of the national HIV workforce and in doing so, consider how the health of this workforce can best be maintained and strengthened. Further research on the effects of volunteering on health and personal resilience would also be useful for the HIV/AIDS sector.

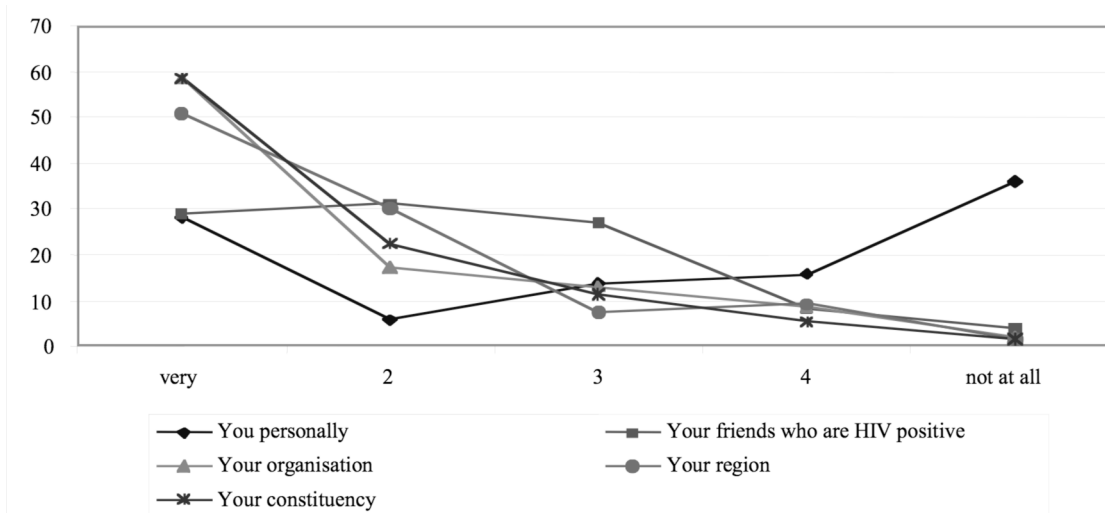
### ■ RECOMMENDATION 6:

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.

### ■ RECOMMENDATION 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.

Figure 7: SIGNIFICANCE OF EMPLOYMENT NEEDS



## COMMUNITY SERVICES

*"We have all fought for what and where we are and maintaining these things is the concern – as we know Government can change our position – just like that."*

Respondents accessed a range of community services other than health services, from both 'mainstream' and HIV-specific organisations. Community services were considered essential to them in maintaining health and wellbeing, particularly for people on income support. For example, one respondent said that,

*"Myrtle Place and BGF (Bobby Goldsmith Foundation) are very important to my needs."*

Care and support are often difficult to separate from other services such as housing and income support, as all were considered essential to general wellbeing. For instance, one respondent observed that:

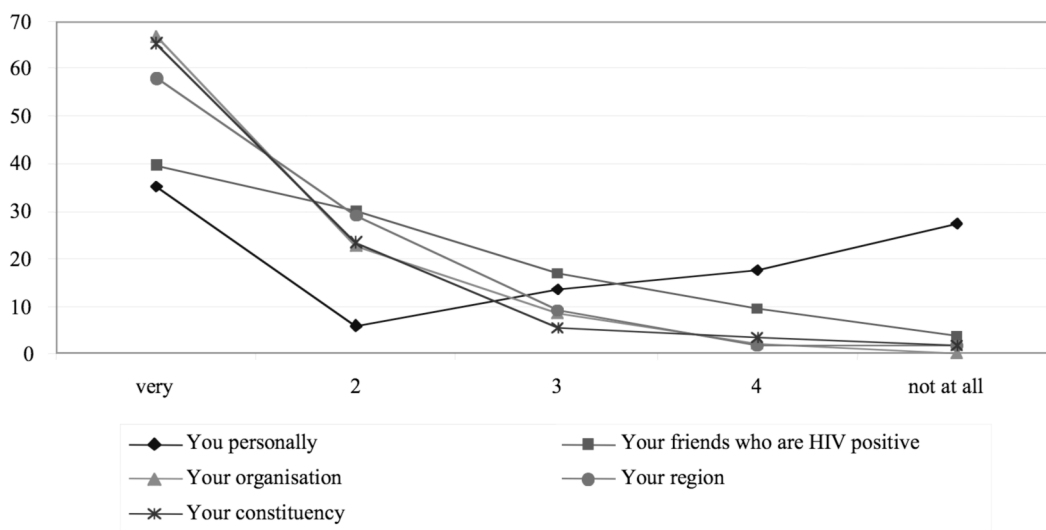
*"Without these needs being met – be it just one of them – my chain is broken and I am unable to function as independently as I do now."*

Particular groups also expressed particular needs in order to maintain this 'chain' of essential services and supports. For example, one woman said:

*"Care and Support needs for positive women are about their children's care, welfare and future. Secure housing is vital. Access to family support and counselling is valued and programs that support children and young adults (camps, outings, holiday events). Unfortunately Centrelink and Housing Trust rules have become very rigid - individuals find dealing with these mainstream services disempowering, hard and there is pressure to disclose just to receive a basic service. Hence upskilling peer support workers within plwha organisations and AIDS Councils is important."*

Many cited "service shortage" issues with particular services and highlighted difficulties in accessing services in smaller capital cities and regional areas; this is discussed in more detail in the following section. Mental health and counselling services were mentioned as high priorities, along with oral health services (also discussed in following sections) and the need for specific supported accommodation services for positive people.

**Figure 9: SIGNIFICANCE OF COMMUNITY SERVICES NEEDS**



## ACCESS TO SERVICES FOR PEOPLE LIVING IN REGIONAL, RURAL AND REMOTE AREAS

There is a serious lack of services available for people living in rural, regional and remote areas; in this respect people living with HIV share the problems of people living with other chronic illnesses. The added burden of living in a rural or regional area emerged strongly as a theme among positive people living outside the major capital cities.

For many, the experience of living with HIV in regional areas was one of isolation.

*"Social isolation is a big issue for positive persons (with a) large percentage living outside of metro areas."*

There are fewer positive people living in regional areas, which are often considered less 'friendly' to gay men and particularly, positive gay men.

*"Being positive in regional Australia, at times is not easy, there is discrimination etc.. in and out of the queer scene."*

Isolation can be even more acute for other groups of people living with HIV, such as women, heterosexual men and so on. As one heterosexual man put it,

*"For a heterosexual male living in Tasmania it is very difficult with no peer-support available."*

If a positive gay man living in Tasmania is isolated, a positive heterosexual man may be even more so.

To add to the sense of isolation, there are fewer services available to positive people living outside the major capital cities. This is the case for a range of services, from GP and hospital care to allied health, housing and other community services, as well as peer support. The following comments from participants are typical:

*"Living in an area with a much smaller population and lower numbers of positive people has a major impact on the level of services available. For example: there really are no care and support services in the (Northern) Territory. There is a lack of supported accommodation services and no return to work services for HIV positive people."*

*"Shortage of hours (that) hospital services (are) available i.e. prescriptions pick up only Mon-Fri, 9am-5pm with one hour closed at lunchtime. How does an employed person have time to collect then? Shortage of openly positive people - no nutritional advice - no health management advice - discrimination in some of the regions' medical units (private practices).*

*"It is worth noting that in the Northern Territory a number of these services – community services, HIV housing, peer support – are just not available."*

This can create a catch-22 situation, with people in regional areas having an increased need for peer support which is less likely to be available. Those services that are available may have less capacity to meet the needs of 'minority' groups.

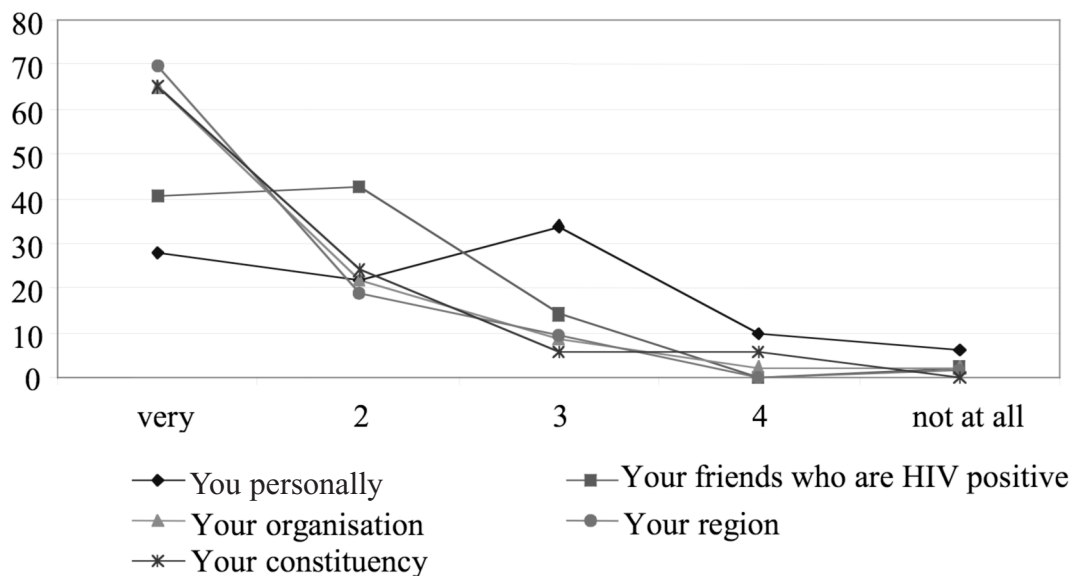
*"The sector itself is mainly geared for gay guys and positive heterosexuals are not very well represented."*

*"Often enough there is no contact from ATSI (Aboriginal and Torres Strait Islander) workers until you're extremely ill in hospital or dying."*

## OTHER HEALTH NEEDS

Allied health needs also rated highly in the survey responses, as can be seen from the table below.

Figure 8: Significance of Allied Health needs



Many people living with HIV access a range of specialist or allied health services, as well as GPs and hospitals. This additional illness burden is expressed by one participant as follows:

*"My experience with dentists, oral surgeons and specialists including dermatologists and head and neck surgeons has all been positive. I should add that these health professionals are all located in the inner city."*

What is interesting about this response is the matter of fact way the respondent describes the range of services required to address a variety of health issues. It should be noted that his experience of these services has been positive, although almost as a throwaway comment, he notes the inner city location of services which would most likely not have been available if he did not live in the city.

The other health needs which emerged most strongly were oral/dental health and mental health services, as well as drug and alcohol services. Issues around mental health and drug and alcohol services were particularly complex.

*"From my volunteer work I believe priority must be given to mental health, drug and alcohol services for positive people."*

*"Fortunately my physical health overall is good. I have encountered dental health problems in the last two years and significant mental health issues as well."*

Oral and mental health service issues are discussed below.

## ORAL HEALTH

*"Dental care is very hard to get because of waiting lists."*

*"I do believe there needs to be more dental care available and counselling services need to be maintained."*

There are a range of factors that impact upon peoples' sense of self and health and wellbeing. Dental and oral care services are important to people with HIV for two reasons: firstly, that HIV can affect the mouth and cause ongoing problems, disease or conditions which need to be treated (like gum problems or thrush), and secondly, because of the extent to which the symptoms can affect peoples' appearance, and self-esteem.

Oral health is a significant factor in HIV care. People living longer term with HIV can experience a range of oral hygiene problems and dental health issues related to the effects of treatments on saliva, receding gums and periodontal disease, and these issues should be treated seriously.

Private dental care is very expensive, and access to public dental programs is limited. Many positive people cannot afford private dental care, but do not have access to publicly funded programs where dental health problems can be managed and treated in a timely and efficient way. It is possible to access some private dental care through Medicare as part of a care plan, but in reality, the scope of treatment is usually specific and quite limited. There is an urgent need for coordinated care planning which takes into account the role and availability of dental and oral hygiene programs for positive people.

## MENTAL HEALTH

*"Mental health is a major issue for plwhas."*

From a range of research<sup>5</sup> it is known that HIV and mental or cognitive health is an important issue. For example, this has been well documented in *Futures* surveys and the pH survey<sup>6</sup>, which indicate that positive people experience significantly higher rates of depression and anxiety than the general population and are prescribed anti-depressants and anti-anxiotics at a comparatively high rate.

Under the broad umbrella of mental health, there are a range of problems which can affect people with HIV. First, there is the organic and clinical illness which can affect people with HIV, such as AIDS-related dementia, or other conditions which can lead to cognitive impairment. Second, there are some of the neuropsychological changes and effects which are related to HIV treatment. Some HIV treatments do appear to have specific effects on peoples' brain and mood, by affecting sleep patterns over long periods, for example. It has been suggested other treatments may have specific links, for example, to depression. More research is needed in this area.

There are also the ongoing psychosocial problems which many HIV positive people report as a direct effect of their diagnosis. These problems may include depression, depressed mood, or anxiety or adjustment disorders. They may also include problems relating to alcohol or drug use. Lastly, the stresses of living with HIV are likely to have a negative effect on the health of people with mental illness who are diagnosed with HIV. The specific impacts of living with HIV on people with pre-existing mental illness are not well-researched.

Further, these problems may be interrelated in ways that are complex, sometimes ambiguous, and not always well-understood by clinicians or service providers. Nonetheless, all need to be accounted for when considering HIV in relation to "mental health" – and how to develop appropriate responses. Positive people need to be able to access mental health support and services across the patient journey in living with HIV.

*HIV Futures* identifies high rates of treatment for depression among positive people, compared to the rest of the community. Depression also came up in responses to the survey:

*"Discrimination is very much out there. Depression is overwhelming at times, withdrawal and isolation takes over I wish there was more access and support financially for alternative medicines."*

The lack of adequate mental health programs and support structures around the nation is a concern for positive people. In some states, there is no counselling specifically for HIV positive people available in any formalised sense. In other places there are counselling programs but a shortage of available counselling sessions, and in some cases the staff and volunteers to run these programs. One respondent observes that:

*"Mental health is a major issue for plwha – independently addressed in most states. Supported accommodation, dementia care, physical impairment – and need for appropriate 'in-house' supports – need to be addressed much better in most states (NSW only state doing much in this area)."*

There are waiting lists for counselling services for positive people in most states. Service providers report that there is a shortage of counselling services to deal with not only the expected adjustment issues in living with HIV, but a range of psychological issues, drug and alcohol issues, and other issues related to living with HIV/AIDS. These require dedicated and specific counselling services and expedient and clear referral pathways into clinical psychiatric and psychological services.

In addition, there are likely to be critical points in the patient journey, such as at diagnosis with HIV, managing treatments or changes in personal health and wellbeing which will likely require specific attention. Research into the ways in which HIV affects people's mental and psychosocial health should be a priority; such research would enable improved targeting of services.

**■ RECOMMENDATION 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.

**■ RECOMMENDATION 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.

**■ RECOMMENDATION 10:**

That the Department of Health and Ageing fund research to improve 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.

## PEER SUPPORT

Peer support programs have been central to the community-based response to HIV since the earliest days of the epidemic. Programs were established in the AIDS councils, firstly of all at ACON in NSW, and later in other states. The early programs, in the late 1980s, were developed along similar lines to programs such as the Shanti Project in San Francisco. Research had shown that social isolation was one of the major issues for positive people following a HIV diagnosis. Peer support programs were developed as a means of reducing this isolation, and helping people stay well for longer, in part by improving their mental health. Beginning in the late 1980s, peer support programs have continued in one form or another till today, although not all states offer comprehensive peer programs.

The philosophy underpinning peer support programs is to provide safe and confidential spaces where positive people can sit with their peers in a safe, confidential space where they know they will not be threatened, judged, or told what to do. In this space, they can talk or get support around important issues currently affecting their life, health and wellbeing.

In the earlier days of HIV, those issues tended to focus on the fact that people with HIV faced at the very least an uncertain future, and in many cases, illness and death. Even today, isolation remains a strong theme in people’s experience of living with HIV. Many talked about their ‘lack of connection’, ‘withdrawal and isolation’, ‘being loners’, ‘lack of confidence in future support systems’, and ‘fearing a loss of peer support’. The following accounts are typical:

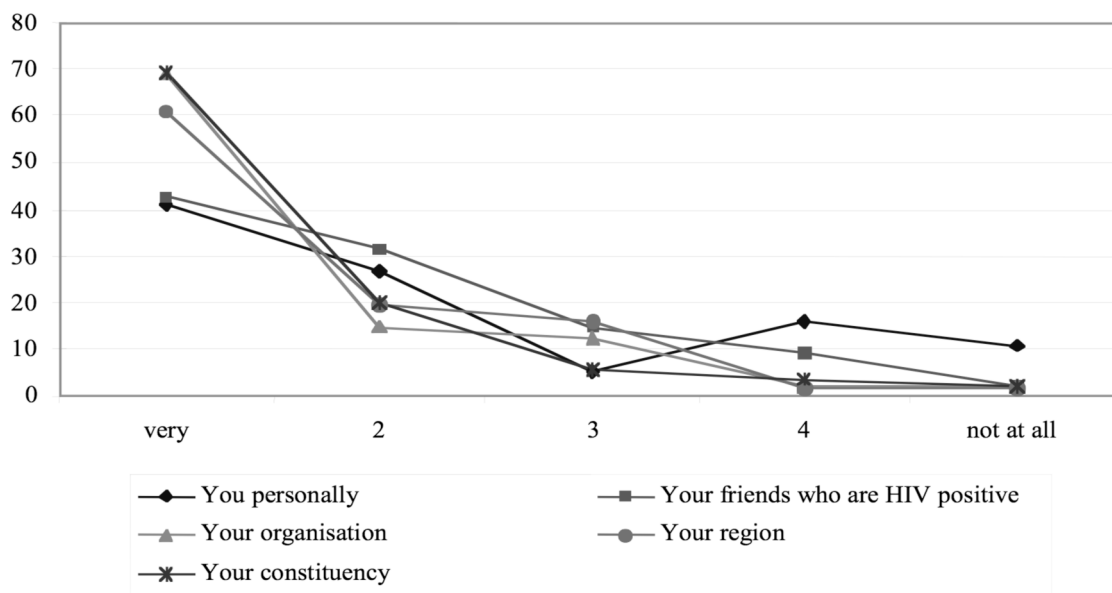
*“Don’t have any friends who are positive.”*

*“I was a loner and stuck to myself when I was first diagnosed as HIV positive in 1991. But over the last four to five years I have joined and helped start up positive groups for gay positive men and found the friendship and support very fulfilling and I am more outgoing now because of it.”*

*“We need our social needs attended to – a drop in place for plwha or peer support groups to deal with isolation. Somewhere where we can come together as a family and look at ways to maintain health and wellness.”*

The continuing need for peer support programs was affirmed strongly in the research, both by respondents to the survey and by service providers. Survey respondents continue to rate ‘personal needs’ highly, and peer support programs are an important mechanism for meeting these needs. The table below details ratings of ‘personal needs’ among respondents to the survey.

Figure 9: SIGNIFICANCE OF PERSONAL NEEDS



Peer support and opportunities for social participation were clearly identified as a key priority. The importance of peer support was repeatedly mentioned along with the importance of connection to other HIV positive people, as the following comments indicate:

*"Ultimately, positive women's support groups are my main inspiration in coping."*

*"I need more peer support, email exchange, get-togethers and social activities."*

*"I have very little contact with agencies and am only beginning to link in with other positive women."*

Peer support approaches today aim to reflect the current realities and positive futures. Interviews and feedback suggests that within the HIV positive population, different support needs have emerged since the introduction of effective treatments. Two major areas of need have emerged, at least within the HIV positive gay population. These are support for people who have been recently diagnosed, and support for those who are living long-term with HIV.

- **"Healthy HIV Living"** – support programs for newly diagnosed

There is evidence that peer support programs for somebody newly diagnosed, such as the Genesis programs that run through the AIDS Council of NSW and through PLWHA Vic, QPP in Queensland and WAAC in WA are very important. Positive people report that these are valued health promotion programs and provide important and necessary information, support and referral. As well, programs have enabled them to meet others with HIV, and have helped them through periods of personal crisis or uncertainty following diagnosis and adjustment to living well with HIV.

Peer support at the point of diagnosis is not the only support or may not be the appropriate support for everyone. However, the Genesis-style programs are an important feature of the care and support landscape.

- **"Living well with chronic illness"** – support programs for long term diagnosed

Other programs apply to people living long-term with HIV or AIDS – programs for people experiencing difficulty on treatments or adjusting to the challenges of returning to work. In addition, support programs for women, heterosexual men and Indigenous positive people are not available to any significant extent around the nation, though they are often called for.

Many HIV positive people have experienced major changes in their lives — for example, as their health and wellbeing has improved or stabilised with treatment. Positive people are now re-entering the workforce, in some cases, after sustained periods without employment. For many, there have been significant challenges associated with this re-integration into work and community life. The challenges of living well with a chronic illness will be different for individuals, but it is likely that these challenges will have a greater significance for those living long term with HIV and those from marginalised groups or vulnerable populations.

- **Social support networks today** – community development

Peer support not only provides support at an individual level, but is an important element in organisational and community development. Participants in Genesis-style peer support groups often move to other forms of social interaction with HIV-positive people. Events may include formal discussion circles, informal outings, specific after hours events for those working or major regular sponsored nights with food and entertainment. These social events provide positive people with unstructured social support and allow for a range of interactions in supportive environments.

Social participation opportunities are valued and play an important role in providing social reintegration and informal support for and between HIV-positive people. Supporting social participation is also an essential element in the coordination of care. These networking opportunities should not be relegated to informal networks of support, but should be supported formally by community organisations and brought into the organisational life in a dynamic way to inform program development. Peer and social support assists HIV positive people to make changes to their life, to have more control of their personal situations and to develop self-management strategies around living with HIV or AIDS.

Arguably, the NAPWA conference is an important national exercise in peer support and in providing a major contribution to social participation opportunities for positive people. This valuing of peer social participation as an opportunity was further described in the NAPWA conference evaluation report and in the peer dialogues.

Further work could be undertaken to ascertain the place of peer social participation opportunities as a mechanism to foster social wellbeing and as a health promotion tool.

**■ RECOMMENDATION 11:**

That the Department of Health and Ageing re-affirm its commitment to funded peer support programs for people living with HIV/AIDS in the next National HIV/AIDS Strategy.

**■ RECOMMENDATION 12:**

That State and Territory health authorities increase investment in the development of "Healthy HIV Living" support programs for newly diagnosed and "Living Well with Chronic Illness" support programs for people who are living long-term with HIV/AIDS.

## Building resilience

*"Although disabled I have a fairly good quality of life and now am moving on with my life and making good friends."*

In this section, respondents spoke of 'moving on', of being in 'good health', 'living fairly well', 'treatments working' and 'decreased dependence'. For some, these comments acknowledge a journey and a return - or the beginnings of one from a place where personal health was affected or damaged by the effects of living with HIV.

The respondents talk about having moved or moving to 'this place', that treatments do work, that life can be normalised and that this is possible even if you are living life with a disability or a controllable illness. For example:

*"I have been living fairly well of late in good health and not currently on treatment."*

*"Happy that my treatments are working and my life is relatively uncomplicated."*

*"Being HIV positive is just one part of my make-up, and that's a really good thing. An interest in politics/history/archaeology probably takes up more of my thought time than being HIV positive - a lot more!"*

*"My treatments health is quite good. I have decreased dependence on medical systems and services. I am fortunate to have secure housing and income."*

*"Fortunate to have a superannuation pension. Health – is relatively well so not an acute need for services."*

*"Life's great for me :-)"*

*"Life is fairly good for me in general except I don't like having to move to new doctors when my doctor moves on to other areas."*

*"I personally do not have significant unmet care and support needs."*

*"Things are much better now health wise. My current support needs services are satisfactory."*

Respondents made a range of positive, optimistic comments about their lives, though these were often tempered by an awareness of how fragile their situation was. What is clear is that there is concern and worry over a range of issues that have the potential to impact negatively on personal health and wellbeing.

In a revealing contrast, many respondents had a pessimistic outlook in relation to the care and support services available to them as positive people. Awareness of funding constraints on government services, including HIV services, and the possibility of future reductions in services, made people gloomy about the future of care and support services:

*"I have no confidence that there will be the necessary support systems in place as the government will have progressively dismantled them."*

*"All services need constant monitoring and (there are) some threats, particularly income support is of particular concern."*

## THE ROLE OF NAPWA

One of the objectives of the survey was to assess the relevance of NAPWA's policy and advocacy work on the range of care and support issues around the country. While the processes used by NAPWA to determine national priorities for policy and advocacy work undertaken are robust, this survey was an opportunity to formally assess the relevance of issues to the perceived needs.

The responses have been analysed by region and constituency for both gay men (including positive men) and women (including heterosexual women). All of NAPWA's current care and support policy and advocacy areas were found to be relevant, all rating in the top third and fourth quartiles.

The very high relevance given to "Improving access to health services" comes as no surprise. This was followed by "Arriving at the true cost of living with HIV". Ensuring the implementation of the 5th National HIV/AIDS Strategy at a state level was the clear third priority.

### Constituency: Gay men

**Table 5: RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO THE NEEDS OF GAY MEN<sup>7</sup>**  
(AS PERCENTAGES)

NAPWA POLICY AND ADVOCACY AREAS	VERY	2	3	4	NOT AT ALL	TOTAL
Health services	84.6	7.7	3.8		3.8	100
Discrimination in insurance	56.0	24.0	8.0	8.0	4.0	100
Long term and supported housing	56.0	12.0	12.0	4.0	16.0	100
Return to work services	54.2	12.5	4.2	20.8	8.3	100
Cost of living with HIV	69.2	15.4	7.7		7.7	100
Implementation of 5th National Strategy	66.7	12.5	8.3	8.3	4.2	100

### Constituency: Women

**Table 6 RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO THE NEEDS OF WOMEN<sup>8</sup>**  
(AS PERCENTAGES)

NAPWA POLICY AND ADVOCACY AREAS	VERY	2	3	4	NOT AT ALL	DON'T KNOW	TOTAL
Health services	90.9					9.1	100
Discrimination in insurance	70.0		10.0			20.0	100
Long term and supported housing	72.7		9.1			18.2	100
Return to work services	63.6	18.2	9.1			9.1	100
Cost of living with HIV	81.8	9.1				9.1	100
Implementation of 5th National Strategy	63.6	27.3				9.1	100

## Constituency: Region

**Table 7: RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO NEEDS OF REGION  
(AS PERCENTAGES)**

NAPWA POLICY AND ADVOCACY AREAS		VERY	2	3	4	NOT AT ALL	DON'T KNOW	TOTAL
Health services	CAPITAL	74.3	22.9				2.9	100
	OTHER	83.3	5.6		5.6	5.6		
	TOTAL	77.4	17.0		1.9	3.8		
Discrimination in insurance	CAPITAL	60.0	17.1	20.0		2.9		100
	OTHER	44.4	5.6	16.7	11.1	5.6	16.7	
	TOTAL	54.7	13.2	18.9	3.8	3.8	5.7	
Long term and supported housing	CAPITAL	68.6	17.1	8.6	2.9	2.9		100
	OTHER	61.1	11.1	16.7	5.6	5.6		
	TOTAL	66.0	15.1	11.3	3.8	3.8		
Return to work services	CAPITAL	57.1	20.0	14.3	2.9	5.7		100
	OTHER	50.0	11.1	22.2		11.1	5.6	
	TOTAL	54.7	17.0	17.0	1.9	7.5	1.9	
Cost of living with HIV	CAPITAL	77.8	16.7	2.8	2.8			100
	OTHER	72.2	22.2			5.6		
	TOTAL	75.9	18.5	1.9	1.9	1.9		
Implementation of 5th National Strategy	CAPITAL	72.2	16.7	8.3		2.8		100
	OTHER	61.1	5.6	11.1	5.6	5.6	11.1	
	TOTAL	68.5	13.0	9.3	1.9	3.7	3.7	

This process of checking the relevance of NAPWA's work has proved to be useful and worthwhile. Respondents to the survey affirmed that the identified areas of systematic policy and advocacy work that NAPWA is involved in are important and relevant around Australia.

There is strong agreement among respondents that the top policy and advocacy areas are strengthening access to health services, measuring the true cost of living with HIV and seeking implementation of the 5th national strategy.

The validation of NAPWA's policy and advocacy work speaks to the importance of addressing these issues in a systemic manner through national and state partnerships.

## CONCLUSION

This section has offered insights into "who we are", providing a detailed look into the very different lives of a diverse range of positive people. The analysis reveals that respondents do represent a diverse cross section of the Australian body positive, although not proportionately representative of national epidemiology, particularly in CALD, indigenous and the more recently diagnosed subpopulations.

Participants spoke about how they choose to identify and have affirmed that an HIV positive identity is important to them, in some ways even more important than other identifications related to sexuality, race or gender. Significantly, they have reaffirmed the importance of having relationship to other positive people.

This section has also discussed feedback from positive people about living with HIV today, from dealing with continued stigma and discrimination to issues in relation to health, community services, and opportunities for peer and social support. Feedback from positive people raises a range of issues for the provision of care and support services, both now and in the future. The implications of these are discussed in more detail in the following section.

# SERVICE ISSUES

This section canvasses key themes in service provision and planning that emerged in consultations with positive people and HIV service providers.

## THE COMPLEXITY OF HIV TODAY

Australia's care and support response has served the majority of positive people well for some years. However, changes in the care and support needs and experiences of positive people means that attention must be paid to the shifting landscape of care and support services.

This report identifies some of the issues currently facing positive people and service providers in responding to an increasingly complex epidemic. Some of these issues were raised in NAPWA's 2005 report *The Impact of Complexity of HIV Clinical Management*. Nonetheless, it is useful to reiterate some dimensions of this complexity here. They include:

- HIV is a substantial health problem for all positive people regardless of current health markers;
- There is significant ongoing stigma and discrimination related to HIV;
- There have been sustained rises in new HIV infections in many states and national increases spanning 4 years;
- There are increasing numbers of people living with HIV or AIDS;
- There are increases in specific sub populations accessing care and some demographic shifts;
- People living with HIV are also an ageing population;
- General health and wellbeing has improved for most people living with HIV since the advent of antiretroviral drugs, but other HIV management issues have arisen;
- Individualised responses to both HIV infection and treatment outcomes is now a feature of HIV management;
- Significant management of generalised HIV infection occurs in primary health care settings and this is likely to continue. However, critical and ongoing points of contact with care services outside the clinical context remain for any person with HIV;
- High rates of co-morbid conditions exist, adding to the complexity of treatment and the necessity for effective coordination of services;
- Changing patterns and diversification of treatments toxicities over time is affecting patient confidence and hospital admissions;
- A range of illnesses related to living longer with HIV and time-related treatments exposure is worrying positive people;
- Significant levels of mental health issues, including anxiety, depression and psychosis, are resulting in an increasing need for specific mental health interventions and support;
- High rates of drug and alcohol usage, adding to mental health and social problems, are still experienced amongst the HIV population;
- Significant numbers of positive people, particularly women, live below the poverty line;
- Rehabilitation and health maintenance challenges continue, placing an added burden on positive people living with HIV long term;
- Changing needs and new life choices for positive people are emerging, most notably around parenting, work and long term financial security, stable housing and aged care options, travel, legal rights, sexual freedom, privacy and transmission risk management; and,
- There are continuing difficulties for positive people accessing mainstream services, particularly mental health, accommodation and home and community care (HACC) services.

This complexity has created 'pressure points' within services for people living with HIV/AIDS. These include:

- Coordination of care
- Mainstreaming
- Prevention and health promotion – at the expense of policy and advocacy
- Workforce development
- Funding – a core problem
- Leadership

These are discussed in more detail below.

## COORDINATION OF CARE

Best practice care and support responses need to be able to respond to a patient's needs across the continuum of care for the duration of the patient journey. This report broadly identifies elements that should be included in a best practice model of care for HIV, and identifies some of the 'pressure points' or issues that need to be considered in developing sustainable future models. While this report does not seek to produce a 'model' of coordinated HIV care and support, it does identify some specific elements that need to be covered.

Best practice models of care should be:

- strategic;
- coordinated;
- reflect best practice in service delivery; and
- sensitive to the changing needs of positive people throughout the 'patient journey'.

"Coordination of care" refers to the process by which we ensure that HIV care services and programs, whether based within the community sector or in mainstream health services, are operating with a consistent, appropriate and agreed model of service delivery. In particular, as some services shift into more mainstreamed environments, it is more important than ever to ensure there are strong and agreed referral pathways and procedures.

Whilst the primary health care site (in particular, general medical practice) is of increasing importance to positive people, there are many other partners needed to provide comprehensive care. These include AIDS councils, PLWHA organisations, social workers, nurses and other allied health professionals. Further, this report has also highlighted the importance of other services, ostensibly outside the strict confines of health sector, such as housing and income support, which are equally essential for people to live well with HIV.

Effective coordination of HIV care requires the various elements to operate within an agreed model of service delivery and include linking HIV patients to a range of services. This should include the strengthening of referral pathways, policies, procedures and practices, and possibly the establishment of specialised access programs or arrangements.

It is also important to understand who currently oversees the coordination of care for HIV-positive people, so that targeted mechanisms designed to improve the access of HIV-positive patients to a range of HIV and mainstream health and care services operate within an agreed model of service delivery for clinical care. Currently, HIV care is provided by a diverse range of health and community sector personnel - all involved to a greater or lesser degree in the coordination of care. These include: both high and low case load general practitioners, sexual health clinicians, medical specialists, support staff in community-based HIV/AIDS organisations, clinic and community nurses, social workers and a range of other allied health professionals.

The range of case management arrangements and approaches operating nationally, both in HIV-specific and mainstream health services, needs to be mapped, as these currently vary widely around Australia. Consultation with positive people about their experience of, and views on, case management should be part of this process.

There also needs to be discussion among and agreement between the states as to how these services should be provided, so that people right across the country can access best-practice care. Our research clearly indicates that some states and territories are performing better than others in key service areas.

Care providers need to recognise the different pathways that the positive people travel in accessing care and information. Service providers need to 'step outside' of their own particular care intervention and consider the experience of the patient in order to understand where a person is positioned on the patient (or client) journey.

The coordination of needs and care arrangements may well be quite different for patients who are, for example:

- newly diagnosed and seeking basic information;
- negotiating care arrangements with agencies;
- entering new relationships and seeking information to assist their partners; or,
- needing assistance with housing or income support.

Knowing which are the appropriate 'entry' points are and the 'exit' points are for health and well-being service delivery is crucial. For increasing numbers of positive people there will be a process of engagement with service delivery which is likely to be around people entering and re-entering services as needs arise and change such as:

- a change in medications;
- sexual health checks;
- a visit to the general practitioner every three months for monitoring;
- seeking specific information on 'where to go' for care or other service needs; or,
- for example, when travelling interstate and a new range of service provision needs to be activated.

Effective coordination of care also requires a resource framework which has the flexibility to respond to changes in both the level and nature of need, as well as different points of access to services.

Future care arrangements will need to:

- identify the range of services and care arrangements that are likely to be required by positive people,
- identify at which points in the continuum of care particular services and care arrangements are more likely to be accessed by positive people,
- pay particular attention to the differing needs of particular groups such as those living well with HIV and those living with chronic illness,
- provide targeted interventions for different groups such as gay men, women, Indigenous or CALD specific interventions where required.

### ■ **RECOMMENDATION 13:**

That MACASSH advise the Minister to direct the Commonwealth Department of Health and Ageing (DoHA) to undertake an assessment of the adequacy of current models of HIV care to meet the current and future needs of HIV positive people. This assessment should include analysis of service utilisation and quality of life issues for positive people to address any gaps within models of care.

### ■ **RECOMMENDATION 14:**

That funding be made available to support the formation of a small cohort of HIV positive people to enable further qualitative research into the patient journeys and experience of positive people in Australia.

## MAINSTREAMING

*"It has not been easy acquiring services in the general community services sector."*

*"I am concerned about the trend of services to mainstream us and downplay the role of peer support."*

*"Everyone I know has the same concerns as me. We have all fought for what and where we are and maintaining these things is the concern – as we know Government can change our position – just like that."*

*"All these services are essential to keep and have available when required."*

*"These identified services, issues and strategies are important to our lives and the quality of our living standards."*

Among positive people – and many community service providers – there is agreement that greater clarity around the issue of "mainstreaming" services is required. 'Mainstreaming' refers to the provision of some aspects of HIV care through systems currently in place to serve the broader community, such as community sexual and mental health services, drug and alcohol counselling, public dental care, or aged care programs and facilities.

HIV positive people and service providers within AIDS Councils and PLWHA organisations are unsure of the process, responsibilities or timing for mainstreaming of HIV services and the extent to which HIV specific services will be maintained and in what areas.

Many state-based HIV organisations express confusion about the nature, extent and direction of care and support policy changes at State level. In particular, there is concern as to whether State policy is always in accord with the goals of the National Strategy, and a lack of clarity around State and Federal responsibilities in the Strategy response. This is causing considerable frustration among those involved in strategic planning and program development.

What is clear from interviews is that there is a need to maintain some core specialist HIV services. The place of dedicated and comprehensive HIV-specific services alongside or within some mainstream services, particularly drug and alcohol and mental health services, also needs to be considered. There are some excellent examples of mainstreamed services working well in practice for HIV positive people. The success of projects like the Food Distribution Network (FDN) in Sydney show that with a collaborative approach it is possible to achieve good outcomes. FDN is a collaboration involving NSW Health and community-based organisations.

However, not all services can properly cater to people with HIV in their current form. It is clear that discrimination against positive people still occurs; this was a key reason that HIV-specific services were originally established. Before moving to mainstream services, particular attention needs to be given to access, demographics, and the needs of specific populations such as gay men to ensure their needs are met. Such programs must be supported by an agreed action plan and implementation strategy that explicitly identifies and addresses these specific needs.

Before significant mainstreaming of services takes place, it is necessary to answer the following questions:

- Is 'mainstreaming' appropriate for all services? Are some services better equipped than others to manage the complexity of HIV care?
- What measures can be taken to make sure that HIV-positive people are not disadvantaged or discriminated against in more general health and community services?
- What mechanisms are needed to improve communication between services?
- How can mainstream services which are addressing aspects of HIV care be accountable to communities affected by HIV?
- Which agencies and organisations should be responsible for which aspects of service delivery?

#### ■ RECOMMENDATION 15:

That the Department of Health and Ageing and State and Territory health authorities undertake meaningful consultation with HIV positive people and service providers regarding any proposals to direct resources to 'mainstream' care and support services.

### WORKFORCE DEVELOPMENT – A PRESSING DILEMMA

There have been significant changes to the staff within HIV clinical and community services that have seen personnel shift from dedicated HIV work into other areas of health work. This sort of change is not necessarily particular to HIV. However, it does reflect major changes, including improvements in the health of people with HIV and changes in the epidemic more generally, as HIV becomes less a palliative illness and more a chronic and ongoing health condition. One effect of this has been a decline in the numbers of workers — in medicine, clinical care, education, health promotion and treatments — with high levels of expertise and training in HIV.

Australia-wide, there are more than one hundred medical practitioners qualified and registered to prescribe Section 100 HIV treatments, but in reality few of these practitioners are exclusively or principally dedicated to HIV management. This trend was discussed in NAPWA's 2005 paper on *Complexities in HIV Clinical Care*, and was more recently the subject of a Commonwealth government-sponsored forum that included a range of HIV experienced clinicians, allied health workers, and people living with HIV.

Among the reasons for the changes in general practice proposed were:

- an ageing workforce;
- reduced need for clinical care as antiviral treatment is effective for many people with HIV;
- policies which make it difficult for young graduates to establish general practices in the high density urban areas where the HIV epidemic is concentrated;
- an increasingly high level of knowledge required to deliver some aspects of HIV clinical care; and
- the impost of the continuing medical education required to remain an S100 prescriber, particularly for doctors who treat few people with HIV.

Nonetheless, the change also clearly reflects the fact that improvements in the treatment and clinical management of HIV have changed the way in which HIV positive people interact with health services. A number of significant breakthroughs have paved the way for new clinical strategies for managing HIV. Care models have changed, with treatment strategies aimed at reducing viral turnover and preserving CD4 cells. The need for palliative and end-stage care has declined greatly, although it is fair to say that some jurisdictions have been quicker to recognise this than others.

This change is not only about doctors. NAPWA has had many reports from across Australia which clearly point to the need to continue and strengthen dedicated HIV training for health care and support workers working in both HIV and mainstream health service staff and volunteers.

There have also been changes in the delivery of community-based HIV treatments information and education services. NAPWA auspices the Treatment Officers Network (TON), a network of workers providing information and support around HIV treatments within community organisations. Until this year the Network was supported by funding from the pharmaceutical industry, which enabled treatment officers to meet regularly and share information and case studies. Since the introduction of combination therapy there has been a steady increase in the complexity of treatments information and management strategies; this challenges the capacity of the sector to both keep up to date and provide consistent, nationally relevant information.

In recent years the capacity of the sector to attract the skilled staff required to fill such positions has been limited. NAPWA continues to provide ongoing HIV education programs for community members, including the Treatment Officers Network, and does this through the AIDS Treatment Project (ATPA) in association with ASHM. The increased knowledge base around health and treatments required by community treatments advocates and sector workers presents ongoing challenges.

#### ■ RECOMMENDATION 16:

That MACASHH prioritise workforce development issues in relation to HIV care and support, including the shortage of Section 100 prescribing general practitioners.

## PREVENTION AND HEALTH PROMOTION

*"Efforts seem concentrated on education and not towards support of positive people when they are in need of some real hands-on support at times of not being in good health."*

Australia's HIV prevention efforts have been regarded around the world as exemplary, both for their effectiveness in keeping HIV rates comparatively low and because they have harnessed the capacity of communities affected most by HIV and AIDS to assist in developing culturally appropriate responses. Since 2000, numbers of new infections and diagnoses have been rising both in Australia and internationally. Australia's response to these rises has included a progressive reinvigoration of all prevention efforts and the strengthening of the prevention framework in the national HIV/AIDS strategy.

NAPWA has been working with our member organisations and cooperating where appropriate with the Australian Federation of AIDS Organisations (AFAO) and other relevant organisations to articulate the ways that positive people currently participate in prevention efforts. To date, NAPWA has hosted a range of discussions, meetings and workshops with the membership to increase prevention literacy and to articulate and capture the range of prevention work that is already being undertaken by PLWHA organisations. NAPWA has now developed a set of principles for the participation of positive people in prevention work.

Some interviewed from PLWHA organisations expressed concerns that this reinvigorated prevention effort, while necessary to fight new infections, is now coming at a cost to other "non prevention" work, such as research, treatments, and care and support. NAPWA member organisations are being called upon to conduct increasing amounts of prevention-related work. Nonetheless, this additional effort comes at a cost. The *AFAO Positive Education Needs Assessment Report* notes that in some jurisdictions, the expectation of collaborative partnership has in reality involved the redirection, deferral or cancellation of proposed work in some other areas to make room for prevention efforts, with either no additional funding or very small allocations. In other words, all this may come at the expense of equally important work in care and support areas or systemic advocacy and policy.

Among a number of NAPWA's state-based member organisations, there has been a shift in the nature of the work and programs. Many are moving away from their previous focus on the provision of individual support and systemic advocacy towards community development and health promotion programs. Services such as HIV treatments information officers, who once provided one-on-one telephone support, are now declining. Some organisations are now producing programs and resources that focus on engaging the community around questions such as body image, discrimination, returning to work, or living with treatments. Whilst this is not universal, it is a trend in many organisations, with funding often being directed towards these broader community health promotion initiatives and a corresponding decrease in individual or systemic political advocacy at state level.

This has led to a considerable amount of confusion among people with HIV as to which organisations have responsibility for making representations and providing advocacy or developing policy on behalf of people with HIV. Similarly, as the *AFAO Positive Education Needs Assessment* notes, there is often confusion as to where to go if you are an individual seeking advocacy on a specific issue.

Some service providers expressed concern that the capacity of HIV-positive people to take an active role in their own health care by engaging in consumer health advocacy through their PLWHA organisations is declining. Member organisations are committed to advocacy work, participating in research, assisting with knowledge transfer, and improving our understanding of the experience of living with HIV on issues as diverse as 'treatments in practice' or 'positive in prevention'. However, the question is how best to achieve this, particularly in the face of a trend away from full-time dedicated policy staff or positions with a specific focus on advocacy or personal support.

Member organisations feel that while the health promotion effort is important, the diminution of capacity for positive participation in policy development and advocacy does not reflect the spirit of the HIV partnership and changes the nature and balance of operating relationships. This has the potential to frustrate a nationally coordinated and collaborative response.

Clearly there are costs as well as opportunities flowing from the health promotion agenda. Some are concerned that health promotion may be viewed very narrowly, and this is evidenced in the highly specific nature of some health promotion programs and funding. Organisations do want to engage in health promotion and in some states are doing it extremely well. However, autonomy in determining priorities of health promotion work is needed, as well as improved communication between community organisations and their funding agencies to ensure that the priorities are those of the affected community and that advocacy work does not disappear off the radar altogether.

**■ RECOMMENDATION 17:**

That systemic and individual advocacy for people living with, and communities affected by, HIV remain a priority, and that specific funding for these functions be maintained.

## FUNDING – A CORE PROBLEM

Throughout the interviews, a common and consistent concern was that many state-based PLWHA organisations are not adequately funded to manage their core work effectively.

PLWHA organisations are finding it very difficult to access the financial resources they need to meet the rising challenges and complexity of the responses required. All but one PLWHA organisation reported that they are being required to do more without any corresponding increase in funding and this is now considered by staff to be at a critical level. State-based PLWHA organisations reported they had received no increase in funding for several years above CPI indexing. At the same time, they reported rises in employment costs, a general lack of funding for infrastructure, and an increasing specificity in the nature of funded program work. Service providers feel that this compromises their ability to deliver on current work, and are concerned that their capacity to participate in the HIV response in a substantive and meaningful way will be affected.

There appears to be some conflict between the needs of community-based HIV service providers and the priorities identified by and funded through governments, whether through program grants or as discretionary funding. Funding from sources other than government is limited. The pharmaceutical industry does support some program work, but this is typically limited to treatments-related projects in the form of unrestricted educational grants.

There are significant differences in the way that HIV positive groups and programs for positive people are funded in different states, and their relationships with AIDS Councils vary significantly between jurisdictions. Programs and groups for different sub-populations are also often funded in different ways. Yet funding difficulties were reported by nearly all PLWHA organisations, often leaving them with little or no policy capacity, which has the potential to negatively impact upon the health and wellbeing outcomes for HIV positive people were quite different nationally.

These state based PLWHA organisational capacity differences need to be more fully understood and reviewed in line with best practice and intended health outcomes. The aim of such a review would be to ensure that positive people have the capacity to actively participate through their own organisations in consumer health advocacy, education and policy development.

### ■ RECOMMENDATION 18:

That the Department of Health and Ageing fund further research to assess changing care and support needs and map changes in patterns of service provision.

## LEADERSHIP – CALLING FOR RENEWED LEADERSHIP

*"Cost of living with HIV is a priority but, people are worried about future needs in care and support and we need to see planning happening on state basis."*

Almost universally, HIV positive people and service providers interviewed in this project called for better leadership to deliver more strategic and coordinated care.

Sustaining national and state responses is a challenge for the HIV sector and government leaders. The interviews conducted in this research drew attention to a new set of leadership challenges. Some of these challenges are listed below.

- Responding to the changes in the epidemic and developing policy and service delivery responses to maintain and sustain the improved health and wellbeing of positive people (*Identifying strategic program development*);
- Ensuring that the views of positive people are incorporated in the development of programs and policies affecting all aspects of HIV care and support services (*Ensuring meaningful engagement*);
- Identifying key strategic research questions needed to guide future policy and service delivery programs (*Identifying strategic research*);
- Conducting community consultation and building consensus on the question of "mainstreaming" HIV services (*Change through consensus building*);
- Developing effective structures to ensure that "mainstream" health services adequately reflect the clinical and care needs of positive people? (*Ensuring a responsive and reflexive health delivery system*)
- Responding to workforce issues to maintain expertise and experience in an increasingly complex HIV clinical environment into the future (*Investing in the workforce*)
- Ensuring that treatments, research and care and support continue to be adequately supported by government in the context of an increasing emphasis on HIV prevention (*Investing in the future*);
- Ensuring meaningful involvement of people living with HIV in prevention initiatives (*Positives in prevention*);
- Involving HIV community organisations in policy, education and systemic consumer health care advocacy programs and providing adequate resources for them to participate effectively in the HIV partnership (*Investing in partnership*);
- Providing national leadership to ensure best practice, integrated and coordinated care arrangements to positive people in all States and Territories (*Improving the coordination of care*).

These challenges need to be addressed in order to support positive people and improve access to both HIV and mainstream health services. Achieving outcomes will require strong leadership at all levels in a coordinated, cooperative effort with strengthened accountability by all partners.

The 5th National HIV/AIDS Strategy clearly delineates responsibilities for all partners in the national response, including government, health care workers, and the research and community sectors. The Commonwealth has established Advisory committees to provide expert advice to the Minister and to his Department on the implementation of the Strategy. These mechanisms enable Australia to respond to the challenges of prevention and to the complex range of treatment, care and support responses required twenty years into the HIV epidemic.

However, many of those interviewed felt strongly that the current leadership has failed to deliver sufficient results, and noted that half way through its life implementation of the National HIV/AIDS Strategy has been disappointing. Further, as many services are the responsibility of the States, urgent action is needed to ensure the state jurisdictions implement change in line with the intentions of the National Strategy. Strong leadership and improved coordination and cooperation - including accountability mechanisms – are needed.

### ■ RECOMMENDATION 19:

That MACASHH be reviewed with the aim of strengthening national leadership on policy relating to HIV/AIDS.

## CONCLUSION: A CULTURE OF CARE

Much of what has been achieved in the national HIV response has occurred because Australia has had a bipartisan political commitment to both HIV prevention and to supporting positive people with world class HIV clinical care, treatments and care and support programs. This commitment has enabled Australia to implement sensitive and sensible policy and program development, research programs. The engagement of communities affected by HIV has also been central to Australia's response. Involving positive people is crucial to understanding needs and patterns of behaviour change.

The centrality of positive people must continue in the development of future models for care and support services. One of the aims of this project has been to 'drill into' a range of care and support service issues by exploring and tapping into the expressed needs and experiences of positive people in relation to particular service needs. These issues included HIV health (services provided by GPs, hospitals, etc.) and HIV living (housing, personal needs, employment, etc). The experiences of positive people expressed in this report indicate that needs are changing; indeed, that individuals often experience changes and fluctuations in both the nature and level of their care and support needs.

In this context, it is necessary to work towards models of care and support that are flexible and adaptive as well as integrated and coordinated. At present, there are still a number of 'pressure points' in service provision where intensive resource investment is still required. Building a network of care and support services that incorporates the flexibility, adaptability and coordination required to meet the needs of people living with HIV and AIDS into the future will demonstrate a genuine culture of care in Australia's response to HIV.

# APPENDICES

## **APPENDIX 1: NAPWA NATIONAL CARE AND SUPPORT AUDIT CRITICAL REFERENCE GROUP (CRG) DURING 2007**

Members of the NAPWA National Care and Support Audit Critical Reference Group (CRG) and the positions they held during 2006/2007 include:

- Gabe McCarthy: President, NAPWA
- Katherine Leane: Director, NAPWA; HIV Peer Support Worker, Woman's Health Statewide, South Australia
- David Menadue: Vice President and Education Convenor, NAPWA
- Rob Lake: Care and Support Convenor, NAPWA; President, PLWH/A (NSW)
- David Barton: Program Coordinator, Heterosexual HIV/AIDS Service, NSW
- David Wallace: Positive Futures Team Leader, Bobby Goldsmith Foundation
- Cipri Martinez: HIV Positive Peer Educator, WA AIDS Council
- John Daye: Health and Treatments Co-Convenor, NAPWA
- John Rule: Manager, HIV Living and International Units, NAPWA
- Bill Whittaker, Health and Treatments Convenor, NAPWA
- Ian Rankin, President, AFAO

CRG members are supportive of the reports' findings which acknowledge a complexity of needs around treatment and care issues directly arising as a result of improved health outcomes post-1996. These changes affect service direction, highlighting gaps in services or difficulties in access, which requires the formulation of solutions when projecting on care and support needs and service responses.

The CRG supports further consultative efforts by NAPWA to gain insights into HIV positive people's needs, quality of life and service utilisation experiences. Further, the CRG believes that this report has spoken on a range of specific issues and their effects, providing the organisation with a powerful lobbying tool as NAPWA refines its work and collects more information about HIV social policy.

## APPENDIX 2: ACRONYMS USED IN THIS REPORT

ACON	AIDS Council of NSW
AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral therapy
ASHM	Australasian Society for HIV Medicine Inc
ATPA	AIDS Treatment Project Australia
ATSI	Aboriginal and Torres Strait Islander
BGF	Bobby Goldsmith Foundation
CALD	Culturally and Linguistically Diverse Background
CPI	Consumer Price Index
CRG	NAPWA National Care and Support Audit Critical Reference Group
CSN	Community Support Network
CSSS	Care and Support Snapshot Survey
DSP	Disability Support Pension
FDN	Food Distribution Network
GP	General Practitioner
HACC	Home and Community Care
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug Use
NAPWA	National Association of People Living With HIV/AIDS
OI	Opportunistic Infection
PATSIN	Positive Aboriginal & Torres Strait Islander Network
PEP	Post Exposure Prophylaxis
PLWHA	People living with HIV/AIDS
QPP	Queensland Positive People
STI	Sexually Transmitted Infection
TON	Treatment Officers Network
WAAC	Western Australian AIDS Council

## APPENDIX 3: SURVEY INSTRUMENT AND FURTHER RESULTS

CSSS feedback survey available from:

NAPWA  
PO Box 917  
NEWTOWN NSW 2042  
Australia  
Tel. 02 8568 0300

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## GROUP AND ORGANISATIONAL CONNECTIONS: CROSS-TABULATIONS FOR STATE RESULTS

**Table 8: RESPONDENTS CONNECTIONS WITH NAPWA (AS PERCENTAGES)**

STATE/TERRITORY	VERY	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
ACT	16.7	50.0	16.7	16.7		100
NSW	30.8	38.5	7.7	15.4	7.7	100
NT		100.0				100
QLD	20.0	20.0	40.0	20.0		100
SA	60.0	10.0	10.0		20.0	100
TAS		33.3	33.3		33.3	100
VIC	41.7	25.0	16.7	16.7		100
WA	16.7	16.7	16.7	33.3	16.7	100
TOTAL	32.1	28.6	16.1	14.3	8.9	100

**Table 9: RESPONDENTS CONNECTIONS WITH AFAO (AS PERCENTAGES)**

STATE/TERRITORY	VERY	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
ACT	20.0		60.0		20.0	100
NSW	7.7	7.7	38.5	7.7	38.5	100
NT				100.0		100
QLD		25.0		50.0	25.0	100
SA		11.1	22.2	33.3	33.3	100
TAS				33.3	66.7	100
VIC			36.4	54.5	9.1	100
WA	25.0				75.0	100
TOTAL	6.0	6.0	28.0	28.0	32.0	100

**Table 10: RESPONDENTS CONNECTIONS WITH PLWHA ORGANISATIONS (AS PERCENTAGES)**

STATE/TERRITORY	VERY	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
ACT	50.0	16.7		33.3		100
NSW	23.1	30.8	46.2			100
NT		100.0				100
QLD	20.0	40.0		40.0		100
SA	72.7	18.2		9.1		100
TAS		33.3			66.7	100
VIC	58.3	33.3	8.3			100
WA	50.0		16.7		33.3	100
TOTAL	43.9	26.3	14.0	8.8	7.0	100

**Table 11: RESPONDENTS CONNECTIONS WITH AIDS COUNCILS (AS PERCENTAGES)**

STATE/TERRITORY	VERY	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
ACT	66.7		16.7	16.7		100
NSW	15.4	23.1	23.1	30.8	7.7	100
NT			100.0			100
QLD	40.0	20.0	20.0	20.0		100
SA	45.5	27.3	9.1	9.1	9.1	100
TAS		66.7			33.3	100
VIC	25.0		58.3	16.7		100
WA	33.3	33.3		33.3		100
TOTAL	31.6	19.3	24.6	19.3	5.3	100

## GROUP AND ORGANISATIONAL CONNECTIONS: CROSS-TABULATIONS FOR REGIONAL RESULTS

**Table 12: RESPONDENTS CONNECTIONS WITH NAPWA BY REGION (AS PERCENTAGES)**

REGION	VERY WELL	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
CAPITAL	41.7	25.0	13.9	5.6	13.9	100
OTHER	15.8	31.6	21.1	31.6		100
TOTAL	32.7	27.3	16.4	14.5	9.1	100

**Table 13: RESPONDENTS CONNECTIONS WITH AFAO BY REGION (AS PERCENTAGES)**

REGION	VERY WELL	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
CAPITAL	9.4	6.3	31.3	25.0	28.1	100
OTHER		6.7	26.7	26.7	40.0	100
TOTAL	6.4	6.4	29.8	25.5	31.9	100

**Table 14: RESPONDENTS CONNECTIONS WITH PLWHA ORGANISATIONS BY REGION (AS PERCENTAGES)**

REGION	VERY WELL	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
CAPITAL						
OTHER	31.6	26.3	10.5	26.3	5.3	100
TOTAL	44.6	25.0	14.3	12.5	3.6	100

**Table 15: RESPONDENTS CONNECTIONS WITH AIDS COUNCILS BY REGION (AS PERCENTAGES)**

REGION	VERY WELL	WELL	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
CAPITAL	32.4	13.5	27.0	16.2	10.8	100
OTHER	31.6	15.8	31.6	15.8	5.3	100
TOTAL	32.1	14.3	28.6	16.1	8.9	100

## APPENDIX 3: CONSULTATION SCHEDULE FOR NATIONAL CARE AND SUPPORT AUDIT

- Positive Indigenous Aboriginal & Torres Strait Islander Network (PATSIN) (11 Feb 06)
- Women@napwa (21 Sept 06) Critical reference group members Gabe McCarthy and Katherine Leanne provided updated information for this project on matters arising from the women@napwa forums.
- NAPWA Social Well-being in Policy (SWIP) Working Group (Included as standing agenda item for regular briefings)

### NAPWA Membership

- Special General Meeting (SGM) Workshops (28-29 April 06 and also 13-14 April 07)
- NAPWA Board and Convenor Workshops (4-5 August 06)
- NAPWA Annual General Meeting (AGM) Workshops (25 November 06)

### Australian Federation of AIDS Organisations (AFAO)

- AFAO Annual General Meeting (AGM) Workshop meeting (November 05)
- AFAO Special General Meeting (SGM) (May 06)
- AFAO Board (February 06, September 06, November 06)

Backgrounder interviews conducted by Peter Canavan with people listed below:

### Queensland Consultations: 26-27 July 06

- Simon O'Connor, General Manager, QPP
- Peter Watts, Health Promotion and Treatments Officer, QPP
- Barrie Morrish, Statewide Administration/ Organisational Support Officer, QPP
- Angus, QPP Brisbane Convenor and Secretary: Robert Langdon, QPP Secretary & Townsville Convenor
- HIV positive woman, QPP Gold Coast

### New South Wales Consultations: 7, 8, 10, 14, 20 November and 10 December 06

- Geoff Honnor, Executive Officer, PLWH/A (NSW)
- Dennis Meijer, Acting Director, Client Services, ACON
- Lance Schema, Manager, Client Services, ACON
- Deb Broughton, Community Support Network (CSN)
- Carl Piraino, Coordinator, Positive Living Centre (PLC)
- Lance Feeney, HIV Living Manager, ACON
- Tania Lienart, Manager, Northern Rivers, ACON
- Roy Starkey, Northern Rivers Branch, ACON
- Chris Clementon, Manager, Hunter, ACON
- Rosemary Bristow, Client Support Officer Hunter, ACON
- Mary Anne Saunders, Client Support Officer, Hunter, ACON

### Victoria Consultations: 19-20 September 07

- Sonny Williams, Executive Officer, PLW/H (Vic)
- John Hall, Acting Manager, Positive Living Centre (PLC)
- Rebecca Matheson, Executive Officer, Straight Arrows
- Dawn Wilcox, Executive Director, Positive Women Vic
- Jeffrey Robertson, Coordinator, Breaking the Chains
- Greg Iverson, President, PLWH/A (Vic)
- David Menadue, Vice President, PLWH/A (Vic)

**Western Australia** ● Consulted with six HIV positive people (organised through WAAC) on 7 April 06

**South Australia** ● Key contact and project reference group member: Katherine Leanne, NAPWA Board

**Tasmania** ● Key contact and project reference group member: Robert Mitchell, NAPWA President

**ACT** ● Key consultation contact: Ken Basham, NAPWA Board

**NT** ● Key consultation contact: Mark Halton, Peer Support Worker, NTHHAC

## NOTES

1 region as defined by capital city/inner or outer suburban, regional centre (population 5,000 or more) or rural

2 See for example: Power, R; Tate, HL; McGill, SM; and Taylor, C. (2003) *A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals*. Sexually Transmitted Infections, 79:2:137-141 See also Collins, E; Wagner, C; Walmsley, S. (2000) *Psychosocial impact of the lipodystrophy syndrome in HIV infections*. The AIDS Reader, September, pp 546-550. Also Persson, A. (2002) *'people can tell you're positive' Lipodystrophy and forced disclosure*. Paper presented at the Australasian society for HIV Medicine Conference, Sydney, October 2002

3 Grierson, J; Thorpe, R; Saunders, M; and Pitts, M. (2004) *HIV Futures 4: State of the [positive] Nation*. Australian research centre for Sex, Health and Society, LaTrobe University, Victoria

4 Grierson, J; Thorpe, R; Saunders, M; and Pitts, M. (2004) *HIV Futures 4: State of the [positive] Nation*. Australian research centre for Sex, Health and Society, LaTrobe University, Victoria

5 Grierson, J; Thorpe, R; Saunders, M; and Pitts, M. (2004) *HIV Futures 4: State of the [positive] Nation*. Australian research centre for Sex, Health and Society, LaTrobe University, Victoria

6 Fogarty, A; Mao, L; Zablotska, I; Salter, M; Santana, H; Prestage, G; Rule, J; Canavan, P; Murphy, D; McGuigan, D. (2006) *The Health in Men and Positive Health Cohorts: a comparison of trends in the health and sexual behaviour of HIV negative and HIV positive gay men, 2002-2005*. (Monograph 1/2006). Sydney, National Centre in HIV Social Research, the University of New South Wales

7 'positive gay men' and 'gay men' were recorded in the one category

8 'positive women' and 'heterosexual women' recorded in one category

## NOTES



