

NAPWA CARE + SUPPORT AUDIT

# pressure points

Peter Canavan, HIV Living Program Coordinator

November 2007

## PRESSURE POINTS

“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 . . .”

### REPORT STRUCTURE

- Introduction
- Background
- Consultation
- Models of Care
- Report Summary

### PART ONE: **EXTERNAL PRESSURES 6**

- Leadership – calling for renewed leadership
- Mainstreaming – a policy shift, which in practice has problems
- Stigma and Discrimination – still experienced at the point of service delivery
- Workforce Development – a pressing dilemma
- The Prevention Focus – at the cost of other areas of investment?
- A Health Promotion Focus – at the expense of advocacy strategies?
- Funding – a core problem

### PART TWO: **COORDINATION OF HIV CARE 13**

- Peer Support – ‘Healthy HIV Living’ and ‘Living Well with Chronic Illness’
- Social Support Networks – a program of community development
- Mental Health
- Dental and Oral Health
- Housing, Respite and Emergency Accommodation
- Coordination of Care
- Care in the Context of Life-long Treatments for HIV Infection

### PART THREE: **FRAMEWORKS AND IMPLEMENTATION 18**

- Increasing complexity
- Developing good models requires an ethical approach
- Expectations of best practice from HIV positive people
- The need for a dynamic and responsive approach
- A culture of care and an ‘adaptive’ model for HIV care

### RECOMMENDATIONS 22

## INTRODUCTION

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, policymakers, researchers, service-providers and others responsible for the development and delivery of HIV programs as a resource and a guide. 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 care delivery 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.

## BACKGROUND

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 (which is a checklist of the current arrangements for care and support) has comprised surveys and interviews. An additional component, utilising health economics modelling, is also underway.

The NAPWA care and support services audit was funded through the Commonwealth Department of Health and Ageing. In part, this has been the result of a sustained case put forward by NAPWA since 2001. 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 that change.

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 the general themes, as this *is* more inclusive for the purposes of policy development.

The "Pressure Points" report represents work, carried out through the NAPWA HIV Living Unit, and includes consultations undertaken with HIV positive people, and a range of community sector partners and organisations involved in the delivery of HIV services. 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 HIV service delivery, and also asked to comment on a number of issues including leadership, barriers to effective service provision, 'mainstreaming', and how change has affected their current practice and the needs of clients. Community partners were also asked to comment on the implications of these changes for future service delivery.

Emerging from these interviews, it is possible to describe increasing 'pressure points' on the provision of services. Some of these relate to the complex and changing needs of individuals with HIV. The report is divided into three parts: firstly, it identifies external factors creating those pressure points; the second part directly addresses the coordination of HIV care; and part three describes the framework in which care and support models should ideally be developed so that response to needs remains current.

## CONSULTATION

In choosing the themes of this report, NAPWA worked closely with the project's Critical Reference Group (CRG), and discussed this report at length in a range of member discussion forums, including NAPWA's Annual General Meeting (AGM) and Special General Meeting (SGM). Themes were extracted by examining the data from the jurisdictional interviews. Interviews were conducted in the three states with the largest HIV burden (NSW, Vic and Qld). There has been feedback and discussion with NAPWA member organisations throughout Australia. Discussions on the content of this report have also included PLWHA representatives from the South Australia, Western Australia, Tasmania, Northern Territory and the ACT. Discussion and input has been invited from the Positive Indigenous and Torres Strait Islander Network (PATSIIN) and Women's Network at NAPWA (see attached consultation schedule).

Further discussion with partners in the HIV response is needed; so that over time understandings can be put into practice, and in a cooperative, coordinated and strategic way, build a better system of care for HIV positive people. This does not mean rejecting the past; the excellence of our past care and service models is recognised. Nonetheless, there have been a number of major changes affecting the lives of Australians with HIV, and the HIV sector needs to collaborate to ensure a continuum of care which addresses these changing needs.

## MODELS OF CARE

Future models of care should be:

- strategic;
- coordinated;
- reflect best practice in service delivery; and
- sensitive to the fact that the needs of positive people will change and fluctuate throughout the 'patient journey'.

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.

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 and relevant future models.

Part One of the report identifies external pressure points and suggests that these need to be addressed. Part Two identifies the elements that need to be considered in any coordinated models. Whilst NAPWA has not intended to produce 'a model' of coordinated HIV care and support, the report does identify some specific elements that need to be covered. Part Three reiterates some of the needs and suggests that there are basic principles to be understood in developing coordinated care and support arrangements.

## REPORT SUMMARY

The 5th National HIV/AIDS Strategy delineates responsibilities for all partners, government and community-based, who are involved in HIV care. Health infrastructure which is able to support HIV positive people to access mainstream services is not operating at optimal levels. Strong – and in some cases renewed – leadership to ensure that the views of people with HIV continue to be incorporated into policy and program development is required. Strategic and appropriate research to guide policy and planning into the future, and ensure programs are effective and accountable, is currently threatened due to funding changes which affect National Research Centres. The reinvigoration of the prevention effort, whilst welcome, must not come at the expense of research programs or care and support services. Similarly, there are concerns that the shift towards health promotion is occurring without recognising the ongoing need to support advocacy work, policy development and service provision at community level: there is currently some confusion as to where responsibility for each of these resides. The funding structures for some organisations may not adequately reflect the complete range of work, with concerns that some key and important tasks within community-based organisations (such as individual advocacy or health policy development) may not be addressed elsewhere within the HIV partnership.

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 today. These include AIDS councils, PLWHA organisations, social workers, nurses and a range of health experts and clinicians.

“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 mainstreamed environments, it is more important than ever to ensure there are strong and agreed referral pathways and procedures. There is a need to ensure that in practice, care services remain flexible enough to recognise the specific and sometimes unique needs of people with HIV. This may include the need for specialised access arrangements or programs, training in sensitivity for staff, or specific policies as required. It is also appropriate that some HIV services should continue to remain in and be provided by members of the HIV-affected community, including peer support programs. Some service areas, such as oral health and mental health, remain under-served generally, with HIV positive people nationally reporting problems accessing appropriate services. NAPWA urges the consideration of specific services or access protocols where this is the case.

## PART ONE EXTERNAL PRESSURES

People interviewed for this report identified external pressures that adversely affect the quality and extent of services provided to plwha. This section explores these "external pressures" and the subsequent effect on accessible care.

To address the deficits caused by external pressures it is necessary for all of the sectors involved in the Partnership Response to HIV in Australia to reform. Structural arrangements that have been in place for over twenty years need ongoing enhancement to keep pace with a changing epidemic. Methods of supporting leadership on HIV/AIDS, mechanisms to reduce stigma and discrimination, maintaining an expert and capable workforce and balancing other priorities are all important to an ongoing and robust response. Financial pressure is clearly reported as affecting the capacity to deliver a full range of suitable services.

### LEADERSHIP: CALLING FOR RENEWED LEADERSHIP

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

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

- What strategic policy and service delivery approaches and responses are needed today to maintain and sustain the improved health and wellbeing of positive people? (*Identifying strategic program development*)
- How are government departments and HIV/AIDS organisations responding to these health and wellbeing changes? (*Responding to changing needs*)
- How and to what extent are leaders in government, clinical care and community-based services ensuring that the views of positive people are incorporated into programs and policies? (*Ensuring meaningful engagement*)
- What are the key strategic research questions needed to guide our future policy and service delivery programs in sustaining health and wellness for people living with HIV? (*Identifying strategic research*)
- If HIV/AIDS services are increasingly 'mainstreamed' into the public health system, what structures are needed to put in place to make sure they still adequately reflect the clinical and care needs of positive people? Half way through the life of the national HIV/AIDS strategy, where are the corresponding state jurisdictional strategy documents, action plans and implementation programs? (*Ensuring a responsive and reflexive health delivery system*)
- Where is the evidence of community consultation and consensus on the question of 'mainstreaming' HIV services? (*Change through consensus building*)
- What are the key workforce development issues that need to be progressed to maintain expertise and experience in an increasingly complex HIV clinical environment? (*Investing in the workforce*)

- With a reinvigorated HIV prevention effort how can the areas of treatments, research and care and support also be adequately supported by government? (*Investing in the future*)
- How do positive people actively participate in prevention efforts without being pressured to participate or compromise their own health needs? (*Positives in prevention*)
- Is genuine partnership evident if positive organisations are not actively involved in policy, education or systemic consumer health care advocacy programs? (*Following the intent of health promotion and the Ottawa Charter*)
- How are HIV community organisations able to manage core work responsibilities without realistic funding increases and shrinking commonwealth discretionary funding sources? (*Investing in partnership*)
- With many state based differences in populations, service delivery expectations and partner relationships, where is the national leadership to ensure best practice integrated and coordinated care arrangements, regardless of where you live? (*Improving the coordination of care*)

These health system leadership challenges need to be addressed 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 arrangement with strengthened accountability by all partners. The Commonwealth has established advisory committees to provide expert advice to the Minister and to his department on the implementation of the Strategy.

However, many of those interviewed felt strongly that the current leadership has been ineffectual in delivering results, and noted that the National Strategy sits largely unimplemented half way through its life. Further, as many of services and infrastructure arrangements 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 coordinated and cooperative arrangements including accountability mechanisms need to be maintained and strengthened.

## **MAINSTREAMING: A POLICY SHIFT, WHICH IN PRACTICE HAS PROBLEMS**

Among leaders within the HIV positive community, and many community service providers, there is overwhelming agreement that greater clarity around the issue of 'mainstreaming' services is required: that is, 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 or facilities.

If there is a trend towards collapsing HIV services into mainstream health sectors, it is important to pause and ask:

- 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 harmed because of gaps in more general health services? and
- What mechanisms are needed to improve communication between services?

- How can mainstream services which are addressing aspects of HIV care be accountable back to HIV affected communities and individuals?
- Which agencies and organisations should be responsible for which aspects of service delivery?
- What is all this likely to mean for people with HIV?

Many state-based HIV organisations are expressing considerable 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 and promises of the National Strategy, and a lack of clarity around state and federal responsibilities in the Strategy response. The process of mainstreaming of HIV services is not entirely new: it was begun about five years ago and has been progressing since that time. The intention of this process was to begin to identify issues around specialist resource needs, access arrangements to mainstream health services and workforce development needs. What is clear from interviews is that there is a need to maintain some core specialist services in capital cities nationally, and to consider the place of the dedicated and comprehensive HIV specific services alongside or within some mainstream services, particularly drug and alcohol and mental health services. 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 HACC and community-based organisations.

NAWPA is not arguing that mainstreaming HIV services is never appropriate or that these services cannot work for people with HIV. However, not all services are going to be able to properly cater to people with HIV in their current form, and 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 should always be supported by an agreed action plan and implementation strategy that explicitly identifies and addresses these specific needs.

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.

## **STIGMA AND DISCRIMINATION – STILL EXPERIENCED AT THE POINT OF SERVICE DELIVERY**

An important question then arises for those who are planning or administering HIV care services: Are all staff adequately trained to recognise, understand and be sensitive towards the needs of HIV positive people? This may include not only ensuring 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 staff are equipped to deal with specific populations such as gay or bisexual men, injecting drug users, or people from diverse cultural backgrounds. It is still common today for people with HIV to report experiences of discrimination or inappropriate treatment within mainstream services, sometimes based on prejudices about sexuality and misunderstandings about HIV and its transmission.

This has 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.

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 remains for many people a significant factor as they access care services.

The *HIV Futures Five* report found that 6.8% of respondents had experienced less favourable treatment in relation to accommodation, 3.5% in the last two years, 27.2% experienced less favourable treatment because of HIV in relation to health services, 10.1% in the last two years.

Other areas where those interviewed reported issues of discrimination 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; a man who reported his HIV status and sexuality was exposed publicly after seeking care in country Victoria; Home and Community Carers who would not work with people with HIV; and case reports of positive people being bashed and harassed on government housing estates.

## WORKFORCE DEVELOPMENT: A PRESSING DILEMMA

Another area that positive people and service providers have reported and stressed as problematic is continuing medical and community education and training around HIV and AIDS issues.

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 shift 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 and 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 over one hundred general 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 has been discussed at length in NAPWA's 2005 discussion paper on *Complexities in HIV Clinical Care*, and was more recently the subject of a Commonwealth government-sponsored forum which included a range of HIV experienced clinicians, allied health workers, and people living with HIV.

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

- an ageing workforce;
- people with HIV for whom antiviral treatment is effective require less clinical care;
- 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. One major change has been a shift to treatment strategies aimed at reducing viral turnover and preserving CD4 cells. There is a greatly diminished need for palliative and end stage care, although it is fair to say that some jurisdictions have only just begun to recognise this fact in their care approaches.

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's Treatment Officers Network (TON), which until this year, was supported with funding from the pharmaceutical industry. This money enabled TON, a network of workers providing HIV treatments information or support within community organisations, to meet regularly, sharing information on treatments and policy, and discussing case studies. Over the years since the introduction of combination therapy, there has been a steady increase in the complexity of treatments information and management strategies that challenges the capacity of the sector to both keep up to date and provide consistent nationally relevant information. Over recent years the ability of the sector to attract the skilled staff required to undertake such important positions has been limited. NAPWA continues to provide ongoing HIV education programs for community members, including TON and does this through the AIDS Treatment Project Australia (ATPA) in association with ASHM. The increased health and treatments knowledge base required by community treatments advocates and sector workers presents ongoing challenges and responsibilities to provide continuing treatments and community education.

## THE PREVENTION FOCUS: AT THE COST OF OTHER AREAS OF INVESTMENT?

Australia's HIV prevention efforts have been regarded around the world as exemplary, both for their effectiveness in keeping HIV rates very low compared to other countries, and because they have harnessed the capacity of communities affected most by HIV and AIDS to assist in developing culturally appropriate responses. Since 2000, rising numbers of new infections and diagnoses have precipitated renewed activity in and focus on HIV prevention. This pattern of rising new infections has also been seen in many major capital cities of the UK, Europe and North America, and appears to be part of a current and recent global trend. 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.

Some interviewed from PLWHA organisations have expressed concerns that this reinvigorated prevention effort, whilst necessary to fight new infections and reverse the current trends, is now coming at a cost to other 'non-prevention' research, treatments, care and support responses under the National HIV/AIDS Strategy's remit. NAPWA is fully supportive of sensible strategic, well-planned and resourced HIV prevention efforts and participates as fully as is possible given policy and program commitments. NAPWA has been demonstrating leadership at a national level in specific work with our member organisations, cooperating where appropriate with the Australian Federation of AIDS Organisations (AFAO), and sometimes in partnership with other relevant institutions, to articulate under this prevention framework the ways that positive people currently participate in prevention efforts. To date, NAPWA has hosted a range of education and awareness discussions, meetings and workshops with the membership so as 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.

NAPWA member organisations are being called upon to participate in furthering prevention understandings through research, and also through community health promotion and prevention education campaigns. Nonetheless, this additional effort comes at a cost. *The AFAO Positive Needs Report* notes that in some jurisdictions, the expectation of collaborative partnership in reality has involved the redirection, deferral or cancellation of proposed work in some other areas, to make room for the new prevention effort, but 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 the area of systemic advocacy and policy work.

## A HEALTH PROMOTION FOCUS: AT THE EXPENSE OF ADVOCACY STRATEGIES?

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 traditional 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, but many organisations are now producing resources and programs which 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, there is often confusion as to where to go if you are an individual seeking advocacy on a specific issue, as noted in the *AFAO Positive Needs Assessment*.

NAPWA is concerned that this diminishes the capacity of HIV positive people to take an active role in their own health care, by weakening the involvement of HIV positive people (through their own organisations) in consumer health advocacy. Member organisations are committed to state-based and national advocacy work, contributions to and participation in research, assisting with knowledge transfer, and improving understandings around HIV positive experiences on issues as diverse as 'treatments in practice' or 'positive in prevention'. Nonetheless, there is the question of 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 note that this is creating some tension over how to fill these traditional and important areas of activity and response on behalf of their positive constituencies. Whilst the health promotion effort is valuable, the diminution of the 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 the operating relationships. This could easily frustrate a nationally-coordinated and collaborative response. NAPWA is fully supportive of the Ottawa Charter for health promotion and is aware that the pillars of this charter do embrace a very broad agenda, and the charter does view opportunities for health promotion to include education, advocacy and policy development in its very broadest of applications.

However, there are costs as well as opportunities flowing from the health promotion agenda, and some are concerned that this may see the agenda being narrowed, by the very 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. But there remains a need for autonomy in determining the details and priorities of health promotion work, and a need for improved communication between community organisations and their funding agencies to make sure that the priorities include those of the affected community, and that advocacy work does not disappear from the radar altogether.

## FUNDING: A CORE PROBLEM

Throughout the interviews, a common and consistent concern was that many state-based PLWHA organisations are not 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 and more without any corresponding increase in funding levels and this is now considered by the executive staff to be at a very urgent and critical level in most state-based PLWHA organisations. 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. Executive staff members have said this compromises their ability to deliver on current work, raises concerns about capacity in the future, and there are concerns this will affect organisational capacity to participate in the HIV response in a substantive and meaningful way.

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 usually limited to treatments-related projects, usually in the form of unrestricted educational grants. Although funding difficulties were reported by nearly all PLWHA organisations, there were quite significant differences reported between PLWHA organisations for sub-populations, and, with different expectations of service delivery expressed. As well, the relationships with AIDS councils 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, aiming to provide capacity to state-based PLWHA organisations to actively participate through their own organisations in consumer health advocacy, education and policy development. NAPWA is asking for this review as currently there are significant local differences in the way that HIV positive groups and positive education or health promotion are funded, with little or no policy capacity, all of which has the potential to negatively impact upon the health and wellbeing outcomes for HIV positive people.

## **PART TWO COORDINATION OF HIV CARE**

By focusing on what it means to have coordination of care for positive people, and highlighting some elements that positive people say assist them in supporting health and wellbeing, this section of the report identifies the critical components of effective and well organised care and support programs.

### **PEER SUPPORT**

Peer support programs have been central to the community-based response to HIV since the earliest days of the epidemic, and positive people say they want these programs continued. 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 undertaken by Levinia Crooks, through the University of Wollongong, 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 peoples' mental health. It was on this basis of a potential trade-off between the costs of hospitalisation and the considerably lower cost of running peer support programs, that an important community cultural development within the HIV/AIDS community sector began. Peer support programs began in the late 1980s and have continued in one form or another till today, although not all states offer comprehensive peer support programs.

The philosophy underpinning peer support programs is to provide safe and confidential spaces where positive people can sit with other people in a similar situation in a confidential safe space, where they know they're not threatened and they know they're not judged and where they know they are not going to be 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. Today approaches aim to reflect the current realities and positive futures. Interviews and feedback suggest that within the HIV positive population, different support needs have emerged since the introduction of effective treatments. Two major needs have emerged within at least the HIV positive gay population as follows:

#### **'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 healthy HIV Living.

Peer support at the point of diagnosis is not the only support or may not be the appropriate support for all newly diagnosed, 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 and for those experiencing difficulty on treatments or adjusting to the challenges of return to work. In addition, support programs for women, heterosexual men and Indigenous positive people are not available to any significant extent around the nation, yet 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 is a model which offers people a basis for not only support at an individual level, but is an important social element for organisational and community development. Participants in Genesis-style peer support groups often transition to forms of social interaction with other HIV-positive people. Social contact may be limited to those from similar support groups or involve a wider positive participation. Events may cover formal discussion circles, informal outings, specific after hours events for those working or major regular sponsored and hosted nights with entertainment, food and beverages. 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 an important element in social reintegration and informal support for and between HIV positive people. HIV positive people have the right to social participation through support networks which allow them to network, communicate, learn and share, and to participate in broader organisational and community life. Supporting this is 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 lives, to have more control of their personal situations and in developing self management strategies around living with HIV or AIDS.

## **MENTAL HEALTH**

Under the broad umbrella of mental health, there are a range of situations 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, for example, by affecting sleep patterns over long periods. It has been suggested other treatments may have specific links, for example, to depression. This is a complex area, where much clearer research is needed. Lastly, there are 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, for example, problems relating to alcohol or drug use.

The interplay between these areas is complex, sometimes ambiguous, and not always well-understood by clinicians or care providers. Nonetheless, all need to be accounted for when considering HIV in relation to mental health, and how to develop appropriate responses. One priority should be to develop a research program to better understand the evidence for the various ways HIV affects people's mental and psychosocial health, and prioritise target services more wisely.

*HIV Futures* identifies high rates of treatment for depression among positive people, when compared to depression treatment in the rest of the community. The lack of sufficient and adequate mental health programs and support structures around the nation is seen as a concern. In some states, there is no counselling specifically for HIV positive people available in any formalised sense. In some other places, there are counselling programs, but in all places there is a shortage of available counselling sessions, and in some cases the staff and volunteers to run these programs.

There are waiting lists for counselling services for positive people in most states around the nation. It has been reported by service providers that there is an urgent need to pay attention to the shortage of counselling services to deal with not only the expected adjustment issues in living with HIV, but for 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 professional psychiatric and psychological services.

This report has already described the role that peer support plays. Positive people also need to access counselling services, acute and ongoing psychiatric and psychological services, and a range of specialist services, such as drug and alcohol counselling. Positive people need to access mental health support and services across the patient journey in living with HIV. 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.

## **DENTAL AND ORAL HEALTH**

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. Dental care is very expensive, and access to public dental programs is limited. Many positive people say they cannot afford the costs of 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's 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. Coordinated care planning should take into account the role and the availability of dental and oral hygiene programs for positive people nationally; this is an urgent need.

## **HOUSING, RESPITE AND EMERGENCY ACCOMMODATION**

The other area of need identified nationally by positive people is housing support. There is also a most critical need for emergency and respite accommodation for HIV positive people. 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. The lack of affordable and appropriate housing is a source of great frustration among positive people in most states of Australia. There is considerable ongoing uncertainty about these arrangements, in particular, whether or not and to what degree these programs will continue to be funded in the future.

Access to secure and affordable housing, including emergency accommodation, is a well-known and extensively documented factor affecting peoples' health and wellbeing within the community. The departments responsible for health and housing need to urgently work together to establish a system which will support, rather than undermine, the health and social wellbeing of the many HIV positive people who report the experience of finding and retaining appropriate housing as an extremely difficult and frustrating one. Coordination of care arrangements should incorporate housing, respite and emergency shelter programs for positive people.

## COORDINATION OF CARE

For the coordination of HIV care it will be important to ensure that the elements of care examined above operate within an agreed model of service delivery and include the linking of HIV patient care to a range of health care services and the strengthening of referral pathways, policies, procedures and practices. This may in fact need to include 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 appropriately 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 coordinated for HIV positive people by a diverse range of medical and community sector personnel, all involved to a greater or lesser degree in the coordination of care. These include both high and low caseload general practitioners, sexual health doctors, hospital specialist support staff in community-based HIV/AIDS organisations, social workers at hospitals, clinic and community nurses, and a range of other allied health professionals.

There is urgent need to understand that range of case management arrangements and approaches operating nationally, both in the HIV specific and mainstream health services, as these currently operate with great variance between states and services. It is important to ask positive people how they feel about any service delivery model which favours a case management approach to the provision of care.

Care providers need to recognise the different pathways that the positive people travel in seeking information and care. It is important that care providers step outside their own particular care intervention and consider the path of the patient in understanding 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 welfare.

Knowing which are the appropriate 'entry points' and 'exit points' for health and well-being service delivery is critical. 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 3 months for monitoring;
- seeking specific information on 'where to go' for care or other service needs; or
- for example, when moving interstate and a new range of services needs to be provided.

It is important to arrive at an appropriate resource framework, which will be responsive and reflexive to changing needs over time, acknowledging the different levels of engagement that positive people have with both the HIV and mainstream health sectors.

## COORDINATION OF CARE IN THE CONTEXT OF LIFE-LONG TREATMENTS FOR HIV INFECTION

Care arrangements for the future will need to identify the range of services and care arrangements that are likely to be required by positive people at different points. Further, to identify at which points in the continuum of care, particular services and care arrangements are more likely to be accessed by positive people, paying attention to the differences between those living well with HIV and those living with chronic illness. As well as other gender-specific, Indigenous or CALD-specific interventions need to be considered.

The lifelong engagement of HIV positive people with service delivery introduces another particular challenge to the coordination of care for those responsible for the workforce development of service delivery staff. It would be useful to consider ways to strengthen the lifelong learning needs of the workforce. At the very least, every HIV worker should have an induction process about basic HIV treatments information and available services. It could be appropriate to make better use of the HIV Short Courses for Community Workers run by the ATPA and the associated professional training courses run by ASHM as part of a process of accreditation for workers in the area of HIV by adding a session to the courses which is dedicated to the coordination of care.

Resolving the above issues needs to involve the skills and expertise of the HIV sector as it is the HIV sector which knows what it is that is specific about HIV and understands the various pressure points.

## PART THREE FRAMEWORKS AND IMPLEMENTATION

Australia's care and support responses to date have served the majority of positive people well over many years. However, it is in response to the complexity of changing care and support needs and experiences of positive people, evidenced in a variety of ways, that means some attention must be paid to what NAPWA is describing as 'pressure points'. NAPWA is advocating for care and support responses which will be there across the continuum of HIV care for the duration of the patient journey. Further, that care and support responses should be based upon best practice healthcare delivery whether delivered through the mainstream health services or, where necessary through dedicated and HIV specific programs and services.

### INCREASING COMPLEXITY

Much of this has been covered in the paper produced by NAPWA in 2005 titled *the Impact of Complexity of HIV Clinical Management*. But it might be useful to recall that some dimensions of this complexity include:

- HIV is a substantial health problem for all positive people regardless of current health markers.
- There have been sustained rises in new HIV infections in many states and national increases spanning 4 years.
- There are rising numbers of positive 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.
- Individualised responses to both HIV infection and treatment outcomes is now a feature of HIV management.
- General health and wellbeing improvements have occurred since improved treatments but other HIV management issues have arisen.
- Significant management of generalised HIV infection occurs in primary health care settings and is likely to stay this way but there remain ongoing and critical points of contact with care services for any person with HIV outside of the clinical context.
- High rates of co-morbid conditions exist, adding to HIV complexity and continuing patient morbidity.
- Changing patterns and diversification of treatments toxicities over time is affecting patient confidence and hospital admissions.
- A range of HIV related illnesses related to living longer with HIV and time related treatments exposure is worrying positive people.
- Significantly high mental health issues, including anxiety, depression and psychosis are resulting in increasing need for 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 live below the poverty line with a disproportionate affect on women.
- Rehabilitation and health maintenance challenges continue with added burden for those living long-term.
- Changing needs hierarchy and new life choices are emerging in many areas, most notably in parenting, work and long term financial security, stable housing and aged care options, travel, legal rights, sexual freedom, privacy and transmission risk management.
- There is significant ongoing HIV related stigma and discrimination continues.
- Difficulty in coordination of care and support needs have re-surfaced.
- There are increasing difficulties accessing mainstream health services, particularly mental health, accommodation and home and community care (HACC) services.
- Shifts from HIV specific to mainstream health services is causing disruption.

## **DEVELOPING GOOD MODELS REQUIRES AN ETHICAL APPROACH**

Every person involved in the care and support of positive people has an important role to play and is positioned to do this through applying their particular, skills, talents, attributes and in bringing their personal and community values into creating a shared understanding of what is needed; the application of this is called 'ethics'. Importantly it is about acting in the best interests of those who are the recipients of care models and keeping alert to the experiences and needs of positive people.

Models in HIV must recognise the value of each person, paying respect to individual rights. Models in HIV must be resourced in order to deliver the intended health and wellbeing outcomes and be prioritised through strategic planning and budget allocation processes to inform sensitive policy development and finally be carried forth by leadership through to full and proper implementation across all jurisdictions of the national response in HIV.

## **EXPECTATIONS OF BEST PRACTICE FROM HIV POSITIVE PEOPLE**

NAPWA is asking for engagement that spans across the continuum of care required from primary infection through to palliative care, and that particular attention be given to understanding and supporting the uniqueness of HIV disease as both a life threatening disease and a chronic illness. It is NAPWA's view that in order to address this complexity in realistic and meaningful ways, it is necessary to acknowledge that social issues do affect health and wellbeing outcomes, and from there work to arrive at models that address both the clinical care and support needs as well as the social wellbeing needs of positive people.

Future HIV models need to be based upon best practice principles and engaged with the realities that affect the lives of positive people. NAPWA believes that if new models of care can be developed, resourced appropriately and implemented these models will complement recent clinical advances and ensure improved health outcomes for positive people.

Positive people expect that the Commonwealth government will provide leadership, strategic direction and funding through the implementation of the National HIV/AIDS Strategy and that state and territories through their health or human services departments will provide the same to ensure adequate responses across all jurisdictions.

- Positive people have an expectation that HIV clinical and care and support services will receive adequate funding, which acknowledges epidemiology, sub populations and the specifics of HIV clinical care and support need.
- Positive people expect that operational and structural responses in HIV care and support will be reviewed from time to time and may need to be updated or changed in response to corresponding changes in the needs of positive people, their experiences of service utilisation and other important quality of life issues.
- Positive people expect to be centrally involved in strategic review processes of current or future models and programs for the delivery of care and support as these directly impact upon our health and safety.
- Positive people want equal access with other Australians to mainstream health services and expect policies and procedures, not personality, relationships or preferences to guide decision making in service access eligibility.
- Positive people consider that there remain compelling reasons to have some dedicated HIV specific services outside of the mainstream health services as a direct result of the population demographics and the HIV stigma and discrimination that persists.
- Positive people want access to care services which are located within the community in which they live and expect that these services will offer a reasonable baseline of support for ongoing health maintenance and have direct relationships with more specialised HIV services.
- Positive people want a care system which recognises that HIV is still a stigmatised disease and manages client information with appropriate sensitivity, privacy and confidentiality.
- Positive people want access to services which are free from discriminatory practices or attitudes by staff.
- Positive people expect to be treated with dignity and respect as health care consumers and to have formal mechanisms to communicate their views and experiences of service utilisation.
- Positive people realise that they have health consumer rights and responsibilities and that these guide practice and are fundamental to mutual responsibility and care delivery accountability mechanisms.
- Positive people highly value the role and expertise of their health specialists, nurses and allied health care practitioners and believe that there needs to be better and improved communication and coordination in the overall management and provision of their care and support.
- Positive people want to access services where staff receive training and are educated on the specifics of HIV disease, transmission, its manifestations and personal impacts.
- Positive people want to be able to live as full lives as possible in their communities of choice and expect that their care providers will respect and work to facilitate this as a life and living goal.
- Positive people want to have unbiased information on the availability, location and criteria of care and support services.
- Positive people require access to a range of health and social service sectors, including mental health, aged care, reproductive and sexual health, housing, transport and welfare.
- Positive people view their lives holistically and expect that their non clinical needs will be integrated into overall health management strategies.

## THE NEED FOR A DYNAMIC AND RESPONSIVE APPROACH

NAPWA has stressed that today's complexity creates the imperative to define more clearly for the future, changes required to current service delivery.

Some of the factors that will influence these dynamics are as follows:

- The nature and extent of future changes in clinical care and support needs and experiences.
- Changes to health and wellbeing outcomes affecting clinical care and support need.
- Changes within the epidemiological spread and population and sub population demographics, including ageing.
- Changes to patterns of service delivery and utilisation, including any shifts between hospital based care and ambulatory care.
- Changes to case mix funding arrangements between the Commonwealth and the state jurisdictions.
- Changes to the nature of community health provision.
- Changes in the roles of AIDS Councils and community based HIV service organisations.
- Social policy shifts which affect the social mechanisms through which people communicate or gain access to services.
- Changes within the health, welfare and community health sectors leading to the need for specific linking mechanisms, pathways or programs to improve service utilisation, quality of life measures or health and wellbeing outcomes. These would include dental and oral health, aged care, and mental health and welfare pathways.
- Changes to the ways that HIV client information is gathered, shared or stored.
- Changes to Commonwealth and states or territories funding agreements in sectors affecting health and social services with direct impact upon determinants of health, including transport and housing.
- New information and practices that affect the range, nature or provision of HIV treatments, diagnostic tests which are likely to impact upon pathogenesis and treatments, prognosis or outcomes and consequently changes to care patterns.

## A CULTURE OF CARE AND AN 'ADAPTIVE' MODEL FOR HIV CARE

In talking about care, it is useful to ask what it is that creates the essence of 'care', what is meant by talk of 'care' and 'caring'? It is culture when significance is given to the things shared in common; language portrays aspects of culture. Culture is when there is a common recognition and remembering of the way 'things are done'. In the context of achieving and developing a culture of care in HIV, talking of HIV care today, brings into focus the elements that are valued sufficiently enough to be remembered and named. These elements have been described throughout this report, both in terms of what are currently in place and some of the areas in the HIV service delivery model where pressure points exist. Recognising that there are pressure points still being experienced by HIV-positive people is the further development, of a culture of care. To deny the reality of these pressure points, as expressed by positive people and their carers, is to deny or dismiss the development of a culture of care.

Much of what has been achieved in the national HIV response has occurred because Australia has demonstrated time and time again that there is 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 been at the forefront of sensitive and sensible policy and program development, research programs and importantly has involved affected communities. Critical to this success is the involvement of HIV positive people in a pivotal way in all of these aspects, precisely because positive people are critical to understanding needs and patterns of behaviour change. It is NAPWA's view that this positive centrality must continue as a cornerstone for the future in development of an 'adaptive' model in HIV care where keeping awareness of changing needs is built into models in an alive, dynamic, reflexive and responsive manner, ensuring necessary responses are finely tuned to achieve outcomes for all. An adaptive model of care is necessary as needs keep changing. Lifelong treatment for HIV infection is predictive of different levels of care for different population groups. As there is now no uniform need across the whole population, care models need to remain flexible. This report suggests that there continues to be a range of pressure points at which intensive resource investment is still required.

## RECOMMENDATIONS

The recommendations are drawn from Part One and Two of the Report and signal future work to be undertaken by all involved in the HIV partnership. This and is provided as a reference point for consideration of all stakeholders.

1. Many of those interviewed felt strongly that the current leadership has been ineffectual in delivering results, and noted that the national strategy sits largely unimplemented half way through its life. Further, as many services and infrastructure arrangements are the responsibility of the states and territories, urgent action is needed to ensure the jurisdictions implement change in line with the national strategy. Strong leadership and coordinated, cooperative arrangements, including accountability mechanisms, will need to be strengthened and maintained.
2. HIV positive people and service providers within AIDS Councils and PLWHA organisations consistently state they are unsure of the processes, responsibilities or timing for mainstreaming of HIV services, and the extent to which HIV-specific services will be maintained. This requires further clarification through Commonwealth and respective state and territory jurisdictions.
3. It is still common today for people with HIV to report experiences of discrimination or inappropriate treatment within mainstream services, sometimes based on prejudices about sexuality and misunderstandings about HIV and transmission. HIV sensitisation and training needs renewal. There is clearly the need to continue and strengthen dedicated HIV training for health and care workers, and volunteers, in both HIV sector and mainstream health services and considers this one of the most pressing needs.

4. There remains a need for autonomy for HIV positive people and organisations in determining the details and priorities of prevention and health promotion work. There is a continuing need for improved communication between community organisations and their funding agencies to make sure that the priorities are those of the affected community, and that systemic and individual advocacy continues. There are significant jurisdictional differences in the way that HIV positive groups and positive education or health promotion are funded, with insufficient policy capacity, which has the potential to negatively impact upon the health and wellbeing outcomes for HIV positive people. This must be addressed within a uniform national strategic approach.

5. There must be investment in the development of "Healthy HIV Living" support programs for newly diagnosed and "Living Well with Chronic Illness" support programs for long term diagnosed.

6. HIV positive people have the right to social participation through support networks which allow them to communicate, learn, share, and participate in broader organisational and community life. Supporting this is an essential element in the coordination of care. This communication should not be relegated to informal networks of support, but should be incorporated formally by community organisations and linked to organisational directions in a dynamic way to inform program development.

7. A priority should be to develop a research program to better understand the evidence for the various ways HIV affects people's mental and psychosocial health, and prioritise target services wisely.

8. Coordinated care planning should take into account the role and availability of dental and oral hygiene programs for positive people nationally as an urgent need.

9. Departments responsible for health and for housing must work together to establish a system which supports the health and social wellbeing of the many HIV positive people who report the experience of securing appropriate housing as extremely difficult and frustrating. Coordination of care arrangements necessarily include, housing, respite and emergency shelter programs for positive people.

10. It is important that care providers recognise the different pathways positive people utilise when seeking information and care. Care providers step outside prescribed care interventions and consider the path of the client in understanding where an individual is positioned on the patient/client journey.

11. Research programs need to be resourced and maintain a focus on the changing care and support needs and changing care and support service patterns.

## 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 and 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

## CONSULTATION SCHEDULE FOR NATIONAL CARE AND SUPPORT AUDIT

**Positive Indigenous Aboriginal & Torres Strait Islander Network (PATSIN)** (11 February 06)

**Women@napwa** (21 September 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 Constable-Townsend, QPP Brisbane Convenor and Secretary
- Robert Langdon, QPP Secretary and Townsville Convenor
- HIV Positive woman, QPP Gold Coast

### New South Wales

Consultations: 7, 8, 10, 14 and 20 November;  
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 Feeny, HIV Living Manager, ACON
- Tania Lienart, Manager, Northern Rivers, ACON
- Roy Starkey, Northern Rivers Branch, ACON
- Chris Clemenson, 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 Mattheson, 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

Consultation: 7 April 06. Consulted with six HIV positive people (organised through WAAC)

### 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 and NT

Key consultation contact for NT:  
Mark Halton, Peer Support Worker, NTHHAC  
Key consultation contact for ACT:  
Ken Basham, NAPWA Board





