

napwa

National Association of People Living With HIV/AIDS

**STRATEGIC
PLAN
2000 - 2004**

December 2000

FOREWORD

NAPWA began to undertake the process of developing its strategic plan in November 1999 after recognition by the organisation that it would be of great benefit to articulate the strategic directions and strategic priorities that flow from such a process.

It has been widely recognised that many complex areas of HIV/AIDS advocacy require a sustained focus and concerted effort. The purpose of developing NAPWA's strategic plan is to lend just such focus to the myriad of issues that it deals with.

NAPWA has embarked on comprehensive consultation within the HIV/AIDS sector and in particular with positive people. We recognise the importance of relationships between positive people, between organisations, and between positive people and organisations.

As the environment in which we work becomes more complex, with the rapidity of change and as the issues the environment throws up becomes more complex, it is the quality and strength of these relationships that allows us to take risks and expand the limits in finding innovative ways to move forward into the future. United in the work of bringing about social justice and improving the quality of life of positive people

The consultation process has encouraged the airing of divergent views. It is my belief that the way forward is likely to be found through a range of different people, with a range of different experiences, with a range of different views coming together to explore these differences.

The challenge for NAPWA has been to look at a variety of approaches and distil from these the elements that will strengthen our response in setting out our organisational priorities.

Of the many challenges that confront positive people and the importance of the voice of NAPWA as the national representative voice in dealing with these issues, the strategic planning process has identified a number of key arenas of activity fundamental to the advocacy work of our organisation.

The three core arenas of activity have been identified as; **national positive advocacy and representation; issues coordination, community consultation and our organisational capacity building.** This strategic plan articulates and explores in detail the processes to achieve success with these objectives.

The task of developing our strategic plan has been immensely rewarding, especially seeing the level of engagement of positive people and their enthusiasm for the initiative.

It must always be remembered that the value of having a strategic plan lifts the ability of an organisation to set out strategic priorities, which forms the framework for our response. The strategic plan is a living document of what we are about to achieve and as a guide it is invaluable. The duration of the strategic plan is over three years but the organisation will retain flexibility to respond to new issues as they emerge, which are inevitable over this time.

I wish to thank all those involved in making this strategic plan possible especially John Rule and the support of Jo Watson. It gives me great pleasure to commend to you our strategic plan, which will help guide the future endeavours of NAPWA.

Peter Canavan
President
26 November 2000

WHY A STRATEGIC PLAN AND WHY NOW ?

The terms "changing needs" and "shifting focus" have appeared with regularity in discussion of the contemporary response to the epidemic in Australia. Changes both positive and negative in the lives of most plwha and subsequent changes in priorities for health services, support and information as well as shifts in the economic, political and sociological pictures have forced many sector organisations to engage in strategic planning.

The Australian Federation of AIDS Organisations, the AIDS Trust of Australia, the Australasian Society for HIV/AIDS Medicine, as well as some state based AIDS Councils and PLWH/A organisations have been reviewing their operations in the light of the above changes.

NAPWA has intended its strategic planning to coincide with other movements within the sector and in particular to move in directions, which are in keeping with the recently released 4th National Strategy. The timing is right and is consistent with sector shifts.

A number of crucial considerations have been identified which impacted on NAPWA's future (From a meeting held in Nov 1999)

- HIV positive people's time commitments (as volunteers) to be involved or committed to the work of NAPWA
- Engaging the diversity of personal and professional experiences that are now needed in the operation of an organisation like NAPWA
- Maintaining the skill base of the organisation by sustaining those who have experience and a history of involvement
- Allowing for the movement in and out of the association as may be required for people living with an illness like HIV/AIDS

Other trends have been noted, well reported at recent national conferences and are thoroughly documented elsewhere;

- Evidence of rising numbers of plwha dealing with mental health issues.
- Greater pressure for plwha to 'return to work'.
- Pressure on housing and income support arrangements that have sustained many plwha.
- Maintaining and continuing to develop effective HIV treatments and support in a constricted economic environment.
- An increase in the sense of isolation being experienced by plwha.

All of the above have led to a reappraisal of structure, how NAPWA works and how it should work for the life of this strategy.

INTRODUCTION

The Executive members of NAPWA have overseen the preparation of this document. An Implementation Action Group has managed detail of the strategic planning process. Significant staff and organisational resources have been devoted to both the process and the production of this documentation. Many other sector organisations have contributed to the planning process – appendix 2 lists those who have participated in the consultations.

The current 4th National HIV AIDS Strategy commits to the involvement of affected communities at every level of the response. The centrality of positive people has been emphasised as part of a partnership approach. NAPWA acknowledges that this has been specifically strengthened and upheld in statements from AFAO and the Commonwealth in recent months. NAPWA identifies many opportunities to strengthen their participation within the partnership approach and as a strong voice of positive advocacy in Australia.

NAPWA is the peak body identified as representing the issues and concerns of plwha living in Australia. The organisation carries the singular responsibility for representing the many voices that are to be found amongst our positive populations whilst at the same time responding to challenges that require a united position. The purpose of the work that has brought us to this document is to map out the strategies that will maintain and enhance the strong voice and represent a national profile, which will give visibility to the lives of plwha in Australia.

As NAPWA has evolved and grown, centrality of the positive voice has become acknowledged and respected within the Australian response to HIV/AIDS. The energy that has been committed by positive representatives over the years has encouraged others to continue with the tasks. The energy should not be undervalued and NAPWA acknowledges the responsibility it wears representing plwha at a national level at the interface between government, medical and other community stakeholders.

The process of the merger between the ATPA and NAPWA has begun and is seen as an acknowledgment of the leadership role in treatments issues. This demonstrates the important role that an organisation of positive people can contribute to the national response. The wealth of experience and the skills created cannot be underestimated. With similar energy NAPWA believes that other identified areas of work within the organisation can reach the achievements of those gained in the treatments area.

BACKGROUND ISSUES

The National Association of People Living With HIV/AIDS (NAPWA) was originally created as the National People Living With AIDS Coalition (NPLWAC) and was established on the recommendation of HIV positive people who attended the National AIDS Conference in Hobart in 1988. It was actually the forerunner of many state PLWH/A groups and part of its brief was to help state groups to set up their own advocacy organisations.

The organisation was established to be the national advocacy body for people living with HIV/AIDS, to present the views and perspectives of positive people to government, services providers and AIDS Councils on a national level. It continues this role with its membership consisting of state-based PLWH/A groups around the country.

Initially the organisation was based in Canberra with one paid staff position. With the move of the office to Sydney in the mid 1990's the Federal Government declined to fund the organisation for more than one full-time staff position and funds had to be channelled through AFAO. In 1999 the co-location of the AIDS Treatment Project of Australia (ATPA) into the NAPWA office brought additional staff, expertise and resources to the organisation to work on shared goals and outcomes.

From 2000 onwards NAPWA has set up separate financial arrangements and accounting systems and has secured its own Programme Of Activities (POA) funding contracts with the Commonwealth. As NAPWA grows and further enhancements are negotiated for the first time the organisation will be operating with a professionally resourced secretariat that can move beyond such a huge dependency on volunteer efforts.

It is timely at this point in concluding the historical brief, to consider and acknowledge the hundreds of plwha over the years that have all contributed to bringing NAPWA to this point.

DESCRIBING THE PLANNING PROCESS

In articulating the organisational objectives NAPWA members prioritised and chose what they considered to be the main focus of the work of the organisation. Within those discussions two main criteria were identified as the basis for NAPWA's present and ongoing work.

This strategic criteria was identified early in the process (From the meeting held in Nov 1999) as being

- to provide a powerful representative voice for plwha on a national level
- to assist all Australian plwha to maximize their health and quality of life.

NAPWA claims to have the knowledge of the Association's member's interests. It claims a place in what is sometimes a contested arena. It claims to be smart establishing and working at desired outcomes.

NAPWA also claims to be part of a constantly changing social reality, a social reality in which the participation of different groups of people determines who gains privilege or advantage or dominance. To identify this is also to identify issues of social justice and injustice. And discussions of social justice have also featured in this process. We know that there exist marginalised groups of plwha. The process has determined to be engaged with all groupings and this was ensured by the extensive consultations carried out over the last six months.

This is a detailed and extensive strategic plan that has built upon those plans and processes that have come before it. The background material and history of NAPWA along with the more recent consultations brings a recognition that the very existence of NAPWA as an Association has been a basic strategy all along.

This is a strategy that organises a positive response through the activity of plwha themselves. That is an integral strength of the Association as well as the HIV/AIDS community response, which in turn leads to the strengthening of the national HIV/AIDS response.

Details of the time frame of consultative mechanisms are shown in Appendix 2.

OUTLINING THE STRATEGIC CHOICES

This is a statement of the **organisational objectives**. These are the reasons why the organisation exists.

a. To Provide National Positive Advocacy and Representation.

The intention of this objective is to facilitate NAPWA's participation in the decision-making structures of the HIV response. To take leadership in the promotion of improved access to HIV treatments for plwha in Australia, and to continue formal relationships with the Australian drug regulatory and drug funding process, including the involvement of the Australian pharmaceutical industry. To work with State and Territory HIV/AIDS groups and NAPWA membership to enhance their ability to advocate for the needs of plwha.

b. To provide issues coordination and community consultation.

The intention of this objective is to work with State and Territory HIV/AIDS groups and NAPWA membership to ensure coordination and communication of key issues and strategies in the Australian community response to HIV/AIDS. To facilitate a transparent and meaningful engagement with PLWH/A groups and representatives around the country. To ensure representation of diverse and comprehensive PLWH/A responses to HIV/AIDS issues and to promote a responsive and considered approach to constituent issues.

c. To provide Organisational Capacity Building.

The intention of this objective is to promote capacity of member PLWH/A groups and representatives to respond to changes in the impact of HIV/AIDS.

The organisational objectives can be further broken down into discrete **goal statements**. These are statements of where the organisation wants to go. Some of these goal statements could be locked into more than one of the objectives.

National Positive Advocacy and Representation

1. NAPWA will strengthen its position and build the profile of the organisation as the primary national representative and peak spokesperson for plwha and PLWH/A groups.
2. NAPWA will continue to liaise with and lobby the pharmaceutical industry and drug regulatory bodies.
3. NAPWA will advocate for, and, where appropriate, instigate and support research on relevant HIV/AIDS issues.
4. NAPWA will continue to negotiate with the Commonwealth Government for ongoing and where appropriate increased funding for the organisation. In its work with State based PLWH/A groups it will also offer support as necessary.

Issues Coordination and Community Consultation

5. NAPWA will maintain close integration and alliance with ATPA and continue to be central to any national discussion of treatment issues.
6. NAPWA will develop and distribute new national policies, guidelines and best practice documents on identified issues which impact on plwhas as well as acting as a clearinghouse for already established state based and other policy, guidelines and best practice documents.
7. NAPWA will facilitate at a national level exchange and distribution of information to and between state-based PLWH/A groups.

Organisational Capacity Building

8. NAPWA will advocate on behalf of plwha and PLWH/A groups at a national level with AFAO and other government and non-government organisations supporting PLWH/A to be empowered at a state level.
9. NAPWA will, where appropriate, facilitate capacity and skills building for PLWH/A groups

These goal statements have been agreed upon and specific **strategies** have been suggested as a way to achieve these goals. The achievement of these specific strategies will form the basis of performance criteria against which progress can be measured. They provide a grid of activities that can be monitored at regular intervals.

National Positive Advocacy and Representation

Goals	Strategies
<p>1. NAPWA will strengthen its position and build the profile of the organisation as the primary national representative and peak spokesperson for plwhas and PLWH/A groups.</p>	<ul style="list-style-type: none"> • over the next twelve months a media and communications strategy will be developed building on NAPWA's well established formal and informal networks • the strategy will begin with an audit of existing communication media that NAPWA will tap into • the strategy will continue to develop links with AFAO media and other PLWH/A and AIDS organisations media and communications networks
<p>2. NAPWA will continue to liase with and lobby the pharmaceutical industry and drug regulatory bodies.</p>	<ul style="list-style-type: none"> • the President of NAPWA and Treatments spokesperson along with the convenor of ATPA will develop a planned approach to ensuring input into the operation of drug regulatory authorities • NAPWA and ATPA will enhance mechanisms to work more closely with regulatory authorities, especially over drug access issues • NAPWA and ATPA will assist in the preparation of briefing papers and material for CTARC and PBAC
<p>3. NAPWA will advocate for, and, where appropriate, instigate and support research on relevant HIV/AIDS issues.</p>	<ul style="list-style-type: none"> • NAPWA will continue to liases with NCHCR and other national centres on key priorities of concern for the positive community • NAPWA will participate in reference groups e.g. Futures II to ensure that positive peoples perspectives are represented • consultation with research communities will continue through national conferences and other appropriate areas
<p>4. NAPWA will continue to negotiate with the Commonwealth Government for ongoing and where appropriate increased funding for the organisation. In its work with State based PLWH/A groups it will also offer support as necessary.</p>	<ul style="list-style-type: none"> • NAPWA will provide letters of support (as requested) for state based and local organisations • at a state based level, in a situation of crisis, as determined by the executive, when all other avenues have been explored, NAPWA will offer to act as a broker between disaffected parties • NAPWA will seek and provide information about alternative sources of funding that can be accessed by compiling a list of possible philanthropic organizations prepared to support the work of PLWH/A groups

Issues Coordination and Community Consultation

Goals	Strategies
<p>5. NAPWA will maintain close integration and alliance with ATPA and continue to be central to any national discussion of treatment issues.</p>	<ul style="list-style-type: none"> • the relationship between the ATPA steering committee and NAPWA will be described in a clear manner through an updated MOU and this relationship will be communicated to all representatives and constituents • NAPWA (through ATPA) will support the continuation of the treatment officer network and treatments working groups as a way of identifying projects, providing information and reflecting the lived experience of those dealing with treatment issues
<p>6. NAPWA will develop and distribute new national policies, guidelines and best practice documents on identified issues which impact on plwha as well as acting as a clearinghouse for already established state based and other policy, guidelines and best practice documents.</p>	<ul style="list-style-type: none"> • NAPWA will continue to work with AFAO and improve partnership around current policy matters, making sure that responses are timely and well developed and that any gaps identified continue to be pursued • NAPWA will consider the establishment of a national 'needs assessment' process around issues such as housing, poverty and mental health. That this assessment process feeds into policy positions which are written up and distributed within the HIV sector as well as taken to federal government • in the next twelve months NAPWA chooses one major policy area e.g. mental health, and attempts to distribute some information about best practices within this area
<p>7. NAPWA will facilitate at a national level exchange and distribution of information to and between state-based PLWH/A groups.</p>	<ul style="list-style-type: none"> • NAPWA will attempt to ensure that state based groups have the information technology to deal with the circulation of information; in particular, approach the AIDS Trust to expand the package that was made available through Microsoft • NAPWA will begin the posting of important issues on the NAPWA website and encourage debate around current issues by setting up email and e-discussion groups • NAPWA will provide quarterly briefing papers on issues that are relevant to plwha from a national perspective • NAPWA will continue to work on plwha conferences on a bi-annual basis

Organisational Capacity Building

Goals	Strategies
<p>8. NAPWA will advocate on behalf of plwhas and PLWH/A groups at a national level with AFAO and other government and non-government organisations supporting plwha to be empowered at a state level.</p>	<ul style="list-style-type: none"> • encourage and support the involvement of positive people in local and state authorities in the HIV sector eg. AIDS Councils • continue to work with AFAO on outcomes of the Federations strategic plan • encourage and support the direct involvement of positive people on other non-government organisations that are convened with issues affecting plwha e.g. ACOSS, CHF
<p>9. NAPWA will, where appropriate facilitate capacity and skills building for PLWH/A groups.</p>	<ul style="list-style-type: none"> • NAPWA will seek funding for and run a training, planning and capacity building workshop with the executive committee in the next six months • NAPWA will seek funding to review the workshop outline and material contained in the capacity building folder developed for NAPWA in 1998. This folder will be made available to state groups to prepare members and skill up positive people for participation in PLWH/A groups • NAPWA will consider the facilitation of partnerships and mentoring arrangements between those PLWH/A organisations that are strong, well organised and have a critical mass with those state that don't have a critical mass eg. Vic/Tas, QLD/NT, SA/WA and NSW/ACT

Monitoring and Evaluation

The objectives, goals and strategies have been stated as intended outcomes. This is quite useful in terms of monitoring and evaluation. The preceding pages form a grid of outcomes that NAPWA hopes to achieve. Another language for the outcomes intended is a *performance indicator*. As a very straightforward tool for monitoring and evaluation the above grid will be reviewed on a six monthly or yearly basis to view the performance of the organisation against its stated objectives, goals and strategies.

In line with the funding agreement between NAPWA and the Commonwealth, NAPWA's program of activities have agreed contract performance indicators. These support NAPWA's own objectives and will act as a record of documentation for these evaluation purposes.

GOVERNANCE ISSUES

The rules and guidelines of the Association were last reviewed in March 1997. The current arrangement of representative committee, office bearers, executive, portfolio and policy spokespersons has for the moment been assessed during the consultation process as a satisfactory way of continuing to control and manage the organisation. Under the heading of governance, there are three questions that have arisen. One has been resolved through the strategic planning process, the others remain outstanding and are identified as an area of work for the period covered by this plan.

1. Proposed merger with the AIDS Treatment Project of Australia.

Over the last six months, through the NAPWA executive, the ATPA steering committee and the Implementation Action Group the memorandum of understanding between NAPWA & ATPA has been updated. Separate governance entities will be retained during the period of the memorandum although governance representation, ATPA Steering Committee, NAPWA Executive roles and operational procedures have been clarified and are clearly spelt out in the memorandum. It has been agreed that this MOU and merger will be reviewed in twelve months.

2. Broadened membership.

The rules of the organisation set out categories of ordinary membership, honorary membership and associate membership. Through the recognition of incorporated and unincorporated state and territory based PLWH/A groups as ordinary members the organisation relies on a states & territories framework. What has been questioned is the mechanism for involvement of the emerging groups, who may not have yet made those state and territory based connections. This could include, particularly, groups from culturally and linguistically diverse backgrounds.

This is an area for further discussion and assessment within the period of this strategic plan by the executive and committee.

3. Executive & Committee Structure

The current NAPWA Executive structure includes the following portfolios:-

- President
- Vice-President
- Care & Support
- Education
- Indigenous
- International
- Legal
- State & Territories Liaison
- Treatments
- Women's

All portfolios carry representative responsibilities on behalf of NAPWA executive as well as a degree of activity not specifically described in the body of this document.

The NAPWA representative committee are elected by the State and Territories PLWH/A organisations. There are two positions from each organisation. These representative committee members elect the NAPWA Executive.

The consultation process has raised some questions regarding the efficacy of this structure. It is not seen as urgent but continued discussion is intended during the currency of this plan.

GLOSSARY OF TERMS AND ACRONYMS

NAPWA	National Association of People Living With HIV/AIDS Inc
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
plwha	Person/s living with HIV/AIDS
PLWH/A	People Living With HIV/AIDS organisation
ATPA	AIDS Treatment Project Australia
AFAO	Australian federation of AIDS Organisations
ANET	AFAO / NAPWA Education Team
ACOSS	Australian Council of Social Services
CHF	Consumer Health Forum
MOU	Memorandum Of Understanding
NCHECR	National Centre HIV Epidemiology and Clinical Research
NCHSR	National Centre in HIV Social Research
NCHVR	National Centre in HIV Virology
CTARC	Clinical Trials And Research Committee
PBAC	Pharmaceutical Benefits Advisory Committee
POA	Programme Of Activity

Advocacy

Is the function of representing and speaking in favour of another.
To urge by persuasive the support of others.

Lobbying

Is the activity of seeking to influence others and gaining their support. It refers to representing issues of concern to government, agencies and service providers.

Appendix 1.

Organisational structure diagram

Appendix 2.

Consultation Timeline

November 1999 – Strategic Planning Day

Present at this meeting were David Edler (Recorder), Paul Van Reyk (Facilitator), Levinia Cooks (Facilitator), Carl Greenwood, Mark Boyd, Michelle Humphries, David Menadue, John Daye, Greg Horn, Sean Godden, Marcus Bogie, David Davis, Paul McQueen, Andy Quan, Jo Watson, Geoff Honnor, Pene Manolas, Ken Irvine, Nadine Binstead, Robert Rodgers, Frank Farmer, Patrick Walsh, Robert Mitchell, Mark Mills, Katherine Leane, Sean McCausland, John McKenna, Graham Norton, Antony Nicholas, Amelia McLoughlin, Susan Paxton, Robert Baldwin, Douglas Barry, Peter Canavan, Shellee Korn, Alan Brotherton and Kane Race.

May 2000

John Rule employed to carry out the Strategic Planning Process.

Implementation Action Group convened (to oversee strategic planning process – members included Peter Canavan, John Daye, David Menadue, Trevor Cowan, Gary Meyerhoff, Frank Farmer, John McKenna, David Edler (offering policy advice from AFAO) Tony Creighton (advising on Indigenous issues), Amelia McLoughlin (advising on Womens issues) and later Jo Watson with Geoff Honnor (from ATPA) joined the group.

28TH & 30TH May

Discussions with AFAO, ATPA and AIDS Trust of Australia about the strategic directions.

1st & 2nd June

Consultations with groups in NSW including BGF, PLWH/A NSW Inc, ACON, the Positive Living Centre and Poz Hets.

28TH & 29TH June

Consultations were held in Victoria including PLWH/A Victoria, Positive Women and Straight Arrows. Input was received from Mike Kennedy(VAC), Vikki King(VAC), Stephanie Moore, Suzanne O'Callaghan(Info Centre), Michael Rogerson, Debra MacLean, Rebecca Matheson, Jeffery Grierson (ARCSHS) and Michael Bartos (ARCSHS).

12TH & 13TH July

Consultations held in Queensland included the regional branches of QPP. Individuals involved were Colin Griffiths, Trevor Cowan, Gabe McCarthy, Ray Anderson, Steven Gallagher (QuAC), Stephen Scott (QuAC), Warren Fitzgerald (QuAC) and Roy Starkey(QuAC).

18th & 19th July

Consultations in ACT. Present were Chris Purcell, Tony Blattman (AACACT), Andrew Seymour, Gloria Read-Bloomfield, Michael Beck, Brad Parks, Kevin Fugle (AACACT), and Daniel Coarse (AACACT).

31st July & 1st August

Teleconferences with SA (John McKenna), WA (Frank Farmer), TAS (Robert Mitchell), NT (Gary Meyerhoff).

August 23rd

Review of plan by NSW & National HIV/AIDS sector workers those present were John Rule, Phillip Medcalf, Geoff Honnor, Amelia McLoughlin, Vivienne Munro, Graham Norton, Dermot Ryan, David Edler, Ken Irvine, Kane Race, Robert Attwood, Michael Dwyer, Bridget Haire, John Cumming, Alex Taylor, Michael Hurley, Timothy Moore, Michael Woodhouse, Andrew Sajben, Douglas Barry, Robert Rodgers, John Robinson, Adrian Ogier, Phillip Keen, Tim Leach and Kirsty Machon.

Implementation Action Group members met via teleconference three (3) times over this period.