

napwa national association of
people living with HIV/AIDS

**Consultation Submission to the
National Women's Health Policy 2009**

The Australian Government made an election commitment in 2007 to develop a new National Women's Health Policy, in recognition of the fact that it has been 20 years since the last Australian women's health policy has been developed. The revitalised women's policy will recognise gender as a basic determinant of health, which gives rise to different health outcomes and different needs for women and men. In line with international developments and the Australian Government's social inclusion agenda, the policy will emphasise prevention, health inequalities and social determinants.

In early 2009, the Department of Health and Ageing invited community-based organisations to provide formal submissions into the policy process. NAPWA has worked in direct consultation with the NAPWA Positive Women's Network in the development of its own paper, submitted July 1, 2009 to the Commonwealth.

In addition to this the Australian Government has committed to undertake

further consultations with state and territory consumers, the community, health service providers, key women's groups and governments, to ensure the new National Women's Health Policy meets the varied needs of all Australian women. NAPWA looks forward to further work contributing to the development of the National Women Health Policy and congratulates the government on its engagement with this vital health policy reformation and the ensuing consultation process.

NAPWA would like to acknowledge the invaluable assistance that the Positive Women's Network provided in the development of the NAPWA submission.

Submitted July 1, 2009
NAPWA Positive Women's Network &
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The National Association of People Living with HIV/AIDS (NAPWA) is the peak Australian body representing people living with HIV (PLHIV) community based groups and organisations across the country. NAPWA's mission is to strengthen and maintain a responsive national leadership body that is credible, informed and guided by the interests of people living with HIV. NAPWA activities include policy development and analysis, national communication and issues coordination, and health and research based program development. NAPWA has utilised the Public Health Association of Australia's (PHAA) guidelines in the structuring of this submission. NAPWA's contribution to the National Women's Health Policy has been set in the order of the five suggested principles that underpin the Australian government's proposed policy.

Comment National Women's Health Policy

NAPWA supports the revitalisation of the Women's Health Policy, recognising the importance of evidence-based policy development in this area. NAPWA congratulates the government on its engagement with important health policy development for all Australian women.

Positive Women's Network

Integral to NAPWA's submission contribution has been the direct involvement of NAPWA's Positive Women's Network. The Positive Women's Network is a nationally-based advisory group, constituted to provide NAPWA with an ongoing forum to discuss issues of importance for HIV positive women, and to enable collaboration between those involved in the work of policy and advocacy for women living with HIV in Australia. Membership of this network is based on participation with positive women's networks, involvement with NAPWA processes as well as State and Territory Positive organisations. The women's network recognises that the experience of living with HIV is often very different for women than for men in Australia. The network also recognises the importance of creating an environment where the needs of positive women can be voiced at a national level.

Background

The HIV epidemic has had a unique impact on women, which has been exacerbated by their role within society and their biological vulnerability to HIV infection. Globally women and girls make up more than half of all people living with HIVⁱ, however in Australia women remain a relatively small group within the epidemic, with an estimated 1200ⁱⁱ women currently living with HIV in Australia. Although a small number, women are an important group within the positive

population, particularly as HIV is quite a different disease for women, with a host of distinct issues, both biological and sociological. Biologically women are twice more likely to become infected with HIV through unprotected heterosexual intercourse than menⁱⁱⁱ, and women living with HIV experience different clinical symptoms and complications. Sociologically, women living with HIV face distinct barriers to treatment and care as well as differences in quality of treatment and care compared to men.

Since the advent of combination antiretroviral therapy in Australia in 1996, HIV increasingly is perceived as a manageable chronic illness by medical professionals. HIV can also be characterized by episodic, unpredictable periods of wellness and illness. At times individuals may experience health-related consequences of HIV and its associated treatments as a disability, where HIV and significantly affect daily activities. For women living with HIV this can have a significant impact during their life course, through life changes such as menopause, it also has a particular importance regarding positive women in carer roles as either sole carers or in sole care.

In Australia is important to understand the diversity of women living with HIV in order to recognize the spectrum of social determinants that effect this population. Positive women come from diverse age ranges, socioeconomic backgrounds, urban, remote, regional settings, and family circumstances. Positive women and women affected by HIV include; women from Culturally and Diverse Backgrounds (CALD), Aboriginal and Torres Strait Islander women, sex workers, female injecting drug users (IDU), women in custodial settings, female migrants and asylum seekers, lesbians, bisexual and heterosexual women.

Gender Equity

HIV Stigma & positive women

HIV is socially marginal and stigmatised within the wider heterosexual culture where many positive women are placed. HIV in this context tends to be deeply coded by heteronormative ideas around gender and sexuality, and in the wider community HIV is thought of primarily as a *gay mens disease*^{iv}. This stereotyping of HIV marginalises both positive and negative women within the HIV response^v, as it dramatically affects community attitudes and shapes the provision of clinical services, health promotion activities and wider service delivery initiatives.

Many positive women experience discrimination due to assumptions made regarding assumed sexual practices and/or drug use. The dual issue of HIV stigma and racial inequality can be of extreme significance to women from Culturally and Linguistically Diverse Backgrounds (CALD) and for Aboriginal and Torres Strait Islander women.

HIV Stigma and discrimination was identified in the Australian National HIV/AIDS Strategy 2005-2008^{vi} as one of the five priority areas for action to be addressed over the life of the Strategy, however, to action these strategies support must be provided within sustainable and adequately resourced frameworks. Activities that address HIV stigma would promote understanding and acceptance through creative education, training and media programs explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV and women^{vii}. Activities should address issues of passive discrimination where HIV preventative education messages and technologies do not meet the current sexual and reproductive health needs of women.

Reproductive services for positive women and serodiscordant couples

Many women living with HIV in Australia are aged within their reproductive years, and although the advances in HIV-treatment have vastly improved the likelihood of a normal and sustained standard of life for many people living with HIV, sexual health policies, programs and services often fail to take into consideration the reproductive needs and wishes of women living with HIV. Recognising the reproductive health needs for people living with HIV is an essential step towards strengthening and expanding appropriate services. Clinical care and the involvement of specialists from a range of medical disciplines will greatly decrease the risk of HIV exposure for the couple and within the pregnancy. It is vitally important that health services and health professionals create open environments where the full range of sexual health, reproduction and parenting issues can be openly discussed; the denial of these services is tantamount to any other form of HIV discrimination.

In order to provide a more inclusive public health model, national reproductive and pregnancy protocols must be developed for positive mothers and serodiscordant couples. Health services need to provide programs, information and care so that positive people are enabled to make informed decisions about reproductive health, and research into the area of reproductive sexual health needs to be expanded in Australia.

Services for women in the HIV sector

Although the HIV epidemic in Australia has largely occurred in male populations, it is important to acknowledge that an increasing number of new HIV infections have occurred amongst women in Australia^{viii}. As health consumers HIV positive women use a high proportion of medical and clinical services, however, they remain largely an invisible group and vulnerable to deficits in the health system. HIV in Australia has predominately occurred through sexual contact between homosexual men, with the history of the local epidemic closely linked with the gay community. In Australia HIV services, health promotion and education strategies have for the most part targeted gay men. The paradigm where female-shared experiences join them as a group is quite divergent to the values and practices that constitute a gay community. Where gay men may adhere as a 'community' on a significant number of cultural and social fronts, women living with HIV tend to be a more disparate group and spread further across geographical divides. In order to address this social determinant and the consequences of a heavily distributed population, it is important that positive women's national and state-based advocacy and social networks are continually supported and enhanced.

It is important for those involved in the design and implementation of services to ensure that the needs and desires of positive women are not relegated to the periphery of the HIV sector. For example in November 2005, NAPWA supported their first National HIV Positive Women's meeting^{ix}, an event that was attended by over 50 HIV positive women from across Australia. Key areas of concern identified at that meeting were; HIV treatments and women, pregnancy and parenting, menopause, aging, care and support, inclusion and HIV related stigma and discrimination^x. Although some areas are mutual shared by men, positive women have significantly different experiences, issues and concerns. A specific example within health promotion and harm reduction programs is the need to develop and provided specific programs that address HIV and HCV co-infection^{xi} that target women, as women experience significantly higher numbers than men of HIV and HCV co-infection within those disease epidemics.

Health equity between women

Positive women and carers

As the primary carers in families, women often bear the burden of holding the family unit together, of caring for the sick, and of coping with the emotional and physical demands of

providing 'care'^{xii}. The psychological burdens and responsibilities carried by women in these circumstances are great and will be exacerbated where the women herself is infected with HIV. Although positive women may be fulfilling an invaluable carers role in our community, they often experience HIV discrimination from the wider community regarding their roles as appropriate carers and nurturers. The implications of this stigmatisation usually arises in mainstream health care settings. When positive women access specialised HIV services that are meant to cater to the needs of the needs of the HIV community, they find these services male dominated and rarely geared towards the needs of women. For instance, health services must ensure that they are adequately equipped to assist positive women with paediatric care and information during pregnancy, as positive women face particular challenges in order prevent transmission of HIV to their children through pregnancy.

The impact of the HIV epidemic on women is not necessarily confined to their own HIV status. The need to support HIV affected women carers, who are not positive but are carers of a positive family member, loved one, or child is also vital as they too face similar issues of social isolation, misunderstanding and HIV stigma.

Like many female carers in Australia, positive women and women affected by HIV who are in carers roles will 'pay the price' and carry the burden of being a carer. Many positive women are already significantly financially disadvantaged, in addition to this carers generally experience high levels of stress, low sense of wellbeing, limited opportunity for respite and poor health^{xiii}. A key contributor to this is the high level of financial stress they face as an informal carers, this can have a significant impact on an individual's ability to work^{xiv}. Many carers leave paid employment either permanently or on a part-time basis to become carers. Spending all or a significant proportion of one's working years out of the workforce also means that there is limited opportunity to invest towards retirement through superannuation. With high household expenditure levels relative to income, and the expensive nature of HIV treatment, there is little opportunity for household savings. The impact of the lived experience of carers and their cost burden is not well researched in the context of HIV.

Female carers are disproportionately affected by the HIV epidemic and further research into the area is required. In order to make appropriate changes the HIV sector needs to better comprehend the complexity of positive women's lives and the challenges women face caring for

themselves and for others. Service evaluations and research that recognises this unpaid contribution is necessary to improve services and ensure appropriate pensions are provided to positive women and cares.

A Focus on prevention

HIV preventative sexual health

To fully engage with the concept of shared responsibility¹ and reverse HIV across the many diverse groups of women effected by HIV (CALD, Aboriginal and Torres Strait Islander women, sex workers, women who inject drugs, women in custodial settings, women migrants and asylum seekers, lesbians, bisexual and heterosexual women) Australian women need accurate, age appropriate information that empowers all women to take control over their sexual and reproductive health^{xv}. All women, particularly sexually active young women², should be knowledgeable of and have access to the full range of sexual health protection equipment; this would include affordable and ready access to the female condom. NAPWA's national positive women's network has actively promoted the need for Australian sexual health promotion programs to adopt the distribution and promotion of the female condom at a national-level^{xvi}.

HIV testing of older women

HIV testing rates amongst ageing Australians (55 or over) are low – particularly for older people in regional settings, older heterosexual populations and older women. Older adults are frequently tested for HIV late in their disease course. As a consequence, they are more likely to present with opportunistic infections. An individual who receive a late diagnosis can often experience serious health complications and there is a greater risk of death due to illness. In an Australian setting it is unconscionable that standardised Blood Borne Virus (BBV) testing protocols are not rigorously adhered to; medical staff particularly those in regional settings

¹ 'Shared responsibility' is a dynamic concept that involves; society's role in assisting people living with an illness, including people with HIV, the role of individuals to help protect themselves and others, government's role in HIV research, as well as treatment and care for people living with HIV, and the government's role in education and prevention.

² 2009 Department of Health and Ageing research found that 16 to 29 year old Australians are not well informed about the benefits of condom use
[http://www.health.gov.au/internet/ministers/publishing.nsf/Content/4A854E5E51A0A3CDCA2575C5000F488B/\\$File/nr074.pdf](http://www.health.gov.au/internet/ministers/publishing.nsf/Content/4A854E5E51A0A3CDCA2575C5000F488B/$File/nr074.pdf).

should be prioritised by the government as medical staff that require professional development in this area. HIV community-based health promotion activities should also adequately support a culture of HIV testing not only within the gay community but also extend that to the wider community, through innovations as the voluntary 'National HIV testing day' supported in Victoria. Testing for HIV regardless of age, gender and cultural background has also been supported within South Australia's HIV action plan^{xvii}.

Regressive criminalisation of HIV

There is growing international concern regarding the criminal prosecution of people with HIV for offences involving HIV exposure or transmission through sexual contact. Such prosecutions are increasing in many countries including Australia^{xviii}. Key community organisations such as NAPWA, Scarlet Alliance and the Australian Federation of AIDS Organisations (AFAO), have provided documentation to the Australian government regarding the negative impact this regressive legal framework will have on the public health response to HIV^{xix}. Criminalisation of individuals does not recognise the important role of shared responsibility, and increasingly it is the negative media coverage of cases that is enforcing HIV stigma and discrimination. There is little national coordination or consistency between Australia States and Territories in regards to these criminalisation cases, and there are few mechanisms available to influence policy at a federal level^{xx}. Instead of a punitive model, the Australia HIV response has for the most part been based on a human rights approach. Many of HIV public health successes in Australia can be directly attributed to the Commonwealth's overarching support of human rights in the context of HIV. Australian policy development should continue to focus on supporting people to protect themselves from infection (including programs that support the distribution of the female condom), empower individuals living with HIV to avoid infecting others, encourage individuals to know their health status and disclose it (by revise national HIV testing protocols), and encourage practices that protect the individual from HIV transmission without coercion (this would include the development of reproductive services for positive women and serodiscordant couples).

A strong and emerging evidence base

Documenting the experience of HIV positive women

It is important to guard against the oversimplification of gender dimensions of the HIV epidemic. To avoid this there needs to be more systematic approach to understanding and responding to

the specific HIV related service needs of positive women. There is a need to analyse data groups, and ensure that tools are modified to better capture the lived experience of positive women^{xxi}. Women can often be subsumed into broader clinical and social studies where their experiences are compared with those of men rather than understood in their own sexual or cultural context. Issues of primary concern include; the relationship of the positive women to HIV services, issues of late HIV diagnosis and presentation, issues surrounding disclosure, social isolation and social connections, sexual practices, drug use, stigma and discrimination, as well as to observe issues relating to CALD and Aboriginal and Torres Strait Islander women.

Conclusion

Although some areas are mutual shared by men, positive women have significantly different experiences, issues and concerns. For a woman living with HIV her physical health and life course is significantly impacted on as HIV and its treatment exacerbates the effects of ageing, menopause, pregnancy, childrearing and magnifies other underlying health issues. There are a number of key activities that once implemented would begin to better address and reduce the burden of the HIV epidemic amongst women. These include; promoting and protecting women's rights, increasing HIV education and awareness among younger and older women and encouraging the development of new preventative technologies. Sustainable resourcing and funding should be at the cornerstone of national policy direction and development.

Key Recommendations;

1. **Address HIV Stigma and Discrimination** - Support activities, through appropriate resourcing, that address HIV stigma and discrimination and the effect that HIV stigma and discrimination has on the lived experience of HIV positive women and women affected by HIV. Examples specifically relating to women are threaded through this document.
2. **Positive women and their intrinsic involvement in HIV prevention and HIV education programs** - Positive women should be fundamentally involved and enabled to contribute their real-life knowledge to HIV education and HIV prevention programs. This reciprocal engagement with positive women should be at the cornerstone of Australian HIV education and HIV prevention programs.
3. **Address the invisibility of positive women and subpopulations** - Ensure HIV public health messages are delivered to the diverse community of positive and effected women. This activity would ensure that HIV sector organisations are dedicated to promoting equal participation of women in governance and decision-making.
4. **Support the development of a national policy response** - The lived experiences of positive women are diverse and wide, making it vitally important that national Australian policies that effect this population are interlinked; National Women Health

Strategy, National HIV/AIDS Strategy, National Disability Strategy, National Hepatitis C Strategy, National Drug Strategy, National Breastfeeding Strategy National Mental Health Strategy and other relevant policies.

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