

HIV “Prevention” in the United States: *Implications for the Australian Response*

Discussion Paper

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In 2005, current HIV prevention efforts in the United States are dramatically different to how we might have remembered community-based responses to HIV in the mid-eighties. While prevention efforts have significantly changed throughout the world as the epidemic has shifted and various communities have taken up their roles in responding to this challenge, generally the basic tenets of community empowerment and self determination have remained as an important underlying principle in the way we carry out our work. However in the United States these principles, which often lead to wider community engagement, are being increasingly eroded. This has come about due to the conflation of a variety of issues: increasingly over-prescriptive interventions that do not value ongoing community input and local responses to the epidemic; an ever-growing conservative social policy that stems from a Federal Government level and permeates throughout a range of funding structures – both public and private; and overly bureaucratic reporting mechanisms that are not sensitive to the human experience. As a result this has led to a paralysis around agenda setting at a community level, whereby community experience and expertise is not the driving force behind the response to HIV education and health promotion. Instead many community responses now seem to act as an arm of government for the sole purpose of service implementation.

In the early years of the epidemic community-based responses to HIV that were emerging within the United States were among the first. Organisations such as Gay Men’s Health Crisis (GMHC) played a significant role in nurturing such a response. In lieu of an effective government uptake of the issues associated with the emerging US epidemic, GMHC began to develop a range of responses and services that included a multi-faceted HIV prevention and education program. In short this program delivered some of the first community-inspired messaging and social marketing campaigns targeting gay men.

However, over the years, political pressure has deeply affected the community response to HIV. Social conservatism has grown and as a result an important component of the prevention equation has fallen silent. Due to changes in funding sources, community-wide, discourse-generating opportunities have been removed from HIV prevention efforts targeting gay men and other men who have sex with men (MSM). Funding opportunities from philanthropic institutions are increasingly difficult to lure, hence forcing health promotion work into the hands of rigidly administered and highly-scrutinised public funding. Such restrictive funding sources mean the bulk of work developed to address HIV “prevention” and broader health promotion for gay men/MSM in the US is centred on individual counselling, group-level workshops, condom distribution and (a new addition to this work) HIV rapid testing. This current model of work means that the central tenets by which communities once organised themselves and implemented their work are severely compromised.

By focussing solely on individual and group work, a response that encourages community development and community articulation of its own needs is significantly hampered. Community dialogue is restricted at all possible levels of partnerships, be they intra-community, research, government or commercial enterprise. This response places the sole onus of behaviour change on the individual. It does not support a framework whereby *community* is rightfully acknowledged, let alone valued in the “prevention” equation.



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This therapy-based service model suggests that people who engage in risk behaviours will want to participate in behaviour change interventions and will then go on to make sound behavioural choices resulting from this participation. It assumes that individuals need to be “clientized” so they can be “fixed”. And by offering few options for people to engage with health promotion in their day-to-day lives, it suggests that individuals are not capable of making sound judgments outside of this prescriptive model of work. The model on offer has little scope for community-based organisations to develop a broader approach to HIV education and health promotion whereby community-level interventions are developed to complement the array individual and group-level work. Activities such as social marketing, community advocacy and activism, as well as mobilisation efforts that might be occasionally developed often draw the wrath of government funding bodies. As a result many CBOs shy away from these activities. Therefore the ability to reach individuals who do not seek a service is almost non-existent. In other words, the overarching HIV “prevention” effort in the US has evolved into one-on-one and small group approaches that aim to tackle the 40,000 new HIV infections each year.

The question must be asked: Is the devaluing of community participation in the delivery of education and health promotion efforts the result of poor community strategising or “successful” conservative policy-making?

To understand the landscape of community-based responses in the US it needs to be noted that the vast majority of community-based organisations (CBOs) act as independent agencies with little or sometimes no affiliation to a wider network of coalition partners. Often when wider networks do exist they are not well resourced due to the lack of funding available for these types of activities or the need for organisations to direct limited resources to care and support service provision since it is not adequately taken up by government services. An example of this conundrum is the fact that 40 million Americans do not have health insurance. People from this group who want to be tested for sexually transmitted infections (STIs) would be likely to go to a local CBO that offers STI testing for free or on a sliding scale (based on income). This example provides one scenario whereby resources of CBOs are unduly stretched due to problematic policy-making that results in significant gaps in service provision.

Due to limited funding to conduct community-based service provision agencies are often heated competition with each other struggling to win service contracts. Hence wider strategic networking and a strong unified voice of community stakeholders is politically weakened leading to a compromised response in community agenda setting.

In 2003 the Centers for Disease Control and Prevention (CDC) announced that it was going to refine its focus of funding for HIV prevention efforts around the US. This change was to include a sole focus on prevention for positives along with an expansion of rapid HIV testing programs. The crude interpretation of the theory underpinning the proposed changes was that once an individual was identified as being HIV positive via increased rapid testing then extra “prevention” resources and services would be targeted at them, via prevention for positives. These services, focussing on behaviour change outcomes, would then lead to a reduction in HIV incidence due to the growing number of positive people being “fixed”.

The April 18 2003 edition of the CDC’s *Morbidity and Mortality Weekly Report* announced the new proposal in this way:

The new initiative, Advancing HIV Prevention:

New Strategies for a Changing Epidemic, is aimed at reducing barriers to early diagnosis of HIV infection and increasing access to quality medical care, treatment, and ongoing prevention services. The HIV initiative emphasizes the use of proven public health approaches to reducing the incidence and spread of disease. As with

other sexually transmitted diseases (STDs) or any other public health problem, principles commonly applied to prevent disease and its spread will be used, including appropriate routine screening, identification of new cases, partner notification, and increased availability of sustained treatment and prevention services for those infected. Stable HIV-associated morbidity and mortality, concerns about possible increases in HIV incidence, and the recent availability of a simple, rapid HIV test combined with strong prevention collaborations among communities heavily affected by HIV support the need to reassess and refocus some of CDC’s HIV-prevention activities. An emphasis on greater access to testing and on providing prevention and care services for persons infected with HIV can reduce new infections and lead to reductions in HIV-associated morbidity and mortality. In addition, simplifying prenatal and other testing procedures can lead to more effective use of resources that CDC provides to prevent perinatal and other HIV transmission.

Later that year at the CDC-sponsored national HIV prevention conference in Atlanta alliances were made between CBOs, researchers and various state and local government bodies. The CDC proposal was vehemently challenged. The main arguments in opposition to the proposal centred around the total exclusion of education efforts for HIV negative people and the shift in funding for education initiatives to HIV testing (rather than a separate allocation of funding for testing). Also, community groups strongly opposed the public health assumption that newly tested positives could be netted and tracked for the purpose of delivering service and follow-up evaluation to measure the medium-term sustainability of the newly offered behaviour change interventions.

Several months later the CDC offered a nation-wide call for expressions of interest for organisations to bid for several million dollars worth of grants under the HIV “prevention” umbrella. To bid for money from this bucket, organisations were invited to write proposals that outlined how they would implement their HIV programs, highlighting prevention for positives, rapid testing and prevention for “high-risk” negatives (a late addition after the CDC received such a negative response to their plan earlier in the year).

In terms of methodology the prevention program had to be one that had been previously developed and implemented in the United States and had been proven to be an effective behaviour change intervention after an extensive CDC evaluation. As a result would-be proposal writers had a narrow menu of options to choose from. The proposals needed to be less about an agency’s understanding of the local issues, the local population, the local research and the local epidemic, but instead more about how much the local agency could deliver of the Atlanta-based CDC approved programs. Ultimately, the reviewers would be looking for how many individuals from the target population an agency could recruit, how many they could maintain in intervention participation, and how many participants they could follow-up for evaluation purposes.

Would-be HIV prevention programs could only work with methodologies that were in keeping with the evolutionary shift that had been occurring in US prevention for years: that is, one-on-one counselling, group-level interventions or workshops, and condom distribution or outreach, along with the addition of having HIV negative “high-risk” individuals “rapid tested”. While community mobilisation featured on the menu of prevention options it was limited to the delivery of condoms by community members to bars, clubs and sex venues, rather than the premise of community mobilisation understood by its definition of political organising, activism and advocacy (i.e., community mobilisation and empowerment).

HIV education that was built on foundations of high-profile community engagement and discourse development, such as social marketing and community mobilisation, are no longer included in the CDC’s *Compendium of HIV Prevention Interventions with Evidence of Effectiveness*. Over the past four years of the Bush Administration these types of programs have been slowly deleted from the compendium in favour of “prevention” efforts that have less of a profile. Sadly, as a result, this “*off the radar*” menu of activities is removed from contemporary community responses to the epidemic

leading to low engagement by members of the target population. In New York City, probably the most critical issue that faced the one-year implementation anniversary of the new CDC interventions was the low target audience participation (“bums-on-seats”) to highly structured one-on-one and group-level work funded by the new initiative. Organisations that received funding for this work were faced with the challenge, after twelve months of HIV “prevention” service provision, of not being able to attract participants for case management programs and workshop activities.

Each intervention type had been scientifically proven by the CDC to reduce HIV transmission based on individual behaviour change. With no opportunity to allow the development of programs that were outside of this prescriptive menu, and extremely restrictive opportunity to modify what’s on offer, the primary funder of HIV education in the United States has determined the approach to HIV “prevention”: individualism. It is the individual – and *only* the individual – who has the key to lowering transmission rates of HIV. And by implication, due to the HIV+ focus of the CDC funding program, it is people living with HIV who carry the responsibility for halting the epidemic.

This premise is complemented by the wider conservative agenda. By only funding individual and group level work the CDC does not have to be concerned by right-wing lobbying to censor high-profile explicit material that is developed to be gay-positive, sex-positive and non-stigmatising to people living with HIV. In other words, material that is developed for the purpose of building self-esteem and building community dialogue around particular issues rather than developing interventions that demonise individuals and behaviours.

Many would argue that *proven* effective interventions that have been rigorously evaluated by the CDC and originally developed by community seem like a logical addition to the CDC’s compendium and therefore funding opportunities. However the reality is many community developed interventions within the compendium are heavily modified by the CDC. In some instances evaluation processes do not commence until the intervention is *sanitised* to meet the acceptability of the CDC-based bureaucrats. Community developed interventions that are frank in relation to sex, sexuality and gayness, as well as drug taking behaviours, are sometimes censored by evaluators before any formal evaluation process commences. Hence this ensures that the final product is less of a community-based resource – grounded in local knowledge and expertise – but more a *palatable* CDC resource.

Why doesn’t change happen?

There are rare instances where CBOs develop, implement and evaluate resources without utilizing public funding. However this is almost an impossibility given the shrinking number of private funding opportunities that arise across the country to do contemporary HIV education. And even when these occasions do occur; some private funders are reluctant to fund resources that are frank and explicit, often concerned about repercussions from an increasingly conservative government.

Advocacy that is often used regarding the need to develop culturally relevant material targeting race and ethnicity does not seem to be aligned in the development of culturally-specific material targeting men who have sex with men. It seems the cultural experience of gay men’s lives around sex and sexuality – particularly when dealing with an epidemic that is primarily transmitted between gay men due to unprotected anal *sex* – is of little importance in the development of material for this population.

It should be noted however, that while many CBOs across the country implement the CDC funded program as prescribed there is a refreshing voice of constructive critique that challenges the prevailing culture. Throughout the community sector response to HIV there are individuals and agencies who articulate a counter-vision to that imposed by the CDC. Unfortunately, given the CDC funding stream is by far the largest pot of money available to HIV education these counter-opinions are often silenced from within their own ranks due to the political advantages to the “leadership” of organisations in winning CDC contracts over creating engaging, community-driven responses to the epidemic and providing a sustainable strategic vision that that would assist in securing suitable funding to pay for it.

What implications does this hold for our local response to the epidemic?

- In an increasingly conservative local environment it is necessary to remind ourselves of our original commitment to the communities we serve. At times this might mean reminding our funders of our mission and need to engage our target population over our need to please a non-target population.
- To-date, Australia’s sex positive approach to HIV education has resulted in a reasonably sustained engagement by the target populations in which we serve. It is vital that this approach be maintained and that our opportunity to engage is not eroded by moralising.
- Australia’s original partnership approach to the epidemic was regarded as the cornerstone of our response. Policy changes in recent years have seen an erosion of this partnership whereby community has less of a voice in the decision-making that impact on our constituents. It is critical that Australia’s partnership approach is maintain and reinvigorated so that the deep disconnect in the US between community and government planning does not occur here.
- That the responsibility of HIV transmission and acquisition is a shared responsibility to all individuals who engage in risk behaviours. By focussing only on a population of people living with HIV any burden of responsibility is removed from an HIV negative person providing a false sense of security and an undue weight of accountability to PLWHA.
- To maintain our commitment to the GIPA principles (Greater Involvement of People Living with HIV/AIDS). This principle ensures that community involvement is integral in planning and prioritising and that PLWHA are a critical aspect of this participation.
- Individual and group responses – particularly those based on identity around race and/or sero status – only further marginalise some populations if they are offered in isolation, without an opportunity to engage a wider audience in the pertinent issues facing these populations. For example, ongoing groups of HIV+ gay men do not necessarily act as vehicles to inform at a community-level the issues of sexual negotiation between men of sero-discordance.
- While sero-sorting strategies might be negotiated by two HIV+ men for the purpose of reducing HIV transmission to other people, policies that force sero-sorting individual-responsibility onto HIV+ men should be resisted. That is, sexual partners must determine their own set of “rules” without policy makers levelling the burden of responsibility on HIV+ men and therefore forcing sero-sorting upon them.
- People living with HIV and gay men should maintain their historical efforts to create a response to HIV that is based on self-determination. Australia’s epidemic has been managed very successfully to date, due to a well resourced community response aligned with a partnership model. Top down policy changes, such as that seen in the US, have not assisted community in doing its work.
- Community responses such as social marketing should be maintained to ensure that vehicles are constantly developed that engage as broader cross-section of the community as possible; hence driving debate and discourse.
- Principles such as the Ottawa Charter are maintained and revisited and remain a central aspect of planning and implementation of our work.
- Resist moralising agendas that ultimately serve to alienate and stigmatise those most at risk.
- Do not assume that the only way to offer HIV education and health promotion is via therapy-based approaches that often do not engage with the majority of members of the target population. Employ strategies that are broad-based and engaging; that generate community engagement and debate, that is, resist being silenced.

