

PRIMARY PREVENTION REVISITED: A CHALLENGE TO AIDS INC.

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Background

The uneven distribution of HIV in the population is a well-substantiated, if not publicly acknowledged fact. Gay men and other men who have sex with men, sex workers, people who inject drugs, and transgender women are 24, 13.5, 24, and 49 times more likely to acquire HIV, respectively, than adults in the general population (15 years old and older). Globally, new infections among these “key populations” accounted for 36% of all new HIV infections in 2015. This figure is likely to be an underestimate, given the intense stigma associated with disclosing and reporting acquisition risk for HIV among gay men, sex workers, people who use drugs, and transgender people.

“Key populations” are rendered “vulnerable” to HIV by bad laws and politically driven policies, creating stressors that exacerbate risk for acquisition, making the problem of HIV worse. Moreover, the absence of protective laws and policies and the promotion of rights enable unchecked stigma and discrimination in healthcare and social service settings to persist. Complicating matters is the reality of an increasingly bio-medicalized global HIV response driven by the introduction of powerful and life-saving anti-retroviral medications. This is a welcome development. However, access to medical interventions is hampered by the costs of medicines and the politics of funding. In addition, gay and bisexual men, sex workers, people who use drugs, and transgender people are not prioritized for anti-retroviral treatment or offered only limited number of places in treatment programs because these groups are not seen as deserving. Moralistic decision-making (e.g., the requirement of absolute abstinence from drug use) about who should have access to treatment is common. Lack of funding to support community-led and peer driven interventions that can support access contributes to uncertainty about sustainability

External funding to address HIV in low and middle-income countries is being redirected and is shrinking. There is now a global scramble to do more with less, over a sustained period. The HIV sector is now revisiting the viability and necessity of prevention but current global-level discussion center around the use of anti-retroviral medications. And while there are important examples of successful HIV incidence reduction programs driven by bio-medical interventions, the success for those programs are or will largely be situated in the global north among general populations. The introduction of targeted pre-exposure prophylaxis (PrEP) is also beginning to gain momentum, at least with men who have sex with men, with dramatic results. However, there are concerns about the acceptability, accessibility, and affordability of PrEP. In addition, there are questions about the sustainability of comprehensive PrEP programs beyond demonstration initiatives in the global south.

While access to anti-retroviral medication used prophylactically or as treatment is urgently needed human right, primary prevention should be conceptualized more broadly than expanded coverage of anti-retroviral medications. When viewed more authentically, determinants to HIV incidence reduction will more likely be multi-factorial, involving various prevention strategies that are thoughtfully combined, tailored and delivered by or in meaningful partnership with communities most impacted by HIV. Recent reports of dramatic reductions in new HIV infections among men who have sex with men in New South Wales, corroborates these points. Taken together, the social shape of the HIV epidemic requires a return to a classic primary prevention strategy that is proactive, addresses ‘upstream’ factors, re-centers communities most impacted by HIV, and properly resources combination approaches chosen and led by communities for which prevention efforts are intended.

Primary Prevention: Revisiting Definitions

Primary prevention, in the sense that the term was originally intended, should be thought of as *a network of strategically and necessarily combined strategies*. Primary prevention strategies in the HIV sector are (or should be) qualitatively different than dominant, stand-alone, bio-medicalized public health practices and actions enacted to anticipate and avert new infections and to contain the epidemic. Given current trends in the HIV field, it is important to lay bare what primary prevention is, and what it is not. The following definition for primary prevention is adapted from other works, include from a U.S. Report on mental health, commissioned in 1977:

Primary prevention is proactive in that it seeks to build adaptive strengths, coping resources, and health in people – a focus on containment of disease or assumptions about deficit misses the point;

Primary prevention is concerned about total populations, and not about the provision of services on a case-by-case basis;

Primary prevention's main tools are education and social/structural-level change, not therapy or medicines, although some insights for its approaches grow out of the insights gathered from clinical experience;

Primary prevention assumes that ensuring that people have the resources they need for thriving is the best of all ways to ward off problems before they happen.

Commissioned exactly 40 years ago, the report went on to assert the view that stressful social conditions have a major influence on health by disrupting and damaging social relations in general. It acknowledged the devastating effects of alienation, depression, and anger associated with upstream factors like poverty, institutionalized oppression, and discrimination.

Primary prevention encompasses activities that are directed towards populations at high risk designed to avert new HIV infection and promote sexual health. Several primary prevention strategies have evolved across different health sectors. Here, we stress four major dimensions that are often overshadowed or diminished by contemporary, overly bio-medicalized HIV approaches:

1. Peer-delivered, voluntary education with the purpose to factually inform, so that individuals are best equipped to make the best decisions for themselves;
2. Community organization/mobilization and systems change, to address resource inequities or disenfranchisement caused by harmful institutional and legal practices;
3. Opportunities for social support and belonging, because genuine, empathic, trusting, caring, and safe relationships have the power to build and sustain resiliency;
4. Competency promotion, which starts by building on the strengths of individuals and their communities rather than fixating on or inventing deficit and disease. Being strength-based is important because in addition to the power of belonging, people require frequent opportunities to make meaningful contributions to their general welfare and that of their communities.

In 1985, psychologist George W. Albee developed a formula for incidence of mental health problems in society. Dr. Albee described incidence as the combination of organic factors and stressors that are moderated by coping skills, self-esteem and social support. His conceptualization of incidence is salient

to contemporary challenges to the primary prevention of HIV. We have adapted Dr. Albee's formula to underscore the complexity of HIV incidence:

$$\text{HIV INCIDENCE} = \frac{\text{BIOLOGIC VULNERABILITY} + \text{SOCIAL/STRUCTURAL DISENFRANCHISEMENT}}{\text{RESOURCES (INDIVIDUAL, FINANCIAL \& COMMUNITY)} + \text{SOCIAL SUPPORT}}$$

It's clear to see in this equation that the bigger the numerator and smaller the denominator, the greater the incidence of HIV. Conversely, a smaller numerator and bigger denominator will result with a reduction in HIV incidence. Albee's incidence formula is helpful in highlighting the multiple entry points necessary for the primary prevention of HIV acquisition.

In the HIV sector, we have heard for years the maxim, "*we cannot treat our way to the end of AIDS.*" This is because individual treatment has no effect on population-level incidence, especially given that treatment is not equitably accessible, with stigma, discrimination, criminalization, and violence standing in the way. Only primary prevention can reduce the number of new HIV infections. Yet, the sector has experienced great difficulty moving beyond the next new trend, sloganeering sound bites, or the 140-character limit of bombastic tweets. Indeed, Western cultures and Global Northerners have a propensity for the magic bullet and quick fixes. HIV is as much a complex social problem as it is a complicated bio-medical challenge. There are no simple or quick fixes. However, there is good news: the strategies needed are staring us in the face and ready to be actuated.

Primary Prevention: A Network of Strategies

Since 2007, UNAIDS has recommended combination approaches to HIV prevention for gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, while addressing more broadly their human rights. In fact, for governments planning and developing HIV prevention programs, the UNAIDS recommendations for a minimum standard package of prevention services for governments planning and developing HIV prevention programs begin by asserting the importance of human rights and the removal of legal barriers that undermine access to HIV-related services such as laws that criminalize non-heterosexual behavior, gender non-conformity and non-cisgender identity, sex work, and drug use. UNAIDS guidance for HIV prevention goes on to recommend empowerment of key population communities to participate equally in social and political life (including non-tokenistic representation in national HIV planning and implementation processes); availability of safe physical and/or virtual spaces for members of marginalized communities to seek information and referrals for care and support; and access to medical and legal assistance for gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people that experience sexual coercion and/or violence.

The World Health Organization, in its 2015 Consolidated Guidelines for Key Populations recommends 'critical enablers' that include revising harmful laws and policies; implementing and enforcing anti-discrimination laws and decriminalizing same-sex behaviors. These strategies are in addition to PEP, PrEP, needle and syringe programs, opiate substitution therapy, mental health services, risk minimalization counseling, STI, HIV, hepatitis, HPV testing and treatment as well as promotion of condoms and water-based lubricants at scale. These strategies were reaffirmed in 2009, 2011, 2014, and 2016.

The universal adoption of UN and WHO-endorsed prevention strategies remains a serious challenge. For example, the 2011 Political Declaration included a target to halve HIV transmission amongst people who inject drugs by 2015, but this was missed by a staggering 80%. Despite the absolute centrality of needle and syringe programs and opiate substitution therapy as primary prevention strategies for people who use drugs, these services are too few and too vulnerable and coverage remains substantially below the minimum levels needed to sufficiently address HIV amongst people who inject drugs. Globally, only 10% of people who need harm reduction have access. Evidence shows that countries that implemented needle and syringe programs have averted HIV epidemics amongst injecting drug users, but due to moralizing attitudes and political expediency, cutbacks and closures of harm reduction services are occurring at a time when scale up is critically needed.

TABLE 1. Network of HIV Strategies Recommended by WHO and UNAIDS

Primary Prevention	HIV-negative, low risk	<ul style="list-style-type: none"> ✓ Community mobilization, organizing ✓ Comprehensive sex education ✓ Social marketing, social media, ICT ✓ Prevention counseling, condom & lubricants ✓ PrEP, PEP ✓ Risk minimalization counseling ✓ Peer support/safe spaces ✓ HIV, STI, hepatitis, HPV screening ✓ Needle exchange, opiate substitution ✓ Harm reduction programs ✓ STI and HIV treatment 	Delivered WITH & LED BY Community: Advocates Outreach staff Educators Counselors Testing staff
	HIV negative, high risk		
Secondary Prevention	HIV-positive, newly diagnosed	<ul style="list-style-type: none"> ✓ Anti-retroviral treatment ✓ Adherence counseling ✓ Viral load testing and other diagnostics ✓ Peer support 	Advocates Outreach staff Educators Counselors Testing staff Nurses Doctors
	HIV-positive, virally suppressed		
Care and Treatment	HIV-positive, unmanaged viral load	<ul style="list-style-type: none"> ✓ Anti-retroviral treatment ✓ Adherence counseling ✓ Viral load testing and other diagnostics ✓ Peer support ✓ Case management services 	Advocates Outreach staff Educators Counselors Testing staff Social workers Nurses Doctors
	HIV-positive, opportunistic infections		

EXPAND & down-stream role of COMMUNITY by redistributing resources & task-shifting

New data about the efficacy of test and treat approaches with men who have sex with men in Asia reinforces doubt about the appropriateness of one-size-fits-all, stand-alone bio-medicalized approaches to reducing HIV incidence among key populations. With an estimated 1.9 million new HIV infections a year (REF 2016 UNAIDS GAP Report), a lop-sided proportion of which are among key populations, a network of community-led primary prevention strategies, differentially and strategically deployed, is urgently needed.

Centering Community to Amplify Effects

As the world witnesses the proliferation of important and well-researched HIV prevention guidance from global institutions and researchers, it is vital that HIV advocates become deeply engaged in creating a common voice to ensure that guidance be enacted at the community level. Gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, including people living with HIV, should be leading research, program, and policy efforts to address HIV in their communities. Moreover, community advocates should not become subordinate to repressive government policies or political agendas that result in a deviation from evidence-informed and rights-based guidance. Nor should researchers, public health officials, or policy makers succumb to draconian, overly medicalized, punitive, or individualistic disease control paradigms since such paradigms typically lead to diminished or substandard programs and services. Research has shown no public health advantage to adopting more prescriptive STI or HIV program and policy approaches (i.e., mandatory HIV or STI testing, prevention messages that are negatively framed as imperatives).

Public health strategies have their biggest impact when: a) they are collaboratively designed and implemented by members of the community for which they are intended; and b) individuals and communities are self-motivated and given the freedom and resources to participate in health promoting behaviors they have worked to develop. HIV and other sexual health services done *with* or *led* by community members for which the services are intended are more likely to result in earlier, comprehensive, and more frequent service engagement, and improved retention, yielding better health outcomes. (REF) In addition, men who have sex with men, sex workers, people who use drugs, and transgender people are best equipped to help members of their own communities because they: 1) share experiences of stigma, discrimination, and/or violence; 2) have knowledge about and access to supportive networks of other men who have sex with men, sex workers, people who use drugs, and transgender people, who can sensitively inform outreach and service implementation; 3) are more likely to be comfortable discussing sensitive matters concerning the experiences of being part of socially marginalized (and in many instances, criminalized) groups; and therefore 4) can more easily establish trust with service recipients and gain their confidence. As such, the global HIV response should pivot its service direction from a *for community* stance to a *by community* orientation. Men who have sex with men, sex workers, people who use drugs, and transgender people, including those living with HIV, should be actively engaged and participate in all aspects of HIV program design, implementation, management, evaluation, resource mobilization, and governance. The GIPA principles is the earliest expression of the importance of community involvement.

Funding to Make Primary Prevention Possible

Primary prevention remains seriously undermined by low funding levels that are grossly misaligned with the number of estimated new infections worldwide. Underfunding exacerbates poor coverage of primary prevention for gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people. A recent study of budgets within new grants signed and approved over the 2014 and 2016 allocation period, conducted by the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), confirms underinvestment in HIV programs targeting gay men and other men who have sex with men, sex workers, people who use drugs and transgender people. Of the 5.9-billion-dollar portfolio in the 2014-2016 funding period, \$648 million (12%) was specifically dedicated to programs intended for all key populations (4.16% for sex workers, 3.5% for people who inject drugs and

4.4% for men who have sex with men and transgender people aggregated as a single group). Programs funded included costs for HIV testing and treatment services as well as expenses associated with research, training, and management. The study also revealed that less than 10% of funding earmarked for key populations is used to support interventions targeting upstream factors like community organizing and mobilization, promoting supportive legislation, sensitizing against anti-stigma and discrimination, or mitigating violence. (REF – Unpublished analyses and personal communication, Global Fund, 2017).

TABLE 2. 2014-2016 Global Fund Investment in National HIV Programs for Key Populations

<i>Total Global Fund Funding 2014-2016</i>	Key Populations Combined	Men who have sex with men and transgender people	People who inject drugs	Sex workers
\$5,968,658,499	\$799,098,297	\$275,882,882	\$242,341,714	\$252,919,906
National Grants	\$724,373,701	\$264,573,281	\$211,322,903	\$248,477,517
	12.14%	4.44%	3.54%	4.16%

To grasp the fullness of the problem when it comes to investment in programs for key populations, one must understand how the Global Fund contribution fits within overall funding for HIV. Consider the following:

1. The total estimated investment needed to achieve global HIV targets by 2020 is \$25 billion.
2. Per UNAIDS, 25% of the total investment should be devoted to prevention;
3. The Global Fund’s contribution to the total global HIV response is estimated to be 10%;
4. U.S. PEPFAR program contributes an additional 20% to the total, of which, less than 50% is directed towards prevention;
5. Other bilateral contributions add an additional 10% to the total estimated HIV investment;
6. 60% of total HIV investment is now coming from domestic sources.

While the Global Fund’s recent study of its own budgets show incremental improvement in investment for key population programming, its investment is miniscule in comparison with overall funding and what is needed. And although domestic investment is modestly increasing and now is the main source of funding for the HIV response, those investments rarely include consideration for the HIV prevention needs of key populations. In fact, governments’ reluctance to fund evidence-informed and rights-based programs for key populations raises serious questions for international donors about their role as funders of last resort.

Community-based organizations led by key populations and that are best positioned to reach and support their own communities remain inadequately resourced. Many organizations rely on volunteers and experience difficulty in retaining staff. Erratic funding and inadequate support for core costs, undermine the stability of community-led organizations. Complicated grant requirements and subsequent compliance regulations can be overwhelming, deterring many innovative and effective community-led organizations from seeking funding. In addition, grants to community-led organizations may have limited impact unless they are accompanied by customized, community determined capacity building and sustainability plans from the outset. Bottlenecks within donor bureaucracies can also delay disbursement of funding to community-led organizations, resulting in stop-and-start programs. These issues are compounded for community-led organizations operating in hostile legal or policy environments that limit their opportunities to develop organizational capacity and donor accountability

mechanisms. Because of under-developed capacities, many donors are reluctant to invest in smaller organizations. This has forced many community-based organizations led by men who have sex with men, sex workers, people who use drugs, and transgender people, to operate at the margins or in the shadow of much larger, well-established and better-resourced, parastatal or international non-government organizations, many of which end up acting as gate-keepers to resources. These factors limit true community engagement and feed a self-perpetuating cycle of under-resourcing for community-led responses.

Exacerbating matters, community-led organizations delivering HIV services to men who have sex with men, sex workers, people who use drugs, and transgender people are often the targets of vandalism, harassment, and police raids. Under such conditions, men who have sex with men, sex workers, people who use drugs, and transgender people are significantly less likely to seek the services they may need.

To scale up the primary prevention of HIV, community-based organizations led by and serving key populations should be well-supported through funding and capacity development assistance (e.g., task-shifting, training, peer-delivered technical assistance, emergency assistance, and information exchange). In addition, we must support community-led organizations to work in partnership with local healthcare providers and law enforcement officials to address the structural barriers of misogyny, homophobia, transphobia, whorephobia, drug-user phobia, HIV stigma, discrimination, blackmail, extortion, and violence. In addition, community-led organizations must be supported to more effectively and systematically collect, understand, and apply data in their day-to-day work. This is important to ensure reflexivity and course correction, allowing for greater efficiency in the implementation of HIV prevention strategies and the ability to react quickly in changing, often hostile conditions.

Let's Talk About Sex and Drug Use

Advocates worldwide remain troubled by the inclination of policymakers, both inside and outside of the AIDS Industrial Complex (AIDS Inc. for short), to understate the problem of HIV. Political rhetoric often misrepresents HIV epidemiology, conveniently rendering gay men, sex workers, people who use drugs, and transgender people invisible. Country government control (in international development jargon) to designate 'key populations' has not, does not, and will not change how people acquire HIV. Additionally, the persistence of revisionist characterizations of HIV has never and will never change the biology of acquisition. Except for infant HIV acquisition that occurs during pregnancy, childbirth, or through breastfeeding, HIV is primarily transmitted sexually and via blood through the sharing of injecting equipment.

It is not possible to imagine an effective primary prevention response to HIV without openly acknowledging, addressing, and talking about sex and drug use. And yet, governments and mainstream program implementers continue to concoct national strategies and interventions that pathologize and problematize HIV, without directly addressing how HIV is primarily acquired and transmitted. Openly talking about sex, sexual orientation, gender identity, and drug use requires that we acknowledge and engage gay men, sex workers, people who used drugs, and transgender people. The only thing governments and mainstream program implementers loath more than addressing sex and drug use, is having to be accountable to the expressed needs of gay men, sex workers, people who use drugs, and transgender people. For primary prevention to stand a chance, the silence, denial, negativity, and moralism surrounding sex and drug use must end.

The Dangers of Tokenizing Youth Rhetoric

The acquisition and transmission risk for young people and adults are the same – HIV is transmitted sexually and via the use of non-sterile injecting equipment. And like adults, HIV risk among young people is exacerbated by a myriad of social and structural factors like, sexism, homophobia, transphobia, whorephobia, drug phobia, and criminalization. They also include factors like consent, emancipation, autonomy, and privacy laws, which are unique to young people.

The primary prevention of HIV therefore requires specific consideration be given to young people. HIV prevention practice is dynamic and ongoing. It requires constant updating and iterative manoeuvring to respond to the specific needs of its target audiences. That includes their developmental needs. Primary prevention of HIV for school-aged youth should be qualitatively different from prevention efforts enacted for middle-aged adults. The primary prevention of HIV among young people needs constant renewal since there will always be a new cohort hungry for knowledge and information for whom strengths and skills must be reinforced. This must include broad-based implementation of age-appropriate comprehensive sexuality education.

Rhetoric about young people and HIV often glaze over these facts and ignores the disproportionate vulnerability to HIV among young gay men, young sex workers, young people who use drugs, and young transgender people. Donors and policy makers often gloss over HIV acquisition and transmission risk among young key populations in favour of generic discourse about youth. They also often speak in tokenizing ways about young people in the HIV response, never having consulted with organizations led by youth. Young people, including young gay men, young sex workers, young people who use drugs, and young transgender people should be directly engaged when planning HIV prevention programs. Moreover, we must remain proactive in calling out tokenism and rhetoric that invisibilize young key populations.

Gender as a Key Population Issue

Gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people are the routine targets of gender-based violence. Stigma, discrimination, violence, and criminalization directed at LGBT people, sex workers and people who use drugs are the consequences of deeply-held stereotypic beliefs and expectations about the hierarchical social roles men and women can take, in which men are considered superior to women. These beliefs underlie gender inequalities that are reinforced through social and cultural institutions and enshrined by public policy and law. Moreover, gender inequality is a main driver of homophobia, transphobia, and whorephobia. For example, violence directed to gay men is correlated with societal misogyny. Gender equality is therefore central to a primary prevention agenda, especially for key populations. This position stands in stark contrast to mainstream HIV and international development responses that narrowly consider gender equality as predominantly focused on the needs and rights of heterosexual cisgender women and girls. Narrow mainstream notions of gender equality tend to ignore the needs of both transgender and cisgender women and girls who use drugs, are sex workers, or are lesbians.

The HIV needs and rights of cisgender women and girls merit separate and dedicated attention. Efforts to designate women and girls as key populations misses this point and is a disservice to both cisgender women and key population groups, of which women and girls are members.

Moving Forward: Core Principles of Practice

Principles of practice have long been deliberated, published and advocated by AIDS service providers and advocates but are often overlooked in policy discussions because of a public health focus on evidence or science in substantiating HIV-related interventions and program strategies. The following are some important core principles of practice that can serve as broad guidelines in the design, implementation, and evaluation of primary prevention programs for gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people:

- The imperative of reducing new sexually transmitted infections, including HIV, should not impinge on personal freedoms;
- All people, including gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, have the right to self-determination;
- All people, including gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, deserve the same level of support, health, access to services, and political rights as anyone else;
- All people, including gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, have the right to privacy and are entitled to a fulfilling and satisfying sex life;
- gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people, should be actively and meaningfully engaged at all stages and levels in research, program and policy development, implementation and evaluation—participatory processes should be utilized throughout.
- HIV prevention programs and services should not be risk or deficit oriented—instead successful HIV prevention efforts should leverage, and be rooted in the strengths, resources, competencies, social connections, capacities, and resiliency that are already present in individuals and communities.
- Pleasure, gender, satisfaction, intimacy, love, and desire are key concepts in a fuller understanding of sex and sexuality among gay men and other men who have sex with men, sex workers, transgender people, and of drug use amongst people who use drugs, and therefore in formulating more meaningful research, programmatic, and policy responses; and
- Researchers, prevention practitioners, healthcare professionals, and policymakers should consider structural, situational, and contextual factors in understanding HIV acquisition and transmission risk and in developing sexual health interventions tailored to the specific needs of gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people.

Broader adoption of these principles will provide a common foundation for the ongoing development and promotion of the primary prevention of HIV among gay men and other men who have sex with men, sex workers, people who use drugs, and transgender people.

