

Social Capital and Effective HIV Prevention: Community responses

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Most work on health governance has been concerned with global and national coordination; this paper assesses the governance challenge of building HIV prevention programs on community responses. It analyzes situations where HIV prevention has been successful, suggesting they developed multi-level governance integrating the national program with the community response. This ensured national HIV programs were built on the basic governance unit of the community. This governance approach allowed HIV programs to mobilize the important resources for HIV prevention which reside in social networks as social capital. The paper first assesses the links between governance and social capital, following which case reviews of HIV program data are used to highlight the importance of community level responses in effective HIV prevention. Finally, detailed community interview data are analyzed to identify key governance barriers and linkages to better integrate community responses into national HIV programs (from the Communicating AIDS Needs Project). As with the growing understanding of aid and development, HIV prevention programs need to leverage a much greater source of resources than exist in programs in order to deliver population health outcomes. This requires a wider view of governance, which can build national HIV prevention programs on the basic unit of community responses.

INTRODUCTION

In 1981 in New York and San Francisco, gay men began to notice a new condition appearing in their community. Having been diagnosed in teaching hospitals, communication on AIDS spread rapidly through gay networks, which mobilized care, support, and community responses (like the Gay Men's Health Crisis established in January 1982). Formal public health projects were built on these community responses, risk and behavioral patterns changed, and declines in HIV incidence occurred first in white, and then in black and Hispanic gay men.¹

At the same time, on the banks of Lake Victoria, Ugandans identified and started talking about a new disease.² They gave it the evocative name "SLIM"; communicating more than the split acronym HIV/AIDS used later and elsewhere. In 1983 SLIM was "discovered" by epidemiologists in these Ugandan villages and by the government who initiated its HIV program as early as 1986.³ In this very different setting, similar community responses were already developing and forming the basis of HIV programs, which changed communications, behavior, and the epidemiology of HIV.^{4,5,6}

By necessity, HIV programs in these situations were built on community responses. They developed strong multi-level governance which extended their activities from national to the community level. Yet most work on health governance has been focused on formal global and national coordination.^{7,8,9,10} These experiences with HIV prevention suggest the importance of multi-level governance that coordinates formal and informal responses from national to community levels. Some countries have shown

remarkable success in coordinating HIV programs with community responses, others like Botswana and South Africa have not shown similar successes despite spending greater financial resources on HIV prevention.

The paper has three aims: (1) investigating the importance of multi-level governance for integrating national HIV prevention programs with community sources of authority, which can mobilize social capital; (2) assessing the role of community responses in situations where HIV prevention has been effective; (3) assessing the details of the barriers between national HIV programs and community responses from a community perspective. The paper highlights situations where the governance of HIV programs included community responses and the barriers where this has not occurred.^{11,12}

HEALTH GOVERNANCE AND SOCIAL CAPITAL

Recent definitions of health governance have stressed “effective collective action by governments, business and civil society to manage health risks and opportunities,”¹⁵ Some popular definitions still suggest “governance is what a government does,”¹³ though generally government is seen as a “particular and highly formalized form of governance.”¹⁴ This formal source of governance needs to be associated with “informal mechanisms (e.g. custom, common law, cultural norms and values)” to promote collective action in communities.¹⁵ As mentioned by Dodgson *et al*, an “essential element of global health governance is the need to involve, both formally and informally, a broader range of actors and interests.”¹⁵ This is particularly the case for HIV prevention programs which need to affect behaviors and norms among individuals and within social networks as well as deliver health services. This paper therefore uses the wide definition of health governance as “the actions and means adopted by a society to organize itself in the promotion and protection of the health of its population.”¹⁵

Rosenau stresses the importance of understanding decentralized governance that is dispersed where “a variety of steering mechanisms and institutions have come into being as instruments of governance.”¹⁶ He contrasts “state-centric” views of governance where “rule systems are presided over by states and their governments, while international institutions and regimes maintain others” with multi-centric views where “numerous steering mechanism(s) are to be found in NGOs, and still others consist of informal spheres of authority that may never develop formal structures.” He notes a particular challenge of “multilevel governance” between formal and informal, national and local sources of governance, as NGOs, communities, and governments attempt to exert collective action and “a modicum of control over their affairs.” HIV prevention highlights the challenges of collective action in the context of decentralized and multi-level governance—where national programs need to coordinate with community activities. Effective HIV prevention programs require financial and human capital but also resources in social networks which can influence behavior, communication, and norms. Just as human capital refocused attention on education and health in “human development,”¹⁷ social capital has highlighted the importance of social movements, networks, and behavior for collective action. Social capital is the resource that resides in social networks.¹¹ The concept of social capital has been developed separately in sociology, economics, and politics, and more recently this has been applied to mental health and public health.^{11,18,19} It was recently summarized and defined by Putnam as

“features of social organization, such as trust, norms and networks that can improve the efficiency of society by facilitating coordinated actions.”²⁰ The strength of this definition, and its link to governance, is in the focus on “coordinated actions” and the “soft authority” of networks, norms, and trust which facilitate such actions and create what Putnam terms “sociological glue.” Putnam distinguishes social capital from other forms of capital: “whereas physical capital refers to physical objects and human capital refers to properties of individuals, social capital refers to connections among individuals.”²⁰ Coleman concludes that the effective working of the economy requires the presence of four types of capital: bio-physical capital (land and the environment), financial, human, and social capital.²¹ Social capital has a number of features that distinguish it from other forms of capital:

- It resides in groups rather than being owned by individuals.
- Stocks of social capital increase rather than decrease with use.
- Social capital is easier to destroy than create.
- It improves the functioning of human and physical capital (it is generally complementary to other forms of capital).
- It has intrinsic as well as instrumental value: health, education, friendship.

Critics have argued that the meaning of social capital is too diverse a concept and functions so differently from other forms of capital as to not be well captured by the term.²² Others have pointed to its perverse properties in crime organizations, the mafia, excluding outsiders, and stigma in relation to AIDS.²³

Many early HIV prevention programs built on social movements and networks which extended their reach far into communities. This is illustrated by the Gay Men’s Health Crisis in New York and The AIDS Support Organization (TASO) in Uganda (described below). As well as institutional governance, programs were aware of the “soft power” of community networks in engaging with norms and behaviors.²⁴ HIV prevention highlights the governance challenge of coordinating HIV programs with community sources of authority, combining formal and informal, national and local, sources of governance.²⁵ The paper therefore stresses a constituency governance model where national programs need to build on community sources of authority as a basic unit of governance.

METHODS

The paper analyzes contexts in which HIV prevention has been effective, while highlighting multi-level governance where national HIV programs were built on community responses. The methods involve case reviews of epidemiological, behavioral, and program data to highlight the role of community level responses in HIV prevention. These cover diverse case studies in Africa, Asia, and America and different periods from the 1980s, 1990s, and 2000s. The analysis relies on secondary data, program descriptions, and peer-reviewed literature. HIV behavioral surveys and surveillance data on HIV prevalence and sexually transmitted infections (STIs) were analyzed.

Second, qualitative data are analyzed to assess in more detail the positive and negative effects of governance on integrating community responses in HIV prevention programs. These are collected from three community sites in South Africa as part of the

Communicating AIDS needs project (undertaken by the Centre for AIDS Research and Evaluation, CADRE located in South Africa) from 2001-2006.^{26,27} They involved participant observation, interviews, diaries, and focus groups in communities. Transcripts were selected to capture links between community responses and HIV prevention programs covering testing, care, condom use, and HIV diagnosis. The qualitative analysis from communities highlights the governance and programmatic barriers to combining formal and informal, as well as national and community sources of authority in HIV prevention programs.

There are limitations to the study. The program information is often reconstituted retrospectively and relies on self-reported behavioral data. There are limitations to the concept of communities, which are often fragmented into social groups and networks. There is continued debate on the role of community mobilization in HIV prevention, and the measurement of its impact.²⁸ The qualitative data is not representative and is from a few sites, even though it aims to investigate some of the general barriers to multi-level governance of HIV prevention. In addition, there are limitations to generalize the findings from program cases of HIV prevention, particularly to very different contexts. There are also demonstrated strengths in the program case approach to testing general hypotheses in individual cases, which can draw on quantitative and qualitative material.^{29,30} The data and methods combining program cases with detailed listening to communities are incomplete but important in understanding the integration of HIV prevention programs with community responses.³⁰

MULTI-LEVEL GOVERNANCE OF HIV PREVENTION: BUILDING ON COMMUNITY RESPONSES

There have been successful community HIV prevention responses in several, very different settings in Africa, Asia, USA and Australia.³¹ In these contexts, HIV prevention programs have often built on community responses to engage with social networks, their values, and behaviors. The paper assesses the hypothesis that effective HIV prevention has involved multi-level governance with national HIV programs and community groups jointly steering HIV prevention. Figure 1 shows the diversity and scale of HIV prevalence declines.³² Each situation has shown a combination of formal HIV prevention programs and community responses, which are often not fully documented.^{1,6} Important program examples from different regions and stages of the epidemic are assessed below.

Figure 1: Epidemiological and behavioural changes in situations where HIV prevalence has declined significantly in diverse populations and stages of the epidemic

Country	Decline (with range)	Years	Population	Indicator used	Data
			Epidemiological		
Uganda	54% (21.1% - 9.7%)	1991-1998	Antenatal clinical attendees (ANC)	HIV prevalence	Sentinel surveillance
	55% (18% - 8%)	1991-1996	Army military recruits	HIV prevalence	Sentinel surveillance
	58% (7.6 - 3.2 per 1000)	1990-1998	Adults, male and female	HIV incidence	Population cohort
Kenya	38% (16% - 10%)	1997-2003	Adults	HIV prevalence	Estimated from ANC & DHS
	25% (12% - 9%)	2001-2003	ANC, urban, age 15-49	HIV prevalence	Sentinel surveillance
Rwanda	19% (16.3%-13.2%)	1998-2003	ANC, Kigali, age 15-49	HIV prevalence	Sentinel surveillance
	39% (9.5% - 5.8%)	1998-2003	ANC, other urban, age 15-49	HIV prevalence	Sentinel surveillance
	25% (2.8% - 2.1%)	1998-2003	ANC, rural, age 15-49	HIV prevalence	Sentinel surveillance
Ethiopia (Urban)	38% (24.2%-15.1%)	1995-2001	ANC, urban, age 15-24	HIV prevalence	Sentinel Surveillance
	14% (14% - 12%)	2001-2003	ANC, urban, age 15-49	HIV prevalence	Sentinel Surveillance
Malawi (Urban)	38% (26.9% - 16.7%)	1999-2003	ANC, urban, age 15-49	HIV prevalence	Sentinel Surveillance
Haiti (Urban)	45% (5.5% - 3%)	2000-2003	Women, age 15-44	HIV prevalence	Sentinel Surveillance
Thailand	88% (4% - 0.5%)	1993-2002	Male conscripts, age 21	HIV prevalence	Surveillance, male conscripts
	56% (28.2% - 12.27%)	1996-2002	Female sex workers	HIV prevalence	Surveillance, sex workers
	45% (2.8% - 1.5%)	1995-2002	ANC, Northern and Central	HIV prevalence	Sentinel Surveillance
Cambodia	35% (4% - 2.6%)	1999-2002	Adults	HIV prevalence	Surveillance
	32% (42.6% - 28.8%)	1998-2002	Female sex workers	HIV prevalence	Surveillance, sex workers
	55% (2% - 1.9%)	1998-2006	Adults	HIV prevalence	Surveillance, modeling
Australia	29% (194 -138)	1995-1998	Homosexual men	HIV incidence	Surveillance, modeling
	8.1% per annum	1996-2000	Homosexual men, age 15-65	HIV notifications	Surveillance, HIV notifications
Zimbabwe	47% (29.3% -15.6%)	1997-2007	Women, age 15-49	HIV prevalence	Surveillance
			Behavioural		
Uganda	60% decline casual sex	1989-1995	Adults, urban and rural, age 15-55	Non-regular partners	Behavioural surveys
	62% decline casual sex	1989-1995	Men, rural, age 15-55	Non-regular partners	Behavioural surveys
	72% decline casual sex	1987-1992	Adult men, 15-49	Two or more partners	Population cohort study
Thailand	55% decline	1990-1993	Men	Men visiting sex workers	Behavioural surveys
	46% decline	1990-1993	Men	Non-regular partners	Behavioural surveys
Cambodia	58% decline	1997-2001	Police, urban	Men paying for sex	Behavioural surveys
Haiti	20% decline	1994-2000	Urban	Multiple partners	Behavioural surveys
Kenya	43% decline	1998-2003	Men	Multiple partners	Demographic Health Surveys
	50% decline	1998-2003	Women	Multiple partners	Demographic Health Surveys
Malawi	67% decline	1996-2004	Men, urban	Multiple partners	Demographic Health Surveys
Ethiopia	64% decline	2000-2005	Men, urban	Multiple partners	Demographic Health Surveys

Sources: 6,31,32,34,35,36,37,43,44,50,52,52

SOCIAL NETWORKS AND COMMUNITY RESPONSES: UGANDA

Uganda remains one of the best examples of multi-level governance of HIV prevention at the national and community levels, and of how changes in population behavior and communication reduce HIV. HIV prevalence declined nationally from 21.1 percent to 9.7 percent from 1991-98 across 15 antenatal clinic sites, supported by trends in data from urban and rural areas, population cohorts, and sentinel HIV surveillance, although there has been debate on the scale of the declines.^{6,28,54} These declines are repeated in other

national datasets. HIV prevalence declined 55 percent among army recruits from 1991 to 1996, blood donors, as well as from all strata of society, urban and rural. The major mechanism, as reported in a number of surveys and cohorts, was a reduction in non-regular sexual partners by 60 percent over the period from 1989 to 1995, and an associated contraction of sexual networks. The scale of these changes is equivalent to a “social vaccine” of 75 percent efficacy.⁶

Open communication on AIDS was implemented in the HIV program from national to community level, using the sources of authority of local leaders—cultural and political. Communication is often reduced to the provision of messages, media campaigns, or the transfer of knowledge. The response in Uganda was catalyzed by a distinctive communication process discussing AIDS through social networks and personal knowledge of individuals with AIDS.⁴ In Uganda, personal channels dominated the way people communicated and learned about AIDS (in urban and rural areas, men and women), with a shift from impersonal to personal channels from 1989 to 1995 (Figure 2a).

First, there was a clear HIV policy implemented by the government to mobilize a community response using multi-level governance and local sources of authority.⁵ Crucially, prevention messages were spread by channels of social communication through local networks of chiefs, churches, musicians, and village meetings. Awareness campaigns began with the beating of a drum—the basic and traditional method of mobilizing a community against imminent danger. President Museveni visited Ugandan villages, talked to community leaders and churches, and with cultural leaders, created a space where many individuals could respond to AIDS. AIDS was known as people in the community, fear, care and not a little stigma, it was Philly Lutaaya the musician giving his farewell concert, an army major, a priest, a friend with AIDS. The response was based on multi-level governance and the understanding that Ugandans have many of the unique resources and local networks to respond to AIDS.

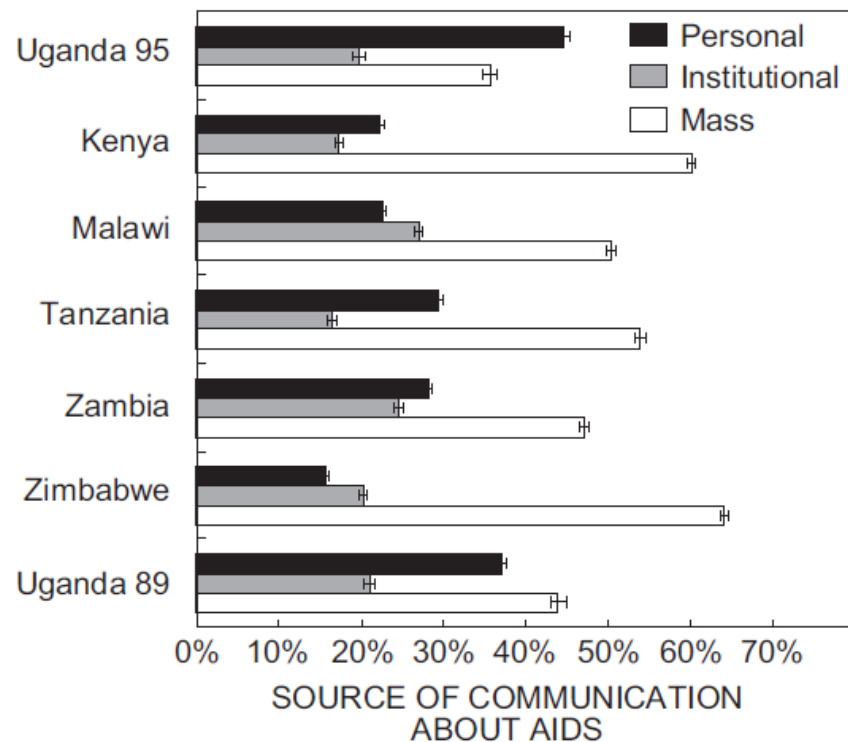
Second, the community governance of formal groups like the AIDS support organization (TASO) and other NGOs were essential in mobilizing social networks and resources for care.³³ The AIDS support organization (TASO) was formed in 1987 by a group of 16 volunteers in Kampala, 12 who had HIV or AIDS. They promoted “shared confidentiality,” openness about HIV status with a limited circle of trusted people, opening up channels of support and care. They steered responses to AIDS across communities and connected informal sources of authority to the formal HIV program, and were replicated across communities in Uganda. The community groups provided depth to the HIV program locally, while the HIV program allowed these community responses to be extended nationally across the country.

Through multi-level governance integrating the national program with community responses, the formal HIV program was able to steer a much wider response, leveraging social capital deliberately in its governance and interventions. This is reflected in the range of behavioral responses reported by Ugandans as shown in Figure 2b.⁵ The public health program was focused on going face to face with AIDS, not on a prescriptive response, either A, B, or C. Stigma was also part of the response; a key message—“don’t point fingers, care for people with AIDS,” was critical. HIV governance was based on a community response—all politicians were required when going to the community to speak of AIDS, programs worked through local leaders, churches, and

AIDS was recognized officially in communities allowing care networks like TASO to form.

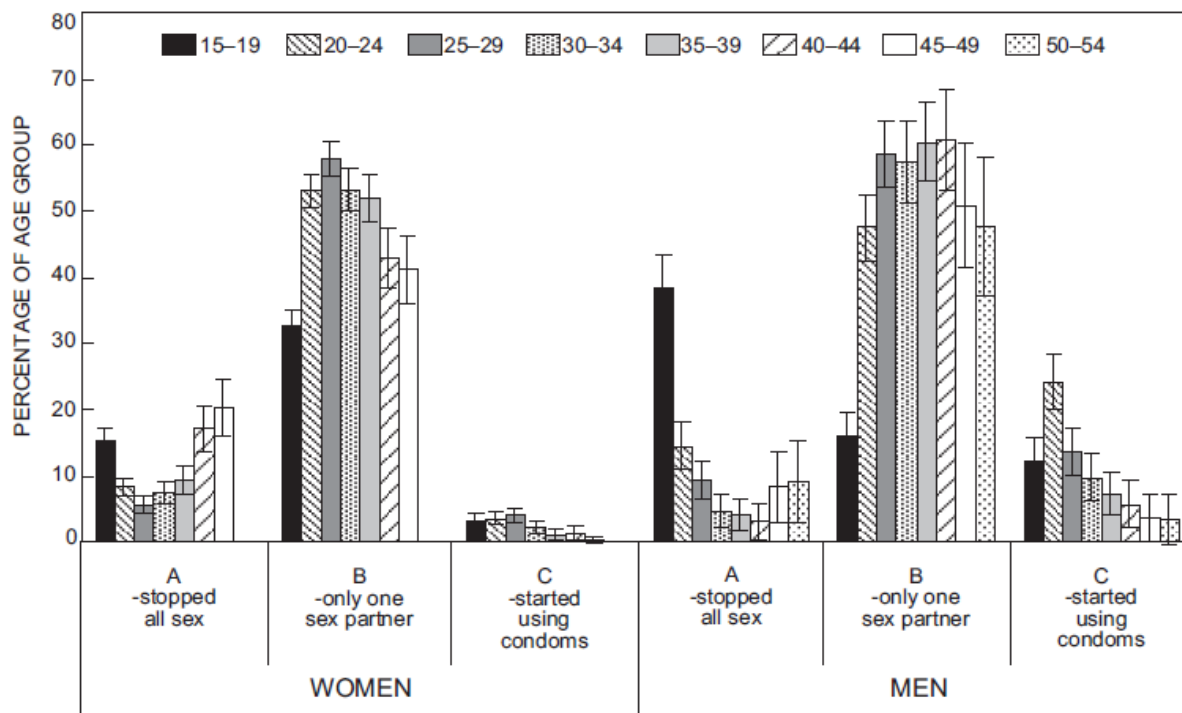
What does it suggest about HIV prevention? First, if national programs can mobilize community responses, HIV prevention can be highly successful in changing the course of an epidemic over a matter of years, even in resource-poor settings. Second, HIV prevention is built on behavior changes to avoid the risks of HIV, a response at the population level to the epidemic. Yet how programs leverage this population response is critical. Other interventions, for example, the demand for voluntary counseling and testing services (VCT) and care networks are greatly enhanced if this basic population response is mobilized.

Figure 2a: Differences in source of communication about AIDS: classified by personal networks, institutional, and mass sources



Source: DHS surveys in Uganda (1995), Kenya (1998), Malawi (1996), Tanzania (1996), Zambia (1996), Zimbabwe (1994), Uganda 1989 AIDS survey, WHO, 95% confidential limits shown.

Figure 2b: Reported behavior changes due to AIDS in Uganda - Self reported response by five year age and sex, Uganda DHS 1995



Source: DHS survey in Uganda 1995, 95% percentage limits shown

DELIVERING HEALTH SERVICES AND SOCIAL CHANGE: ASIA

There was a similar, though less well recognized, multi-level governance of HIV prevention in two of the most effective HIV prevention programs in Asia—in Thailand and Cambodia. Important programs for delivery of services to individuals, like condom distribution and testing (services to individuals described as type 1 prevention)³⁴ were coordinated with interventions to mobilize a community response (population social change described as type 2 prevention).³² The delivery of services that protect individuals has largely been the focus of universal access. Yet, equally important is HIV prevention to mobilize those at risk directly at the population level. It is important to combine these two modes of HIV prevention to catalyze the impact of prevention efforts at the population level.³⁴ In these two situations, HIV prevalence declined by over 80 percent among young military recruits and 45 percent among pregnant women in Thailand from 1993 to 2002, and by 55 percent in Cambodia among adults from 1998 to 2006.

In Thailand, HIV prevention was supported by widespread social communication starting in 1989 and accelerating by 1991 as the new Prime Minister made AIDS a priority, with AIDS messages presented every hour on all the major 500 radio and 7 TV stations (with hourly 15 second slots).³² This was accompanied by direct mobilization of social networks by the national HIV program consisting of NGO outreach in factories and villages, national self-help groups of people with HIV, and intensive government prevention with army recruits, sex workers, in private work places, and with taxi drivers.

In Cambodia too there was a distinctive focus on social communication from 1998 across all radio and TV stations, and community events. Cambodia piloted many elements of the Thai program in 1998 and implemented them nationally in 1999. They ensured service delivery, particularly of condoms, was associated with integration of over 90 NGOs into the national program, as well peer education among military, men who have sex with men (MSM), injecting drug users (IDUs) and street children, and over 400 support groups for HIV-positive people to involve them in the response.

A large range of behavior changes occurred beyond the program goals of 100 percent condom use with sex workers in Thailand and Cambodia. In both countries, declining risk behaviors and infections (e.g. STI and HIV prevalence trends in Thailand) preceded the high level coverage of discrete interventions (for example condom use with sex workers).^{35,36,37} The programs worked carefully with the networks related to sex workers, including brothel owners, taxi drivers, and clients themselves. The focus and intensity of the program helped support increasingly consistent condom use with sex workers.¹

There was an equally important population response, with visits by men to sex workers decreasing by 55 percent, and any non-regular partners decreasing from 28 percent to 15 percent in repeated national surveys between 1990 to 1993 in Thailand; and by 58 percent among urban police in Cambodia between 1997 to 2001.^{5,38} These population responses preceded and exceeded the aims of health programs, such as Thailand's "100% condom use program." Similarly, in Cambodia HIV prevention combined services to individuals and social change at the population level.³² In both situations, the formal HIV program played a critical governance role in linking to community networks and working through horizontal social networks of community groups, brothel owners, taxi drivers, and NGOs.

JOINT STEERING OF HIV PROGRAMS AND COMMUNITY RESPONSES: KENYA, MSM COMMUNITY IN THE UNITED STATES, AND OTHER CONTEXTS

In a very different setting, the gay community provides an important example of joint steering of HIV prevention between formal institutional mechanisms and the informal community response. A community and behavioral response which preceded and exceeded health programs is apparent in the gay community in the USA.³⁹ Public health departments worked very quickly to coordinate communication and support through gay community organizations in the early 1980s. In New York, the Public Health Department provided an early sub-contract with the Gay Men's Health Crisis (GMHC) to ensure health prevention information entered social networks. This gave the last ten meters to their interventions to ensure they were present where HIV was. By 1984, the Centers for Disease Control (CDC) had requested GMHC assistance in delivering HIV prevention, as had the New York Public Health Department.

The joint governance of HIV prevention programs helped steer a wide, coordinated community response to HIV, mobilizing financial, human and social capital. The outcomes of this integrated program and community response were declines in risk and behavioral indicators and then HIV incidence and prevalence rapidly from 1985.^{40,41,42} Some commentators have argued that while medical and financial responses have intensified since the 1990s, the community response has not

been maintained and as a result increases in HIV incidence in young cohorts have occurred.⁴³

Multi-level governance mechanisms to coordinate formal and informal, and national and local sources of authority appear critical in other situations at later stages of the epidemic. In Kenya, HIV prevalence declined from 16 percent to 10 percent between 1997 to 2003, which was associated with similar declines in risk behavior in the general population.^{44,45} This coincided with a significant governance change to the program in late 1999.⁴⁶ In 1999 parliamentarians realized that the AIDS program was not working. They brought in two major changes at the national and local level. First, they initiated intense, open social communication on AIDS from the national level to put it on the agenda of social networks. AIDS was declared a national security item and emergency in November 1999 and communicated nationally. Local leaders, CEOs of companies, and most ministers tested themselves publicly, and politicians attending community meeting had to discuss AIDS.⁴⁷ All 221 members of parliament (MPs) were trained in AIDS information to present to their local constituencies in November 1999. Each weekend they were expected to return to their communities throughout Kenya to talk about AIDS, show videos, and mobilize their communities.

Second, after an emergency parliamentary meeting, the Kenyan government introduced multi-level governance at ministry, provincial, district, and local constituency levels to ensure formal AIDS activities worked through local sources of authority.⁴⁷ The President established multi-level HIV governance creating a national AIDS council in November 1999 and 210 local constituency AIDS committees which reported to it.⁴⁸ These used the MPs' constituency office, but were independently bringing together local leaders, schools, and committees of elders. Free airtime on state radio and television for AIDS awareness broadcasts was provided to ensure intense, national communication. In addition, AIDS education was implemented in all schools and colleges in January 2000.

There were many factors in the declines in HIV prevalence in Kenya. However, Kenya shows that multi-level governance and community responses can be added to the HIV program, working through local leaders, politicians, and community meetings. Kenya shows that formal HIV prevention programs can build on a community response at later stages of the epidemic.

There is evidence of HIV prevalence and behavior changes in other less well-documented examples of HIV prevalence declines in urban Malawi, Rwanda, Ethiopian cities, Niger, Zimbabwe and in Australian men who have sex with men.^{49,50,51}³¹ Program reviews have not been done in detail in many of these, and the role of programs and community responses behind behavior changes are still to be investigated. However Australia in particular is a leading example of strong multi-level governance of HIV prevention between the health program and the local populations most at risk.⁵²

BUILDING GOVERNANCE ON COMMUNITY RESPONSES: LINKAGES AND BARRIERS

The many situations where HIV prevention has not been successful and has not built on community responses are striking. Critically, health governance does not support coherent social communication and service delivery from national to community levels.⁵³ The Communicating AIDS Needs project undertaken by CADRE in South Africa has assessed some of the important aspects of multi-level governance coordinating

formal national and provincial health programs and community networks in more detail.²⁶

Figure 3: Transcripts of real conversations around community funerals and reporting of AIDS in communities

3a. Social communication after a community funeral

“Then the neighbour [T’s best friend] came over as we were talking .. She came asking for washing powder soap.

My mother-in-law asked her, “How did the funeral go?”

The neighbour said, “It went well.”

My mother-in-law asked, “What did she die from?”

The neighbour said, “She had piles.”

My mother-in-law said, “Oh shame she had piles. Why didn’t she consult a doctor?”

The neighbour said, “She went to the doctor but she still died.”

My mother-in-law said, “Shame now who will look after the child, at least the grandmother is still alive it won’t be such a big hassle.”

Then the neighbour went.

That’s when my mother-in-law said,

“Aids is killing children.””

Source: Communicating AIDS Needs Project, CADRE

3b. Communication concerning HIV reporting and diagnosis in clinics

TLB: How many of your patients are affected by HIV

IS: About 1/3rd of patients in gastroenterology have HIV

TLB: Do you talk to the patient about their condition

IS: No, although both the patient and doctor may know that he or she has HIV, we do not mention it, or mark HIV on the medical records. Partly this is due to insurance but also mistrust

TLB: So how do patients know what condition they have

IS: Often they do not, often they do, but we don’t talk about it

TLB: Is there not an ethical responsibility of a doctor to talk about the patient’s underlying condition with him or her

IS: I suppose so, but the patients themselves don’t want it in their records, and for the doctor there is so much paperwork in mentioning AIDS compared to other conditions (testing, counseling etc.), and although both know it is HIV, they do not talk about it

Source: Communicating AIDS Needs Project, CADRE

Based on qualitative data analyzed from community sites in South Africa, Figure 3 illustrates barriers to consistent social communication on AIDS from national to community level in two contexts—conversations after a community funeral and HIV reporting in a clinic. Figure 3a shows there is recognition of AIDS among the immediate family (“AIDS is killing children”), but the powerful secondary social communication around AIDS is switched off (in public “She died of piles”). Figure 3b illustrates how in clinical settings HIV is not reported or identified in medical records (“we do not mention it or mark HIV on the medical records”), and the critical communication between health workers and patients with HIV does not occur (“although both the patient and doctor may know that he or she has HIV, we do not mention it, or mark HIV on the medical records”).

The qualitative data from community sites in South Africa which illustrate the barriers to joint steering of HIV prevention between formal programs and community responses are summarized in Figure 4. They are summarized by key programmatic area (HIV testing and diagnosis, condoms, HIV treatment and care, communication programs) with comments on national and local governance also grouped. The gap in communication and trust between national and community level is apparent in comments that HIV prevention “is a strategy devised by the government”, and that “people who are infected who go out and educate people about HIV are being bought by the government.” The provincial AIDS programs are seen as formally “multi-sectoral and multi-departmental ... but they don’t come, they don’t attend those meetings (at community level) ... they don’t feel they have the right to stand on platforms and talk about HIV if they are the government”.

Figure 4: Selected community quotes on HIV governance and community programs

National governance	<p>"We even dismiss its existence by developing the myth that the people we see everyday who claim to be HIV positive are lying, and it's all a strategy devised by the government to scare people from having sex, thereby decreasing the population level"</p> <p>"So that myth is still dominant in the community, that the people who are infected who go out and educate people about HIV are being bought by the government .. That myth is still there, especially amongst school going youth"</p> <p>"You can have lots and lots of funding but if it's not servicing the people it's supposed to be servicing, then it's like throwing water into the ocean "</p>
Local governance	<p>"The provincial government is multi-sectoral and multi-departmental on those grounds, but they don't come, they don't attend those meetings. Even if they say they will come they change their minds at the last minute. So you start to wonder whether they really take this thing of HIV seriously... Also on a personal level maybe, they don't feel they have the right to stand in platforms and talk about HIV if they are part of the government"</p> <p>"The NGO coalition is busy embarking on that profile of the region, so that we know who is doing what, where, the organizations dealing with aids should have formed their consortium a long time ago ... They should have had their own big platform or common ground"</p> <p>"The AIDS councils it's something that comes from government. It's not because we the people involved with HIV wanted to have that in the first place"</p>
Community events and activities	<p>"He says because there are so many other illnesses that AIDS can come from, meningitis will be identified as the cause of death and not AIDS. Meningitis is used because people do suffer from meningitis and die from it without having contracted HIV .. I don't want to lie to you, not even once have I been to a funeral where people actually disclosed.</p> <p>"Her answer is that we need to focus on the issue of prevention thoroughly, because you find that one organization is doing a lot of things within HIV but there is no intensive focus on one area".</p>
Communication Programs	<p>"This AIDS thing is something that should take priority even on TV. I think that we should be shown so much of it that a person would rather switch off their television sets. Maybe let's say at 3pm in every channel... Now we don't really take it serious"</p> <p>"I think that Nkosi Johnson made a great impact. He brought great change in our communities when it comes to changing behavior (was this sustained?) not in every situation. Maybe out of ten people, four people will change their behavior while six will remain with the same attitude"</p>
HIV testing and diagnosis	<p>"But I had a lot of difficulties about getting tested, I won't lie. I would go to the clinic, look around and see someone I know and pretend as if I am enquiring about something important from the receptionist, then I would quickly get out of there. I would walk my girlfriend to the clinic, and while I was there I would ask about this HIV test, the nurse would explain, I would say no I have not personally come for that, I'm just accompanying the lady"</p> <p>"It's a rumour so to speak, because nobody has the actual testimony unless you were a close family friend. Even the doctor doesn't say he died of AIDS"</p>
Condoms	<p>"There are condoms and they have names or labels there is trust, lovers plus. Then a girl will tell you that she does not want you to use "Manto's condoms" .. They call them Manto's condoms because they are provided by the government and they are free, and the person who introduced them is Manto the Minister of health .. You see if she doesn't like the free ones that I have access to, then we might as well not use any"</p>

HIV treatment and care	<p>"You see most people don't even want to take this treatment, so then the doctors just end up dealing with just opportunistic diseases rather than the root cause of all these other diseases"</p> <p>"Care there is not enough and it is the major thing that is needed, their families don't help them, their parents took them here and they won't visit them again .. I do not even tell my friends I am a carer, if I told them, they would think it is a very bad thing"</p>
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Source: Qualitative data from community sites in South Africa

The governance gap between HIV programs and community responses also presents serious barriers for the delivery of services, as shown in Figure 4. In these communities “Even the doctor doesn’t say he died of AIDS” and in community events “Meningitis is used because people do die from it without having contracted HIV”. Similarly there is a lack of overall community governance of HIV prevention activities “One organization is doing a lot of things within HIV but there is no intensive focus on one area.”

Health services are also directly affected by the level of integration with community responses and communication through social networks. HIV testing becomes more complicated (“I would go to the clinic, see someone I know and pretend and then quickly get out of there”), free condom distribution (“a girl will tell you she does not want to use “Manto’s condoms” provided by the government), and care (“I do not even tell my friends I am a carer, if I told them, they would think it is a very bad thing”). Behaviors are central to the effectiveness of most services.

In summary, the analysis of program cases and the qualitative information from community sites in South Africa suggest three components of governance and two supporting structures which can better integrate formal national programs with community responses in HIV prevention:

- **Intense, open social communication on AIDS** from national level to open up the agenda; this needs to recognize and coordinate joint steering of HIV prevention by national politicians and local sources of authority.
- **HIV program governance which engages systematically through social networks** of local leaders, community groups, local radio, and most at risk populations to leverage a wider response.
- **Community governance mechanisms to coordinate NGOs and link them to formal programs:** These mechanisms were lacking in these South African communities, who did not have the equivalent of TASO to coordinate fragmented community activities. The lack of integration to the national program makes it difficult to scale their local activities across the country.

The following supporting structures are important:

- **Network, not closed governance:** Ensure formal governance reaches out to mobilize local leaders, chiefs, churches, schools, local politicians and that HIV is on their agenda and raised in local meetings, funerals, and discussions.
- **Coalitions within community organizations** to link up to provincial or national governance. This can also work through a community focal point to coordinate activities and link to governance.

Multi-level governance needs to coordinate a community response, alongside coordination of financing and health services.

CONCLUSION: GOVERNANCE CHALLENGES OF STEERING HIV PREVENTION

HIV prevention illustrates many of the recent challenges of health governance to coordinate formal and informal sources of authority, national programs and community responses. This paper has highlighted a constituency governance model where national programs need to build on community responses and sources of authority as a basic unit of governance. In Kenya this was seen through political constituencies, which provided a basic unit of the HIV program; in Uganda community resistance councils and NGOs like TASO were formed; and in the gay community in the United States a much wider community movement responded to AIDS. This joint steering between national HIV programs and community sources of authority is a major governance opportunity and challenge for effective HIV prevention.

The paper has argued for a wider view of health governance which focuses on how national programs build on community responses. Where this has occurred, there has been coordination between (a) the vertical delivery of health services, and (b) the horizontal mobilization of social networks for social and behavior change. A similar process has occurred in very different settings in Asia, Africa, and America where HIV prevention has been effective. The governance of HIV prevention involved: (1) Intense, open social communication on AIDS from the national level to open the agenda; (2) HIV program governance which engaged systematically through social networks of local leaders, community groups and most-at-risk populations to leverage a wider response; and (3) Community governance mechanisms to coordinate NGOs and link them to formal programs. TASO and the Gay Men's Health Crisis provide two examples in different contexts. Where prevention services and community responses are coherent, HIV prevention is amplified.

However the community response can easily be confused and marginalized, as has been the case for examples in South Africa and Botswana where the national program did not initially build effectively on community responses,⁵³ and in specific groups like MSM and IDUs in Thailand.³⁴ This has significant implications for health governance: it is important to include an intermediary constituency of local leaders, community groups, and most at risk populations as a basic unit of governance.

The focus on wider, multi-level governance presents opportunities and limitations for health programs. If the resources in social networks (social capital) can be mobilized, health programs can have a much greater impact than the financial and technical resources they provide. A major opportunity particularly in Africa is that HIV prevention can work in the poorest situations, with the least financial and health system resources.

There are also many critiques and barriers to the role of HIV programs in mobilizing community networks and local sources of authority.⁵⁴ Three important barriers are the legal status of many most-at-risk populations, gender issues for young and married women, and migration, which fragments communities in Southern Africa.⁵⁵ Some HIV programs like in Botswana have employed professional community

mobilizers who have not been linked or drawn from local networks of authority.²⁴ A barrier is the ability to coordinate multi-level governance as shown in this paper.

There are limitations to the study, including a dependence on self-reported behavioral data and retrospective program cases as described in the methods. There is continued debate on the role of community mobilization in HIV prevention, and the measurement of its impact.²⁸ There are recent changes not captured in this study, particularly in South Africa.⁵⁶

There is an important governance challenge for HIV prevention to ensure multi-level coordination of formal and informal, national, and community sources of authority. When these are well coordinated HIV prevention can be greatly amplified; when they are not, the community response is fragile and can be “switched off.” Collective action at the community level requires formal HIV programs and mobilizing social capital to combine health services and social change. Finally, the paper suggests the importance of an open, multi-level governance for HIV prevention which recognizes the community as a basic constituency unit. As President Museveni comments, “*I am not too sure about this global village, but I know I have my village. If I need advice I go to my village, and see what is going on and can talk to people I trust, it is where my politics start.*”⁵

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