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LEVERAGING HIV-RELATED HUMAN RIGHTS ACHIEVEMENTS THROUGH A FRAMEWORK CONVENTION ON GLOBAL HEALTH

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ABSTRACT

Although AIDS remains a leading cause of death, especially in low- and middle-income countries, the movement to address it has greatly contributed to changing the world's response to health challenges. By fusing activism, political leadership, domestic and international investment, and accountability for results, the course of the epidemic has been radically shifted.

People living with HIV and others directly affected by the epidemic have exerted immense leadership since the first days of the response: they have fought to end discrimination on the basis of sero-status, gender, sexual orientation, disability, migration status, drug use, or participation in sex work. Some of this mobilization has taken the form of strategic litigation, drawing human rights down into concrete demands and defining social, health, legal, and economic policy. The global AIDS response has shown that at the core of health lie considerations of social justice, human rights, and accountability.

As momentum builds for a Framework Convention on Global Health (FCGH), we believe there is an opportunity to take stock of lessons learned from the response to HIV and ensure that they are replicated and institutionalized in an eventual Convention.

We argue that the most critical aspect to the success of the HIV response has been the leadership and activism of civil society. Conventions do not lead to results on their own, and there should be every expectation that the FCGH will be no different. Success requires active monitoring of progress and shortcomings, combined with political and social mobilization to expand investment and access to the services and underlying conditions that protect and advance health. While the FCGH must make civil society support and engagement an indispensable principle, the AIDS movement can contribute substantive content and mobilization for its adoption.

A broad international legal framework for health can help address some of the key legal, policy, regulatory, and programmatic challenges that continue to hinder effective responses to HIV. Thus, the AIDS response potentially has much to gain from the normative and institutional framework, and the expanded commitment to realizing the right to health that can be generated under such a Convention.

INTRODUCTION

For over 30 years there has been a massive movement to confront the HIV epidemic—one of humankind’s greatest threats. This movement has radically changed the world’s understanding and response to health challenges, and has been said to have created the concept of “global health.”¹ Though the epidemic is far from over and AIDS remains a leading cause of death (especially in low- and middle-income countries), major gains against HIV have been won by fusing activism, political leadership, scientific development, domestic and international investment, and accountability for results.^{2,3} Moreover, as a result of progressive AIDS responses, we see communities being transformed in ways that ensure health, dignity, and security for those living with HIV; however, the responses also address broader health and social development challenges beyond HIV. People living with HIV and others directly affected by the epidemic have exerted immense leadership since the first days of the response: they have been fighting to end discrimination on the basis of sero-status, gender, sexual orientation, disability, migration status, legal status, drug use, or participation in sex work. Some of this mobilization has taken the form of strategic litigation at the country level, drawing human rights down into concrete demands and defining social, health, legal, and economic policy.

The global response to HIV has shown that at the core of health lie considerations of social justice, human rights, and accountability. A critical moment in the response to HIV was the United Nations General Assembly’s adoption of the Declaration of Commitment on HIV/AIDS in 2001. This Declaration, among others, established new mechanisms for funding, participation, reporting, and accountability by which to actively monitor progress towards the commitments that were made. Today, as momentum builds for a Framework Convention on Global Health (FCGH), we believe there is an opportunity to take stock of some lessons learned from the response to HIV and ensure that they are replicated and institutionalized in post-2015 development and health frameworks. As enumerated in this paper, these include: the development of participatory governance and accountability platforms that engage both people directly affected and those most marginalized, the mobilization of domestic and international investment, and the galvanization of high-level political commitment.

While high-level, global political commitment can be a galvanizing force, this paper argues that the most critical aspect to date to the success of the HIV response has been the vision, leadership, and activism of civil society, particularly those living with and affected by HIV. Declarations and conventions do not lead to results on their own, and there should be every expectation that the FCGH will be no different. There will need to be active monitoring of progress and shortcomings, combined with political and social mobilization to expand investment, programs, and access to the services and underlying conditions that protect and advance health. As such, this paper advocates that the FCGH make broad civil society support and engagement a central and indispensable principle. The paper also highlights how a broader international legal framework for health—and related accountability and funding mechanisms—can help address some of the key legal, policy, regulatory, and programmatic challenges that continue to hinder effective responses to HIV. Finally, the paper posits that the FCGH can benefit from the HIV movement in terms of the content of the provisions of the Convention and mobilization for its adoption. In turn, the AIDS response potentially has much to gain from the normative and institutional framework, and the expanded commitment to realizing the right to health that can be generated under such a Convention.

TAKING STOCK OF SUCCESSES AND CHALLENGES IN THE RESPONSE TO HIV

Contributions of the HIV movement to the realization of human rights, development, and social justice

The HIV movement has made critical contributions to supporting the realization of human rights, development, and social justice. In the earliest years of the epidemic, when scientists and politicians were struggling to understand a new virus and how it could be contained, the most affected communities began to respond, in order to both provide care to and meet the needs of those infected and to challenge the denial, stigma, and moral judgment that was spreading faster than the epidemic itself.⁴ Recent films such as “How to Survive a Plague” and “United in Anger” have documented the US-based activism from these early days.⁵ In 1983, a group calling itself the Advisory Committee of People with AIDS produced a document called the “Denver Principles,” assert-

ing the right to involvement in policymaking and to access quality treatment and care. In what was then a very radical and bold position, the Principles rejected the many attempts to render people living with HIV as the “problem” or label them as “victims.”⁶ Over a decade later, at the Paris AIDS Summit, the principle of the “greater involvement of people living with HIV” (widely known as GIPA) was formally recognized, and the governments and civil society representatives in attendance committed to making the greater involvement of those affected central to national responses and HIV-related international cooperation efforts.⁷

The political commitment to strengthen HIV responses was slow to emerge, resulting in the tragic, silent, and unrecognized infection of millions of people, many of whom died horrible deaths before the advent of treatment. However, unprecedented political commitment was finally achieved. The United Nations General Assembly at the Special Session on HIV/AIDS in 2001 marked a turning point. This session led to the adoption of the first Declaration of Commitment on HIV/AIDS, and was followed by a monitoring framework and support from UNAIDS—the Joint United Nations Programme on HIV/AIDS—to countries when preparing national reports on progress against their commitments.⁸ This typically included support to national, multi-stakeholder consultations to review progress and challenges, with the active participation of networks of people living with HIV and other civil society organizations.⁹

To enhance the prospect of achieving the political commitments, a new funding mechanism was developed. In 2001, the Global Fund to Fight AIDS, Tuberculosis and Malaria was established as a “war chest” to fight diseases of poverty. It was radical in that it pooled bilateral contributions into a common fund, gave countries the opportunity to articulate their needs and strategies in funding proposals and receive funds on that basis, and enabled civil society to be both “principal recipients” of grants and participate fully in Global Fund governing structures. Former UN Secretary-General Kofi Annan called on countries to “commit to the fight against AIDS and to make it a priority in their national budgets.”¹⁰ The political commitments, together with a new funding mechanism, translated into significantly increased resources for HIV. By 2011, there was US\$16.8 billion available for AIDS responses globally, of which

US\$8.2 billion comprised international investment.¹¹ This represents a tenfold increase from the US\$1.6 billion available for the HIV response in 2001.¹²

International financing reflects an unparalleled global compact whereby high-income countries have committed to provide life-saving health interventions to those in need, including lifelong treatment, in low-income countries. The HIV response has raised the bar, showing what can and should be accomplished through serious global solidarity and commitment. Rather than entertaining cries of “too much money for HIV,” there should be calls for the bar to be similarly raised for other health and development challenges.¹³ The resources are there in a world where military spending is an estimated US\$1.738 trillion—13 times what is invested in official development assistance—and where between 2008 and 2011, European countries committed EUR 4.5 trillion, over one-third of European Union economic output, to rescue their financial institutions.^{14,15}

Just as the HIV response has pushed the notion of the human right to “international assistance and cooperation,” it has also pushed governments to realize their human rights obligations to their citizens by greater domestic investment in HIV.¹⁶ Indeed, in 2011, domestic resources exceeded international investments for the first time. Institutionally and politically, this trend was reflected in a shift toward the norm of shared responsibility and global solidarity. For example, in 2012 the African Union adopted the Roadmap for Shared Responsibility and Global Solidarity for AIDS, TB, and Malaria in Africa. The Roadmap makes AIDS a pathfinder for TB, Malaria, and other diseases in establishing a new paradigm of responsibilities for results.

The response to HIV has also demonstrated that the process is as important as the outcome. By demanding that those living with and vulnerable to HIV be active agents of change rather than passive recipients of assistance, the response has focused on setting up procedures by which participation has been supported. This ensures that funding for civil society action and engagement is available and challenges governments when they fail to protect human rights and medical ethics in the response. Furthermore, the stigma generated by the epidemic resulted in legal and human rights activism that demanded that HIV-related discrimination be recognized as prohibited and be made illegal. This activism often took the form of high-profile legal challenges.¹⁷ As of

1990, the UN Commission on Human Rights began adopting resolutions confirming that discrimination based on health, including HIV status, is prohibited by existing international human rights standards.¹⁸ These international standards have been reflected in many national laws and instruments. As of 2010, nearly three-quarters of countries reported having adopted national laws that make HIV-related discrimination illegal.¹⁹ Many have mobilized to measure HIV-related stigma and create programs to reduce it. People living with HIV have developed a tool for assessing the stigma and discrimination they experience: the “People Living with HIV Stigma Index.”²⁰ To date, the Index has been, or is being, implemented in more than 70 countries and has been instrumental in supporting people living with HIV to know and claim their rights.²¹ The findings represent a powerful source of data to inform advocacy efforts and concrete programming to reduce stigma and discrimination in various sectors and at the community level.

HIV activists have also mobilized for the right to treatment, often in the face of formidable resistance from those who argued that scale-up would never be possible in low- and middle-income countries. Strategic litigation and community action have been key elements of effective strategies. Even in environments that were once characterized by denial and reticence, groups like the Treatment Action Campaign were able to secure legal victories that pushed policy change and spurred program expansion.²² In doing so, the right to health became justiciable, pushing the frontiers of economic, social, and cultural rights and transforming aspirations into realities. While at least seven million people today remain in need of treatment and efforts to ensure they have access must be redoubled, the progress to date has nonetheless been impressive. In 2011, over 8 million people in low- and middle-income countries were receiving antiretroviral treatment—a twentyfold increase since 2003. In South Africa alone, there has been a five-year increase in average life expectancy since 2005, which can be largely attributed to the expansion of HIV treatment programs.²³

The HIV response has created space for public dialogue on what have long been “taboo issues” in many societies, notably sexuality, gender inequality, gender-based violence, and sex outside of marriage. These taboo issues often involve “taboo” populations, or those most marginalized in a society—sex workers, people who use drugs, and in many countries,

criminalized LGBT people.²⁴ The HIV movement has brought those most marginalized into the center of the response, unlike many health efforts that tend to reach the easy to reach. There have been notable examples of HIV activists exerting leadership and playing a key role as coalition partners working toward changing laws and practices that have human rights implications beyond HIV. For example, in India, HIV advocacy and service organizations were among those calling for the repeal of Section 377 of the Indian Penal Code, which criminalized consensual sex between men and transgendered people. In 2009, the Delhi High Court overturned the provision in a historic judgment. In Botswana, HIV, human rights, and women’s rights groups worked together to advocate for the adoption of the Domestic Violence Act (2008). In New Zealand, recognizing the role of injection drug use in the transmission of HIV, the Misuse of Drugs Amendment Act 1987 lifted criminal penalties for selling needles and syringes to people who inject drugs.²⁵ This enabled the establishment of needle and syringe programs and other health and social services for people who use drugs. In 2003, also in New Zealand, the Prostitution Reform Act removed criminal penalties for sex work, making it easier for sex workers to organize, access health and social services, and seek the protection of the police when threatened by violence. Such reforms were largely driven by the urgent need to create enabling environments for effective and human rights-based responses to HIV.

The HIV response has demanded that international trade and intellectual property regimes do not stand in the way of the public health. Civil society organizations and low- and middle-income countries were instrumental in mobilizing for the adoption of the Doha Declaration on the TRIPS Agreement and Public Health at the Fourth World Trade Organization Ministerial Conference in Doha, Qatar in November 2001.²⁶ Since the adoption of the Declaration, the use of TRIPS flexibilities has increased generic competition and lowered the prices of HIV medicines in many parts of the world.²⁷ Brazil, Malaysia, and Thailand have lowered the cost of medicines through the use of compulsory licencing. In the case of Brazil, it is estimated that the government’s use of TRIPS flexibilities has saved approximately US\$ 1.2 billion in ARV costs, enabling coverage to be increased considerably. More assertive price negotiation with pharmaceutical companies, often backed by public campaigns by civil society, has

led to significant savings that has in turn protected access to medicines for the poor.

Great progress, but many challenges

While there have been many positive gains in the response to HIV, particularly in the past 10 years, the “unfinished business” of AIDS is daunting. The more than 8 million people in treatment today will need to be sustained on treatment, and will need access to new generations of medicines that are under patent protections and remain prohibitively expensive. Fifteen million people are in need of treatment today based on existing treatment guidelines and only half of them are receiving it. As treatment guidelines are revised to recommend earlier initiation of antiretroviral therapy, many more will be in need of treatment. Thus, there are twin challenges: how to finance and sustain treatment for millions over their lifetime and how to reach people in need of treatment who do not or are not able to come forward for testing and treatment, including the highly marginalized and criminalized. HIV testing, counselling, and treatment programs will have to find innovative and rights-based approaches to overcome such marginalization and criminalization.

Despite everything known about how HIV is and is not transmitted, as well as the transformation of HIV from a death sentence to a chronic, treatable condition, stigma and discrimination regrettably remain widespread.²⁸ At its worst, such discrimination translates into egregious human rights violations. For instance, reports have surfaced in several countries of the involuntary sterilization of women living with HIV.²⁹ Such violence is a direct affront to the human rights and dignity of women living with HIV, to medical ethics, and to the science that has provided an effective and inexpensive means by which to enable women living with HIV to bear children free of HIV and live to take care of them. Developments in anti-retroviral medicines and prevention of mother-to-child transmission programming have resulted in the virtual elimination of vertical HIV transmission in high-income countries. There is global mobilization to make this a universal reality by 2015.³⁰ The stigma and moral judgement affects not only people living with HIV, but also people vulnerable to and at risk of infection, including sex workers, people who use drugs, men who have sex with men, and transgender people. While there are aspirations to have greater integration of HIV programs with primary health care, such integration will only be viable if health ser-

vices are people-centered, without prejudice and violence. Programs to reduce stigma and discrimination in health care, among police, and in communities, as well as programs to increase access to justice in the context of HIV will require greater investment.³¹

While there have been positive developments to reform legal and social environments, making them more protective and inclusive of people living with and affected by HIV, there are also signs of a resurgence in punitive laws and law enforcement. A number of jurisdictions are considering or have adopted “anti-homosexuality” legislation.³² Sex workers have been subject to police violence perpetrated in “raid and rescue” crackdowns.³³ People who use drugs and the doctors who serve them have been the subject of police interrogation and harassment.³⁴ Such challenges show the importance of broad, multi-sectoral engagement with governments on matters that affect the health of the population. This must include Ministries of Interior and Justice, among others.

There remains a serious deficit in political will when it comes to addressing the health and human rights of prisoners and people in pre-trial detention. This is the case despite the fact that governments face even higher responsibility to populations that are completely dependent on public institutions for their well-being and survival. The crisis of HIV and tuberculosis co-infection in prison and other closed settings is not only a major and ignored human rights violation, it also ultimately becomes a community-level public health crisis, as people return to their families and communities from custody.³⁵ Future health and development priorities must be inclusive and address the rights and needs of people who face the greatest marginalization.

Health and social systems have generally failed to keep up with developments in migration and mobility.³⁶ Globalization has increasingly made international migration a normal part of life. In 2010, the estimated number of international migrants was 214 million, up from 191 million in 2005.³⁷ Yet, people on the move generally face poor access to health and social services. Some countries retain approaches to HIV and mobility that are grounded in the irrational fear of the 1980s, when little was known about HIV, and the ineffectiveness of their attempts to try to stop it at the border persist. As of January 2013, there are still 44 countries, territories, and areas that maintain some form of HIV-related restriction on entry,

stay, and residence. To be effective in the response to HIV in the context of migration, countries will need to expand prevention, treatment, care, and support to people on the move. The health and social needs of migrants, of course, go far beyond HIV.

There is growing momentum for taking a hard look at the global track record on drug control and the lack of investment in drug dependency as a health issue.³⁸ Unless there is a major political and programmatic shift in this area, there will continue to be needless new HIV infections among people who use and inject drugs. Success in this area will require the work of a broad coalition, bringing together people who use drugs, healthcare workers, and courageous political leaders. The challenge goes beyond the HIV response, but it is one where HIV activists have a critical contribution to make in achieving quality, evidence-based and human rights-based treatment, care, and support for people who use drugs.

Over 30 years of experience in the response to HIV has illustrated that the virus thrives in situations of inequality, exclusion, deprivation, and human rights violations.³⁹ HIV has shown that, if health and development gains are to be achieved, critical linkages cannot be ignored. Health, dignity, and security are intrinsically linked. For instance, while there have been great strides in expanding access to treatment, we have also seen that treatment outcomes are greatly influenced by factors such as sustained access to nutritious food, legal status, rural versus urban location, and conflict versus peace.⁴⁰ Success in the next phase of the HIV response will increasingly necessitate broader health, social development, and security gains, to reduce vulnerability to infection and, if living with HIV, to enable people to live well with the virus. As such, this requires much greater investment and progress to achieve gender equality, to eliminate violence, to ensure food security, to reach universal childhood education, and to guarantee livelihoods and social protection and security for individuals and families.

While we have seen unprecedented gains in health and life expectancy resulting from HIV investments, as well as other positive impacts of the response in terms of greater participation and inclusion of civil society in policy making and programming, there has been increasing uncertainty and trepidation about whether HIV investments will be sustained in the medium term. Many traditional donors have come

under pressure due to the global financial crisis and have targeted development spending for cuts. In 2011, there was US\$133.5 billion in official development assistance available globally, which represents a drop in real terms of 2.7% from the previous year.⁴¹ Many actors across the health and development sectors feel increasing pressure to compete for limited resources. HIV is helping to push for innovative financial solutions that mobilize resources for health, development, and human rights—such as a financial transactions tax—in line with the scale of the challenges faced by the people of the world.⁴²

THE FRAMEWORK CONVENTION ON GLOBAL HEALTH: HOW CAN IT SUPPORT THE HIV RESPONSE?

Recent progress in reducing new HIV infections and, particularly, in expanding access to effective HIV treatment is creating a sense that the “end of AIDS” is within reach.⁴³ However, as discussed above, the epidemic is not over and there is much hard work to be done to stop new HIV infections, reach all those in need of HIV treatment, and sustain them through their lifetimes. But the fragile world economy and other compelling global priorities threaten global and national commitments to sustained responses to HIV.⁴⁴ In addition, despite the global commitments that already exist, approaches to HIV that are *not* evidence-informed or rights-based continue to be promoted and implemented.

As the HIV epidemic increasingly exposes entrenched social, cultural, and legal structures of vulnerability to HIV, lack of and inequitable access to HIV services, between and within countries, it is clear that any meaningful and lasting response to this epidemic must address broader national and global policy challenges and structures.⁴⁵ For instance, how can we tackle the world’s fastest growing HIV epidemics in Eastern Europe and Central Asia without a reconsideration of global and national drug policies that continue to deny people who use drugs effective harm reduction services, including treatment for drug dependency, and subject them to incarceration in conditions that expose them to higher risk of HIV and TB infection?⁴⁶ How can we sustain access to HIV treatment for the millions of people on antiretroviral treatment today within the current intellectual property right regime, which maintains high prices for key medications?⁴⁷ How can we take forward access to HIV prevention, treatment, and care services for sex workers in contexts where con-

doms are used as evidence for criminal prosecution for engaging in illegal sex work, where police, in fact, rape sex workers, and where stigma and discrimination in health care facilities and communities stop sex workers from seeking HIV testing and treatment?⁴⁸

As it is currently framed and described, the FCGH may offer some solutions to the above challenges that are essential to sustaining focus on, and commitment to, addressing HIV, as well as other critical health challenges.⁴⁹ Seminal publications that describe the objectives, approach, and possible content of the FCGH point to several distinctive features in this proposed instrument.⁵¹ For instance, Gostin posits that the main “modalities” of the FCGH would include “defining national responsibilities for the population’s health; defining international responsibilities for reliable, sustainable funding; setting global health priorities; coordinating fragmented activities; reshaping global governance for health; and providing strong global health leadership.”⁵² Friedman and Gostin argue that the FCGH would be critical to building the following pillars for advancing global health through national legal and policy reform incorporating right to health obligations and principles: litigation, using creative legal strategies, enhanced training, and promotion of progressive judgments to increase courts’ effectiveness in advancing the right to health; civil society and community engagement, empowering communities to understand and claim this right and building the capacity of right to health organisations; and innovative global governance for health.⁵³ These various features can be summarized into three aspects that show how the FCGH can contribute to advancing the response to HIV and global health, namely: (a) the establishment of clear health-related goals and commitments for national action, (b) the strengthening of justiciable health rights and obligations through a binding international instrument, and (c) the creation of a mechanism for monitoring and supporting progress.⁵⁴ Below, we briefly present these features and discuss how they can benefit the HIV response and global health.

Establishing clear health-related goals and commitments

Goal-led approaches to health challenges have proven instrumental for mobilizing national and world attention on health issues and for generating financial, human, and other resources for addressing them. Specific, measurable, and communicable health goals in the MDGs—the world’s blueprint document for development—were critical to bringing attention

and channelling resources towards key development concerns, including HIV.^{55,56} In the context of HIV, the framing of global and national commitments into specific goals has helped rally, intensify, and measure national and global programs and actions. For example, the 2011 Political Declaration on HIV and AIDS adopted by all UN Member States at the UN General Assembly High-Level Meeting on AIDS, articulates, among others, 10 targets or commitments for action by governments and other stakeholders involved in the HIV response.⁵⁷ These include: reducing sexual transmission of HIV by 50% by 2015, reaching 15 million people living with HIV with lifesaving antiretroviral treatment by 2015, and eliminating HIV-related restrictions on entry, stay, and residence by 2015.⁵⁸ These targets and commitments help focus and drive action, and facilitate accountability for results in the response to HIV.

The goal-oriented approach suggested in the FCGH is therefore potentially very useful. It would elevate and expand the general commitment to health by turning health goals into clear and concrete obligations.⁵⁹ Furthermore, by consolidating key global health objectives and goals within a single instrument, the FCGH offers an opportunity to address fragmentation and to ensure the alignment of health targets. The FCGH should not, however, simply compile various health objectives and targets; an effective FCGH should offer an opportunity to delineate linkages and foster greater integration and mutual reinforcement between health fields and goals.

The goals to be identified by the FCGH should focus on key determinants of (ill) health, and articulate the links between health, dignity, and security.⁶⁰ The selection of these goals should be the result of evidence-informed assessments on what are the critical issues that impact individual and global health. The goals to be projected through the FCGH should be ambitious yet achievable ones. They should be bold enough to illustrate and seek to address the dismal inequalities and inequities in global health, and create the conditions that support an informed and vibrant civil society for advancing the right to health.

Beyond the goals, the FCGH should also suggest key orientations to achieve the goals: a path to the results. The FCGH should clearly put an emphasis on the principles of inclusion, including of young people and women, participation, non-discrimination, and accountability as being critical to achieving

and measuring global health.⁶¹ Lessons from the HIV response show that in the pursuit of health, certain governments and stakeholders simply ignore key human rights principles of participation and inclusion while others push for approaches or programs that infringe upon human rights. For instance, poorly framed and insensitive drives to achieve HIV testing targets have been shown to increase the risk of forced testing and violation of confidentiality, and to lead to poor uptake of HIV treatment and care.⁶²

Strengthening health rights and commitments through a binding international instrument

A binding FCGH offers a great opportunity for turning a broad spectrum of health goals and commitments into concrete government obligations that require action and accountability.⁶³ A number of existing global human rights instruments recognize and protect the right to health as a general right for every individual (for example, the Constitution of the World Health Organization and the International Covenant on Economic, Social and Cultural Rights) and also as a right that benefits specific populations and groups (for example, the Convention on the Rights of the Child for children).^{64,65,66} Regional human rights instruments, such as the African Charter on Human and Peoples' Rights and the Protocol to the African Charter on the Rights of Women, also guarantee the right to health.^{67,68} National constitutions and legislation in several countries further complement these legal protections of the right to health.⁶⁹ The current national, regional, and global norms on the right to health have proven to be important tools for demanding and achieving better health. At national and international levels, civil society organizations have successfully challenged denial of health services and secured access to health care services for specific groups.⁷⁰ Realizing access to antiretroviral treatment for prisoners in South Africa was possible through litigation based on the constitutional protection of the rights to health under the 1996 constitution.⁷¹ Access to effective and humane health care for people with mental disability was upheld by the African Commission on Human and Peoples' Rights using the existing framework of the right to health under the African Charter on Human and Peoples' Rights.⁷² Similarly, the Inter-American Commission on Human Rights used the norms in the relevant regional human rights treaties to issue an order compelling the Government of El Salvador to provide antiretroviral treatment to people living with HIV.⁷³ Existing human rights instruments have also

been powerful advocacy tools used to hold governments accountable for their health obligations.

In spite of all their benefits, the current international and national norms on the right to health suffer from limitations. First, these norms are mostly made of general pronouncements about entitlements of individuals in relation to health, and key principles that should govern the realization of the right to health, such as non-discrimination and equal access.⁷⁴ Though useful, this framework lacks specificity to concretely advance action on key health issues. For instance, affirming that all individuals have the right to health care services is not as specific and useful as affirming that actions must be taken to end new HIV infections among children by 2015.

Secondly, the current legal and human rights framework relating to health is often ignored in legislation and policy dealing with specific health issues. The experience from HIV-related law effectively illustrates this situation. Many of the laws adopted by countries to address HIV ignore sound public health evidence and contradict human rights principles.⁷⁵

Thirdly, existing legal frameworks on health are generally narrow in focus and, too often, fail to comprehensively address other legal issues that may impact health and access to health services including poverty, gender, or housing. Finally, practical aspects of the prevention and management of health are yet to be enshrined in comprehensive and binding instruments that reflect commitments and accountability for global health, including through effective national and global institutions and mechanisms.

An effective FCGH should address these limitations, including by ensuring that global principles are appropriately reflected into national laws and policies. The FCGH should also elevate the right to health and offer a framework for addressing other legal issues of significance to health such as intellectual property law and international trade law. These may prove to be critical challenges. For instance, recent studies on the implementation of the WHO Framework Convention for Tobacco Control suggest that conflict between trade law and public health—and the lack of national enforcement of the Convention—are among the key difficulties hindering its effective implementation.⁷⁶ The FCGH should anticipate and offer specific means to address these concerns. In particular, the pre-eminence of public

health over trade should be expressly provided in the provisions of the FCGH and effective, easy-to-use mechanisms for its enforcement should be spelled out. The FCGH must also provide for a mechanism that supports implementation, including through measures such as a time frame for adopting effective legislation and technical assistance to support countries to adopt such legislation.

The FCGH should position health as an actionable right with clear obligations by governments in relation to addressing the determinants of health. This actionable application of health should frame health in a manner that provides clear obligations to states on what they should do in order to achieve health goals. For instance, in relation to improving women's health, especially in low- and middle-income countries, the FCGH should not be limited to the reiteration of government pledges to increase women's access to health care services. The FCGH should spell out clear obligations for states, including: improving health literacy among women, addressing social, cultural, and other norms that hinder women's access to health care, and reducing violence against women. Insight from the HIV epidemic reveals that reducing women's vulnerability to HIV infection and increasing their access to HIV prevention, treatment, care, and support services are facilitated in contexts where harmful social, cultural, and legal norms do not act as barriers.⁷⁷

As discussed above, there is much that an FCGH can bring to efforts in strengthening health rights and commitments. However, as we strive to make it a reality, we must be mindful that the quest for a global instrument on health also involves risks that deserve attention. First, recent developments on multilateral health-related negotiations and within global health and other bodies reveal powerful and well organized advocacy for ideological and cultural orientations which contradict sound scientific and medical evidence, as well as rights-based approaches. For instance, negotiations for the development and adoption of the 2011 Political Declaration on HIV and AIDS has shown the difficulty of reaching consensus on naming key populations at higher risk of HIV infection and addressing their needs, because of the legal status of members of these groups (sex workers, men who have sex with men and people who use drugs) in many states. Provisions addressing sexual and reproductive health and rights are heavily negotiated. Such difficulties augur the complexities

and compromises that may be involved in reaching a global treaty that would regulate key aspects of health that are considered controversial by some. It is reasonable to fear that the stakes of a new binding health instrument could render global agreement impossible in relation to many critical issues and populations, or lead to agreement on "low common denominators" which may add little to current efforts; at worst, it could even undermine current global health gains. In anticipation of these challenges, one may wonder whether there is merit in investing time, energies and resources into a global treaty on health that may elude difficult questions or lower existing standards on critical issues.

We believe that the incremental, step-by-step approach suggested for the development of the FCGH offers an answer to this question by recommending that the FCGH be constituted by a main general text supplemented by several protocols that may be elaborated progressively.⁷⁸ In this approach, key principles that should govern global health for all, including the most vulnerable and marginalized, such as criminalized populations, would be defined in the general text, while specific legal protections for these populations, as well as other potentially difficult issues, may be addressed in subsequent texts or protocols. The risk with this approach is that such protocols may be delayed.

Creating a mechanism for monitoring and supporting progress on global health

The FCGH suggests a mechanism for monitoring and supporting progress on global health at national and global levels.⁷⁹ Reflecting on experience in the response to HIV, such a mechanism would be instrumental to driving results and ensuring ownership and accountability for governments and others. This monitoring mechanism should be based on a transformed global health structure that allows for a better representation of the diverse voices of states and of civil society, as well as a radical simplification of the architecture organized around the functions of norm development, financing, and advocacy and accountability.⁸⁰ As it currently operates, the global health structure often amplifies the voices and powers of high-income states as agenda-setters and marginalizes many low-income states. Civil society often is neither present nor adequately resourced to have a meaningful role in these mechanisms. A "status quo" global health governance structure is unlikely to serve as an effective monitoring mechanism. This

issue should be addressed up front as part of efforts to establish an effective monitoring process through the FCGH.

The concept of shared responsibility and global solidarity championed in the context of HIV offers critical lessons, pathways, and a powerful vision that can inform the transformation of the current global health structure and efforts to bring about effective monitoring and support mechanisms through the FCGH.⁸¹ Shared responsibility and global solidarity is an approach that emphasizes that all countries—rich, poor, big, or small—have obligations and responsibilities in realizing global health.⁸² It offers a new approach to advancing global health accountability and financing that does not dichotomize funders and recipients, but provides a framework for achieving mutually agreed goals and results with clearly defined roles and responsibilities for each stakeholder. Shared responsibility further breaks barriers between donors and recipients by committing all governments to fill health investment gaps based on “ability and fair share.”⁸³ This approach builds on the international and domestic responsibility to realize human rights enshrined in human rights treaties. It is an approach that has the potential to mobilize all actors around clear results and a framework for accountability and should be considered in devising the monitoring mechanism under the FCGH.

An effective FCGH should also ensure that the voice of civil society and especially of communities and individuals affected are not lost through yet another multilateral treaty with governments at the center and civil society at the periphery, relegated to the role of ignored critics. The FCGH should strengthen mechanisms that enable continued dialogue between all stakeholders – government, civil society, and the private sector—and must guarantee broad engagement at national and global levels in monitoring and supporting progress. At the national level, these mechanisms could include existing bodies responsible for setting and monitoring health priorities and results within the ministry responsible for health. Some of the major achievements in the HIV response have been made possible thanks to the voices and actions of civil society and communities affected as actors on the ground supporting some of the most innovative and effective responses to HIV, and also as watchdogs ready to denounce, agitate, or litigate to address issues of concerns in the response.

Mobilizing the HIV community for the FCGH

Over the 30 years of the HIV epidemic, the HIV movement, led by people living with HIV, has built strategic alliances and seized opportunities for advancing health, dignity, and security for people living with HIV and those affected by HIV. An example is the manner in which HIV activists have used disability protection at a national level to challenge discrimination based on HIV status, have joined disability rights activists in support of the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, and are pushing for access to HIV prevention, treatment, care, and support services for persons with disabilities.^{84,85}

Current efforts toward an FCGH offer another opportunity to the HIV movement to advance broader health causes of significance to the HIV epidemic. HIV activists have already seized this opportunity and are engaged in alliances and groups that champion the FCGH. The Joint Action and Learning Initiative—the main global alliance advocating for the FCGH—includes several HIV activists and experts.⁸⁶ In 2011, HIV activists joined with other health experts and advocates for a meeting in Johannesburg in support of the FCGH.⁸⁷

The support of HIV activists and experts for the FCGH illustrates the long held position, among HIV stakeholders, that HIV is an indicator of broader health disparities and challenges that can only be addressed through attention to social, legal, and economic issues. In 2011, one of the world’s foremost HIV legal groups, the AIDS Law Project in South Africa, was transformed into Section 27, an organization with a broader focus on health, food, water, social security, and other socioeconomic rights issues. The name “Section 27” was adopted in reference to Section 27 of the South African Constitution, which guarantees various socioeconomic rights – including health care services; sufficient food and water; and social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.

Current awareness and support within the HIV community for the FCGH has the potential to be expanded, in particular by highlighting the opportunities that exist to build a broad coalition that seeks to galvanize commitment and investment in the “forgotten frontiers” of global health. There is a need for specific

outreach efforts from the proponents of the FCGH towards members of the HIV community and other HIV stakeholders to highlight the potential benefit of the FCGH in advancing shared objectives. The FCGH represents an opportunity for shaping the end of AIDS and providing a new direction for global health. It is essential that the HIV community, in its diversity and entirety, becomes part of this endeavor.

CONCLUSION

In this article, we have illustrated the pioneering achievements of the AIDS response and movement in introducing, demanding, and reinforcing a range of human rights norms, standards, and protections. In so doing, the AIDS response has contributed greatly to making health justiciable.

The enormous progress that has been achieved, particularly in the past 10 years, is in large part due to the robust accountability mechanism that has been put in place, and whose most prominent feature is the central involvement of people most affected by the epidemic – from the community up to the UN General Assembly level. While communities and civil society are at the heart of this system, strong partnerships involving scientists, multiple sectors of government and others support the system, among other things, through ensuring that systems for monitoring, evaluation and reporting are implemented.

Yet, AIDS is not over and those living with and affected by HIV are determined that their rights be further protected, extended, and secured in more robust legal regimes.

There are reasons to believe that the FCGH would serve to further advance global health, including by establishing clear health-related goals and commitments for national action, strengthening health rights and obligations through a binding international instrument, and creating a mechanism for monitoring and supporting progress in improving health for all.

Given the potential of the FCGH, UNAIDS has joined a broad alliance of progressive proponents of global health to work towards its realization.⁸⁸ It is our view that all people who struggle for universal access to HIV prevention, treatment, care, and support should join others who are working equally passionately to put in place a global framework that would serve their cause as well as those of others.

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85. OHCHR, WHO, and UNAIDS, *Disability and HIV: Policy brief* (April 2009), oo. 1-8. Available at http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf.
86. Gostin et al. (2011, see note 51).
87. Section 27 "SECTION27 hosts groundbreaking Southern African regional activist dialogue on a proposed Framework Convention on the Right to Health (FCGH)" (March 2011). Available at <http://www.section27.org.za/2011/04/08/southern-african-regional-dialogue-on-the-right-to-health/>.
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