

Backing Civil Society to End the **AIDS**, **Tuberculosis** and **Malaria** Epidemics



FRIENDS
OF THE GLOBAL FIGHT
AGAINST AIDS, TUBERCULOSIS AND MALARIA

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Summary

Around the world, **civil society** plays a critical role in the global fight against the **HIV/AIDS**, **tuberculosis (TB)** and **malaria** epidemics.

Civil society is central to the effective and equitable response to the global fight against HIV/AIDS, tuberculosis (TB) and malaria. It helps ensure that country investments in programs are held accountable, that progress is monitored, that aid reaches the populations most in need, that voices of the most vulnerable and stigmatized populations are included at the table and that a path for a country's transition from aid is viable. Put simply, civil society is key to eliminating these three deadly diseases.

Much of the progress made by civil society* is due to robust support by the U.S. and other major international donors. The U.S. should continue to back civil society. Investing now to bolster civil society's capacity and reach will save lives and advance progress toward the epidemiological control of HIV, TB and malaria.

We must recognize, however, that civil society is increasingly under attack in certain regions across the globe, imperiling the significant progress that has been made to end the epidemics for good. It is incumbent on the U.S. and its partners—such as the Global Fund—to strategically apply their considerable diplomatic and financial leverage to ensure that civil society can continue to do its essential work.

*The Global Fund uses the term "civil society" to "designate all those stakeholders who are neither government bodies nor private sector enterprises: groups such as nongovernmental organizations (NGOs), advocacy groups, faith-based organizations [and] networks of people living with the diseases."¹

In March 2018, a group of experts across civil society, the faith community, the private sector and government convened in Washington **to examine the role of civil society in:**

1. Helping to reach vulnerable, stigmatized and other difficult-to-reach populations.
2. Gathering data and advancing understanding of the three diseases (HIV/AIDS, TB and malaria).
3. Conducting critical advocacy work to expand and improve programming and research.
4. Helping affected communities in nations preparing to transition toward greater ownership of disease responses.

This report discusses these topics and offers recommendations on how civil society efforts can be supported and strengthened.



Source: The Global Fund

Civil Society: An Essential Investment for the U.S.

As the leading donor to the Global Fund and as the country that launched the transformative U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the U.S. is uniquely positioned to advocate for civil society as an essential partner in the fight against HIV/AIDS, TB and malaria. To do so, the U.S. government needs to deploy its resources in combination with the full spectrum of its international voice and reach. U.S. experience with global health programs has demonstrated that an investment in civil society is an investment in saving lives. As PEPFAR stated in its 2017 Report to Congress, "PEPFAR encourages the full participation of civil society in every stage of our programming and planning, from advocacy to service delivery, as it is a key to the success and sustainability of PEPFAR and the global effort to combat HIV. Civil society has been a leading force in the response to HIV since the beginning of the epidemic, and this longstanding involvement has resulted in expertise and relationships with local communities that nonindigenous organizations often struggle to achieve. It is critical to ensure that community and civil society are meaningfully engaged and have a voice at the decision-making table."²

Investing in civil society is an impact multiplier. And the Global Fund has proven to offer unique added value in this key area of epidemic response.

Civil Society and Improved Outcomes

Civil society engagement in decision-making helps programming be more effective and responsive to people's needs. The decision by PEPFAR to more fully engage civil society in South Africa's country operational plan (COP) development is a case in point. Experts note that the inclusion of civil society made a genuine difference in helping to spotlight the needs of marginalized populations by opening the door for candid feedback on regulations that were ill-fitted to local contexts in the country. It also bolstered the case for an evidence and human rights-based approach to programming.³ Additionally, interviews with civil society organizations in Georgia, Kyrgyzstan and the Ukraine found that, in some cases, government officials emulated professional best practices from civil society.⁴ One analysis found that community organizations, acting

as primary recipients of Global Fund grants, received more top-rated evaluations (e.g., "Exceeding Expectations" or "Meeting Expectations") than comparable grants awarded to governments acting as primary recipients.⁵

Another study found that the push for the presence of affected populations in Country Coordinating Mechanisms (CCMs)—the national partnership created in each country to submit Global Fund applications and track grant implementation—has helped Global Fund programs reach target populations more effectively.⁶

Civil society's presence on important governing forums like the CCMs and the UNAIDS Programme Coordinating Board strengthen efforts to combat the three diseases. For PEPFAR, civil society has been a "leading force ... since the beginning of the epidemic," providing the comparative advantages of localized expertise and networks.⁷ The Global Fund has facilitated the integration of civil society voices in decision-making and ultimately strengthened accountability even in very challenging settings, according to a 2014 Council on Foreign Relations study.⁸ The U.S. and international community must incentivize trust and relationship building among different stakeholders—particularly within an implementing government—in order for civil society to ensure an effective disease response, and accelerate it.⁹

Saving Lives by Reaching Vulnerable and Stigmatized Populations

Civil society is often able to reach vulnerable, stigmatized and neglected communities with services more readily than governments and other providers. One former head of state of an African country notes that civil society can sometimes move faster than governments by sidestepping onerous bureaucratic hurdles that can inhibit implementation.¹⁰ Moreover, when more mainstream facilities in a country are unavailable, community-based services offered by civil society often work to fill gaps, providing a crucial lifeline to those in need. In Ecuador, civil society organizations supported by the Global Fund created opportunities for community peer educators to serve patients outside of official clinics.¹¹

An NGO in Kenya, “Keeping Alive Societies Hope,” brought together representatives of marginalized groups and the Kenyan police for an advocacy meeting that helped reduce stigma in the community.¹² Moreover, Malaysia, Nigeria and Rwanda explicitly mentioned the need to consult community groups and civil society in health programming during the 2017 U.N. High-Level Political Forum.¹³ Nonetheless, much

[F]ull participation of civil society in every stage ... is key to the success and sustainability of PEPFAR and the global effort to combat HIV.

work remains to be done, particularly when addressing the needs of key populations. Widespread stigma and discrimination, state and non-state violence and harassment, restrictive laws and policies, and criminalization of behaviors or practices put key populations at heightened risks and undermine their access to services. Gay men and other men who have sex with men, sex workers, people who inject drugs, transgender persons, prisoners and other groups are generally included in the definition of key populations—demographic groups that experience both increased impact from AIDS, TB or malaria and decreased access to services.

Civil society can act as a potent voice for social moderation by creating environments that support vulnerable individuals’ dignity and agency. The International Council of AIDS Service Organizations and the AIDS and Rights Alliance for Southern Africa cite many roles beyond traditional service delivery, including “dialogue and engagement, community mobilization, advocacy, community monitoring and efforts to improve social and structural determinants of health, such as human rights and gender equality.”¹⁴

For example, in the early period of the HIV/AIDS epidemic in Africa, civil society helped to address taboos in local communities and faith groups. Faith-based groups can also help communities eschew stigma. Today, faith communities deliver a sizeable proportion of health services. One example, The Churches Health Grants Association of Zambia

(CHAZ), is a leading distributor of Global Fund commodities, including those that combat HIV/AIDS. CHAZ has placed more than 40,000 people in Zambia on life saving HIV anti-retroviral therapy.¹⁵

Through awareness campaigns, civil society also educates communities on the importance of reducing harmful practices that potentially spread disease and violate basic rights. In Ghana, civil society helped ensure that a legal ban on the medically unsound, traditional practice of “sexual cleansing” young girls was actually enforced.¹⁶ Given that women in sub-Saharan Africa are at a heightened risk of HIV infection—with rates among young women and girls more than double those of young boys and men in that region—civil society interventions that empower women and girls need to be brought to scale.¹⁷ Unfortunately, there is widespread acknowledgement that donors “terribly underfund” such civil society advocacy work.¹⁸

Gathering Necessary Data and Analysis About the Diseases

Local civil society groups also play a vital role for policymakers in gathering and analyzing data. Community representatives can help yield a stronger understanding of epidemic drivers and provide insight into which responses are working and which are not. Additionally, civil society shares its data collection and analysis with international specialists and donors. In Mumbai, India, the NGO “Doctors for You” undertook a study revealing how certain slum rehousing projects are facilitating the spread of TB.¹⁹ Technical experts, civil society, governments and the U.N. have repeatedly acknowledged the need for disaggregated data that take into account the needs of different populations, especially vulnerable communities—all areas where civil society has expertise.²⁰ An engaged civil society also helps lower the probability of a single government agency misusing data to discriminate or stigmatize an affected population.

Civil Society and Successful Country Transitions

There is no substitute for local knowledge or national leadership in efforts to end the HIV/AIDS, TB and malaria epidemics. Increased country engagement in HIV and health programming is central to achieve adequate scale in service delivery, improve the acceptability of interventions, increase domestic investments in health and advance integration of programming with national health goals and systems.²¹

Civil society can catalyze country ownership in part through promoting accountability and transparency among governments and NGOs. As countries transition to country ownership, civil society serves as an early warning system, an innovation hub and a potent advocate for domestic health resources and protection of key populations, particularly for those countries where the road to fully funding their own disease response is many years away.

While increased country ownership is fundamental to long-term progress in global health, too rapid a transition and reduction of donor funding runs the very real risk of undercutting access to services and squandering the potential to accelerate progress in HIV/AIDS and other diseases.²²

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To help countries deal with the gradual transition to country ownership, the Global Fund provides transition funding and program support to countries as they shift from Global Fund grants toward full domestic funding for health programs. The Global Fund's co-financing policy has already spurred countries to commit significantly larger amounts of domestic resources for health. Recent data on domestic investment shows an increase of more than 40 percent in the 2018-2020 funding cycle compared with 2015-2017.

Finally, it is important to note that "social contracting" mechanisms are necessary to enable countries to contract directly with civil society organizations and are an important

first step in investing in civil society service delivery capacity. Under this arrangement, implementing countries work directly with and fund civil society organizations as service providers when the country itself is not ready to take on the task. While social contracting mechanisms are arranged during transitions, they sometimes also remain in place after a transition occurs

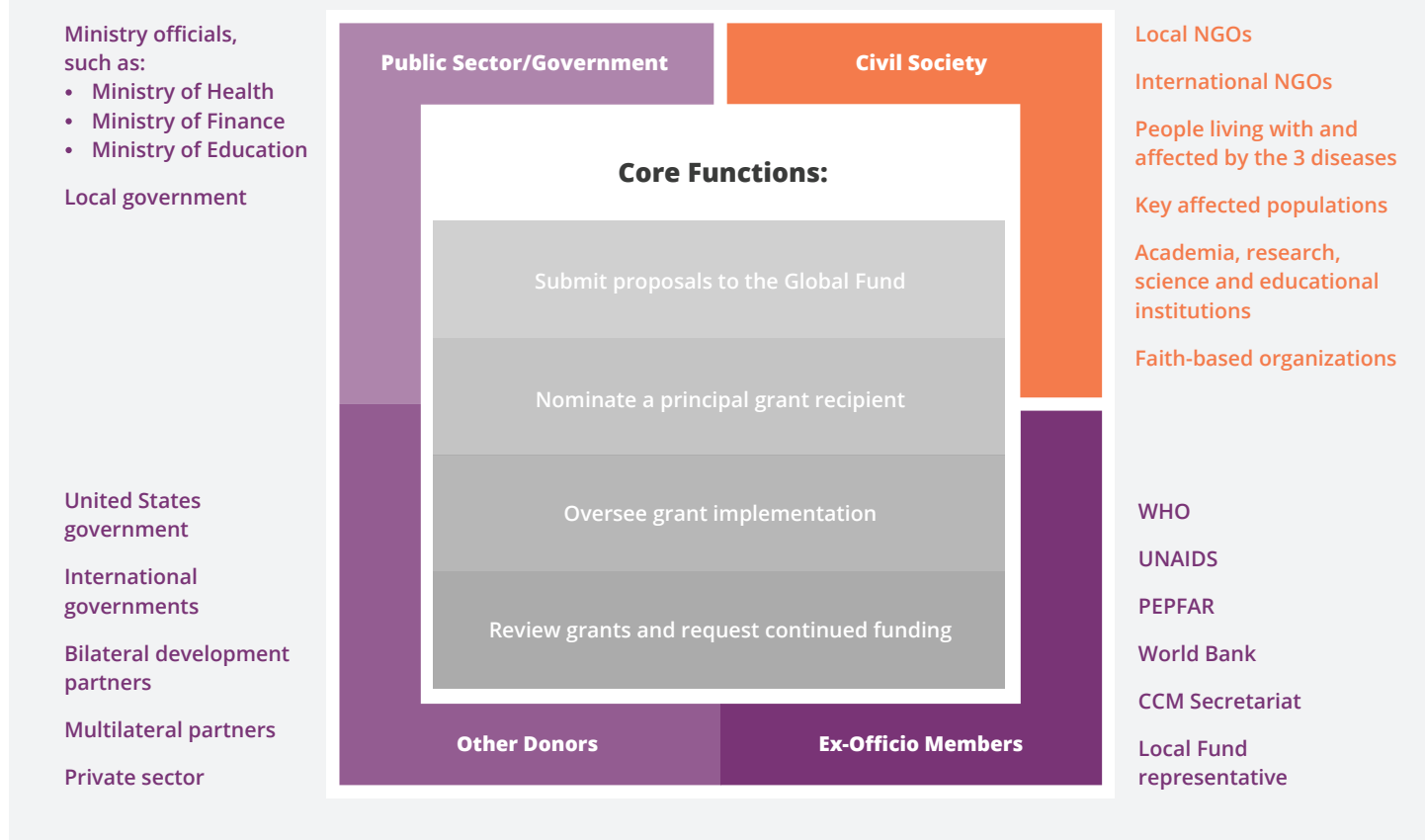
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Boosting Local Ownership

The international community is approaching a critical juncture to help local governments transition to national self-sufficiency. One report estimates that while at least 24 countries are on track to undertake health financing transitions over the next four years, they could face critical gaps in the provision of essential services, especially among vulnerable populations.²³ The same study estimates that 36 countries will face such transitions within a decade. Worst-case scenarios include lapses in immunizations and outbreaks should governments fall off course in their public health efforts. Vietnam, for example, is undergoing financing transitions following improvement in national health outcomes, but progress has been uneven among different regions and ethnic groups.

Some worry about a country's "curse of success." When a country lowers its disease burden, civil society is often defunded during the transition, exacerbating disparities and threatening the fragile progress made thus far.²⁴ Speaking at a Global Fund board meeting in 2018, Prime Minister Zoran Zaev of Macedonia—a nation that successfully transitioned from Global Fund support to independent domestic financing—stressed that civil society helps countries stand on their own in combating these epidemics.²⁵

Global Fund Country Coordinating Mechanism (CCM)



Inadequate transition planning can have dire consequences for service delivery and can put a country at risk for relapsing back into eligibility for Global Fund grants. An important 2017 study examining three countries in southeastern Europe found that poor transition planning created budget gaps and interruptions in services provided by civil society.²⁶

efforts outside of service delivery, such as legal reform, public interest litigation and other advocacy work related to key population equality. Public health experts also warn that funding for service delivery should not come at the expense of advocacy work, since both are essential, interrelated and mutually reinforcing.²⁸

Filling Critical Gaps to Ensure Self-Sufficiency

Many essential advocacy activities are unlikely to be funded by governments and are often absent during country transitions. Civil society groups need support to pursue

Civil Society Under Assault

Despite the multifaceted role that civil society plays in combating HIV, TB and malaria, the space for carrying out this vital work is under assault. In 2017, 109 countries acted to close, repress or obstruct civil society spaces.²⁹ One HIV health policy expert asserts that civil society organizations “are facing one of the most restrictive funding environments of the past 30 years.”³⁰ Reduced funding has restricted civil society’s ability to advance participation, transparency and accountability in its work to both advocate and provide services.

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While civil society can support catalytic HIV/AIDS, TB and malaria responses, it needs civic space to work effectively. Purposeful efforts by some national governments to constrict this space, combined with increased intolerance, have raised barriers for civil society’s work.

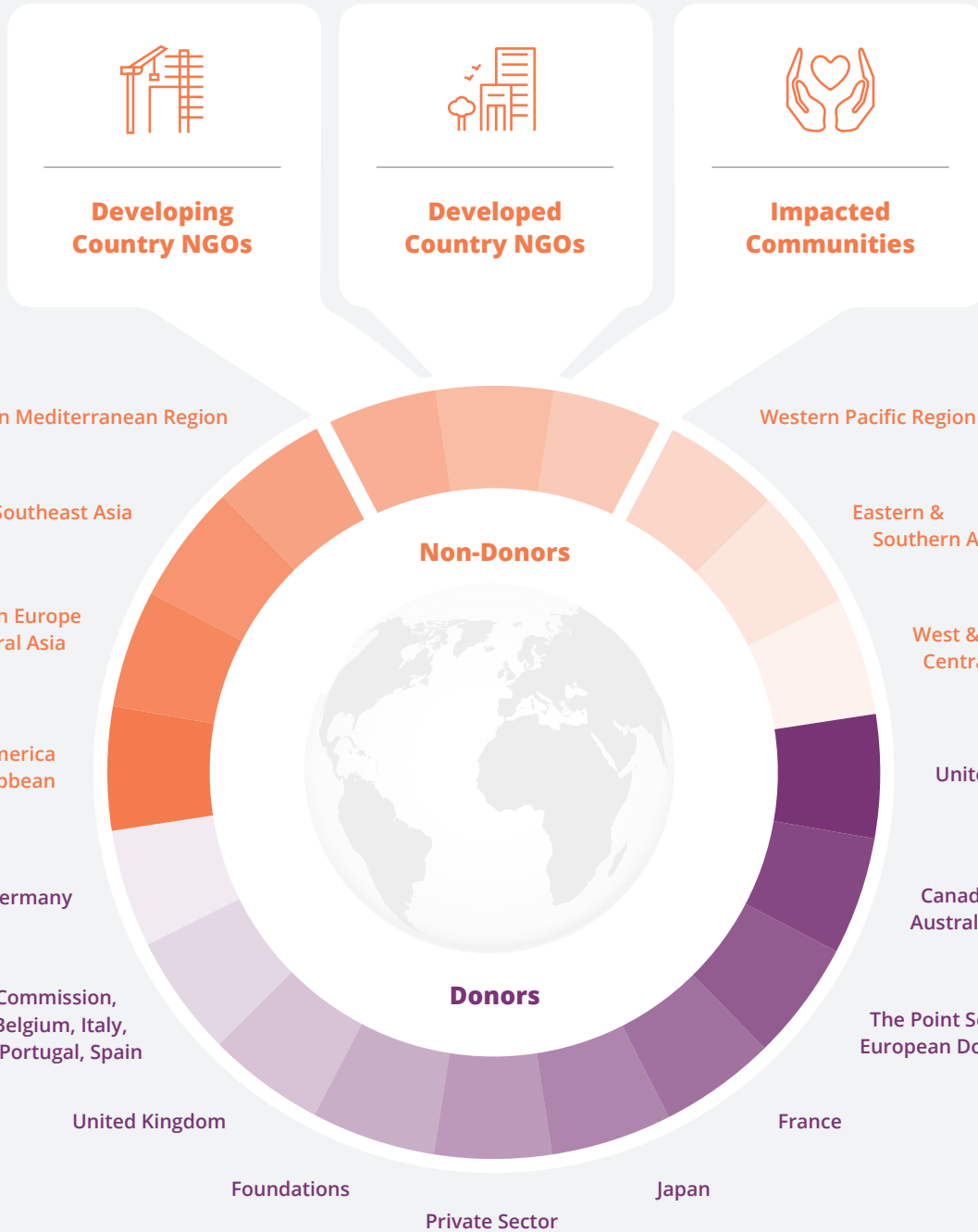
“Leaders need to create an environment where civil society can thrive and be free,” former President of Malawi Dr. Joyce Banda said about effectively combating the epidemics.³¹

The systematic sidelining of civil society not only represents a problem for realizing basic rights and dignity, but also undermines the effectiveness of health programming. In

2011, Ethiopia’s government instituted quotas concerning the operational versus administrative proportions of NGOs’ funding, complicating and slowing anti-malaria efforts. Combined with a particularly restrictive foreign funding law enacted in 2009, the ability of civil society to operate in the country has become more difficult.³² Such actions open the door for neighboring countries to mimic bad practices.

Civil society is working with major global institutions around the world to help ensure that it remains a critical partner in the fight against HIV/AIDS, TB and malaria. Civil society representatives sit on the Global Fund Board and play an active role in the World Health Assembly, the Universal Periodic Review of all member states at the U.N. Human Rights Council, dialogues around the U.N. Sustainable Development Goals and High Level Meetings in the U.N. General Assembly (such as that devoted to TB in September 2018). However, at the U.N., civil society at times faces intimidation and exclusion. Maina Kiai, the former U.N. special rapporteur on the rights to freedom of peaceful assembly and of association, reported that civic groups and LGBT-focused organizations in developing countries face disproportionate hurdles when seeking official U.N. accreditation.³³ In 2016, 22 NGOs—many of which represented marginalized communities—were also blocked from attending the U.N. General Assembly High-Level Meeting on Ending AIDS due to U.N. member state objections.³⁴

Civil Society Voice in Global Fund Board Governance



Recommendations: Strengthening U.S. and International Support for Civil Society

The U.S. has a major stake in empowering civil society to fight the three most devastating infectious diseases. Doubling down on support for civil society will sustain a record of U.S. leadership that includes saving millions of lives globally,³⁵ increasing the prospects of ending the epidemics for good.

Today, 37 million people around the world still live with AIDS, including 1.2 million people in the U.S., with 40,000 newly infected in the country per year. Malaria kills more children than any other disease. One-third of the global population carries latent TB. Rates of TB recently spiked in Caracas,

Civil society must play a central role in the effort to end serious epidemics and expand health services access to all.

Venezuela, and more than 10 million people develop active TB around the world annually.³⁶ In fact, in addition to being the largest infectious disease killer, TB has emerged as one of the top 10 causes of death globally,³⁷ including being the leading cause of death of people with HIV.

Civil society must play a central role in the effort to end serious epidemics and expand health services access to all. The following recommendations suggest ways to support civil society advocacy, engagement and service delivery:

Recognize and Ensure that Civil Society has a Place at the Table in Decision-Making

The U.S. should:

- Reinforce the helpful participation of civil society in the PEPFAR Country Operational Plan process, building on its work in Kenya, Malawi, South Africa, Uganda and Zimbabwe.
- As a member of the Global Fund Board, continue to support the Global Fund's efforts to increase civil society's voice in national CCMs and strongly support funding for technical assistance to civil society.
- Intensify its efforts to back civil society's accreditation and full participation, free of intimidation, with U.N. organizations in Geneva and New York.



Source: The Global Fund

- Ensure that support for civil society includes the funding necessary to stimulate progress in the fight against HIV/AIDS, malaria and TB.
- Along with U.S. embassies and consulates, accelerate building bridges with affected and marginalized populations.³⁸ Diplomacy must emphasize freedoms of peaceful assembly, association and expression to boost civil society inclusion in stakeholder dialogues, as required by the Global Fund.³⁹

Reject Policies that Promote Stigma and Discrimination in All Their Forms

- When implementing countries have discriminatory policies, particularly targeted at key populations, U.S. officials should reject these policies and encourage other countries to also take a stand.
- U.S. and international grant making should back civil society efforts to reduce stigma and discrimination, as well as longer-term, systemic projects advancing social inclusion, fundamental freedoms and good governance in national ownership.⁴⁰ As Global Fund Executive Director Peter Sands notes in *The Lancet*, success in combating these epidemics depends on elevating human rights and addressing gender-based barriers.⁴¹

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Increase U.S. Funding Commitments to the Global Fund and U.S. Bilateral Health Programs

Increased U.S. contributions in the Global Fund and U.S. bilateral programs would assist with:

- Helping governments work with civil society to craft legal frameworks for domestic financing.
- Promoting civil society's advocacy work, including reducing drug prices through pooled procurement.
- Monitoring government health expenditures.⁴²
- Helping build political will to respond effectively to the epidemics.
- Supporting efforts to reduce stigma and discrimination.
- Generating data and analysis to help countries tackle the three epidemics.

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