

A Movement for Global Health Equity?

A Closing Reflection

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This text has stressed that the limited vision of what is currently deemed possible, whether in the halls of power or in the midst of great privatism, is not immutable—just as resources need not always be “scarce” or technologies static. Prevailing notions of the possible may be expanded by new experience, strong partnerships, and strategic advocacy. We have recounted a number of efforts to reimagine the possible in global health, and this chapter will describe a couple more. Some stories are of visionary policymakers; some are about people living with AIDS and their allies, including students; many involve a wide range of individuals and organizations. These are stories of courage in the face of seemingly insurmountable challenges. While moving from inspiration to action may be risky—fraught with unintended consequences—it can be done by accompanying, over the long term, the intended beneficiaries of the action, while cultivating habits of critical self-reflection. One powerful form of engagement in global health work, discussed in chapter 5 but warrants further analysis, links evidence to advocacy and activism.¹

ADVOCACY AND ACTIVISM: GRASSROOTS EFFORTS

Advancing global health equity demands broad-based and transnational movements. Meaningful reforms in domestic and foreign policy rarely come about without sustained advocacy efforts. The roots

of the abolition of the slave trade in the British Empire in 1807 can be traced to a decades-long grassroots movement spawned by a small group of Quakers and a young Baptist minister.² The anti-apartheid movement targeting the South African government during the 1980s and early 1990s mobilized concerned individuals and groups from the slums of Johannesburg to the campuses of American universities. These and other campaigns highlight the ability of informed and dedicated advocates, including students, to bend the arc of history toward justice a little more rapidly.

The past few decades have also furnished examples of effective global health activism focused on increasing access to modern medicine and advancing a broader movement for social and economic rights. Activists, along with health practitioners, researchers, and policymakers, were a key part of the coalition that reimagined the global AIDS effort—and got the rest of the world to do the same. This chapter briefly reconsiders three notable advocacy campaigns in the recent history of global health.

AIDS Coalition to Unleash Power

The U.S. Food and Drug Administration granted federal approval to the first AIDS drug in March 1987. The long-awaited azidothymidine (AZT)—branded as Retrovir—was soon released by pharmaceutical company Burroughs Wellcome with a price tag of \$8,000 per patient per year. The most expensive medicine in history, Retrovir was inaccessible to many Americans needing treatment, especially the poor and otherwise vulnerable, not to mention those in other countries. Burroughs Wellcome defended the price by citing high research and development costs as well as plans to continue research. But with 33,000 new U.S. cases of HIV/AIDS reported in 1987 and an additional 250,000 then expected by 1991, many urged price reductions to make the drug more widely available.³

People living with HIV/AIDS and their friends, families, caregivers, and allies came together in early 1987 in New York City to form the AIDS Coalition to Unleash Power—ACT UP—an organization that aimed to combat “the government’s mismanagement of the AIDS crisis.”⁴ Only weeks after its founding, activists staged their first demonstration, on March 24, 1987, protesting Burroughs Wellcome’s profit model and the drug-approval policies of the FDA, which, they argued, contributed to the limited supply and high price of Retrovir.

In a *New York Times* op-ed released the day before the protest, Gay Men's Health Crisis co-founder and ACT UP founding member Larry Kramer wrote:

There is no question on the part of anyone fighting AIDS that the FDA constitutes the single most incomprehensible bottleneck in American bureaucratic history—one that is actually prolonging this roll call of death. . . . AIDS sufferers, who have nothing to lose, are more than willing to be guinea pigs. . . . We cannot understand for the life of us, or for what life in us many of us still cling to hungrily, why the FDA withholds them—especially when the victims are so eager to be part of the experimental process.⁵

Given that two-thirds of people with HIV at that time were expected to die within five years,⁶ gaining access to new drugs before the FDA had completed its approval process was quite literally a matter of life and death. Of course, many of the drug candidates were simply toxic; Western medicine's long history of ineffective and unsafe therapeutics is the reason for the cautious policies of the FDA.⁷ Nonetheless, as Kramer pointed out, there were viable drugs pending approval that could save patients' lives. Shortly after ACT UP's first demonstration, the FDA announced that it would shorten its approval process for HIV drugs (and, later, for other drugs) by two years.⁸ With continued pressure, including repeated public protests such as the one shown in figure 12.1, the FDA eventually allowed AIDS patients to participate in clinical trials.⁹

Burroughs Wellcome was another of ACT UP's targets. In 1989, two years later in the course of the epidemic, AZT still cost \$8,000 a year and remained the most expensive medicine in history. Activists kept up the pressure. On September 14, 1989, ACT UP members protested the high price of Retrovir on Wall Street, holding banners and chanting, "Sell Wellcome!" at the New York Stock Exchange. Within days, Burroughs Wellcome decreased the price of Retrovir 20 percent, from \$8,000 to \$6,400.¹⁰

Such initiatives had effects beyond policy change. Building on grassroots movements to expand access to family planning, given the role of contraceptive barrier methods as an AIDS prevention strategy,¹¹ AIDS treatment activism helped increase the public's participation in consumer health policy. The AIDS movement spurred citizens to engage with pharmaceutical companies and the FDA to push for the development and approval of treatment options. "AIDS activism has changed activism itself," writes political scientist Patricia Siplon, "partly as a result of



FIGURE 12.1. An ACT UP protest in New York City, June 1993. Courtesy Andrew Holbrooke/Corbis.

some of the special circumstances of the AIDS epidemic. . . . The successes of AIDS activists created a new model featuring direct action, self-empowerment, and self-education first for other health-based groups and ultimately even for activist groups outside the health realm.”¹²

ACT UP was the first AIDS activist group “to draw a broad spectrum of people and unite them into a cohesive organization.” It was said “to have sparked a new rise in nonviolent, nonpartisan, political advocacy,” driven by a diverse group of activists that included people across genders, ages, sexual orientations, and educational and socioeconomic backgrounds, not to mention HIV status, which helped to give it traction. The movement not only utilized civil disobedience tactics to gain attention but also benefited from the work of young, educated activists who learned about the emerging science of HIV in order to better track the research and development of new drugs and treatment programs.¹³

Treatment Action Campaign

The Treatment Action Campaign was initiated in South Africa in December 1998 by a small group of political activists. The two found-

ers, Zackie Achmat and Mark Heywood, were veterans of the anti-apartheid movement and members of the African National Congress. TAC's constitution describes the group's objective: "to challenge by means of litigation, lobbying, advocacy and all forms of legitimate mobilization, any barrier or obstacle, including unfair discrimination, that limits access to treatment for HIV/AIDS in the private or public sector."¹⁴ (Chapter 9 describes TAC's use of legal activism in the fight to secure treatment for AIDS patients.)

When TAC was founded, South Africa's HIV prevalence rate was approaching 25 percent; an estimated six hundred South Africans died of AIDS every day. But while access to antiretroviral treatment remained limited to the wealthy, AIDS claimed little attention in the national political debate. Amid complex cycles of accusation and counteraccusation that surrounded the AIDS epidemic—conspiracy theories, worries of economic ruin, massive loss of life among blacks but not whites, charges that the spread of the virus was evidence of black sexual promiscuity—many of the country's black political leaders were loath to discuss HIV openly.¹⁵

In poor communities beset by AIDS, TAC members taught infected and affected South Africans about the science of HIV; the group also discussed social and economic rights and the responsibilities of the state in the realization of those rights. While AIDS activism in South Africa had been led primarily by a small, mostly white, group during the 1980s and early 1990s, TAC sought to build a broad-based, racially integrated organization. Membership included young people, faith-based organizations, health care professionals, and labor unions. In 2005, Achmat described the group's membership as 80 percent unemployed, 70 percent women, 70 percent young people between the ages of fourteen and twenty-four, and 90 percent African.¹⁶ TAC also built links with AIDS activists in high-income countries—particularly with ACT UP chapters in the United States—to help develop educational materials to build "treatment literacy" for people living with the virus.

While organizing communities at the grassroots level, TAC engaged its membership in large-scale political advocacy. Using methods ranging from civil disobedience, street demonstrations, lawsuits in constitutional court, data-driven pamphlets, and limited antiretroviral treatment programs for members, TAC sought to keep its members healthy and health literate while pressing the public sector to recognize the right to quality health care.¹⁷ When the Pharmaceutical Manufacturers Association filed a lawsuit to overturn South Africa's Medicines Act in

2000, TAC submitted an amicus curiae brief and organized a march that brought five thousand people to the steps of Pretoria's High Court on the first day of the case. Three years later, when it seemed clear that President Thabo Mbeki would not make treatment access a national priority, TAC led a march of twenty thousand protestors to the South African Parliament to demand a national treatment program. These demonstrations, which highlighted the impact of intellectual property restrictions and government inaction on access to essential medicines, drew international media attention.

TAC built the largest organized activist constituency of people living with AIDS in the developing world. Its protests and litigation helped spur price reductions and public-sector programs that began providing antiretroviral therapy for hundreds of thousands of South Africans.¹⁸ Beyond expanding access to treatment, TAC also tried to reimagine what it meant to live with AIDS in South Africa. In 1998, an openly HIV-positive activist named Gugu Dlamini had been stoned to death by her neighbors in KwaZulu-Natal; less than two years later, thousands of South Africans took to the streets in TAC's t-shirts, which read "HIV POSITIVE."¹⁹

2004 and 2008 STOP AIDS Campaigns

Two advocacy initiatives in which students played an especially important role occurred during the 2004 and 2008 U.S. presidential campaigns. In 2004, a coalition of AIDS activist groups, including Health GAP, the Global AIDS Alliance, and the Student Global AIDS Campaign (who sponsored the demonstration pictured in figure 12.2), collaborated in an effort to garner a commitment from every major presidential candidate to double the Bush administration's five-year \$15 billion plan to combat AIDS in poor countries. The tactic of choice was "bird-dogging": questioners were dispatched to hundreds of town hall events in Iowa, New Hampshire, and other states with early primaries to repeatedly ask candidates to pledge to double AIDS appropriations to \$30 billion over five years. The questions came from students, church groups, and people living with AIDS, who coordinated their efforts to ensure representation at as many events as possible. The candidates were often noncommittal at first. But early in the primary season, each of the seven Democratic candidates signed a pledge committing to the proposed funding level if elected. President George W. Bush, who had announced PEPFAR in 2003, did not commit to addi-



FIGURE 12.2. The Student Global AIDS Campaign organized this 2005 march in Washington, D.C., which drew students from more than one hundred colleges and universities to demand greater support for global health programs. Courtesy Andrew Kohan.

tional funding for global AIDS. In part because he held fewer small-scale question-and-answer events during his reelection campaign, he proved a more difficult target for the activists.

Four years later, activist groups reprised the STOP AIDS campaign, demanding that funding increase to \$50 billion over five years. The STOP AIDS 2008 platform also included pledges to train and retain 140,000 new health care workers in poor countries; to repeal the ban on federal funding for syringe exchanges; to expand Medicaid coverage for people in the United States with HIV; and to support trade policies that increased access to generic drugs for important health needs beyond AIDS. Again, candidates responded to voters at pancake breakfasts and barbecues and in hotel lobbies, ice cream parlors, and churches. Once again, each of the Democratic candidates pledged to meet the activists' targets. Then-senator Barack Obama reiterated this pledge at public events and on his campaign website. Although many Republican candidates published platforms on global health and foreign aid, none pledged \$50 billion for global AIDS efforts.

Each of these campaigns introduced demands for funding that

reimagined the possible. When the U.S. Congress considered the reauthorization of PEPFAR in the summer of 2008, three of the candidates who had signed the \$50 billion pledge—Barack Obama, Hillary Clinton, and Joseph Biden—were members of the U.S. Senate, and one—Biden—was chair of the Committee on Foreign Relations, the body tasked with ushering the reauthorization bill through the Senate. With the presumptive leaders of the Democratic Party bound to this pledge, the Democrat-controlled House and Senate passed a reauthorization bill that included \$48 billion over five years to fund the battle against AIDS, tuberculosis, malaria; microbicide development; and health systems strengthening in resource-poor settings. Other elements of the activists' platform, including the repeal of the ban on federal funding for syringe exchange programs, became law in the months following President Obama's inauguration (though the ban on syringe exchange funding has since been reinstated by the Republican-controlled House of Representatives, who inserted such language into the annual federal budget).

There were, of course, many other factors influencing the expansion of PEPFAR: a growing body of evidence from the field that anti-retroviral treatment not only was deliverable and effective in resource-poor settings but also boosted prevention and primary care services and health systems in general; increasing acknowledgment of the links between health and economic development; concern about the pandemic's effect on fragile states and the consequences for U.S. national security. Nonetheless, activists played a key part in this story, as they must continue to do in the ongoing movement for global health equity.

THE ADVOCATE'S TOOLKIT: ACTIVIST STRATEGIES FOR GLOBAL HEALTH EQUITY

This chapter argues that supporters of global health equity do not need to hold official positions of power to make a significant impact. Students, health workers, lawyers, people living with HIV, and other grassroots activists have changed global health policy through effective advocacy; their tactics are available to anyone with a passion for equity. Included here are some of the most useful and accessible tools employed by global health activists.

ENGAGE IN CRITICAL SELF-REFLECTION

Effective advocacy begins with thoughtfully considering your own position, sources of inspiration, and potential role in the movement for global health equity. People in all stations of life can find meaningful roles to play;

the challenge is discerning the reaches of your local moral world in the context of the larger movement and preparing (if possible) for unintended consequences of purposive social action.

FIND GOOD PARTNERS

A number of groups, some of them described in this book, are already engaged in building an advocacy movement for global health equity. Such organizations include, for example, Health GAP, the Student Global AIDS Campaign, RESULTS, ACT UP, the ONE Campaign, Oxfam America, the Treatment Action Campaign, Partners In Health, and many others. These groups understand some of the mechanics of policy change; with local chapters across the United States and around the world, they seek to give visibility to key issues and gain political traction. Find a group that fits your interests, or organize your own, and understand that power resides in partnerships. Remember that your partners need to include those most affected by the problems your activism seeks to address.

KNOW THE ISSUES

Effective advocates are well informed about key global health issues and also the local political climate. Determine the issues on which particular political leaders might have leverage—perhaps in congressional committee work or by sponsoring specific pieces of legislation, for example. Always remember that enduring activism needs to be based on careful and accurate analysis of what are complex biosocial issues; such understanding is a chief tool in promoting global health equity. But also remember that these are human problems, and the ability to engage with them is not limited to those with certificates of advanced training.

START A DIALOGUE WITH POLICYMAKERS

Reach out to representatives in local and national government. Get a sense of their position: if they do not support your concerns, find out why. You might have something to learn from them either about the issue or about the mechanics of political change. Think of ways to align their interests with those of the movement for global health equity. If they offer support, ask them to champion efforts or introduce legislation. The authorization of PEPFAR, documented in chapter 5, shows that these issues can have broad appeal across the political spectrum.

HIGHLIGHT KEY ISSUES

If you encounter resistance or aren't granted meetings with political officials, think of creative ways to demonstrate the importance and promote the visibility of global health issues. Tactics such as these have proven effective in building support among members of Congress, state legislators, and local politicians:

- Calling or writing, especially if you can generate great numbers of calls or letters, can draw officials' attention to an issue.

- Bird-dogging can elicit public comments and pledges from political leaders.
- Drafting, circulating, and presenting a petition can demonstrate broad support and can introduce you to new allies.
- Setting up meetings with elected representatives can start a constructive dialogue about the potential for change and any possible obstacles.
- Placing commentary in the media, whether traditional or social media, is another key tool in building public awareness. Op-eds, letters to the editor, blog posts, and posts on Facebook and Twitter can reach a wide audience. Bring printed copies of published writing to events: it shows that you are engaged with the issues and gives others the chance to do the same.

ORGANIZE A PUBLIC DEMONSTRATION

Public displays—for example, a protest, a boycott, a sit-in, a public fast, or performance art—are among the most effective ways to raise the visibility of key issues. Such actions sometimes work best at political events, where officials can be held accountable for their responses. Press coverage and social media can amplify the impact of such events, so reach out to local outlets beforehand.

BUILD A COALITION

A broad base of thoughtful and engaged individuals is the first step in building a movement for global health equity. Reach out to local organizations—religious, community, service-oriented, political, cultural—as well as to students and peers and other informal networks to build a coalition of support for these issues.

BE THE CHANGE

Being humble means listening before speaking out. Listen carefully to others, especially those who disagree with you. Everyone has a valuable perspective worth considering as you seek to improve your own platform and strategy. Don't underestimate one-on-one conversations with peers. Nothing compares to the strength of genuine connection in creating solidarity around a cause.

ADVANCING GLOBAL HEALTH EQUITY

Every storm must begin with a single drop of rain. And so it is with every worthwhile movement. . . . It begins with an idea that is too simple to be taken seriously . . . and then comes the storm.

—Marco Cáceres

Former U.S. surgeon general Julius Richmond, who taught us a great deal, described three components of policy change: knowledge base,

political will, and social strategy.²⁰ This model is worth adopting in the movement for global health equity. First, as this book emphasizes, policies must be evidence-based; global health practitioners and researchers must continue to build the knowledge base about how to deliver care efficiently and equitably through durable health systems in settings rich and poor. Universities and affiliates, including the students, faculty, and staff, can better contribute to knowledge generation when they are committed to bridging the know-do gap. Second, once we know what works, we need an equity plan. Scaling up evidence-based health care delivery strategies often requires high-level policy change, which demands broad-based political will. One way to build political will—and this brings us to Dr. Richmond’s third point—is social strategy: grassroots groups demonstrating support for an issue can spur politicians and other decision-makers to enact large-scale policy change.

For the most ambitious movements, this third component can be the most difficult. To refer back to the writing of Peter Berger and Thomas Luckmann (discussed in chapter 2), the normalization and institutionalization of injustice embeds structures that perpetuate the status quo among dominant political and economic systems—an economy based on transatlantic human trafficking, for example, or a racist political regime. Hence *structural violence*. Breaking free from these structures often hinges on the ingenuity, persistence, and resilience of large-scale social movements. India’s fight for independence in the 1940s, the U.S. civil rights movement in the 1960s, the fall of apartheid in the 1990s—each of these twentieth-century milestones drew on vigorous social mobilization.

The global AIDS movement illustrates Dr. Richmond’s model. Once it became clear that antiretroviral therapy could be delivered effectively in resource-poor settings—once even a fragment of the knowledge base was established—PEPFAR and the Global Fund funded public and private implementers to increase access to ART around the globe. Millions of lives have been saved. They helped fund the equity plan. Building the political will necessary to launch these ambitious programs—the most ambitious global health initiatives in history—demanded a social strategy capable of bringing together AIDS activists, liberal and conservative U.S. politicians, leading scientists and health practitioners, international policymakers, celebrities, and thought leaders. The history of global health is populated by many other examples. Organizations like the Grameen Bank and BRAC and Village Health Works and Zanmi Lasante have scaled up evidence-

based practices by echoing and amplifying voices from the bottom billion and by building alliances with government officials and international policymakers and with patients and families and students and donors. There is great power in partnership.

This volume focuses on the importance of global health as an *academic field*, one drawing on a handful of key disciplines and methodologies. *Reimagining Global Health* reminds readers—and we hope there will be many—that there have been innumerable good-will attempts to improve the health of the poor over the past centuries. But most have had unintended consequences; some have reinforced power structures and ambitions that do not square with equity and a rights-based approach to global health concerns. This scholarly approach can be complemented by tackling policy and implementation efforts. One sketch of a global health advocacy agenda emerges from this volume: increasing aid while improving aid effectiveness, strengthening health systems, and developing and delivering new health technologies, for example. The mainstream international institutions—from the WHO to the World Bank to UNICEF—are now contemplating each of these challenges.

Beyond academia and development agencies bilateral and multilateral, there are many avenues for engagement in the movement for global health equity. Health practitioners willing to tackle the pathologies of poverty by accompanying the destitute sick and those who seek to provide care for them are in short supply. Skilled teachers and pedagogues are necessary to train the next generation of global health practitioners. Researchers employing methodologies from molecular genetics to pharmacokinetics, from epidemiology to econometrics, and from ethnography to history are needed to build robust critical feedback loops and to continue improving the quality of available tools and technologies as well as the efficiency and equity of global health delivery. Practitioners, trainers, and researchers will often be the same people or will work together closely; integrating research, service, and training is the best strategy we know for making global health more than just a collection of problems. Skilled policymakers and informed advocates are urgently required. And activist organizations in both developed and developing countries continue to play a crucial role.

But there is also great need for engaged individuals in diverse fields that this text has not mentioned in sufficient detail. Engineers, such as the recent inventors of a \$25 neonatal incubator, can find ways of implementing point-of-care diagnostics and preventatives and thera-

peutics in remote areas.²¹ Business entrepreneurs, such as the founders of Aravind Eye Hospital, a low-cost, tertiary-level ophthalmologic care hospital in south India, can improve the efficiency, scale, and accountability of health care delivery in resource-poor settings. Producers of solar panels, wind turbines, and other clean energy innovations can power hospitals in poor places that often have plenty of sunlight and wind but little affordable energy. Writers like Nicholas Kristof, who has vividly depicted gender disparities and many health challenges around the globe, can help garner public attention and swell the ranks of the movement for global health equity.²²

Architects and builders can help raise clinics and hospitals that not only promote infection control but also confer dignity upon their patients through elegant design.²³ Painters and sculptors and artists can further enrich such facilities by making them temples not just of healing but also of beauty and color. Musicians, such as Bono and the members of Arcade Fire, can generate support for global health issues among their fans and become thought leaders in the field. Computer scientists can develop effective electronic medical records systems and help deliver them in low-income settings. Scholars can turn their diverse training toward problems that have plagued humanity from time immemorial. This list goes on and on. Just about every skill or occupation can be leveraged in the movement for global health equity.

We hope young people (and more experienced practitioners) who read this book will find ways to become involved in this movement, no matter their level of training or experience. Students are in a privileged position to learn about global health inequities and become engaged, unencumbered by affiliations with institutions who have vested interests in the status quo; they can develop habits of critical self-reflection necessary for smart and effective global health work. This is a potent combination.

The gradients of global health inequality are patterned by large-scale social forces perpetuating poverty, inequality, food and water insecurity, poor education, unsafe housing, and high unemployment. Economic development—growth in GDP, say—can help lift people out of poverty and vulnerability: in most places, increased family income is associated with better access to nutrition, education, and health care. But, as we've learned the hard way, growth is no panacea. Even most high-income countries fail to provide basic protections to all their citizens, especially the poorest.

Joining the movement for global health equity begins by learning about the disparities that prevent billions from living good lives in full health; this is a lifelong pursuit, but one we hope this book has enhanced for its readers. Joining this movement means finding creative ways to leverage one's own skills and interests and to work with others to advance an agenda for social and economic rights. For many, joining the movement will mean accompanying the sick and the poor and sticking with the task until it is deemed completed not by the *accompagnateur* but by those being accompanied. Global health equity is a noble ambition, but it remains only a beginning to the pursuit of a more just, fair society that allows our children, wherever they are born, a decent shot at a decent life.