

## Rethinking Health and Human Rights: Time for a Paradigm Shift

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*From the perspective of a preferential option for the poor, the right to health care, housing, decent work, protection against hunger, and other economic, social, and cultural necessities are as important as civil and political rights and more so.*

— Leigh Binford, *The El Mozote Massacre*

Medicine and its allied health sciences have for too long been peripherally involved in work on human rights. Fifty years ago, the door to greater involvement was opened by Article 25 of the Universal Declaration of Human Rights, which underlined social and economic rights: “Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”<sup>1</sup>

But the intervening decades have seen too little progress in the push for social and economic rights, even though we may point with some pride to gains in civil and political rights. That these distinctions are crucial is made clear by a visit to a Russian prison. With its current political and economic disruption, Russia’s rate of incarceration — 644 per 100,000 citizens are currently in jail or prison — is second only to that of the United States, where there are 699 prisoners per 100,000 in the population. Compare this to much of the rest of Europe, where the figure is about one-fifth as high.<sup>2</sup>

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In the cramped, crammed detention centers where hundreds of thousands of Russian detainees await due process, many fall ill with tuberculosis. Convicted prisoners who are diagnosed with tuberculosis are sent to one of more than fifty “TB colonies.” Imagine a Siberian prison in which the cells are as crowded as cattle cars, the fetid air thick with tubercle bacilli. Imagine a cell in which most of the prisoners are perpetually coughing and all are said to have active tuberculosis. Let the mean age of the inmates be less than 30 years old. Finally, imagine that many of these young men are receiving ineffective treatment for their disease — given drug toxicity, worse than receiving placebo — even though they are the beneficiaries of “directly observed therapy” with first-line antituberculous agents, delivered by European humanitarian organizations and their Russian colleagues.

If this seems hard to imagine, it shouldn’t be. I have seen this situation in several prisons; there are still prisoners receiving directly observed doses of medications that cannot cure them. For many of these prisoners, the therapy is ineffective because the strains of tuberculosis that are epidemic within the prisons are resistant to the drugs being administered. Various observers, including some from international human rights organizations, have averred that these prisoners have “untreatable forms” of tuberculosis, and few have challenged this claim even though treatment based on the standard of care used elsewhere in Europe and in North America *can* cure the great majority of such cases.<sup>3</sup> “Untreatable,” in these debates, really means “expensive to treat.” For this and other reasons, tuberculosis has again become the leading cause of death among Russian prisoners — even among those nominally receiving treatment. Similar situations may be found throughout the former Soviet Union.

Are human rights violated in this dismal scenario? If we look only at civil rights without taking social and economic rights into consideration, we would focus on a single viola-

tion: prolonged pretrial detention. Those arrested are routinely detained for up to a year before making a court appearance. In many documented cases, young detainees have died of prison-acquired tuberculosis before their cases ever went to trial. Such detention clearly violates not only Russian law, but several human rights charters to which the country is signatory. Russian and international human rights activists have focused on this problem, demanding that all detainees be brought quickly to trial. An impasse is quickly reached when the underfunded Russian courts wearily respond that they are working as fast as they can. The Ministry of Justice agrees with the human rights people, and is now interested in amnesty for prisoners and alternatives to imprisonment. But these measures, helpful though they may prove, will not save those already sick.

What of social and economic rights violations? Examining these yields a far longer list of violations — but, importantly, also a longer list of possible interventions. Prison conditions are deplorable; the directors of the former gulag do not dispute this point. The head of the federal penitentiary system, speaking to Amnesty International, described the prisoners as living in “conditions amounting to torture.”<sup>4</sup> Detainees are subjected to conditions that guarantee increased exposure to drug-resistant strains of *M. tuberculosis*, and to make matters worse, they are denied adequate food and medical care. In the words of one physician: “I have spent my entire medical career caring for prisoners with tuberculosis. And although we complained about shortages in the eighties, we had no idea how good we had it then. Now it’s a daily struggle for food, drugs, lab supplies, even heat and electricity.”<sup>5</sup>

These prisoners are dying of ineffectively treated multidrug-resistant tuberculosis (MDRTB). Experts from the international public health community have argued that it is not necessary to treat MDRTB — the “untreatable form” in question — in this region. These experts have argued that all patients should be treated with identical doses of the same drugs and that MDRTB will disappear if such strategies are adopted.<sup>6</sup> Cost-efficacy arguments against treating drug-resistant tuberculosis almost always fail to note that most of the drugs necessary for such treatment have been off-patent for years. And it is simply not true that MDRTB is untreatable — Partners In Health has done work in Peru and Haiti showing that MDRTB can be cured in resource-poor settings.<sup>7</sup> All the prison rights activism in the world will come to naught if prisoners are guaranteed the right to treatment but given the wrong prescriptions. A civil and political rights perspective does not allow us to grasp the full nature of these human rights violations, much less attempt to fix all of them.

So what does a focus on health bring to the struggle for human rights? A narrow legal approach to health and human rights can obscure the nature of violations, thereby enfeebling our best responses to them. Casting prison-based tuberculosis epidemics in terms of social and economic rights

offers an entry point for public health and medicine, an important step in the process that could halt these epidemics. Medicine enters the picture and can respond to the past-neglected call for action. Conversely, of course, failure to consider social and economic rights can prevent the allied health professions and the social sciences from making their fullest contribution to the struggle for human rights.

#### PRAGMATIC SOLIDARITY:

#### A SYNERGY OF HEALTH AND HUMAN RIGHTS

Public health and access to medical care are social and economic rights. They are at least as critical as civil rights. One of the ironies of our global era is that while public health has increasingly sacrificed equity for efficiency, the poor have become well-informed enough to reject separate standards of care. In our professional journals, these subaltern voices have been well-nigh blotted out. But snatches of their rebuke have been heard recently with regard to access to antiretroviral therapy for HIV disease. Whether we continue to ignore them or not, the destitute sick are increasingly clear on one point: Making social and economic rights a reality is the key goal for health and human rights in the twenty-first century.

Although trained in anthropology, I, like most anthropologists, do not embrace the rigidly particularist and relativist tendencies popularly associated with the discipline.<sup>8</sup> That is, I believe that violations of human dignity are not to be accepted merely because they are buttressed by local ideology or long-standing tradition. But anthropology — in common with sociological and historical perspectives in general — allows us to place both human rights abuses and the discourses (and other responses) they generate in broader contexts. Furthermore, these disciplines permit us to ground our understanding of human rights violations in broader analyses of power and social inequality. Whereas a purely legal view of human rights tends to obscure the dynamics of human rights violations, the contextualizing disciplines reveal them to be pathologies of power. Social inequalities based on race or ethnicity, gender, religious creed, and — above all — social class are the motor force behind most human rights violations. In other words, violence against individuals is usually embedded in entrenched structural violence.

In exploring the relationships between structural violence and human rights, I draw on my own experience serving the destitute sick in settings such as Haiti and Chiapas and Russia, where human rights violations are a daily concern (even if structural violence is not always seen as a human rights issue). I do this not to make over-much of my personal acquaintance with other people’s suffering, but rather to ground a theoretical discussion in the very real experiences that have shaped my views on health and human rights. Each of these situations calls not only for our recognition of the relationship between structural violence and human rights violations, but also for what we have termed “pragmatic soli-

arity”: the rapid deployment of our tools and resources to improve the health and well-being of those who suffer this violence.

Pragmatic solidarity is different from, but nourished by, solidarity — the desire to make common cause with those in need. Solidarity itself is a precious thing: people enduring great hardship often remark that they are grateful for the prayers and good wishes of fellow human beings. But when sentiment is accompanied by the goods and services that might diminish unjust hardship, surely it is enriched. To those in great need, solidarity without the pragmatic component can seem like abstract piety. The goal of our partnerships with sister organizations in Haiti, Peru, Mexico, Russia, and the United States is neither charity nor development. Rather, these relationships reflect a commitment to struggle alongside the poor, and against the economic and political structures that create their poverty. We see pragmatic solidarity as a means to synergize health and human rights — when the destitute sick can fulfill their human right to health, the door may be opened to more readily achieve other economic, social, cultural, and political rights.<sup>9</sup> One telling example comes from Haiti, where HIV-positive patients placed on antiretroviral therapy repeatedly inform us that they can now return to daily life and caring for their children.<sup>10</sup> When we move beyond sentiments to action, we incur risks, and these deter many. But it is possible, clearly, to link lofty ideals to sound analysis. This linkage does not always occur in human rights work, in part because of a reluctance to examine the political economy of suffering and brutality.

I will not discuss, except in passing, the covenants and conventions that constitute the key documents of the human rights movement here. The goal of this article is to raise, and to answer, some questions relevant to health and human rights; to explore the promise of pragmatic solidarity as a response to structural violence; and to identify promising directions for future work in this field. It is my belief that the conclusions that follow are the most important challenges before those who concern themselves with health and human rights.

### HOW FAR HAS THE HUMAN RIGHTS MOVEMENT COME?

The field of health and human rights, most would agree, is in its infancy. Attempting to define a new field is necessarily a treacherous enterprise. Sometimes we appear to step on the toes of those who have long been at work when we mean instead to stand on their shoulders. Human rights law, which focuses on civil and political rights, is much older than human rights medicine. And if vigor is assessed in the typical academic style — by length of bibliography — civil and political rights law is the more robust field, too. That legal documents and scholarship dominate the human rights literature is not surprising (note Steiner and Alston), given that the human rights movement has “struggled to assume so law-like a character.”<sup>11</sup>

But even in legal terms, the international human rights movement is essentially a modern phenomenon, beginning, some argue, with the Nuremberg trials. It is this movement that has led, most recently, to the creation of international tribunals to judge war crimes in the Balkans and in Rwanda. Yet 50 years after the Universal Declaration of Human Rights, and 50 years after the four Geneva Conventions, what do we have to show for these efforts? Do we have some sense of outcomes? Aryeh Neier, former executive director of Human Rights Watch, recently reviewed the history of various treaties and covenants from Nuremberg to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. He said, “Nations have honored these obligations largely in the breach.”<sup>12</sup>

Few could argue against Neier’s dour assessment, but the past few years have been marked by a certain amount of human rights triumphalism. The fiftieth anniversary of the Universal Declaration has led to many celebrations, but to few careful assessments of current realities. Even those within the legal community acknowledge that it would be difficult to correlate a steep rise in the publication of human rights documents with a statistically significant drop in the number of human rights abuses. Rosalyn Higgins says pointedly:

No one doubts that there exists a norm prohibiting torture. No state denies the existence of such a norm; and, indeed, it is widely recognized as a customary rule of international law by national courts. But it is equally clear from, for example, the reports of Amnesty International, that the *great majority* of states systematically engage in torture. If one takes the view that noncompliance is relevant to the retention of normative quality, are we to conclude that there is not really any prohibition of torture under customary international law?<sup>13</sup>

Whether these laws are binding or largely hortatory constitutes a substantial debate in the legal literature, but such debates seem academic in the face of overwhelming evidence of persistent abuses.

When we expand the concept of rights to include social and economic rights, the gap between the ideal and reality is even wider. Local and global inequalities mean that the fruits of medical and scientific advances are stockpiled for some and denied to others. The dimensions of these inequalities are staggering, and the trends are adverse. To cite just a few examples — in 1998, Michael Jordan earned from Nike the equivalent of 60,000 years’ salary for an Indonesian footwear assembly worker; Haitian factory workers, most of them women, made 28 cents per hour sewing Pocahontas pajamas, while Disney’s U.S.-based chief executive officer made \$97,000 for each hour he toiled.<sup>14</sup>

The pathogenic effects of such inequality are now recognized.<sup>15</sup> Many governments, including our own, refuse to

redress inequalities in health, while others are largely powerless to address them.<sup>16</sup> But although the reasons for failure are many and varied, even optimists allow that human rights charters and covenants have not brought an end to — and may not even have slowed — egregious abuses, however they are defined. States large and small violate civil, economic, and social rights, and inequality both prompts and covers these violations. In other words, rights attributed on paper are of little value when the existing political and social structures do not afford all individuals the ability to enjoy these rights, let alone defend them.

There are, of course, exceptions; victories have been declared. But not many of them are very encouraging on close scrutiny. Haiti, the case I know best, offers a humbling example. First, the struggle for social and economic rights — food, medical care, education, housing, decent jobs — has been dealt crippling blows in Haiti. Such basic entitlements, the centerpiece of the popular movement that in 1990 brought the country's first democratically elected president to power, were buried under an avalanche of human rights violations after the military coup of 1991. And although human rights groups were among those credited with helping to restore constitutional rule in Haiti, this was accomplished, to a large extent, by sacrificing the struggle for social and economic rights.<sup>17</sup> In recent years, it has sometimes seemed as if the steam has run out of the movement to bring to justice those responsible for the murder and mayhem that have made Haiti such a difficult place to live. There are notable exceptions — for instance, the sentencing of military officials responsible for a 1994 civilian massacre — but both the legal and socio-economic campaigns have slowed almost to a standstill.<sup>18</sup>

Or take Argentina. The gruesome details of the “dirty war” are familiar to many.<sup>19</sup> Seeking what Aryeh Neier has chillingly termed “a better mousetrap of repression,” the Argentine military government began “disappearing” (as Latin Americans said in the special syntax crafted for the occasion) people it identified as leftists.<sup>20</sup> Many people know, now, about the death flights that took place every Wednesday for two years. Thousands of citizens the government deemed subversive, many of them students and most of them just having survived torture, were flown from a military installation out over the Atlantic, stripped, and shoved out of the plane. A better mousetrap, indeed.

What happened next is well-documented, although it is a classic instance of the half-empty, half-full glass. Those who say the glass is half full note that an elected civilian government subsequently tried and convicted high-ranking military figures, including the generals who shared, in the fashion of runners in a relay, the presidential office. Those who say the glass is half empty note that the prompt pardoning and release of the criminals meant that, once again, no one has been held accountable for thousands of murders.<sup>21</sup> Similar stories abound in Guatemala, El Salvador, the state of Chiapas in Mexico, and elsewhere in Latin America.<sup>22</sup>

These painful experiences are, of course, no reason to declare legal proceedings ineffective. On the contrary, they remind us that some of what was previously hidden away is now out in the open. Disclosure is often the first step in the struggle against impunity, and human rights organizations — almost all of them nongovernmental — have at times forced unwilling governments to acknowledge what really happened. These efforts should serve as a rallying cry for those who now look to constitute international criminal tribunals.

Still, the results to date suggest that we would be unwise to place all our hopes on the legal-struggle approach. This approach has proved insufficient in preventing human rights abuses, and all the civil and political rights ever granted will provide little comfort to the starving and the sick if they are not enforced by the state, as they so often are not. Complementary strategies and new openings are critically needed. The health and human rights “angle” can provide new opportunities and new strategies at the same time that it lends strength and purpose to a movement sorely in need of buttressing.

#### CAN ONE MERELY STUDY HUMAN RIGHTS ABUSES?

A few years ago, the French sociologist Pierre Bourdieu and his colleagues pulled together a compendium of testimonies from those the French term “the excluded” in order to bring into relief *la misère du monde*. Bourdieu and colleagues qualified their claims for the role of scholarship in addressing this misery: “To subject to scrutiny the mechanisms which render life painful, even untenable, is not to neutralize them; to bring to light contradictions is not to resolve them.”<sup>23</sup> It is precisely such humility that is needed, and rarely exhibited, in academic commentary on human rights.

It is difficult merely to study human rights abuses. We know with certainty that rights are being abused at this very moment. And the fact that we can study, rather than endure, these abuses is a reminder that we too are implicated in and benefit from the increasingly global structures that determine, to an important extent, the nature and distribution of assaults on dignity.

Ivory-tower engagement with health and human rights can, often enough, reduce us to seminar-room warriors. At worst, we stand revealed as the hypocrites that our critics in many parts of the world have not hesitated to call us. Anthropologists have long been familiar with these critiques; specialists in international health, including AIDS researchers, have recently had a crash course.<sup>24</sup> It is possible, usually, to drown out the voices of those demanding that we stop studying them, even when they go to great lengths to make sure we get the message. But social scientists with more acute hearing have documented a rich trove of graffiti, songs, demonstrations, tracts, and broadsides on the subject. A hit record album in Haiti was called *International Organizations*. The title cut includes the following lines: “International organi-

zations are not on our side. They're there to help the thieves rob and devour.... International health stays on the sidelines of our struggle."

In the context of long-standing international support for sundry Haitian dictatorships, one can readily see the gripe with international organizations. But "international health"? The international community's extraordinary largesse to the Duvalier regime has certainly been well-documented.<sup>25</sup> Subsequent patterns of giving, addressed as they were to sundry Duvalierist military juntas, did nothing to improve the reputation of U.S. foreign aid or the international organizations, though they helped greatly to arm murderous bands and line the pockets of their leaders. Haitians saw international health, if not from within institutions such as the United States Agency for International Development (USAID), then as part of the same dictator-buttrussing bureaucracy. Such critiques are not specific to Haiti, although Haitians have pronounced them with exceptional frankness and richness of detail. Their accusations have been echoed and amplified throughout what some are beginning to call the global geoculture.<sup>26</sup> A full decade before the recent AIDS research debates,<sup>27</sup> it was possible to collect a bookful of such commentary.<sup>28</sup>

It is in this context of globalization, "mediatization," and growing inequality that the new field of health and human rights emerges. Contextual factors are particularly salient when we think about social and economic rights, as Steiner and Alston have noted: "An examination of the concept of the right to development and its implications in the 1990s cannot avoid consideration of the effects of the globalization of the economy and the consequences of the near-universal embrace of the market economy."<sup>29</sup> This context defines our research agenda and directs our praxis. We are leaving behind the terra firma of double-blind, placebo-controlled studies, of cost effectiveness, and of sustainability. Indeed, many of these concepts end up looking more like strategies for managing, rather than challenging, inequality.

What, then, should be the role of the First World university, of researchers and health-care professionals? What should be the role of students and others lucky enough to be among the "winners" in the global era? We can agree, perhaps, that these centers are fine places from which to conduct research, to document, and to teach. A university does not have the same entanglements or constraints as an international institution such as the United Nations, or as organizations such as Amnesty International or Physicians for Human Rights. Universities could, in theory, provide a unique and privileged space for conducting research and engaging in critical assessment.

In human rights work, however, research and critical assessment are insufficient — analysis alone cannot curb human rights violations. No more adequate, for all their virtues, are denunciation and exhortation, whether in the form of press conferences or reports or harangues directed at

students. To confront, as an observer, ongoing abuses of human rights is to be faced with a moral dilemma: Does one's action help the sufferers or the system? The increasingly baroque codes of research ethics generated by institutional review boards will not help us out of this dilemma, nor will medical ethics, which are so often restricted to the quandary ethics of the individual. But certain models of engagement are not irrelevant. If the university-based human rights worker is in a peculiar position, it is not entirely unlike that of the clinician researcher. Both study suffering; both are bound to relieve it; neither is in possession of a tried-and-true remedy. Both the human rights specialist and the clinician researcher have blind spots, too.

To push the analogy further, it could be argued that there are, in both lines of work, obligations regarding the standard of care. Once a reasonably effective intervention has been identified, it — and not a placebo — is considered the standard against which a new remedy must be tested. In the global era, is it wise to set, as *policy goals*, double standards for the rich world and the poor world, when we know that these are not different worlds but in fact the same one? Can we treat the rich with the "gold standard," while offering the poor an essential "placebo"? Are the acrid complaints of the vulnerable necessary to remind us that they invariably see the world as one world, riven by terrible inequality and injustice? A placebo is a placebo is a placebo.

That we have failed to meet high goals does not imply that the next step is to lower our sights, although this has been the default logic in many instances. The next step is to try new approaches and to hedge our bets with indisputably effective interventions. Providing pragmatic services to the afflicted is one obvious form of intervention. But the spirit in which these services are delivered makes all the difference. Service delivery can be just that, or it can be pragmatic solidarity, linked to the broader goals of equality and justice for the poor. Again, my own experience in Haiti, which began in 1983, made this clear. The Duvalier dictatorship was then in power, seemingly immovable. Its chief source of external financial aid was the United States and various international institutions, many of them ostensibly charitable in nature. The local director of USAID at the time had often expressed the view that if Haiti was underdeveloped, the causes were to be sought in Haitian culture.<sup>30</sup> The World Bank and the International Monetary Fund seemed to be part of the same giant blur of international aid organizations that Haitians associated, accurately enough, with U.S. foreign policy.

Popular cynicism regarding these transnational institutions was at its peak when my colleagues and I began working in Haiti, and that is precisely why we chose to work through nascent community-based organizations and for a group of rural peasants who had been dispossessed of their land. Although we conducted research and published it, research did not figure on the wish list of the people we were trying to

serve. Services were what they asked for, and as people who had been displaced by political and economic violence, they regarded these services as a rightful remedy for what they had suffered. In other words, the Haitian poor themselves believed that social and economic rights were central to the struggle for human rights. As the struggle against the dictatorship gathered strength in the mid-eighties, the language was explicitly couched in broad human rights terms. *Pa gen lapè nan tèt si pa gen lapè nan vant*: There can be no peace of mind if there is no peace in the belly.<sup>31</sup> Health and education figured high on the list of demands as the Haitian popular movement began to swell.

The same has been true of the struggle in Chiapas. The Zapatista rebellion was launched on the day the North American Free Trade Agreement was signed, and the initial statement of the rebellion's leaders put their demands in terms of social and economic rights:

We are denied the most elementary education so that they can use us as cannon fodder and plunder our country's riches, uncaring that we are dying of hunger and curable diseases. Nor do they care that we have nothing, absolutely nothing, no decent roof over our heads, no land, no work, no health, no food, no education. We do not have the right to freely and democratically elect our own authorities, nor do we have peace or justice for ourselves and our children.<sup>32</sup>

It is in settings such as these that we are afforded a rare clarity about choices that are in fact choices for all of us, everywhere. There's little doubt that discernment is a daily struggle. We must decide how health professionals might best make common cause with the destitute sick, whose rights are violated daily. Helping governments shore up failing public health systems may or may not be wise. As mentioned earlier, pragmatic solidarity on behalf of Russian prisoners with tuberculosis included working with their jailors. But sometimes we are warned against consorting with governments. In Haiti in the eighties, it made all the difference that we formed our own nongovernmental organization far from the reach of the governments of both Haiti and the United States. In Chiapas, the situation was even more dramatic, and many poor communities simply have refused to use government health services. In village after village, we heard the same story. In some "autonomous zones," the Mexican Army — again, as many as 70,000 troops are now stationed in Chiapas — entered these villages and destroyed local health records and what meager infrastructure had been developed. To quote one health worker: "The government uses health services against us. They persecute us if they think we are on the side of the rebels." Our own investigations have been amply confirmed by others, including Physicians for Human Rights:

At best, [Mexican] Government health and other services are subordinate to Government counter-insurgency efforts. At worst, these services are themselves components of repression, manipulated to reward supporters and to penalize and demoralize dissenters. In either case, Government health services in the zone are discriminatory, exacerbate political divisions, and fail utterly to address the real health needs of the population.<sup>33</sup>

It's not acceptable for those of us fortunate enough to have ties to universities, and to be able to do research, to throw up our hands and bemoan the place-to-place complexity. Underlying this complexity are a series of very simple first principles regarding human rights, as the liberation theologians remind us. Our commitments, our loyalties, have to be *primarily* to the poor and vulnerable. As a reminder of how unique this commitment is, remember that the international agencies affiliated with the United Nations, including the World Health Organization, are called to work with governments. Think, once again, of Chiapas. The individual member of any one of these international institutions may have loyalties to the Zapatistas, but have no choice in his or her agency's primary interlocutor: This will be the Mexican government. Membership in a university (or hospital or local church) permits us more flexibility in making allegiances. This flexibility is a gift that should not be squandered by mimicking mindlessly the choices of the parastatal international organizations. Close allegiance with suffering communities reminds us that it is not possible to merely study human rights abuses. But part of pragmatic solidarity is bringing the real story to light.

Merely telling the truth often calls for exhaustive research. In the current era, human rights violations are usually both local and global. Telling who did what to whom and when becomes a complicated affair. The chain of complicity, I have learned, reaches higher and higher. At the time of the Haitian military coup, U.S. officialdom's explanation of human rights abuses in Haiti, including the torture and murder of civilians, focused almost exclusively on local actors and local factors. One heard of the "culture of violence" that rendered this and other similarly grisly deaths comprehensible. Such official analyses, constructed through the conflation of structural violence and cultural difference, were distancing tactics.

Innumerable immodest claims of causality, such as attributing a sudden upsurge in the torture of persons in police custody to long-standing local custom, play into the convenient alibi that refuses to follow the chain of events to their source, that keeps all the trouble local. Such alibis obscure the fact that the modern Haitian military was created by an act of the U.S. Congress during our 20-year occupation (1915–1934) of Haiti. Most official analyses did not discuss the generous U.S. assistance to the post-Duvalier military: over

\$200 million in aid passed through the hands of the Haitian military in the 18 months after Jean-Claude Duvalier left Haiti on a U.S. cargo plane in 1986. Bush administration statements, and their faithful echoes in the establishment press, failed to mention that many of the commanders who issued the orders to detain and torture civilians were trained in Fort Benning, Georgia. At this writing, human rights groups in the United States and Haiti have filed suit against the U.S. government in order to bring to light over 100,000 pages of documents revealing links between Washington and the paramilitary groups that held sway in Haiti between 1991 and 1994.<sup>34</sup>

The masking of the mechanisms of human rights violations has occurred elsewhere. In El Salvador, the massacres of entire villages could not in good conscience be considered unrelated to U.S. foreign policy, since the U.S. government was the primary funder, advisor, and supporter of the Salvadoran government's war against its own people. Yet precisely that fiction of deniability was maintained by officialdom, even though we were also the primary purveyors of armaments, as physical evidence was later to show. It was years before we could read accounts, such as that by Mark Danner, who, on investigating the slaughter of every man, woman, and child in one village, concluded: "of the two hundred and forty-five cartridge cases that were studied — all but one from American M16 rifles — 184 had discernable headstamps, identifying the ammunition as having been manufactured for the United States Government at Lake City, Missouri."<sup>35</sup> The fiction of local struggles ("ethnic," "religious," "historical," or otherwise picturesque) is exploded by any honest attempt to understand. Paramilitary groups linked tightly with the Mexican government were and are responsible for the bulk of intimidation and violence in the villages of Chiapas. But, as in Haiti, federal authorities have insisted that such violence is due to "local inter-community and interparty tension" or to ethnic rivalries.<sup>36</sup>

Immodest claims of causality are not always so flagrantly self-serving as those proffered to explain Haiti's agony, or the violence in El Salvador and Chiapas. But only careful analysis allows us to rebut them with any confidence. Physicians, when fortunate, can alleviate the suffering of the sick — but explaining the distribution and causes of suffering requires many minds and resources. To explain each individual's suffering, one must embed individual biography in the larger matrix of culture, history, and political economy. We cannot *merely* study human rights abuses, but we must not fail to study them.

#### WHAT CAN A FOCUS ON HEALTH BRING TO THE STRUGGLE FOR HUMAN RIGHTS?

Scholarship is not always readily yoked to the service of the poor. Medicine, I have discovered, can be. At its best, medicine is a service much more than a science, and the latest

battery of biomedical discoveries, in which I rejoice, has not convinced me otherwise. Medicine and public health, and also the social sciences relevant to these disciplines, have much to contribute to the great, often rancorous debates on human rights. But what, precisely, might be our greatest contribution? Rudolph Virchow saw doctors as "the natural attorneys of the poor."<sup>37</sup> A "health angle" can promote a broader human rights agenda in unique ways. In fact, the health part of the formula may prove critical to the success of the human rights movement. The honor in which public health and medicine are held affords us openings — again, a space of privilege — enjoyed by few other professions. For example, it is unlikely that my colleagues and I would have been welcomed so warmly into Russian prisons if we were social scientists or human rights investigators. We went instead as TB specialists, with the expectation that a visiting group of doctors might be able to do more for the rights of these prisoners than a delegation from a conventional human rights organization. It is important to get the story straight: the leading cause of death among young Russian detainees is tuberculosis, not torture or starvation. Prison officials were opening their facilities to us, and asking for pragmatic solidarity. (In Haiti and Chiapas, by contrast, we were asked to leave when we openly espoused the cause of the oppressed.)

Medicine and public health benefit from an extraordinary symbolic capital that is, so far, sadly underutilized in human rights work. No one made this point more clearly and persistently than the late Jonathan Mann. In an essay written with Daniel Tarantola, Mann noted that AIDS "has helped catalyze the modern health and human-rights movement, which leads far beyond AIDS, for it considers that promoting and protecting health and promoting and protecting human rights are inextricably connected."<sup>38</sup>

But have we gone far beyond AIDS? Is it not a human rights issue that Russian prisoners are exposed, often during illegally prolonged pretrial detention, to epidemic MDRTB and then denied effective treatment? Is it not a human rights issue that international expert opinion has mistakenly informed Russian prison officials that treatment with second-line drugs is not cost-effective or just plain unnecessary? Is it not a human rights issue that, in wealthy South Africa, where participants at the XIIIth International AIDS Conference were reminded in the glossy program that "medical care is readily available in South Africa," antiretroviral therapy that could prolong millions of (black) lives is declared "cost ineffective"? Is it not a human rights issue that villagers in Chiapas lack access to the most basic medical services, even as government medical facilities stand idly by? Is it not a human rights issue that thousands of Haitian peasants displaced by a hydroelectric dam end up sick with HIV after working as servants in Port-au-Prince?

Standing on the shoulders of giants — from the authors of the Universal Declaration to Jonathan Mann — we can

recognize the human rights abuses in each of these situations, including epidemic tuberculosis within prisons. But what, precisely, is to be done? Russian penal codes already prohibit overcrowding, long pretrial detention, and undue risk from malnutrition and communicable disease. Prison officials already regard the tuberculosis problem as a top priority; that's why they have let TB specialists in. In a 1998 interview, one high-ranking prison official told me that the ministry saw their chief problems as lack of resources, overcrowding, and tuberculosis.<sup>39</sup> And the *pièce de résistance* might be that Boris Yeltsin had already declared 1998 "the year of human rights."

Passing more human rights legislation will not be a sufficient response to these human rights challenges, because many of the (nonbinding, clearly) instruments have already been disregarded by those in charge. The Haitian military coup leaders were beyond the pale. But how about Chiapas? Instruments to which Mexico is already signatory include the Geneva Conventions of 1949; the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; the International Labor Organization Convention 169; the American Convention on Human Rights; the Maastricht Guidelines on Violations of Economic, Social and Cultural Rights; and the Convention on the Elimination of All Forms of Discrimination Against Women. Each one of these is flouted every day in Chiapas.

As the Haitians say, "Laws are made of paper; bayonets are made of steel." Law alone is not up to the task of relieving such immense suffering. Louis Henkin has reminded us that international law is fundamentally a set of rules and norms designed to protect the interests of states, not their citizens. "Until recently," he observed in 1989, "international law took no note of individual human beings."<sup>40</sup> And states, as we have seen, honor human rights law largely in the breach — sometimes through intention, and sometimes through sheer impotence. This chief irony of human rights work — that states will not or cannot obey the treaties to which they are signatory — can lead to despair or to cynicism, if all of one's eggs are in the international law basket.

Laws are not science; they are normative ideology and tightly tied to power.<sup>41</sup> Biomedicine and public health, though also vulnerable to ideological deformations, serve different imperatives, ask different questions. Physicians practice triage and referral daily. What suffering needs to be taken care of first and with what resources? Medicine and public health do not ask whether an event or process violates an existing rule; they ask whether that event or process can be shown to have ill effects on a patient or on a population. They ask whether such events can be prevented or remediated. Thus medicine and public health, so directly tied to human outcomes, give us an immediate sense of impact and a means of measuring progress — because health fields are well-versed in marrying the analysis of problems with practical solutions. And when medicine and public health are explicitly

placed at the service of the poor, there is even greater insurance against their perversion.

To return to the case of prisoners with MDRTB, the best way to protect their rights is to cure them of their disease. And the best way to protect the rights of other prisoners, and of those who take care of them, is to prevent transmission by treating the sick. Thus, after years of equivocation, all parties involved are being forced to admit that the right thing to do in Russia's prisons is also the *human rights* thing to do. A variety of strategies, from human rights arguments to epidemiologic scare tactics, have been used to make headway in raising the funds necessary to treat these and other prisoners. In the end, then, the health angle on human rights may prove more pragmatic than approaching the problem as one of penal reform alone, in part because the health angle focuses less on public blame and more on finding solutions. This is not to say that human rights advocates should not strive for policy reform, but rather that we need a fast, non-controversial solution that attacks the root of many human rights violations. Previously closed-door institutions have invited international collaboration designed to halt prison epidemics. This approach — pragmatic solidarity — may, in the end, lead to penal reform as well.

#### NEW AGENDAS FOR HEALTH AND HUMAN RIGHTS

Is it grandiose to seek to define new agendas? When one reads the powerfully worded statutes, conventions, treaties, and charters stemming from international revulsion over the crimes of the Third Reich, it seems pointless to call for better instruments of this sort. More recent events in the former Yugoslavia and in Rwanda serve as a powerful rebuke to undue confidence in these legalistic approaches: "That it should nevertheless be possible for Nazi-like crimes to be repeated half a century later in full view of the whole world," remarks Aryeh Neier, "points out the weakness of that system — and the need for fresh approaches."<sup>42</sup> Steiner and Alston, similarly, call for "heightened attention to the problems of implementation and enforcement of the new ideal norms. The old techniques," they conclude, "simply won't work."<sup>43</sup>

A corollary question is whether a coherent agenda springs from the critique inherent in the answers to the questions presented here. If so, is this agenda compatible with existing approaches and documents, including the Universal Declaration of Human Rights? To those who believe that social and economic rights must be central to the health and human rights agenda, the answers to these questions are "Yes." This agenda, inspired by the notion of a preferential option for the poor, is coherent, pragmatic, and informed by careful scholarship. In large part because it focuses on social and economic rights, this agenda, though novel, builds on five decades of work within the traditional human rights framework: Articles 25 and 27 of the Universal Declaration inspire the vision of this emerging agenda, which could rely on tighter



links between universities, medical providers, and both non-governmental and community-based organizations. The truly novel part of the alliance comes in subjugating these networks to the aspirations of oppressed and abused people.

How might we proceed with this effort if most reviews of the effects of international laws and treaties designed to protect human rights raise serious questions of efficacy, to say the least? What can be done to advance new agendas of health and human rights? In concluding, we offer six suggestions, which are intended to complement ongoing efforts.

### **Make health and healing the symbolic core**

If we make health and healing the symbolic core of a new agenda, we tap into something truly universal — concern for the sick — and, at the same time, engage medicine, public health, and the allied health professions, including the basic sciences. Put another way, we need to throw the full weight of the medical and scientific communities behind a noble cause. The growing outcome gap between the rich and the poor constitutes both a human rights violation and a means of tracking the efficacy of our interventions. In brief, reduction of the outcome gap will be the goal of our pragmatic solidarity with the destitute sick.

### **Make provision of services central to the agenda**

We need to listen to the sick and abused and to those most likely to have their rights violated. They are not asking for new centers of study and reflection. That means we need new programs in addition to the traditional ventures of a university or research center. We need programs designed to remediate inequalities of access to services that can help all humans lead free and healthy lives. If everyone has a right “to share in scientific advancement and its benefits,” where are our pragmatic efforts to improve the spread of these advances? How can we make the rapid deployment of services to improve health — pragmatic solidarity — central to the work of health and human rights programs? Our own group, Partners In Health, has worked largely with community-based organizations in Haiti, Peru, and Mexico, with the express goal to remediate inequalities of access. This community of providers and scholars believes that “the vitality of practice” lends a corrective strength to our research and writing.<sup>44</sup> The possibilities for programmatic collaboration range, we have learned, from Russian prison officials to peasant collectives in the autonomous zones of Chiapas. Novel collaborations of this sort are certainly necessary if we are to address the increasing inequalities of access here in wealthy, inegalitarian countries such as the United States. Relying exclusively on nation-states’ compliance with a social-justice agenda is naïve at best.

Fifteen years of work in the most difficult field conditions have taught our group that it is hard — perhaps

impossible — to meet the highest standards of health care in every situation. But it is imperative that we try to do so. Projects striving for excellence and inclusiveness — rather than, say, “cost-effectiveness” or “sustainability,” which are often at odds with social justice approaches to medicine and public health — are not merely misguided quests for personal efficacy. Such projects respond to widespread demands for equity in health care. The din around AIDS research in the Third World is merely the latest manifestation of a rejection of low standards as official policy. That such standards are widely seen as violating human rights is no surprise for those interested in social and economic rights. Efficiency cannot trump equity in the field of health and human rights.

### **Establish new research agendas**

We need to make room in the academy for serious scholarly work on the multiple dynamics of health and human rights, on the health effects of war and political-economic disruption, and on the pathogenic effects of social inequalities, including racism, gender inequality, and the growing gap between rich and poor. By what mechanisms, precisely, do such noxious events and processes become embodied as adverse health outcomes? Why are some at risk and others spared?

We require a new level of cooperation between disciplines ranging from social anthropology to molecular epidemiology. We need a new sociology of knowledge that can pick apart a wide body of commentary and scholarship: complex international law; the claims and disclaimers of officialdom; postmodern relativist readings of suffering; clinical and epidemiologic studies of the long-term effects of, say, torture and racism. But remember, none of the victims of these events or processes are asking us to conduct research. For this reason alone, research in the arena of health and human rights is necessarily fraught with pitfalls:

Imperiled populations in developing countries include extraordinarily vulnerable individuals ripped from their cultures and communities and victimized by myriad forms of abuse and violence. Public health research on violence and victimization among these groups must vigilantly guard against contributing to emotional and social harm.<sup>45</sup>

The fact that research is and should remain a secondary concern does not mean that careful documentation is not critical to both our understanding of suffering and our ability to prevent or allay it. And because such research would be linked to service, we need operational research by which we can gauge the efficacy of interventions quite different from those measured in the past.

### Assume a broader educational mandate

If the primary objective is to set things right, education is central to our task. We must not limit ourselves to teaching a select group of students with an avowed interest in health and human rights, nor must we limit ourselves to trying to teach lessons to recalcitrant governments. Jonathan Mann signaled to us the limitations of the latter approach: "Support for human rights-based action to promote health ... at the level of declarations and speeches is welcome, and useful in some ways, but the limits of official organizational support for the call for societal transformation inherent in human rights promotion must be recognized."<sup>46</sup> A broader educational mandate would mean engaging students from all faculties, but also, as noted, engaging the members of these faculties. Beyond the university and various governmental bodies lies the broader public, for whom the connections between health and human rights have not even been traced. It is doubtful that the destitute sick have much to learn from us about health and human rights, but there is little doubt that, as their students, we can learn to better convey the complexity and historicity of their messages.

### Achieve independence from governments and bureaucracies

We need to be untrammled by obligations to powerful states and international bureaucracies. A central irony of human rights law is that it consists largely of appeals to the perpetrators. After all, most crimes against humanity are committed by states, not by rogue factions or gangs or cults or terrorists. That makes it difficult for institutions accountable to states to take their constituents to task. None of this is to say that international organizations have little to offer to those seeking to prevent or assuage human rights abuses. Rather, we need to remember that their supposed "neutrality" comes at a great cost, and that cost is usually paid by people who are not represented by official advocates in places like New York, Geneva, Washington, D.C., London, or Tokyo. Along with the efforts of nongovernmental organizations, university- and hospital-based programs have the potential to be independent, well-designed, pragmatic, and feasible. The imprimatur of medicine and public health would afford even more weight and independence. And only a failure of imagination has led us to ignore the potential for collaboration with community-based organizations and with communities in resistance to ongoing violations of human rights.

Although we must maintain independence from powerful institutions, this is not to say that collaboration should never happen. If these institutions team up with health and human rights practitioners to facilitate the pragmatic delivery of services, substantial gains can be made. While policy reform is certainly worth striving for, and can be an extraordinary tool, we cannot necessarily rely on institutional bodies to enforce the policies they may adopt under pressure. In

short, pragmatic solidarity should be our goal — and any collaborations among health professionals, human rights activists, and governing bodies should strive toward this end.

### Secure more resources for health and human rights

Of course, it's easy to demand more resources, harder to produce them. But if social and economic rights are acknowledged as such, then foundations, governments, businesses, and international financial institutions — many of them now awash in resources — may be called to prioritize human rights endeavors that reflect the paradigm shift advocated here.

Regardless of where one stands on the process of globalization and its multiple engines, these processes have important implications for efforts to promote health and human rights. As states weaken, it is easy to discern an increasing role for nongovernmental institutions, including universities and medical centers. But it's also easy to discern a trap: *states' withdrawal from the basic business of providing housing, education, and medical services usually means further erosion of the social and economic rights of the poor.* Our independent involvement must be quite different from current trends, which have nongovernmental organizations relieving the state of its duty to provide basic services, thus becoming witting or unwitting abettors of neoliberal policies that declare every service and every thing to be for sale.

The experience of Partners In Health suggests that ambitious goals can be met even without a large springboard. Over the past decade and against a steady current of naysaying, we have channeled significant resources to the destitute sick in Haiti, Peru, Mexico, and Boston. We didn't argue that it was "cost-effective," nor did we promise that such efforts would be replicable. We argued that it was the right thing to do. It was the human rights thing to do.

### CONCLUSION

Some of the problems born of structural violence are so large that they have paralyzed many who want to do the right thing. But we can find resources, and we can find them without sacrificing our independence and discernment. We will not do this by adopting defensive postures that are tantamount to simply managing inequality with the latest tools from economists and technocrats. Utopian ideals are the bedrock of human rights. We must set our sights high and reject a double standard between rich and poor.

Claims that we live in an era of limited resources fail to mention that these resources happen to be less limited now than ever before in human history. Arguing that it is too expensive to treat MDRTB among prisoners in Russia sounds nothing short of ludicrous when this world contains roughly 497 billionaires.<sup>47</sup> Arguments against treating HIV in precisely those areas in which it exacts its greatest toll warn us

that misguided notions of cost-effectiveness have already trumped equity. Arguing that nominal civil and political rights are the best we can hope for will mean that members of the healing professions will have their hands tied. In implementing a paradigm shift that focuses on solidarity with victims of structural violence, and the provision of pragmatic services to those in need, we can begin to address these large problems of inequality and human rights violations. Otherwise, we will be forced to stand by as the rights and dignity of the poor and marginalized undergo further sustained and deadly assault.

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