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## Challenging orthodoxies: the road ahead for health and human rights

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## CHALLENGING ORTHODOXIES: THE ROAD AHEAD FOR HEALTH AND HUMAN RIGHTS

*Paul Farmer*

### ABSTRACT

*Two decades of work delivering health care in poor communities provide a standpoint from which to challenge conventional doctrines in human rights and public health. These orthodoxies include the priority often assigned to civil and political rights over economic and social rights and a narrow concept of cost-effectiveness in public health policy. An analysis based on economic and social rights underscores, for example, that effectively treating infectious diseases in poor communities requires ensuring that people receive adequate food. The challenge of maternal mortality in low-income settings similarly shows the need for an approach to rights that is simultaneously comprehensive and pragmatic. In many settings, paying community health workers for their efforts on behalf of their neighbors can also be seen as a critical strategy to realize rights. Across contexts, the yield on the expanded and pragmatic view of health and human rights adumbrated here may be considerable. In forthcoming issues, Health and Human Rights will continue to investigate the conceptual, but above all the practical aspects of such issues, seeking to shift the health and rights agenda in a way that may make sense to the world's poor and marginalized, the chief victims of contemporary human rights violations.*

### FISSURES IN THE ORTHODOXY

Almost ten years ago, I was afforded several pages in the *American Journal of Public Health* in order to reconsider the vexed question of how medicine and public health might contribute to the broader struggle for basic human rights.<sup>1</sup> The essay was informed by a dozen years of work. Together with hundreds of people working for a group called Partners In Health (PIH), I've been part of an effort to provide basic services — medical care, primary education, clean water, even exhumation and proper burial for the victims of mass violence — in Latin America, Siberia, and inner-city Boston. The people we served had neither a language nor a culture in common. What they had in common, by and large, was poverty. More than half of those we sought to serve were women and children. Most were sick, many with AIDS or tuberculosis or malaria; others were neighbors or relatives of the sick. But regardless of whether they were sick or well, all shared that vague status known widely as “at risk.” Whether in informal settlements in rural Haiti or urban Peru, whether in Siberian prisons (where the great majority were men) or in poor areas of an American city, the people served by PIH were and are at risk of dying prematurely because their basic right to survive had not only been shoved aside by the powerful in their home countries, but was not even considered as a ranking concern by many in mainstream human rights groups. Using the rights argot of our day, I argued against a prevailing human rights orthodoxy: although those we served ardently desired civil and political rights, they spoke more often of social and economic rights. These rights include the right not to starve to death or die in childbirth; the right to treatment, even for chronic and difficult-to-treat afflictions such as AIDS or multidrug-resistant tuberculosis; the

right to primary schooling, and the right to clean water. It was such rights as these, or so I argued in transmitting our patients' views in the pages of the *AJPH*, which should be our focus in the public health and medical communities. The issue was urgent, in part because public health professionals should have been fighting to advance them anyway, and in part because these rights were too rarely mentioned by the "orthodox" human rights organizations based largely in North America and Europe. It was an argument partly about the intrinsic merits of an issue, and partly about its near-invisibility at that time.

I wrote that in 1999. Some things have changed since then; others remain the same. PIH has expanded considerably. Over the last two years, building especially on our experience in Haiti, PIH has launched three new projects in rural Africa. But our recent experience offers scant reason to change the basic thesis advanced in 1999. Both international health and human rights regimes continue to proffer largely what amount to interlocking orthodoxies, which constrain our capacity to solve public health problems and also undermine the power inherent in human rights principles as these were originally articulated. Of course there are many exceptions to this general trend, but here is what I see in rural Africa, as in rural Haiti: in so-called "resource-poor settings"—in other words, among the poor—the orthodoxy in public health today is to formulate policy that promotes "cost-effective" and "sustainable" interventions, which are often noble enough in spirit but lack the commitment needed to stop the epidemics, much less the poverty, registered in the poorest parts of Africa, Latin America, and Asia. In human rights, the orthodoxy is to focus solely on civil, legal, and political rights, putting off issues of food, health, and education to some later stage. Both these orthodoxies fit neatly into a neoliberal political and economic agenda propelled by the world's most powerful governments and international financial institutions. My comments here are not meant to be ideological, but rather argue that we must shield the very notion of public health and our practice from specific ideologies, in particular the harshest neoliberal ideologies. Those ideologies were not crafted by or for the people we seek to serve. People actually living in "resource-poor settings" do not clamor for "cost-effective" solutions to their problems; they want first and foremost *effective* solutions. They want equitable access to health, educational, and other services. And that is, or should be, our specialty. We might not know

how to grow national or transnational economies, but we do know how to protect the health of the poor.

This is the specific background that my colleagues and I bring to our stewardship of *Health and Human Rights*. This is what prompts us to affirm that the journal's vocation lies in challenging — through conceptual analysis and practical action — the interlocking orthodoxies that defraud poor people of the minimal requirements for a healthy life, while fortifying privileged minorities in their lifestyles of lavish excess. The editors who led *HHR* through its first decade, Jonathan Mann and Sofia Gruskin, understood the journal's mission in very much this way. They created a forum in which received ideas in public health, political economy, and rights discourse have been subjected to probing scrutiny. For ten years, *HHR* has disentangled conceptual complexities around the right to health; interrogated injustices and proposed pragmatic solutions; and facilitated a conversation on human rights practice that has increasingly engaged voices from poor communities on the front lines of rights struggles. In taking up the editorship of *HHR*, our aspiration is to continue and reinforce this effort.

The public health and human rights orthodoxies I've outlined above are tightly linked, even though the links are often buried and elusive. Exposing these connections is a part of mapping a way forward for *Health and Human Rights*. Here, and throughout this introduction, I'll seek to support my general argument with specifics. Since I've recently been working in Malawi, where maternal mortality is said to be the third highest in the world and where hunger and other afflictions abound, I'll cite a recent essay by an expert on the country: "The tenets of liberalism in both politics and economy are now shared by all the political parties [in Malawi]. . . . Everybody, it seems, is committed to multiparty democracy, human rights, and the market economy."<sup>2</sup>

How are democracy, human rights, and a "market economy" linked together? Are they so linked for the poor in particular? Amartya Sen, among others, has offered compelling evidence that genuinely democratic governance is associated with more development and less poverty.<sup>3</sup> But there is no magic formula that leads from the "shared tenets" of "multiparty democracy, human rights and the market economy" to a reduction in the appalling privations still faced by many Africans and by hundreds of millions elsewhere.

Our ostensible beneficiaries are sometimes called the “voiceless poor.” But the epithet is misapplied. They have much to say, and they do so, as any clinician or anthropologist knows. Whether or not we listen to them is a different story. Are human rights and public health groups even prepared to listen? In an essay titled “Why More Africans Don’t Use Human Rights Language,” Chidi Anselm Odinkalu, a distinguished new member of *HHR*’s editorial board, puts it this way:

In Africa, the realization of human rights is a very serious business indeed. In many cases it is a life and death matter. From the child soldier, the rural dweller deprived of basic health care, the mother unaware that the next pregnancy is not an inexorable fate, the city dweller living in fear of the burglar, the worker owed several months arrears of wages, and the activist organizing against bad government, to the group of rural women seeking access to land so that they may send their children to school with its proceeds, people are acutely aware of the injustices inflicted upon them. Knowledge of the contents of the Universal Declaration will hardly advance their condition. What they need is a movement that channels these frustrations into articulate demands that evoke responses from the political process. This the human rights movement is unwilling or unable to provide. In consequence, the real-life struggles for social justice are waged despite human rights groups — not by or because of them — by people who feel that their realities and aspirations are not adequately captured by human rights organizations and their language.<sup>4</sup>

Odinkalu’s language is uncompromising. I don’t want to mislead you into thinking that there is little but conflict between human rights groups and the humans desiring to win rights. Despite neoliberal orthodoxy in both international health and human rights, much has changed over the past few years, and some of it for the better. Allow me to take the example of AIDS. Following the lead of groups led by people living with HIV, by student activists, and by a small number of organizations serving the destitute with or at risk of AIDS, the recent influx

of funds designated to treat poor people with AIDS in the spirit of providing a public good, rather than a commodity, has challenged modern public-health orthodoxy, which, pushed by international financial institutions, has too often sought to “cap” health expenditures and focus on “cost recovery” in some of the most afflicted places in the world.<sup>5</sup> This is like a call for conserving water just after the house catches on fire. But imposing user fees and selling therapy for AIDS did not work in Africa. It was not until diagnosis and care were made rights rather than commodities that people living with AIDS and in poverty had any hope of help. Although many will no doubt conclude that it is ultimately cost-effective to lessen, through the only means possible, the horrific mortality registered among poor people living with HIV, the large-scale efforts I am referring to were not launched on grounds of cost-effectiveness. Instead, they were the result of powerful thinking about ethics and the alleviation of suffering. Human rights and social justice, once staples of public health, are slowly being revived on a grand scale.

How did this come to pass? Could this experience shape rights-based approaches to other problems of poverty? Speaking from our own experience, PIH, having focused for over a decade on AIDS prevention, launched AIDS treatment for the poor of central Haiti in 1998, an initiative cheered by patients but dismissed by influential international health leaders as neither cost-effective nor sustainable.<sup>6</sup> PIH was then small and without the influence necessary to do more than challenge such orthodoxy. So we turned to the human rights community, launching, in 2001, the Health Action AIDS campaign with Physicians for Human Rights (PHR). To make a long story short, Jim Kim and I went to the PHR board and argued that *this* was what a human rights campaign around AIDS needed to look like: we sought to protect the civil and political rights of people living with HIV at the same time that we protected their right to live. And that simply could not be achieved without diagnostic tools, medicines, and even food and water. PHR, it transpired, had never before launched a campaign for social and economic rights. But together we did so gamely, and this effort galvanized many students across the country, echoed and amplified the voices of courageous AIDS activists, and preceded the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria and major bilateral programs such as the President’s Emergency Plan for AIDS Relief (PEPFAR). These funding mechanisms may have

their weaknesses, but at least we're no longer spending all our time arguing about whether or not we should bother even trying, in Africa, to prevent and treat these three major infectious killers — all of which will become more difficult to treat in the future, since prevention and supervised therapy need to be more aggressive in the absence of effective vaccines, and since the organisms all develop resistance to the antibiotics used against them.

### “FOOD, FOOD, FOOD”

The willingness of the public health community to embrace and promote the right to health is the fulcrum of our ability to address these complexities. Particularly crucial are the responses of those of our peers who are global public-health leaders. For example, will the inexorable rise of drug-resistant HIV, TB, and malaria lead those at no risk of these diseases to argue, whether from Geneva or New York or London, that it is acceptable to use now-inexpensive first-line drugs for AIDS, TB, and malaria, but that it is neither sustainable nor cost-effective to treat even more complex forms of these diseases? What if we confess, from Haiti or Rwanda, that many of our patients are hungry and that, last time we checked, the only treatment for hunger is food? What if we tell those who hold the purse strings that we do not really know how to treat diseases, much less how to prevent them, without promoting basic social and economic rights for the poor? Will the next orthodoxy in public health be that it is acceptable to offer medicines but not acceptable to offer, say, access to microcredit, school fees, or food? That it is not “sustainable” to pay community health workers for their labor on behalf of their neighbors, even though we pay ourselves handsomely enough as international health consultants engaged in a network that spans rich world and poor?

Not long ago, in Malawi, I confessed to a small group of friends and co-workers that I was anxious about being invited to deliver a plenary address to the annual meeting of the American Public Health Association (APHA). My colleagues and I had just spent part of that day visiting, in their homes, people living with (or dying from) HIV. Most of these patients had not yet received antiretroviral therapy; several also had tuberculosis. They were slated to be enrolled in a treatment program that, though community-based, did not include paying community health workers; nor did it include assistance with transportation to

and from health centers; nor did it include food or the means to buy it. At the end of the day, over dinner — my colleagues and I enjoyed ready access to food — I asked my friends what my message to the APHA should be. “Food, food, food,” intoned one of my colleagues, a former medical student of mine who had completed his training and had spent 18 months in Malawi working on a research effort. One word, repeated three times. But we all knew just what he meant: that without what some term “wraparound” services (including food), it will not be possible to scale up ambitious programs, because poor people in places like Malawi often don't have enough to eat, nor do they have the resources to go to health centers for a work-up, or the money to pay whatever hidden user fees lurk in ostensibly free AIDS treatment programs. Over the past few years, we've seen some governments adopt, sometimes reluctantly, treatment programs that are “free” to their poor citizens. The poor show up, only to learn that it costs money to be tested for HIV or that they need an ID card or another laboratory test or a chest film. We've seen programs that claim to prevent transmission of HIV from mother to child but do nothing to provide breastmilk substitute, weaning foods, or clean water to women living in poverty. We've even seen programs providing free therapies even as condoms or prophylaxis for opportunistic infections are sold through social marketing schemes funded by resource-rich institutions. These institutions have promoted a public-health orthodoxy that leads most people in the richer countries to conclude that it is impossible to sustain public health interventions that do not generate profit or break even.

Food, food, food. How on earth can we make sure that those sick with consumptive diseases like AIDS or tuberculosis recover unless they have access to both medicines and food? That said, even those of us involved in treating such diseases in places like Malawi or Rwanda or Haiti (where food riots recently claimed several lives) know that there is a role for sustainable development. That's why we're involved in efforts to improve seed quality, increase access to fertilizer, water, and microcredit, and implement land reform. These will be difficult programs; “mission creep” will abound. But if we believe in health and human rights, we will need to broaden, very considerably, our efforts to promote social and economic rights for the poor. This, I would argue, is the leading human rights issue now facing public health.

## THE CASE OF MATERNAL MORTALITY

Lest this sound too general, allow me to consider maternal mortality. Gender inequality and poverty — together, not apart — are the cause of almost all deaths during childbirth: half a million women die each year in childbirth, but these deaths are registered almost exclusively among poor women. They can all be prevented, but to do so requires that women with obstructed labor have access to modern obstetrics: an operating room, electricity, sutures, blood, clean wards, and good post-operative care.<sup>7</sup> (Preventing maternal deaths in regions of high HIV endemicity will also require improving coverage levels for prevention and treatment of major infectious diseases, including AIDS, tuberculosis, and malaria, which have been shown to contribute substantially to maternal mortality rates in some areas.<sup>8</sup>) I wish that when I first traveled to Haiti, in 1983, someone had told me that to promote human rights there, we'd need to consider learning to build operating rooms and to procure equipment and supplies; it would have saved us a great deal of time and made us more effective. We did learn that lesson, but only after presiding over the grisly spectacle of young women dying because they were pregnant and poor. One community-based survey conducted in rural, southern Haiti in the early 1980s pegged maternal mortality at 1400 per 100,000 live births — far and away the highest in the hemisphere.<sup>9</sup> Rates of caesarian delivery were about zero in rural Haiti. Imagine my surprise when I later learned that, elsewhere in Latin America, public health advocates were fighting to *reduce* rates of caesarian delivery. This is the nature of inequality in Latin America: human rights activists could in one setting (Mexico) spend their efforts trying to reduce the number of caesarians, while others similarly inspired worked in Haiti to increase poor women's access to caesarian delivery. I'd say something here about the ironies of inequality if the story weren't so abominable as to be beyond irony.

I saw the same thing again recently in Malawi. In the largest public maternity ward in the country, in Lilongwe, two obstetricians and a handful of nurses were struggling mightily to deliver 12,000 babies each year. This is slightly more than the number delivered in Harvard's Brigham and Women's Hospital, where I was trained and still work. The Brigham delivers more babies than any hospital in New England: we have, in just that one hospital, more than one hundred obstetricians, without counting the dozens of doctors and students training in obstetrics and

gynecology. In the Malawian hospital, there is a single OR; in the Brigham there are over 40, with four in the women's health center alone. It's almost unheard of for women to die during childbirth in the United States, though victims of maternal mortality in this country are predominantly poor women of color. Here are some numbers: the maternal mortality ratio in Malawi is pegged at 1800 per 100,000 live births. In the United States, an estimated 17 women die per 100,000 live births. Twenty-nine other countries, most of them affluent countries with national health insurance, match or beat that ratio. The figure is zero for Iceland.<sup>10</sup>

In Malawi, I spent some time with Tarek Meguid, one of the two obstetricians tending to the women who deliver their babies, or fail to do so, in the maternity hospital. Tarek describes in this issue of *HHR* the conditions that he and his patients confront. The day I first visited, Tarek showed me a hospital that was fairly clean but sorely lacked supplies and personnel. The blood bank closed at five p.m.; the only way to care for critically ill women or infants was to transfer them to another under-resourced public hospital, a difficult procedure since calls had to be made, transport arranged, and so forth. (Two kilometers separated these two facilities, but it took an hour or more to arrange emergency transfers.) Tarek spoke explicitly in human rights terms even as he detailed the material shortcomings of his facility. Outside the doors of the single OR was a gurney piled high with surgical drapes in tatters. He referred to the hallway as "post-op." (I wondered, just then, how often he'd been obliged to receive visitors like us, and what they did to help the hospital.) "This is an abuse of human rights," he said, lifting up one of the rags. "It would never happen if people considered the women we serve as human beings." The doctor felt sick, he said, that maternal mortality *within* the hospital was 300 per 100,000 live births, even though one might note, by way of consolation, that this was a six-fold reduction in the national rate. It seemed better to say nothing.

Should there be a right to sutures? To sterile drapes? To anesthesia? In 2007, colleagues and friends at PHR took on a second issue — maternal mortality — in explicitly social- and economic-rights terms. PIH again supported this effort, helping to organize a focus group for PHR's investigation into maternal mortality in Peru. Critically, CARE Peru, a local organization with experience providing services to women in remote rural areas, was also instrumental

in the project.<sup>11</sup> But a much wider set of partners is needed to address the sources of maternal deaths among poor women in Peru and elsewhere, since, again, we will need electricity. We will need gloves. We will need sutures and antihemorrhagics. We will need drapes and hot, clean water. We will need unfettered access to family planning. This is uncharted territory for human rights organizations but is exactly the direction in which we need to go if we wish to move beyond studies, conferences, and exhortations and actually reduce the number of deaths.

Certainly, there are many groups that understand that it's impossible to make rights meaningful without the material resources I mention above. But human rights orthodoxy has left us weak in this arena. While many who care about rights are prepared to discuss gender inequality, too few of us are ready to buy generators, c-section kits, sutures, or OR lamps. Not even contraceptives are considered in pragmatic enough terms. But how on earth will we ever stand in solidarity with women living in poverty if we're unable to move resources, the fruits of modern science and technology, to them? Of course, it is public authorities that can move such resources most effectively and equitably. A significant part of our work must consist in pressuring political officials to enact those redistributive transfers on the scale required — and holding them accountable for performance. Yet even as we grapple collectively with the political challenge, those of us positioned within well-resourced private institutions can and must find short-term strategies to move vital goods quickly from settings where they abound in dizzying excess to places where their utter absence exacts a daily toll of suffering and death. So many NGOs, however, including human rights organizations, regard such pragmatic solidarity as off-topic, beyond their mandate. Research universities are worse, by and large, and rich-world public health authorities are trammled by administrative boundaries of county, state, and nation, even though they know that Malawi's nurses, like Malawi's epidemics, are, in fact, transnational: nurses move out, epidemics move in. The NGOs that fight for the right to health care by serving the African poor directly frequently do so at the expense of the public sector. Their efforts too often create a local brain drain by luring nurses, doctors, and other professionals from the public hospitals, like the one in Lilongwe, to "NGOland," where salaries are better and the tools of our trade

more plentiful. The chronic dearth of resources that undermines staff retention in the public sector is due not only to corruption, which is oft underlined, but also to the structural adjustment programs imposed by the international financial institutions staffed in part by people like us, the editors and readers of *Health and Human Rights*.

How can this sorry human rights situation best be addressed? It's been analyzed exhaustively — let's just say no to more surveys sure to reveal the same problems already revealed by previous surveys. And although I confess that PIH, an NGO, has moved into Malawi, I'll add quickly that we do not wish to expand the population of NGOland, nor to repeat our past mistakes. NGOs committed to the rights framework have to learn how to strengthen the public sector, since only governments can guarantee their citizens' rights. No one elected us to set things right. We're all self-appointed. Those of us in public health will have to learn to move beyond crude notions of cost-effectiveness and sustainability and to return to the concept of social justice, which once inspired public health but now seems to embarrass us. First-world universities, which are very much in evidence in African capitals, not only have to learn how to challenge public health and rights orthodoxies; they also have to learn how to share their abundant resources if they wish to conduct research across steep grades of inequality. It's fine that there are more American pediatricians than African ones in some of that continent's poorer cities and towns, including Lilongwe, but what are our long-term plans for helping to rebuild health care infrastructure and for training and retaining local professionals in these areas? What are our plans for making certain services, including safe childbirth, a right rather than a commodity?

All this is to say that health and human rights needs to move beyond its traditional exhortatory role, which stems from insistence on respect for conventions to which most states are signatory, and think about such prosaic issues as supply chains for sutures, generators, magnesium sulfate, and OR lights. And of course we need to do this at the same time that we continue and expand our struggle for civil and political rights. Enforcing rights is another matter altogether, since it is often the signatory states themselves who are responsible for rights violations, from torture to neglect of the public sector. Even

more disturbing are the shadow governments above the state: the international financial institutions; the tacit pacts among powerful nations that agree to disagree on Darfur or to ignore genocide in Rwanda until it's too late; and the worsening concentration of health and wealth in our inegalitarian world. But where's the lesion? Health and human rights needs a legal framework to impose on national governments, true, but who is responsible for spending caps on health and education in the world's poorest countries? Certainly not the hapless medical professionals of those countries, and not the Ministries of Health, either. How can we legislate in an effective manner when governments such as Malawi's and Haiti's work with national budgets far less than that of a single Harvard teaching hospital? To understand why there are so few personnel and supplies in Malawi's largest maternity hospital we'll need more than an immediately local analysis; we'll need to lift our eyes to look hard at history, political economy, and the powerful transnational institutions that have determined many policies in post-colonial Africa and in much of Latin America. Where is the support for applying a legal framework to those institutions?

The yield on an expanded and pragmatic view of health and human rights might be greater than we think. Preventing disease, saving lives, eradicating malnutrition, and promoting universal primary education will help to reverse the concentration of power in the hands of a few. It might not be naïve to argue that when people are not facing both destitution and disease, they might be able to participate more in civic processes, both local and national (although, granted, this hopeful hypothesis is not always borne out in affluent democracies). In short, as a public health activist I advocate challenging the present priorities, which place civil and legal rights first and adjourn substantive rights for another day. It is when people are able to eat and be well that they have the chance to build democratic institutions.

#### MEASURING THE EFFICACY OF ACCOMPANIMENT

So where does one start in an effort to support "an expanded and pragmatic view of health and human rights"? Even though there are no secret formulas, there is an urgent need to support what may seem to be a rather prosaic agenda. I mentioned food above, and also sutures, medications, electricity, water, and

other basic goods that may not seem very sexy to most people now commenting on health and human rights. Is this all there is? The transfer of mundane enough material resources, and also money, to the very places that lack them? Well, pragmatic solidarity of this kind would come as a huge relief to populations who right now occasion much commentary but little in the way of such transfers to those living in poverty (plenty of cash is transferred, but it too rarely reaches the poor). And although it's true that there's no magic bullet to counter poverty, ill health, and a lack of both materials and personnel, there's much that could be done to address poverty and the diseases and complications that accompany it.<sup>12</sup> Perhaps the most important of these concrete steps, in the places in which PIH has worked, has been the recruitment and training of community health workers.

Much is made of the brain drain and the lack of medical personnel in places like rural Haiti or rural Malawi. As research shows, under-resourced systems such as the public sector in each of these countries are unable to retain the nurses and doctors trained there, even though they were educated, by and large, within publicly financed facilities; their medical training is supported as much by the local poor, who are taxed indirectly, as by private financing, including tuition.<sup>13</sup> In order to reverse the brain drain, we will have to invest heavily in institutions such as the maternity hospital in Lilongwe; we will have to make sure not only that health professionals receive salaries that are adequate but also that they have the tools of the trade. One study in urban Kenya shows that, although young physicians are unhappy with their salaries and the way they're treated by their superiors, they are also unhappy because they don't have the diagnostic tools and medications needed in order to treat their patients. "Before training," said one young Kenyan physician, "we thought of doctors as supermen... [now] we are only mortuary attendants."<sup>14</sup> How long can African doctors and nurses tolerate being little more than spectators to the grisly parade of suffering and premature death within the walls of that continent's public hospitals? No small amount of that suffering is caused within these institutions, which are right now the very settings in which nosocomial outbreaks of tuberculosis, including extensively drug-resistant tuberculosis (XDR-TB), are registered.<sup>15</sup>

Even as we make long-overdue investments in the public sector in Africa, there is also reason

to invest in people who do not work within the hazardous confines of the public hospital, including community health workers (CHWs). Community health workers are mostly poor people; most have little in the way of formal education; most were unemployed or underemployed prior to becoming CHWs. Community health *workers* are distinct from community health *volunteers* (CHVs), the preferred term in NGOland, reflecting the fact that most NGOs and governments do not pay local people who contribute time and labor to improving their communities' health. Community health *workers* are paid, however modestly, for their efforts on behalf of their neighbors. Such compensation constitutes, unfortunately, yet another challenge to a regnant orthodoxy — in this case the assumption that local community members' time and effort need not be valued equally to those of other partners in health work.

As community members in many settings assume a greater role in health action, a debate simmers over equitable payment for all those who work within the community health arena. Some would have you believe that there's no difference between CHWs and CHVs — i.e., between a model in which local people are paid for their work and one in which they are expected to perform similar tasks with no remuneration. This is a fraud perpetuated by our own “community of experts.” Those experts who argue that we should encourage volunteerism, and not pay the poor for their labor, have not imagined themselves in the situation of the vast numbers of rural or urban poor people who would happily become community health workers. The problem with volunteerism is that the people called upon to donate their time are themselves poor (and often sick) and can scarcely afford to spend hours each day checking on their neighbors when they are obliged, NGO fantasies to the contrary, to plant millet and corn in order to feed their own families. That local people are sometimes prepared to accept the non-remunerated CHV role does not mean they don't prefer (and need) the CHW model. If volunteers are poor enough to warrant food assistance, then they may declare themselves happy enough to volunteer in order to obtain such support; however, this mutually tolerated fraud is in no way genuinely mutual: the “international health community” promotes it, and the rural and urban poor tolerate it, because without this charade, they would receive even less assistance

as they seek to prevent premature death in their beleaguered communities.

But there's more. We have argued — and argue is the operative word — that community-based care involving CHWs is the very highest standard of care available to the poor who live with chronic disease, whether that disease be AIDS or diabetes or major mental illness. There's a reason that we have taken the model developed in Haiti and applied it not only in rural Rwanda or urban Peru, but also in the poorer parts of Boston: in seeking to promote excellent outcomes in treating chronic infectious disease, we've found that doctors and nurses, and even social workers, cannot ensure that our patients are able to adhere to complex regimens unless our patients are offered what we've referred to as “accompaniment.”<sup>16</sup> Although public health jargon is full of other terms to describe close, community-based follow up, and although we ourselves have too often contributed to this jargon, we've come to understand that something far better than supervision emerges when we support CHWs with even modest honoraria or incentives.

Over the past decade, we've sought to present the task of sustaining community-based care in settings of poverty as a human rights challenge. Don't expropriate the labor of the poor; champions of volunteerism within our ranks should feel free to volunteer but should be uncomfortable asking the destitute to do the same. So, although we're embarrassed that the honoraria we provide to our CHWs are so modest, we nonetheless insist on supporting them and seek to promote such remuneration in all of the settings in which we work. We've rejected the community volunteer model and its underlying assumption that poor people's work can be had for nothing. We've been rebuked for this stance, but the rebukes have never come from the CHWs or their families or their patients. The rebukes have come from our peers, those obsessed with “sustainability” and “cost-effectiveness.” Within international public health circles, we've found ourselves swimming against a strong undercurrent of censorious opinion.

Perhaps if our profession had embraced a rights-based model rather than those now in vogue in public health, we would not be obliged to spend so much effort arguing that such care is cost-effective, although it almost certainly is.<sup>17</sup> We have every intention of stooping to the level of our critics in an

effort to show that our model is indeed sustainable — we're not proud. But we also argue that the first thing to be sustained is first-world commitment to global pandemics and other problems of the world's poor and that this is the way to begin a “virtuous social cycle” that might lift the destitute sick out of extreme poverty.<sup>18</sup>

To bring these disparate themes together in a rights-based framework is, I hope, a useful exercise, as we seek to chart directions for *Health and Human Rights* and to identify some of the problems the journal will take on. If we believe that health care is a right, we need to address problems such as AIDS and maternal mortality with the highest standard of care possible. If we believe that the treatment for hunger is food, we need to address food insecurity with both short-term and long-term strategies, even if this means that we must learn about improving seed quality and procuring fertilizer and promoting fair trade, which means taking on rich-world agribusiness subsidies. If we believe that it's wrong to appropriate the labor of the poor, we need to insist that community members doing health work be compensated for their labor, even as we welcome volunteerism by those who can afford to offer their services without pay, for instance the readers of a journal such as this one. If we put even a shred of stock in the notion of solidarity, then we must press for basic social and economic rights for the poor, regardless of whether we term our efforts “wraparound services” or accompaniment.

#### FOCUS ON PRAXIS

The vocation of *Health and Human Rights* is to investigate the conceptual underpinnings, but also and above all, the practical aspects of such challenges. This is the frontier that *HHR* in its new format is poised to explore — using interactive capabilities that will usher in a fresh relationship between the journal's editorial team, those who publish in its pages, and an expanding, engaged, and vocal readership (with front-line practitioners strongly represented in all three groups). The journal's new open access format, enabling readers and contributors alike to comment in “real time” on writing that appears in these pages, will facilitate an ongoing conversation. Published articles, essays, and blog postings are the beginning of a dialogue — incomplete until other voices respond and comments are exchanged, new connections are made, and new strategies for action are debated, refined, and implemented.

The focus of *HHR* in its new format is “human rights in the doing.” However, emphasis on action does not mean that we now consider conceptual analysis irrelevant. The two dimensions nourish and sustain each other. To achieve its objectives, action on the ground must be guided by rigorous conceptual work. To remain relevant, conceptual analysis must be nourished by contact with communities' real needs, and with concrete policy-making and implementation processes.

This idea of a mutually reinforcing connection between reflection and action is, of course, the essence of the concept of “praxis” developed in Marxist thought and popularized by educator, philosopher, and activist, Paulo Freire.<sup>19</sup> To many, this concept now seems quaint. Fashions in northern academic settings have long since marginalized the term and the realities to which it points, adopting instead more comfortable ways of understanding the nature of intellectual work. This trend is evident across the humanities and social sciences, where ironic detachment, “textual subversion,” and arcane methodological disputes have largely supplanted concrete political engagement on the progressive end of the political spectrum — with welcome exceptions. In public health, the causal links between political-economic structures and health outcomes described by Engels, Virchow, and Salvador Allende are obscured in favor of a diffuse “web of causality” that leaves nothing and no one in particular responsible for health inequalities.<sup>20</sup> Endless epidemiological studies mobilize increasingly sophisticated statistical methods to *describe* health inequities in ever-more exacting detail; taking action to reduce this mass of unnecessary human suffering seems far down on the list of concerns.

Under its new editorship, as previously under Jonathan Mann and Sofia Gruskin, *HHR* is dedicated to changing the world through rights-oriented action. Of course, many of our scientific and medical colleagues continue to worry that good science and activism don't mix. We will attempt to show in the journal's pages not only that this is not the case, but that the opposite may be true — that, at least in the case of public health, the best science (that is, the knowledge that most effectively meets essential needs related to the health of human populations) springs from and is guided by an activist commitment to work with disadvantaged communities in realizing their economic and social rights. Science can learn

from innovation and insight at the grassroots level, born of rights struggles in every corner of our world. The communities suffering the brunt of today's global health inequities — along with environmental devastation, armed violence, and economic exploitation — know well that science is never “pure,” that knowledge always emerges in a matrix of interests and power relations. We will do well to acknowledge this fact frankly, along with its corollary that science is always already part of an “activist” agenda: the only question is, which one, and for whose benefit?

It merits reflection that one of the branches of the academy where the connection between thought and action has remained vigorous is in business schools. Here, real-world relevance is, in principle, the *sine qua non* of intellectual success, and theoretical models are checked against practical performance. What is theoretically acceptable is what works on the ground; success or failure in implementation is the chief yardstick of an idea's validity. A dose of this kind of pragmatism might do the human rights community good.

Humanitarian and health professionals have spent a generation now shaking our heads at the fact that, in many of the settings where we are unable to provide food, health care, and primary education with any reliability, global corporations consistently deliver chilled soft drinks, and arms traders have no trouble at all delivering weapons. This situation reflects structural asymmetries of power and resources among sprawling corporations, a debilitated public sector, proliferating but often ineffectual NGOs, and poor communities plagued by their own internal tensions. But such chronic implementation failures also have to do with human rights and humanitarian actors' collective unwillingness to draw lessons for our implementation work from the efficiency with which some businesses organize and manage complex systems to deliver ideas, goods, and services in challenging environments. The implications of this hypothesis for human rights action will be one part of our exploration of praxis in the pages of *HHR*. The approach may yield strategies that will challenge orthodox mindsets on both the political left and right. We can already see this happening in the new field of global health delivery, where Jim Kim and our colleagues are harnessing pedagogical and

implementation strategies from business to tackle barriers to the effective delivery of health care and social services for the poor.<sup>21</sup>

#### CONCLUSIONS: A NEW (OLD) RIGHTS PARADIGM

In many senses, nothing I've written here is new. The struggle for social and economic rights has been outlined many times before; the Universal Declaration of Human Rights mentions them explicitly, and 155 countries have ratified the International Covenant on Economic, Social and Cultural Rights. My own country is not among them, which will not surprise public health advocates, since we all have a long way to go before we see the right to health care in the United States. But if the basic ideas are hardly novel, the commitment and opportunity to turn them into action mark a fresh departure.

There's much to be done right now if we wish to address orthodoxy in health and human rights. US-based human rights organizations focused on social and economic rights are mostly still small and new. However, their work is gathering momentum, and they are not timid about tackling tough problems, as the article in this issue by Anja Rudiger of the National Economic and Social Rights Initiative (NESRI) confirms. Among a wide range of other program activities, NESRI applies an economic and social rights analysis to the politics of health care in the United States and supports grassroots organizations from Massachusetts to Montana in driving, from the ground up, rights-based action for health system reform.<sup>22</sup> Meanwhile, some larger, established organizations traditionally focused exclusively on civil and political rights are also coming on board. Amnesty International (AI) now boasts leadership with a clear commitment to social and economic rights and has begun to implement programming in this arena.<sup>23</sup> Indeed, the right to health, and the reduction of maternal mortality in particular, will be a central focus of Amnesty's forthcoming campaign on economic and social rights, planned for launch this year.

To fully grasp the significance of Amnesty International's recent inclusion of social and economic rights in its proposed programming, it is worth considering not only the importance of the right to health care — including the right to safe

motherhood, which is the primary goal of AI's new effort to decrease maternal mortality — but also the cost of erasing the social and economic underpinnings of rights abuses writ large. The narrowly restricted view of rights which, since the outset of the Cold War, has dominated the rights movements based in (and funded by) affluent democracies has often erased not only any serious consideration of social and economic rights; this view has also distorted or at least shaped our understanding of rights abuses as conventionally defined in North America and Western Europe.

It's hard enough, some argue, to understand recent violations of civil and political rights (What, precisely, constitutes them? When do they occur? Why? How might they be prevented? What effective legal remedies exist?) even before we allow that there are other rights, including those discussed at length in this issue of *Health and Human Rights*. This elision, this erasure, has not always occurred because of pressure by powerful ideological forces on rights groups, through funding restrictions and within an ethos shaped by the Cold War, to privilege some rights over others. This certainly happened, as Carol Anderson has insisted in her magisterial *Eyes Off the Prize*,<sup>24</sup> but more insidious and corrosive erasures also occur. The social constructs now identified as human rights have, in every setting, a history.

Since no social movement is immune from the heavy hand of history, it is important to understand the history of the modern, contested rights movements based in what are termed Western democracies, and to see what, during these often-bitter struggles, has been brought into relief and what has been erased. Elsewhere and quite recently, discerning observers have written about the sinister ways in which human rights struggles in and regarding Haiti — in so many ways the very place in which French claims to promote “The Rights of Man” were revealed to be hypocrisy, since Haiti, not France, was first to abolish slavery — have been set back in recent years through funding from self-declared human rights groups.<sup>25</sup> But, as Odinkalu noted in the blistering critique cited earlier, Amnesty International is not funded by powerful governments; it remains, to this day, an organization funded by individuals objecting to torture and other forms of abuse, and to the silencing of the citizenry and the press. (As a caveat, my first experience as a

member of a human rights organization was when, as a college student, I joined a group writing letters on behalf of those designated by Amnesty as “prisoners of conscience.” I've never regretted it.)

But even groups leery of funding from powerful governments, including Amnesty International, may be “blinkerered,” as Naomi Klein has noted in a new book that every proponent of human rights should read.<sup>26</sup> She reminds us that Amnesty International, in the “loaded context” of the Cold War, developed a “doctrine of strict impartiality: its financing would come exclusively from its members, and it would remain rigorously independent of any government, political faction, ideology, economic interest or religious creed.” This was a reflection of much-needed integrity at a time in which rights were too often defined and supported in order to meet the needs of the powerful. But in its eagerness to eschew any partisan bias, writes Klein, the self-defined independent human rights organization neglected to bring into relief the social and historical backdrop of the rights abuses then occurring in Latin America. Mistakes were made whenever it was deemed unnecessary to explain *why* such abuses occurred, and whenever the sole point was to document and describe abuses. What was really at stake, then as now (writes Klein), was lost in the grim details of detention, torture, and disappearance: “Amnesty’s position, emblematic of the human rights movement as a whole at that time, was that since human rights violations were a universal evil, wrong in and of themselves, it was not necessary to determine why abuses were taking place but to document them as meticulously and credibly as possible.”

In the 1970s, Latin America was, in a sense, ground zero of this hemisphere's struggle for human rights. Tens of thousands of civilians, likely many times that number, died during efforts to promote basic rights, however they are defined. Almost no one would argue that headway was made during that decade, whether one defined rights primarily as civil, political, economic, or social. Although this death and suffering gave rise to several “transnational” rights movements, including Amnesty and many others, there remained a fog over those who sought to link, during military dictatorships, gross and obvious violations of rights (torture, murder, the silencing of the press) to the more insidious erosion of the rights of the poor to

health care, primary school, water, and employment. The former list of rights generated the lion's share of commentary among the emerging mainstream rights organizations; the latter list of rights generated little commentary among those able to write about what was occurring in so many countries, including Argentina. Klein's assessment of this failure is worth citing at length:

The narrow scope is most problematic in Amnesty International's 1976 report on Argentina, a breakthrough account of the junta's atrocities and worthy of its Nobel Prize. Yet for all its thoroughness, the report sheds no light on why the abuses were occurring. It asks the questions "to what extent are the violations explicable or necessary" to establish "security" — which was the junta's official rationale for the "dirty war." After the evidence was examined, the report concludes that the threat posed by left-wing guerrillas was in no way commensurate with the level of repression used by the state...But was there some other goal that made the violence "explicable or necessary"? [sic] Amnesty made no mention of it....It offered no comment on the deepening poverty or the dramatic reversal of programs to redistribute wealth, though these were the policy centerpieces of junta rule. It carefully lists all the junta laws and decrees that violated civil liberties but named none of the economic decrees that lowered wages and increased prices, thereby violating the right to food and shelter — also enshrined in the UN charter.

When the editors of this journal invoke "the UN charter," it is not with any special reverence. But we do seek to be part of a broader movement, as both scholars and participants, to promote the right to health and also to promote solid scholarship. Klein's analysis, published this very year, seems hard to refute now. So how might *HHR* be part of an effort to link sound and rigorous analysis to the movements necessary to "realize" the rights that so many have deemed worthy of so much suffering and struggle?

When Jim Kim, director of the François-Xavier Bagnoud Center for Health and Human Rights, invited me to assume the editorship of *Health and Human Rights*, I accepted with no small amount of trepidation, since I have been more deeply involved in programs to expand access to medicine and public health than in the hard work of receiving and reviewing manuscripts in what is, and will remain, a contested and at times rancorous field. But I consider it a privilege to assume this role, with the understanding that Sofia Gruskin and others who've made this journal into such a precious resource will continue to help shift the paradigm in health and human rights. This doesn't mean changing directions so much as assuming even more responsibility. It does not mean abandoning the legal scholarship and assessment of existing rights documents and laws and conventions. It *does* mean challenging orthodoxies in both public health and human rights discourse. It does mean understanding the ways in which poverty seeps into every aspect of both health and human rights. I pray that we can agree to consider not only the sorry spectacles of Guantánamo or Abu Ghraib or state-sponsored torture and execution — the grotesque tip of the abuse iceberg — but also the long and painful processes through which the world's poor meet a premature end. When we can discuss solemnly the "right to sutures" even as we discuss gender inequality and torture, we will have succeeded in shifting the agenda in a way that makes sense to the world's poor and marginalized. This should be the goal of the health and human rights movement in the 21<sup>st</sup> century.

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the governments of the United States, France, and Canada joined forces with the anti-democratic — and thus anti-rights — elite in Haiti to unseat elected governments in Haiti, see <http://www.ijdh.org>, which has sought to document the fate of the democracy and rights movements in Haiti in recent years.

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