WILL WE TAKE SUFFERING SERIOUSLY?
REFLECTIONS ON WHAT APPLYING A HUMAN RIGHTS FRAMEWORK TO HEALTH MEANS AND WHY WE SHOULD CARE¹

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ABSTRACT
Since this journal was first published, rights-based approaches to health have proliferated in the health and development communities. At the same time, human rights advocacy organizations, courts, and UN actors have increasingly been engaged in applying rights norms in health contexts. Together with others in this issue, this article is a call not to lose sight of the radical potential of using a human rights paradigm to promote health — even as we go about the pragmatic work of translating rights frameworks into practice in our research, advocacy, litigation strategies, program planning, and service delivery. Drawing together points made in other pieces in this issue, the article describes certain conceptual and practical implications of a transformative engagement between health and human rights. It argues that an appropriate starting point is to take suffering seriously; in so doing, approaches in both health and rights will necessarily shift. A human rights approach challenges biological individualism in both clinical medicine and public health, and builds on work in social epidemiology by providing frameworks for accountability. At the same time, using rights to advance the health of marginalized peoples around the world requires critiquing and expanding limited approaches to human rights, in theory and practice.

INTRODUCTION
Health is perhaps the most radical of subjects for human rights because it challenges more than any other the boundaries of what is “natural.” If health is a matter of rights, it cannot simply be a question of divine or genetic fate, of random biological events, or individual behavior. If there is, for example, a “right to be free from avoidable maternal mortality,” we must grapple with what is “avoidable.” To assert that health is an issue of rights is to assert that the state and other actors bear some responsibility in ensuring fair distributions of the social determinants of health as well as availability and access to care. If, 60 years after the adoption of the Universal Declaration of Human Rights (UDHR), governments in the North had heeded its call for an “international order” in which the rights in the UDHR could be fully realized, the landscape of global health would be dramatically different today. For example, we would not merely lament — yet tolerate — the savage inequities in access to emergency obstetric care or the fact that, in some countries a girl has a greater chance of dying in childbirth than graduating from primary school, or the deaths of approximately 11 million children under the age of 5 each year from poverty-related diseases. These circumstances would be perceived as global injustices of almost incalculable magnitude that demanded redress.²

In the years since this journal was first published, rights-based approaches (RBAs) to health and development have proliferated among non-governmental organizations (NGOs) as well as international agencies.³ At
the same time, human rights advocacy organizations, courts and quasi-judicial bodies, and UN treaty-bodies and offices, among others, have increasingly been engaged in interpreting and applying human rights norms in health contexts, from HIV/AIDS to maternal mortality. Although very diverse, common themes can be identified across these efforts, including emphasis on non-discrimination/equality/equity; participation/agency; and accountability. In forthcoming issues of this journal, we will be exploring in much greater depth how these principles, together with international assistance and cooperation, are applied across a multiplicity of contexts in practice.4

Given the opportunity of the journal’s re-launch, I join with the other authors in this issue in a call not to lose sight of the radical potential of using a human rights paradigm to promote health — even as we go about the pragmatic work of translating rights frameworks into practice in our research, advocacy, litigation strategies, program planning, and service delivery. Drawing on and synthesizing points made in Paul Farmer’s introduction as well as other pieces in this issue, I describe certain conceptual and practical implications of a transformative engagement between health and human rights.

I argue that our starting point should be to take suffering seriously.5 In so doing, we are challenged to reconfigure our approaches to both health and rights. As we recognize the shaping power of what we take for granted — not only the orthodoxies in our professional disciplines, as Farmer asserts, but also in our assumptions about justice, society, and humanness itself — we can begin to imagine, and in turn, to work toward, alternatives that go beyond re-packaging the same tired approaches with different names.6

In a human rights framework, health is a matter of justice — a product of social relations as much as biological or behavioral factors. It is the inequalities in these social, and inherently power, relations for which the state (and sometimes other actors) can and should be held accountable from a human rights perspective.7 Such an approach, which builds on work in social medicine and social epidemiology, demands a fundamental shift in the way that health is generally understood and addressed within medical and public health schools, as well as by policy-makers, researchers, and practitioners.

Yet, rights must be seen as sites, as well as tools, of struggle.8 Despite impressive advances in clarifying the content of the right to health as well as other economic, social, and cultural rights (ESC rights) under positive international law, narrow conceptions of rights continue to be reflected in public discourse and underpin neoliberal paradigms of economic development and globalization. Such restricted conceptions of rights are far from emancipatory for those Paul Farmer refers to as “the destitute sick.”9 Using rights to advance the health of impoverished and marginalized peoples around the world requires more than reference to positive norms; it also demands critiquing and expanding limited understandings of rights in theory and practice. Implicitly, doing so also requires challenging underlying premises about justice and power.

**RE-THINKING HEALTH**

It is impossible to separate the question of why we should care about a rights-based approach to health from questions of what human rights imply about health — and being human. While adaptable to myriad traditions, human rights depend on an understanding of human beings that goes beyond their being mere containers of desires to be maximized in a utilitarian calculus.10 Thus, for example, in health policy, the blind application of disability-adjusted life years (DALYs), a widely used health utility index, to determine health priorities and resource allocations runs counter to our rights-based intuition that the worst off in society cannot be treated as expendable simply in order to get the proverbial “bigger bang for the buck.”11 Across countless cultures and philosophical as well as religious traditions, there is a concern for the “equal dignity of the human person.”12 Such a seemingly simple concept implies tectonic shifts in neoliberal economic growth policies, which have left waves of human discards in their wake, from the slums of Lagos to the aptly-named *villas miserias* of Buenos Aires.13

Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans. To assert that health is a matter of human rights implies, as Amartya Sen argues, that: 1) it is of special importance, and 2) it is subject to social influence.14 That health is of special importance has been persuasively argued on both normative and empirical grounds. As a normative matter, we need not decide whether health is of special importance because we...
are concerned with preserving people’s normal range of opportunities, or with their achieving capabilities, or simply with protecting well-being; any of these grounds will suffice to establish that health is more than just another commodity to be allocated by the market. As an empirical matter, it has often been pointed out that in virtually every culture there are sayings and rituals that evidence the special significance of health.

That social conditions profoundly affect a broad range of health outcomes has been abundantly demonstrated in an ever-growing body of literature from social epidemiology, as well as work in social medicine and medical sociology. In particular, since this journal first appeared, the burgeoning field of social epidemiology has brought attention to the overarching importance of social determinants to population health — relating patterns of disease with the way that society is organized in terms of, for example, class and racial inequalities, and employment, educational, and housing patterns. Social determinants go far beyond health care or the health sector.

This understanding is consonant with the definition of health set out in the preamble to the newly-formed World Health Organization’s (WHO) Constitution in 1946, which first proclaimed “[t]he enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” Thus, health — and not just health care — is the appropriate subject of rights. The WHO Constitution went on to define health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.” That is, health is a matter of social well-being, of social — that is, power — relationships, as well as mental and physical well-being.

Definitions: Challenges to biomedical paradigm

This WHO definition of health represented a dramatic expansion of the biomedical paradigm, in which health is, in fact, construed as the absence of disease or infirmity or, slightly more broadly, the absence of pathology. The biomedical paradigm is so entrenched in both research and training of physicians and other health professionals, as well as in public discourse about health, that it is widely taken for granted. For our limited purposes, the two facets of this paradigm, which cannot be comfortably decoupled, can be summarized as follows: first, health and disease are defined by experts as scientifically and objectively ascertainable in isolation from the broader context in which people live; and, second, the judgments prescribed by those experts come to instantiate a truth that is beyond question by either individual patients or by the public in general. Critiques from bioethics have attempted generally to increase the autonomy and authority of patients in patient-doctor interactions but have not assailed the core premises of biological individualism.

In contrast, rights-based approaches present a more fundamental critique of this paradigm’s portrayal of reality. Let me be clear: a rights-based approach to health is not an anti-clinical or anti-scientific stance. Indeed, the astounding pace of progress in biomedicine makes it even more urgent to address the inequities in the enjoyment of those advances, as the articles in this issue eloquently argue. However, in a rights framework, health is produced, experienced, and understood in the social, political, historical, and economic contexts in which we live. This perspective forces us to see the suffering that is not the result of “natural” biological causes but rather stems from human choices about policies, priorities, and cultural norms, about how we treat each other and what we owe each other.

Rights-based approaches to health and the right to health

It is important to draw a distinction between a rights-based understanding of the determinants of health and the delineation of the content of the right to health. The core formulation of the right to health under international law is set out in the International Covenant on Economic, Social and Cultural Rights (ICESCR) as the: “right to the highest attainable standard of physical and mental health,” with no explicit reference to social well-being. The steps that states are to take in realizing the right to health include ensuring reproductive, maternal, and child health; the improvement of environmental and occupational health; the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases; and “the creation of conditions which would assure to all
medical service and medical attention in the event of sickness.”

Thus, the contours of the right extend “not only to timely and appropriate health care” but also to preconditions for health, such as adequate and safe water, sanitation, and nutrition.

However, the UN Committee on Economic, Social and Cultural Rights (ESC Rights Committee) has also explicitly stated that patterns of health and ill-health are shaped by discrimination, poverty, and exclusion and acknowledges that women’s health is influenced by “both biological and socio-cultural factors.”

More recent treaties and relevant international declarations have included the phrase “social well-being,” found in the WHO definition and have attempted, at the same time, to delineate concrete measures that states should take to protect and promote women’s rights to health, reproductive and sexual health, and the like.

Thus, steps to realize the right to health — for which governments and other actors can be held accountable — can be given some specificity and content. At the same time, we must acknowledge that the enjoyment of that right — which is the aim of RBAs — is interdependent on and indivisible from the enjoyment of other rights that relate not only to social determinants of health (for example, education, housing, work), but also, crucially, to a broad spectrum of civil and political rights.

The distinction in these documents between health and overall well-being or quality of life is, admittedly, a fuzzy one. Although Armando De Negri and other authors appear to reject this distinction, I believe that it calls out for normative clarification, as well as the further development of appropriate metrics for measurement. The right to health is a fundamental tool for living a life of dignity, but it does not, and cannot, encompass everything we might value in a “good life.”

Nonetheless, the inclusion of “social well-being” underscores how we are not individual biological beings floating in a societal context. It instead affirms that an important dimension of our human experience comes from being constituted by our social — for example, gender, ethnic, class, race — relationships and identities.

Nancy Krieger, a leading figure in social epidemiology, refers to the concept, “embodiment,” to capture the idea, among others, that “people literally embody and biologically express experiences of economic and social inequality, from in utero to death, thereby producing social inequalities in health across a wide spectrum of outcomes.”

**Challenges to mainstream public health**

A rights framework poses a fundamental challenge not only to the boundaries of clinical medicine but also to the mission of mainstream public health, which is deeply influenced by biological individualism. As Jonathan Mann wrote at this journal’s inception, the traditional framing of the public health question as “we have a cancer problem, now what do we do about it, within the existing social system?” inevitably leads to a focus on individual behavior,” which is largely construed as a matter of personal volition in mainstream public health.

The dynamics of power at work in structuring health outcomes remain largely invisible if analysis focuses on the independent effects of individual risk factors, precluding fundamental challenges to the status quo. In a rights framework, a core public function of epidemiology is precisely to make the connections among impoverishment, discrimination and inequality, and health visible, which requires contextual, multi-level analyses.

Under this approach, misfortunes are understood as injustices — violations — and are therefore, as Krieger suggests, “actionable, rather than be ignored or accepted as inevitable.”

Arguably, what a rights framework most distinctively adds to mounting work from the fields of social medicine and social epidemiology is precisely to demand justifications and accountability, and thereby to “expose the hidden priorities and structures behind violations.” Christopher Jochnick notes, “The real potential of human rights lies in its ability to change the way people perceive themselves vis-a-vis the government and other actors. A rights framework provides a mechanism for reanalyzing and renaming ‘problems’ as ‘violations,’ and, as such, something that need not and should not be tolerated.”

The rights-based emphasis on assigning responsibility is not an afterthought about how to garner sufficient political will to make “technical interventions” effective; such an approach instead focuses from the
beginning on mapping the operations of power at work in responding to public health problems, as well as in shaping vulnerability. Peter Uvin comments that such an approach does not “take resource constraints as natural givens but [treats] them as the result of past choices.”

Such a posture need not imply that resource constraints do not exist; absolutist claims to meeting all needs “as a matter of rights” have never gotten us far. Indeed, refusal to acknowledge resource constraints in health can lead to absurdly unjust outcomes even in the wealthiest countries because of what ethicists term “insatiable needs problems.”

At the same time, the domesticated pragmatism that leads to constant refrains of “scarcity” needs to be challenged, as De Negri and Farmer both assert in this issue. The mantra of scarcity imposes powerful and unnecessary restraints on our ability to make our aspirations prevail over current institutional arrangements and practices, which are after all historically contingent. As Farmer notes, expansions of access to anti-retroviral therapies as well as to drug regimens for multi-drug resistant tuberculosis in recent years have proved that the impossible need not be.

Elements of RBAs in practice

What do RBAs mean in practice — for service delivery organizations and ministries of health attempting to implement them? As Farmer suggests, an RBA does not and cannot mean we lose sight of the short-term needs of real people — from sutures to food. Indeed, in attending to those pragmatic needs — whether access to medicines or nutrition — a rights framework demands that equity and non-discrimination be placed at the center of a public health agenda, which all too often remains in the thrall of pure health maximization. In measuring impact, national averages are not sufficient from a human rights perspective; disparities among populations can be more revealing of underlying obstacles to the achievement of well-being for certain historically disadvantaged groups in society.

Moreover, as Hunt and Backman argue in this issue, a rights-based approach also means, crucially, that we locate our responses within a functioning health system. In a rights framework, a health system is to be understood as a core social institution — “akin to the justice system or a fair political system” — rather than a delivery apparatus for goods and services, which implies integrated care rather than isolated, vertical programs that can undermine the overall system.

Also, RBAs treat people not as passive recipients of goods and services but as participants in decisions that affect their well-being. Both De Negri and Farmer refer to listening to the voices of those on behalf of whom we are ostensibly acting. As Hunt and Backman suggest, participation is a matter of process in RBAs, as well as outcome. Meaningful participation depends upon transparency and access to information in both government and NGO programs. It is also closely related to agency and social mobilization, which, as London argues in this issue, are fundamental to a rights-based approach. Participation also includes the voice of health professionals, who are themselves often silenced within hierarchical and punitive health systems.

Agency and social mobilization are, in turn, closely linked to accountability. As noted above, perhaps what a rights-based approach to health uniquely adds to other work in medicine and public health focused on social justice lies precisely in the definition of relationships between rights-holders and duty-bearers, which permits the creation of a framework for and mechanisms of accountability, including effective recourse in the event of violations. However, accountability goes beyond the legal realm and, as London rightly reminds us, should go beyond punitive sanctions on already disempowered individual providers. Hunt and Backman point out that institutional and systemic accountability are closely linked to effective monitoring and transparency.

In order to be transformative, all of these characteristics of RBAs must be tied to our conception of health and society. Thus, instead of understanding gender and racial hierarchies or socioeconomic status as backdrops for more “proximal” factors, such as behavioral patterns, in a rights framework we would consider them as fundamental causes of disease, in that the associations between gender subordination, as well as social class, and disease are robust across time periods and social contexts. Therefore, in an RBA we would seek contextually-grounded strategies to chip away at these “pathologies of power,” as Farmer terms them. Implementation roles differ depending upon our institutions, and not everyone can or should do everything. But adopting an RBA would include emphasis on such measures as intersectoral initiatives (for example, health, education,
agriculture, housing, and employment); legal, policy, and institutional reform; basic and popular education, as well as curriculum changes in medical and health professional schools; capacity-building in civil society as well as government; and the establishment of effective accountability mechanisms at multiple levels.47

Challenges to service delivery programs
A rights-based approach to health implies a distinct change in the missions and operational approaches of most service delivery organizations, which have historically focused on technical assistance divorced from social and political context.48 Because a rights framework focuses centrally on the conditions under which people are able to exercise meaningful agency with respect to their health, it challenges such groups to take account of inequality, exclusion, and oppression in both the processes and the outcomes of their work. In other words, this kind of programming work is both inherently contextualized and inherently political, in the broad sense. A CARE policy paper on RBAs asserts in this regard: “A rights-based approach … requires us to constantly question why people are marginalized. … the fact is that CARE’s interventions are always and inevitably political, and a rights approach challenges us to be more intentional in how we affect political structures and systems.”49

We should not underestimate the practical difficulties of adopting RBAs in the field — a topic that we will explore in much greater depth in coming issues of this journal. As Farmer acknowledges, if we are not careful, RBAs can be overly broad, and organizational missions can become diffuse; we ill-serve struggling people by being ineffectual — or worse, carelessly un-strategic and, therefore, counterproductive. Further, Uvin aptly notes that the consequences of engaging in explicit political analysis — in which development and service delivery groups are not trained — “may create conflicts with many current and potential employees and funders, and pose danger to staff in the field.”50 Not every institution needs to — or should — do everything, of course.

Nevertheless, once we understand health promotion to be a matter of changing the power dynamics at the root of people’s suffering, as much as delivering a package of goods and services, our perspective inevitably shifts. To paraphrase Desmond Tutu, hewing to narrow, technical roles can seem a cynical excuse for indifference when witnessing an elephant stepping on a mouse’s tail. Worse yet if we expect the mouse to thank us for giving her a band-aid after the fact.

Re-thinking rights
In his introduction to this new incarnation of the journal, Paul Farmer cites Chidi Anselm Odinkalu’s assertion that, in Africa “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 or their language.” As London’s piece in this issue attests, countless thousands of others in Africa who have benefited from human rights organizations’ campaigns to secure access to life-saving medications, among other things, would strongly disagree. Elsewhere around the world we might find equal diversity of opinion. Yet, Odinkalu is not alone in his critique.

As the eminent Indian legal scholar, Upendra Baxi, has suggested, in contexts of great inequality and deprivation, taking rights seriously requires taking suffering seriously.51 Historically, the evolution of human rights during the Cold War meant that, even as rights discourse increasingly came to dominate our collective imagination, suffering due to violations of ESC rights has not always been taken seriously.52 And human rights have not been universally embraced by those seeking greater social justice.53 It is as recent as the 1980s and 1990s that feminists and other social movements increasingly came to find in international human rights a common language that could be used to underpin their claims as well as provide access to the machinery of the international system through which to vindicate them.54

The narrative of how human rights language has been appropriated, more and less effectively, by different social actors and movements (including in the domain of health) underscores how rights — and paradigms of rights — are not self-standing truths, but loci of contestation over power. Rights are terse formulations of profound arguments about distributive justice and humanity. If we seek to use rights to promote social justice in health, it is a strategic mistake to think that merely using the short-hand is enough to circumvent the argument.55
Critical Concepts

Members of marginalized groups — from Persons Living with AIDS (PLWAs) to indigenous persons — to conceive of themselves as subjects whose demands are underpinned by notions of political, as well as legal, entitlement.

Evidence indicates that it is misleading to draw a sharp dichotomy between social mobilization and court-centric strategies. As London’s example of the Treatment Action Campaign in South Africa suggests, it is often easier to mobilize consciousness about health rights as real rights if there is a concrete case involved. Beyond the healthcare context, in a number of countries in Latin America, cases involving exploitation of indigenous lands have been crucial not only to securing specific remedies for violations of the rights to health and a healthy environment, but also to having these indigenous communities organize themselves politically, which, in turn, has led to the creation of entire movements as well as indigenous political parties.

In addition to pressing for the international and domestic legal reform and judicial victories, many human rights NGOs — especially in the global South — have been increasingly active in educational and political mobilizing campaigns around health and other ESC rights. Issues ranging from water privatization to oil contamination to the impacts of trade agreements on access to medicines are being fought by NGOs as rights issues, when in the past they would have been merely “policy issues” and relegated by governments to the realm of “technical experts.”

Coalitions that include both health and development groups and human rights advocacy organizations have placed health and other social concerns on the democratization agenda in countries from South Africa to India to Peru. Moreover, in many of these contexts, rights advocacy groups, as London suggests, are recognizing that health professionals need to be allies in realizing health rights and transforming health systems. Efforts to establish accountability have gone beyond blaming individual providers to examine systemic and institutional factors leading to discrimination and abuses. In this regard, some national human rights ombuds offices have played critical roles, forcefully investigating such issues as involuntary sterilization as fundamental rights concerns, and bringing about sweeping policy changes as a result.
Pinochet, Alberto Fujimori, and Carlos Menem, in Chile, Peru, and Argentina, respectively, have often entrenched highly autocratic and abusive regimes that would seem to undermine the conceptual rationale for neoliberalism, which is to secure not merely economic development but also political liberty.

Narrow liberal conceptions of rights, entrenched during the Cold War, depend upon a misleading distinction between so-called “negative” and “positive” rights. Negative rights (that is, civil and political rights) are thought to require only freedom from state interference, while positive rights (that is, economic and social rights, including health) are thought to imply affirmative entitlements to state intervention, including the expenditure of money. These distinctions were unfortunately reinforced by differential treatment in the twin covenants on human rights; the language in the ICESCR calls for “progressive realization” to the “maximum” of a state’s “available resources,” while there is no such tempering of the states parties’ obligations in the covenant on civil and political rights.

In truth, economic and social rights require forbearance on the part of the state — such as refraining from forced evictions and permitting workers to organize — and civil and political rights require affirmative actions and expenditures. Consider, for example, the massive expenditures and state apparatus necessary to permit “fair and free elections” or the right to a fair trial. And in practice, no rights can be implemented from one day to the next; all require progressive realization.

In recent years, international law has, to some extent, eroded these unhelpful distinctions. The UN ESC Rights Committee has clarified that some obligations, such as eliminating discrimination, are of immediate effect and that states cannot indefinitely defer taking steps to realize economic and social rights. Moreover, as Farmer contends, there are deep linkages between narrow understandings of human rights and the market-focused development model that now appears to reign as the unquestioned paradigm for the rational organization of human societies over most of the Earth. Ignoring these connections and failing to explore what is at stake, will leave us with approaches that cannot hope to challenge many of the abuses of power that systematically produce patterns of ill-health within and across societies.

Neoliberal economic policies, which generally speaking, seek to transfer control of the economy from the public to private sector, depend upon certain liberal (and more particularly, libertarian) conceptions of rights and justice. That historically the poster children for neoliberal policies, such as Augusto
Nonetheless, this more recent conception has not been widely translated into domestic legal frameworks and ESC rights continue to be neglected in policy-making, as well as scholarship and activism. Indeed, as frustrating as it is for those of us who are long-time ESC rights advocates, “negative” (that is, civil and political) rights are still regularly treated as the only “real rights” in policy and media discussions. For example, in a May 2007 editorial, the Economist attacked the tendency to “dilate” traditional civil and political rights by “mixing in a new category of what people now call social and economic rights”: “Food, jobs and housing are certainly necessities. But no useful purpose is served by calling them “rights.” When a government locks someone up without a fair trial, the victim, perpetrator, and remedy are pretty clear. This clarity seldom applies to social and economic ‘rights.’ It is hard enough to determine whether such a right has been infringed, let alone who should provide a remedy, or how.”

Examining assumptions about society and justice

Neoliberals who glorify the laissez faire state reject calling food, jobs, housing, and health rights because their realization requires using the power of the state to redistribute wealth. But we should be clear that, as the North American legal scholar, Cass Sunstein, writes: “Those who denounce state intervention are the ones who most frequently and successfully invoke it. The cry of laissez faire mainly goes up from those who, if really ‘let alone,’ would instantly lose their wealth-absorbing power.”

The distribution of wealth and privileges in a society and across societies is the result of socially created customs, laws, and regulations that permit and entrench those distributions, including ones that favor market expansion and limit social protections. For example, with respect to neoliberal health sector reforms aimed at “modernizing” and “minimizing” the state, Asa Laurell debunks the idea that the state “retracts” and merely allows the market to function: “on the contrary, the state plays a decisive and active role in dismantling its former institutions and functions. That is, a vigorous state intervention colored by authoritarian trends is required to ‘diminish the intervention of the state.’”

We know that neoliberal policies serve the interests of the wealthy and powerful, but it is also important to challenge the specific conceptions of rights, society, and justice that underlie them. Just as in mainstream public health, in which disease is construed as “a dynamic event occurring within a basically static or fixed society,” narrow liberal conceptions of rights also accept societal parameters as essentially given. For example, in the approach to human rights mentioned in the Economist editorial — identifying a violation, a perpetrator, and a remedy, which describes much of mainstream human rights practice — there is an underlying idea of society as being in a state of equilibrium. The violation upsets the equilibrium; the remedy restores it. However, if we understand patterns of disease to be socially produced, we cannot seek to return to a status quo ante, but rather to fundamentally challenge it. Progressively realizing the highest attainable standard of health for diverse individuals and groups necessarily involves constantly evolving claims about what we owe each other and how to arrange social institutions to best provide it.

Furthermore, just as in much of biomedicine and mainstream public health, restricted liberal paradigms of rights also depend on a conception of the individual isolated from social context. Rights are understood as tools to enable people to exercise choice, but in this narrowly circumscribed paradigm, freedom is seemingly exercised in a vacuum. The history of abortion debates in the United States illustrates the limitations of framing an entitlement in terms of an abstract right to “privacy” divorced from the wider conditions of a woman’s life. Moreover, the framing of the rights issue has implications for public health responses. When rights are focused on protecting privacy, such issues become, as Lynn Freedman writes, “strictly individual problems conceived of as ‘risk factors’ to be treated with education in strategies of avoidance. Thus as the legal language imposes deeper and deeper constrictions on our expectations of entitlement and our understanding of justice, the corresponding health debate becomes more and more impoverished as well.”

Beyond the state

The correlation between GDP per capita and the realization of the economic and social rights that underpin many of the social determinants of health is strong but not automatic; social policy can mitigate the effects of poverty and certain aspects of rights are more policy responsive than others. However, resources do matter; they matter a lot. It is not just that poor states are often not in a position to make...
the necessary investments in their social sectors that are required to realize the multiple rights underpinning health. It is also that, in the era of neoliberal globalization, many of the sources of unjust inequalities in population health are found not within states but in the structures of the global political economy. Examples abound—from debt, to trade and agricultural policies, to water privatization.

To cite one illustration touched upon by various authors in this issue: beginning in the 1980s “structural adjustment policies” that emerged out of the neoliberal Washington Consensus imposed changes in labor regimes in the global South, which led to a health skills drain, among other things. At the same time, health skills drain was also fueled by systematic “pull” policies in donor states, which deliberately attracted immigrants from poor countries to solve their own healthcare labor shortages. More recently, as international efforts to address HIV/AIDS, as well as malaria, TB, and other diseases, to a lesser extent, were scaled up, donor states and northern NGOs exacerbated the situation further by creating parallel programs, which drew already scarce health workers away from the primary health system to “NGO land,” in Farmer’s terms. Moreover, the International Monetary Fund’s imposition of wage ceilings for all public sector employees as a loan condition further constrains the ability of poor states to attract and retain health workers in the public sector. As Hunt and Backman argue, a powerful rights approach requires building equitable health systems; it also requires situating that endeavor in an inexorably globalized world in which claims for what we owe each other as a matter of justice transcend state borders.

Yet, under international human rights law, the state bears primary responsibility for respecting, protecting, and fulfilling the rights critical to health. As Christopher Jochnick writes, the narrow focus on states “is not only out of step with current power relations, but also tends to obscure them. . . . The focus on state responsibility also creates a false sense of rigidity or inevitability about social and political hierarchies and existing inequities.”

To his great credit, Paul Hunt has emphasized throughout his two terms as UN Special Rapporteur that “In addition to obligations at the domestic level, developed States have a responsibility to provide international assistance and cooperation to ensure the realization of economic, social and cultural rights in low-income countries. This responsibility arises from recent world conferences, including the Millennium Summit, as well as provisions of international human rights law.” Hunt and other Special Rapporteurs, as well as treaty monitoring committees, have clarified that donor countries assume human rights obligations directly, as members of international organizations, such as the World Bank, the International Monetary Fund, and the World Trade Organization, and as host countries for transnational corporations.

Yet in practice OECD countries have not approached their commitments under those world conferences to donate 0.7% of Gross National Income per year; the WHO projects that an additional investment of $100 billion from these developed countries by 2015 would save millions of lives per year. How human rights praxis might contribute to addressing this situation in practice is a complex question, which has many potential responses. What is clear is that taking suffering seriously requires finding ways to hold both donor countries and transnational corporations—which also have enormous influences on population health—to account for their actions, priorities, and policies.

Challenges to conventional human rights organizations’ practice

Applying rights frameworks to address specific public health issues creates challenges for traditional human rights advocacy organizations. It requires new forms of evidence and argument; new forms of engagement with governments and multiple other actors; new understandings of the importance of context in determining how rights are metabolized within institutions and communities; and new ways of thinking about ourselves and our work that include, but also extend beyond, exposing and denouncing abuses (the so-called “naming and shaming” methodology).

It is not just that multiple levels of responsibility and public indifference to the perpetual degradation of poor people may reduce the ability of NGOs to
stigmatize certain actors with incantations of “health rights violations!”

It is also that, bringing rights to bear to effectively promote health is no longer just a story about good guys and bad guys, but about how rights can work in our world now — from the macro-level to the most micro-level. As Farmer suggests, working effectively in the health domain will require us to leave our comfort zone of clean hands and pure principles. We will need to roll up our sleeves and engage with processes of budgetary priority-setting and systems analysis, in order to be able to discern where problems lie — not only to assign respective responsibility, but also to propose solutions.

Recommendations from rights NGOs generally focus on the level of laws and policies. However, experience from the pragmatic world of public health reveals that, to create conditions under which people can know, understand, and claim their rights, we also require conversations about such mundane realities as the quality of infrastructure and housing; the design of schools and health centers; supply and reimbursement chains; relationships (for example, between providers and patients, and between peripheral center providers and the health system hierarchy); and ways in which money is allocated and spent.

Just as public health people are not trained in legal and policy advocacy, human rights advocates are not trained in systems, budget, and program analysis. Interdisciplinary collaboration is a challenge but also a necessity for RBAs that hope to be meaningful for people who find themselves living on the proverbial ground.

In addition to interdisciplinary collaboration, as London asserts in this issue, underlying all strategies “is the need to enable active social mobilization, without which [RBAs] lack sustainability and power.” In turn, such social mobilization often depends upon forms of solidarity with social movements that are too often eschewed by mainstream human rights organizations as “political.” But rights are fundamentally political in the broad sense — that is, about remaking society — and not just political in the narrow sense — that is, questioning specific partisan choices. Objectivity need not mean detached indifference in the face of suffering wrought by economic oppression. The legitimacy — that is, the “accumulated moral capital” — of human rights NGOs is arguably more threatened by their remaining in roles of self-appointed and largely unaccountable “spokespeople” for the vulnerable and downtrodden than by seeking to engage in solidarity with larger social movements.

CONCLUDING REFLECTIONS

I have argued that defining health as a question of human rights is intimately and inextricably linked to how we understand our own suffering and that of others. If health is a matter of rights, we must question what amount of death, disability, and disease are “preventable;” which inequalities are actually inequities; and where the moral, legal, and economic boundaries for state action lie. Claiming health as an issue of rights calls into question traditions long taken for granted and denaturalizes policy arguments based upon reflexive pronouncements of “scarcity.” At the same time, taking suffering seriously requires challenging narrow conceptions of rights — what they say about justice and ways of being in this world.

A transformative engagement between health and rights changes our approaches in both fields. As we design research and implement health programs, we can train ourselves not to see facts of poverty and patriarchy, but rather contingent processes of exclusion. As we work to meet people’s immediate clinical needs, we can still bear witness to how social pathologies are translated into and embodied in individual ills. As we engage in rights advocacy, we can seek not only to counter discrimination and procure redress, but also to propose programmatic and structural reform, including economic reform.

How we translate critical understandings of both health and rights into strategic praxis will be themes for this journal for many issues to come. However, in the midst of grand visions of macro-level change, it is useful to recall that, sometimes the most transformative change needs to happen in seemingly small places, close to home. In the Peruvian Altiplano recently, a local health promoter — a destitute widow, who spoke only broken Spanish — described to me her experiences of monitoring her local health center
in conjunction with a rights-based maternal health project. A hostile doctor yelled at her, “go home; this is my house. I don’t go to your house and tell you what to do; don’t try to come to mine and tell me what to do.” She smiled as she recounted to me how she had responded: “This is not your house; this is a public health center and you are a public servant. As long as this patient wants me here, I have a right to be here — as a citizen.” The doctor allowed her to stay. Along with her colleagues, she later presented her findings to a district-level health authority charged with making policy. Sometimes the most potentially transformative impacts of RBAs lie in permitting people to conceive of themselves as rights-bearers. To paraphrase what Eleanor Roosevelt said 50 years ago, without concerted action to advance health as a matter of rights close to home, we shall look in vain for progress in the larger world.

REFERENCES

1. As alluded to below, this title is drawn from an article by Upendra Baxi, “Taking Suffering Seriously: Social Action Litigation in the Indian Supreme Court,” Review of the International Commission of Jurists 29/35 (1982): pp. 37, 47. I am grateful to colleagues on the editorial board as well as at both the Petrie-Flom Center for Bioethics, Biotechnology and Law, and the Human Rights Program at Harvard Law School for comments on drafts of this article as well as on related materials, which have enriched my thinking.


4. According to Article 2 of the International Covenant on Economic, Social and Cultural Rights (ICESCR): “Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures”: ICESCR, G.A. Res. 2200 (XXI), UN GAOR, 21st Sess., Supp. No. 16, at 49, UN Doc. No. A/6316 (1966), Article 2.


7. Uvin (see note 3): p. 131.3.


11. The blind application of DALYs — or any other cost effectiveness measure — seeks to maximize health benefits at the margin per dollar spent. It
gives no priority to meeting the needs of those who are worst off or in greater need; it further favors aggregation of small benefits to large numbers of people over significant benefits to a small number of people. More broadly, a rights-based approach may call into question the utility-centered ethics upon which CEAs are based. See discussion in N. Daniels, *Just Health: Meeting Health Needs Fairly* (New York, NY: Cambridge University Press, 2008): pp. 89-92, 114-117.

12. An-Na’im (see note 10). This principle is sometimes explicated as requiring that people be treated as ends and not mere means. The liberal philosopher, Immanuel Kant, was a leading articulator of this view: “Everything has either a price or a dignity. Whatever has a price can be replaced by something else as its equivalent; on the other hand, whatever is above all price, and therefore admits of no equivalent, has a dignity. But that which constitutes the condition under which alone something can be an end in itself does not have mere relative worth, i.e., price, but an intrinsic worth, i.e., a dignity,” in I. Kant, *Grounding for the Metaphysics of Morals*, J. W. Wellington, trans. (Cambridge: Hackett Publishing Company 1785/1981): p. 434. From a very different tradition, see also, for example, M. Buber, *I and Thou*, trans. Walter Kaufmann (New York, NY: Touchstone, 1970).

13. This concept was, similarly, the basis for a dramatic paradigm shift in population policies from one that, historically, constructed women’s bodies as vessels to fulfill demographic imperatives to one of reproductive choice and rights. UN Population Division, Programme of Action of the International Conference on Population and Development, Report of the International Conference on Population and Development, UN Doc. No. A/CONF.171/13 (1994).


16. For example, in virtually every language, toasts are commonly raised “to your health,” and expressions equivalent to “so long as you have your health” exist. See, generally, J. M. Mann, S. Gruskin, M. A. Grodin, and G. J. Annas (eds), *Health and Human Rights* (New York, NY: Routledge, 1994).


20. Ibid.


health is inequality, both between men and women and among women in different geographical regions, social classes and indigenous and ethnic groups.”


29. General Comment 14 (see note 28).

30. Ibid., paras. 9, 19, 20, and 21.


32. Note that Paul Hunt and Gunilla Backman use the term “right-to-health approaches,” as Hunt has, throughout his mandate, because he is coming from the perspective of that mandate. Those right-to-health approaches recognize the interdependence of the right to health with other rights.

33. For just one example, Jean Drèze and Amartya Sen have persuasively illustrated how democratic openness and access to information is crucial to preventing famines — that is, rampant violations of the social right to food. J. Drèze and A. Sen, The Political Economy of Hunger, Vol. II: Famine Prevention (Oxford, UK: Clarendon Press, 1991).

34. De Negri appears to want to erode the distinction. For discussion on this point, refer to Ruger (see note 22): p. 314.


38. A rights-based analysis invites us to jump between “levels” of causation, to understand, for example, that the criminalization of abortion or IV drug use is more meaningfully understood to be determining (rather than distal) factors. Krieger writes in a similar vein: “Driving health inequalities are how power — both power over and power to do, including constraints on and possibilities for exercising each type — structures people’s engagements with the world and their exposures to material and psychosocial health hazards. Notably, neither type of power readily maps onto a metric of proximal or distal.” N. Krieger, “Proximal, Distal, and the Politics of Causation: What’s Level Got to Do with It?” American Journal of Public Health 98/2 (2008): pp. 221-230, 223.


40. Ibid.


42. Uvin (see note 3): p. 191.

43. The problem of insatiable needs refers to the possibility that a few people who are very badly off may absorb all (or even the lion’s share of) resources even when the magnitude of benefit they receive dwarfs in comparison to the adverse consequences for the rest of the population. Imagine, for example, spending bottomless resources on an extremely expensive condition for a terminally ill patient. On a societal level, consider, for example, the enormous share of health care resources devoted to people in the last two years of life in the United States. For a general description of this problem, see, for example, K. J. Arrow, “Some Ordinalist-Utilitarian Notes on Rawls’s Theory of Justice,” review of A Theory of Justice, by J. Rawls, The Journal of Philosophy 70/9 (1973): pp. 245-263, 251.


50. Ibid.

51. Baxi is writing specifically about India and is alluding to Ronald Dworkin’s Taking Rights Seriously (Cambridge, MA: Harvard University Press, 2007); U. Baxi, “Taking Suffering Seriously: Social Action


55. As Norman Daniels writes, “rights are not moral fruits that spring up from the bare earth fully ripened, without cultivation.” N. Daniels (see note 11): p. 15. See also Ruger (see note 22): p. 273.


57. General Comment 14 (see note 28); CEDAW, General Recommendation 24 (see note 45); Committee on the Rights of the Child, General Comment 4, Adolescent Health and Development in the Context of the Convention on the Rights of the Child, UN Doc. No. CRC/GC/2003/4.


63. See, for example, work of the Center for Policy Analysis on Trade and Health relating to trade agreements. Available at http://www.cpath.org.

64. See the article by Turiano and Smith discussing the People’s Health Movement in this issue.

65. See, for example, Latin American and Caribbean Committee for the Defense of Women’s Rights, Nada Personal: Reporte de Derechos Humanos Sobre la Aplicación de la Anticoncepción Quirúrgica en el Perú 1996-


67. For example, ESCR-Net has multiple listservs, including one on the right to health. Available at http://www.escr-net.org.


69. Amnesty International is launching a global Campaign for Dignity this year, which will focus on specific economic and social rights, including health. Human Rights Watch has addressed issues relating to health rights, in particular discrimination, in some of its reports, and does work on both “health and human rights” and HIV/AIDS specifically. See for example, Human Rights Watch, Hidden in the Mealie Meal: Gender-Based Abuses and Women’s HIV Treatment in Zambia. Available at http://hrw.org/reports/2007/zambia1207/.


71. London shows us that even in South Africa, where the Mandela government introduced free health care for pregnant women and children as its first post-Apartheid social policy, there is now a growing governmental “reluctance to acknowledge the socio-economic rights dimensions of claims to health.”

72. Although some have tried to claim that neoliberal globalization is inimical to “human rights,” I believe the reality of the relationship is more nuanced. For an example of this argument, see, for example, P. O’Connell, “On Reconciling Irreconcilables: Neo-Liberal Globalization and Human Rights,” Human Rights Law Review 7/3 (2007): pp. 483-509.


74. During the Cold War, the West raised the specter of socialism to argue that only negative rights are those compatible with democratic freedoms, the former Soviet Bloc called for the primacy of meeting economic and social needs.


76. Vast resources are poured into meeting minimum standards for “fair and free” electoral processes, and often more, in impoverished regions, which requires massive international assistance. According to a 2006 UNDP report, the cost averaged $1 to $3 per vote, per election, in the United States and Western Europe; $4-$8 per vote in “consolidating democracies,” such as Mexico, El Salvador, Lesotho, and the Russian Federation; and up to $45 per vote in post-conflict situations (1993 Cambodia); Getting to the CORE: A Global Survey on the Cost of Registration and Elections (IFES/UNDP; 2006). Available at http://www.undp.org/governance/docs/Elections-Pub-Core.pdf.


78. For one of the first articulations of this tripartite understanding of state obligations, see UN Sub-Commission on the Prevention of Discrimination and Protection of Minorities, Report on the Right to Food as a Human Right, UN Doc. No. E/CN.4/Sub.2/1987/23 (1987). See also General Comment 14 (see note 28) and, for its application to civil and political rights, Human Rights Committee, General
Comment 28, Equality of Rights between Men and Women (Article 3), UN Doc. No. CCPR/C/21/Rev.1/Add.10 (2000).

79. General Comment 14 (see note 28).


81. In Libertarianism, a distribution of goods is deemed just insofar as that distribution was brought about by free exchanges by consenting adults and was made from a just starting position, even if large inequalities result from the process. Thereafter, it is unjust to use the government’s fiscal and regulatory powers to redistribute economic resources to meet the needs (including health needs) of the poor. But there is no just starting position, no relevant, pre-societal distribution of goods. For a description of Libertarian philosophy, see generally R. Nozick, Anarchy, State and Utopia (New York, NY: Basic Books, 1974).


84. Mann (see note 37): pp. 229-233.


86. Thus, individuals are assumed to be “free” so long as the state does not force an individual to do something against her will — for example, to violate bodily integrity, to restrain speech, to detain without due process. Rights are conceived, in Roberto Unger’s words, as “a loaded gun that the right holder may shoot at will in his corner of town.” Society and community are, to a significant degree, construed as artificial constructs rather than processes through which our identities emerge. R. Unger, “The Critical Legal Studies Movement,” Harvard Law Review 96/3 (1983): pp. 561-675.

87. The emphasis on privacy has meant that poor women who cannot afford abortions do not have meaningful rights to them. In Harris v. McRae, 448 US 297 (1980), the Supreme Court held that States that participated in Medicaid (a federally funded program to provide health care to people living in poverty) were not required to fund medically necessary abortions for which federal reimbursement was unavailable as a result of a federal law (the Hyde Amendment), which restricted the use of federal funds for abortion.


89. For example, increasing measles immunization rates may be far more tractable to increased income per capita while reducing under-five mortality will require multiple strategies.

90. See O’Connell (see note 72): p. 488.

91. The role of debt does not just apply to the small number of Heavily Indebted Poor Countries, eligible for multilateral debt relief. For example, Peru is a middle-income country; at the end of 2003, its foreign debt represented 38% of GDP. The Peruvian government spends more than four times as much on debt service annually as it does on health. The amount of debt that Peru is forced to pay drastically limits the “maximum extent of available resources” — the requirement under human rights law — which it has to spend on health and other social priorities. See information from the World Bank describing the enhanced HIPC initiative: http://web.worldbank.org/WEBSITE/EXTERNAL/TOPICS/EXTDEBTDEPT/0,,contentMDK:20260411~menuPK:64166739~pagePK:64166689~piPK:64166646~theSitePK:469043,00.html; On Peru, see E. Vásquez, Presupuesto Público y Gasto Social: La...

92. This example is drawn from the discussion in Daniels (see note 11): pp. 337-39.


97. See, for example, recent Concluding Observations from the Committee on the Elimination of Racial Discrimination regarding the United States’ extra-territorial obligations relating to the effects on indigenous rights of US-based transnational corporations. Committee on the Elimination of Racial Discrimination, Concluding Observations of the Committee to Eliminate All Forms of Racial Discrimination — United States, UN Doc. No. CERD/C/USA/CO/6 (2008), para 30.


102. Some organizations have already done critically important work in this regard. For example, Fundar in Mexico has analyzed the Mexican government’s spending on HIV/AIDS as well as on maternal health. Available at http://www.fundar.org.mx/quienessomos/equipo.htm. The International Budget Project has also developed tools and materials to assist NGOs in budget monitoring. See http://www.internationalbudget.org.

103. See Uvin (see note 3): pp. 131-136; Kenneth Roth discusses the potential threat to accumulated moral capital as a caution to NGOs that seek to expand into ESC rights: Roth (see note 85): pp. 63-73.

104. This project emerged out of a joint investigation between CARE Peru and Physicians for Human Rights (PHR), which I directed. See Physicians for Human Rights (see note 91).

105. Eleanor Roosevelt, remarks to the United Nations, March 27, 1958, quoted in Chavkin and Chesler (see note 54).