Abstract

Examples drawn from Peru suggest both challenges and possibilities for linking the health and human rights fields more systematically in a campaign for health as a basic question of social justice. Criteria that distinguish a human rights framework can be derived from an understanding of health as an issue of power relations as much as from biological or behavioral factors. A human rights approach to service delivery differs from conventional public health approaches and also raises challenges, such as balancing independence with collaboration with the governments. The implementation of the right to health also raises challenges for human rights groups, requiring them to go beyond their traditional, adversarial role and to work in coalitions that include elements of the government. The framework we use also determines our response to problems or abuses in the field, as evidenced by the case of involuntary sterilizations in Peru.

Des exemples au Pérou suggèrent que les défis et les opportunités soulevés par une association plus systématique des thèmes de la santé et des droits civiques dans une campagne de santé relèvent d’une justice sociale élémentaire. Les critères distinctifs d’un cadre de travail sur les droits civils peuvent être dérivés de la conception de la santé comme un problème de rapports de force ou résulter de facteurs biologiques ou comportementaux. Une approche de la prestation de service reposant sur les droits civils diffère des approches de santé publique conventionnelles et fait surgir des défis tels que l’équilibre nécessaire entre indépendance et coopération avec le gouvernement. La mise en œuvre du droit à la santé génère également des défis pour les groupes de travail sur les droits civils, leur imposant de dépasser leur rôle traditionnel d’opposants pour former des coalitions pouvant inclure des éléments gouvernementaux. Le cadre utilisé détermine également notre réponse aux problèmes et aux abus sur le terrain, comme l’illustre le cas des stérilisations forcées au Pérou.

Unos ejemplos tomados del Perú sugieren tanto desafíos como posibilidades para establecer lazos entre los campos de la salud y los derechos humanos de una manera más sistemática. Se puede resaltar unos criterios que distinguen un enfoque de derechos humanos, basados en el entendimiento de la salud como un tema de relaciones de poder tanto como de factores biológicos o de conductas. La prestación de servicios que se hace desde un enfoque de derechos humanos difiere de modelos convencionales de salud pública y asimismo éste implica desafíos, como es el encontrar un equilibrio entre colaboración con el gobierno e independencia. La implementación del derecho a la salud también implica desafíos para los defensores de derechos humanos, como es el ir más allá de su papel tradicional para trabajar en coaliciones que incluyen elementos del gobierno. El marco que utilizamos también determina nuestras reacciones ante abusos o problemas, así como se constata en el caso de las esterilizaciones involuntarias en el Perú.
Challenges and Possibilities for Innovative Praxis in Health and Human Rights: Reflections from Peru

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In the theoretical literature, “health and human rights” has come to mean much more than either addressing the health effects of torture and other abuses or, alternatively, looking into the restrictions on civil liberties imposed by certain health policies. Yet the continuously mounting data on the social and economic determinants of health and the impact inequality has on health point to the urgent need to find ways to translate this research into practical advocacy strategies that promote the right to health as an issue of social justice. Although a vibrant and growing group of academics has linked social factors with health, relatively little of this work has used the idiom of human rights or has been connected to the work of human rights activists in the field. Some examples of innovative praxis drawn from Peru suggest both challenges and possibilities for linking the two fields more systematically in a campaign for health as a basic component of social justice.

The connection between economic, social, and cultural rights—such as the right to health, on the one hand, and civil and political rights, on the other—has for decades been painfully evident in Peru and in Latin America, in general, where dictatorships and, in some cases, nominal democracies imposed brutal repression to facilitate economic austerity programs. Peru is emerging from 10 years of extreme-
ly corrupt and autocratic rule under Alberto Fujimori, who imposed neoliberal economic policies with almost religious zeal. Now, with Peru's recently installed Truth and Reconciliation Commission, the society is just beginning to face the sequelae of years of brutal, internal civil conflict. In the region of the world with the greatest disparities between rich and poor, Peru's inequalities stand out as among the worst. These features of Latin American sociopolitical context, and of Peru in particular, coupled with the historic strength of the human rights and women’s rights movements have undoubtedly contributed to efforts to apply human rights frameworks to health promotion.

In an effort to help clarify the practical difference human rights can make in health campaigns, this article first suggests a set of criteria that distinguish a human rights framework, based on an understanding of health as an issue of power relations as much as it is one of biological or behavioral factors. Citing examples principally from Peru, the article then examines how these conceptual criteria can be used in the work of both health professionals and human rights advocates. The piece goes on to provide an example of how a human rights approach to service delivery differs from conventional public health approaches and also raises particular challenges, such as balancing independence with collaborating with governments. It further asserts that implementing the right to health raises challenges for human rights groups, requiring them to go beyond their traditional, adversarial role and to work in coalitions that may include elements of the government. Finally, the article argues that the framework we use also determines our response to problems or abuses in the field. In discussing the case of involuntary sterilizations in Peru, the article distinguishes a human rights perspective from a medical ethics or quality-of-care approach, which may be more familiar to health professionals.

**What Makes a Human Rights Approach Different?**

Although clearly there can be no single “human rights approach” to health, Stephen Marks has argued that at least “four assumptions . . . appear to be widely shared by those
who contribute to thinking and action on health and human rights": (i) a commitment by the medical profession to the ethical treatment of patients and to the use of human rights norms to guide certain aspects of the treatment of patients; (ii) the importance of a population-wide approach, and in particular the insights of social epidemiology, in complementing the individualistic, biomedical approach; (iii) the definition of the right to health as “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health,” as set forth under the International Covenant on Economic, Social and Cultural Rights (ICESCR); and (iv) the idea that states have specific legal obligations to respect, protect, promote, and fulfill the right to health under international law and are accountable for compliance.6 Marks, however, goes on to say that only in the areas of torture, reproductive and sexual rights, and HIV/AIDS have “there been significant thinking and action using a [health and human rights] approach.”7 The disciplines have yet to come together to systematically promote the economic right to health in the field.

In Latin America, a human rights approach to health can usefully build on work done in social medicine, which has long linked social factors with health problems in the region.8 That is, in a human rights paradigm, health is a reflection of relationships with different members and groups in society—a reflection of social relationships as much as of biological processes or behavioral interactions with a person’s environment. To the extent that those relationships, which are based on class, gender, and ethnicity as well as on personal characteristics, are constitutive of us, the tenor of them and the degree to which we participate in constructing and shaping them has direct bearing on our capability for well-being. Moreover, as all social relations are also power relations, entrenched disparities in power are, not surprisingly, reflected in egregious disparities in health status.9 Conversely, in this view, changing such disparities in health requires changing what Paul Farmer termed the “pathologies of power” that afflict Peru and so many countries in the region—and indeed the world.10

Based on this understanding of the right to health as a
tool for empowering people to guide the course of their own lives, this article argues that as with all other human rights, implementing the right to health in Peru and elsewhere, follows certain identifiable principles, which are detailed below.

**Minimum Core Content/Adequate Progress**

Once health is understood as a legal right, as opposed to merely a social good, it ceases being simply an aspiration and trumps other considerations in budgetary allocations and social policy. In language that is echoed in economic and social rights provisions of other treaties, the ICESCR obligates States parties, such as Peru, to “take steps toward progressive implementation [of all of the rights contained in the Covenant] to the maximum available extent of its resources.” Although the right to health will clearly not be implemented overnight, it is now widely recognized that governments have an obligation to demonstrate adequate progress in fulfilling all treaty rights to which they have subscribed, including the right to health. There is a strong presumption that regressive measures violate international law.

In addition, under international law, a government does not have unlimited discretion to define the extent of its “maximum available resources” that can be devoted to the implementation of the right to health. The Economic, Social, and Cultural (ESC) Committee that monitors compliance with the ICESCR has forcefully stated that violations of the ICESCR occur when a state fails to satisfy a “minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights.” These minimum obligations apply irrespective of “the availability of resources of the country concerned or any other factors and difficulties.” In short, asserting a right to health means that not only has a government moral or humanitarian responsibilities to attend to the health needs of the most vulnerable and economically disenfranchised of the population, but it also has legal obligations that, at minimum, require it to establish a normative framework consistent with international law, to reflect health as a priority in its budget, and to
devise a plan to take deliberate steps to move toward the progressive realization of the right to health.

**Nondiscrimination**

As with all human rights, the right to health should be guaranteed “without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”\(^{16}\) Nondiscrimination is perhaps the most fundamental principle underlying all of human rights law. Discrimination implies the exercise of power over a person due to either some arbitrary and generally immutable factor not of his or her making or choosing or the expression of ideas and convictions, which lies at the core of what makes us human.

Jonathan Mann was perhaps the first to express how the epidemiology of HIV can be seen as the epidemiology of exclusion and discrimination.\(^{17}\) Although still a nascent field, epidemiological research is tackling increasingly the effects of discrimination on population health.\(^{18}\) By explicitly formulating socioeconomic, gender, racial, and other forms of discrimination as matters of power over people’s lives, it is readily apparent why national averages are not sufficient indicators of a human rights perspective; disparities within populations often do more to reveal the underlying obstacles certain historically disadvantaged groups in society have faced in achieving well-being.\(^{19}\)

Under international law, discrimination need not be intentional nor *de jure*, but it needs merely to have the “effect of nullifying or impairing the equal enjoyment or exercise” of the right to health to violate various relevant treaties.\(^{20}\) In Peru, for example, enormous disparities in health indices between different population groups reflect differential access to basic health services, education, employment, decent living conditions, and food security. Rooted in decades of misguided development policy and exacerbated by structural adjustment programs, these disparities can have the effect of, among other things, discriminating against ethnically indigenous populations who, by and large, live in rural areas.\(^{21}\)
**Authentic Popular Participation**

Popular participation in all spheres of decision making and implementation is key to truly realizing the right to health, as well as to all human rights. According to the ESC Committee, an “important aspect is the improvement and furtherance of participation of the population in the provision of preventive and curative health services, such as the organization of the health sector, the insurance system and, in particular participation in political decisions relating to the right to health taken at both the community and national levels.”\(^{22}\) Of course, lip service can all too easily be paid to “participation” in designing programs that are otherwise entirely centralized, where the role of the community is to provide local, low-cost labor and is used as a maneuver to improve either public relations or cost-efficiency—a critique often leveled against the former Fujimori administration.\(^{23}\) A rights-based approach calls for the democratization of the entire health sector, which would transfer planning and decision-making power to the individuals and communities that the health system is supposed to serve.

On the other hand, participation need not be limited to the local level of “the community,” the definition of which is itself laden with complex power issues. Civil society organizations, including feminist groups, labor unions, environmentalists, human rights nongovernmental organizations (NGOs), and health NGOs, can also participate in designing, executing, evaluating, and monitoring projects and programs. Needless to say, for these groups to participate in such ways, they must have access to adequate information, including budgetary numbers and health statistics—making it apparent that the right to health is interdependent on the right to information.\(^{24}\)

**Accountability/Access to Effective Remedies**

It is increasingly well-established that every person has the right to effective recourse in the face of violations of the right to health, as with all fundamental rights.\(^{25}\) Both the recent General Comment from the ESC Committee and General Recommendation from the Committee on the Elimination of Discrimination Against Women (CEDAW)
have stressed that any person or group whose right to health has been violated should have effective judicial or other appropriate remedies at both national and international levels. The ESC’s General Comment states clearly that all victims of violations “should be entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of nonrepetition.” For its part, CEDAW’s General Recommendation mentions specifically the enactment and enforcement of laws to provide sanctions for, among other things, discrimination in access to health care, gender-based violence, which has health impacts, and sexual abuse of women patients by health care professionals.

Moreover, an Additional Protocol to CEDAW, which entered into force in 2001, and a draft Additional Protocol to the ICESCR, which has yet to be finalized, could eventually allow for individual petitions relating to violations of the right to health to be sent to international bodies once domestic remedies have been exhausted. Also, extra-judicial remedies, such as those that might be afforded by a Human Rights Ombudsman or an administrative procedure, may at times be equally or even more effective than the formal judicial system in promoting systemic changes in the standard of care and reducing mistreatment of patients.

What is significant is that the realness of rights in people’s consciousness is directly tied to the enforceability of those rights. The more people have access to remedies, the more they think of health as a matter of social justice over which societal and governmental control can be exercised and, in turn, the more they seek ways of vindicating their right. Thus, accountability is not simply a punitive exercise but goes beyond the legal realm to become an integral part of establishing a culture of rights.

**Multisectoral Approaches to Health**

Implementation of the right to health depends on a functioning judicial system to vindicate the right as well as on multisectoral strategies that include education, housing, and work. The right to health also establishes health as vital to sustainable human development and basic citizen-
ship. A human rights approach encompasses the full spectrum of rights set out in international instruments, linking campaigns for improved health with broader questions of democracy, social equality, and nondiscrimination, and considers such cross-cutting issues as macro-economic policies. The ESC's recent General Comment emphasizes the need for framework legislation that treats health as a multisectoral issue, rather than a question of medical care.34

This human rights perspective coincides with new thinking in the health field that asserts that to decrease disparities in health outcomes, we must look “upstream”—beyond the point of delivery.35 For example, Daniels, Kennedy, and Kawachi write that “‘Upstream’ from the health care system, justice demands fair distribution of liberty, opportunity, and basic resources. Achieving those fair distributions . . . turns out to be a crucial determinant of public health.”36

In short, because a human rights framework focuses on power relations rather than simply biological truths or isolated behaviors, it has the potential to transform praxis. This focus helps us discern the responsibility that society and government have for the conditions under which some people are consistently put at risk for disease, as well as the necessarily social—and not simply biomedical—strategies needed to address those conditions. Consequently, a human rights approach urges us to focus on inequality of access to and control over health-related resources—economic, human, and information—in both assessing the determinants of diseases and prescribing interventions to address health problems. The following sections examine how the criteria set out in international human rights law can be applied in practice to implementing programs and policies and fostering accountability for violations.

Building Programs and Coalitions: Incorporating Human Rights in Programmatic Implementation

A human rights analysis is not separate from providing services; the availability of, access to, and quality of care form part of the right to health under international law.37 Practical experience shows that programmatic implementa-
tion and service delivery can indeed be central to advocacy for the right to health. However, managing and promoting transformative programs raises challenges for health NGOs, such as determining the kind of relationship to establish with a government. An example from Peru illustrates that human rights NGOs cannot only be valuable interlocutors for patient groups and health system users but can also play innovative roles in creating alliances in which the government can communicate with nongovernmental sectors in an effort to foster popular participation.

Many organizations are dedicated to providing services to people in situations of extreme poverty or even in complex humanitarian emergencies. Not all of these organizations, however, view their role in terms of social justice rather than humanitarianism. Increasingly, many service delivery programs also use the rhetoric of human rights to formulate and discuss ethical and quality of care standards at the facility level; but not all of these connect their work to the broader political context.

Partners in Health, headquartered in Boston, Massachusetts, has worked extensively with community-based organizations, including those in Peru and Haiti. An explicit goal has been to “remediate inequalities in access [to care].” Paul Farmer, founder of Partners in Health, writes: “Services were what [Haitians] asked for, and as people who had been displaced by political and economic violence, they regarded these services as the rightful remedy for what they had suffered. In other words, social and economic rights were deemed central to the Haitian struggle for human rights.”

The work of Partners in Health (hereafter, Partners and its sister organization in Peru, Socios en Salud) in slum areas of Lima, Peru, has focused on achieving access of the poor to treatment for multi-drug-resistant tuberculosis (MDR-TB). The work Partners has done is groundbreaking because it did more than provide treatment for the poor; it actually changed the paradigm for service delivery and public health planning in Peru and elsewhere. That is, not only did Socios en Salud change Peruvian government policy, but it also played a large role in persuading the World Health Organization (WHO) to modify its policy guidelines.
Previously WHO had considered comprehensive treatment for poor people with MDR-TB to be too expensive but eventually recognized the need for such treatment. Although WHO may have been swayed by the realization that not treating MDR-TB patients would ultimately cost more, Partners did not use conventional cost-effectiveness calculations to make its point but rather based its work on an explicit human rights perspective. In Peru and elsewhere, Partners insisted that the benefits of scientific progress—including access to the highest standard of care—should be available on a nondiscriminatory basis to all people, regardless of their economic status and ability to pay.

Human rights is based on a critical independence. Providing services raises the issue of how to collaborate, if at all, with governments, which often offer the only possibility of implementing large-scale, service-delivery programs. Moreover, long-term sustainability of programs generally depends on incorporating service delivery into a broader political agenda or framework, which requires governmental commitment. Governments often realize that they face a ravaging HIV/AIDS crisis or that their child-mortality rate is unacceptably high, but they may not have the means or knowledge to pursue a policy or implement a program that follows human rights principles. Sometimes governments need technical assistance as much as denunciation and criticism to comply with their health-related obligations under international law. In this regard, Rebecca Cook and Bernard Dickens wrote: “The task of physicians and others seeking preventive allocations of health care resources is not to defeat indifferent governments but rather gain their attention and achieve their collaboration in effective preventive and remedial strategies.”

In practice, however, pursuing a human rights approach involves discerning ways to strike that delicate balance between collaboration and independence, as well as how much NGOs should substitute for apathetic or abusive governments. Farmer aptly notes: “[H]elping governments shore up failing health systems may or may not be wise. In Chiapas [Mexico, since the Zapatista rebellion in 1995] many communities simply refuse to use government health services,” believing that they are an arm of the government.
counter-insurgency campaign. Partners has faced this dilemma elsewhere. In Haiti, under the Duvalier dictatorship, Partners worked through independent, community-based organizations; in Chiapas, it supported health promoters working within autonomous, nongovernment-controlled zones. In Peru, Socios en Salud worked independently and collaboratively with the Peruvian government but did not rely on that government for funding—a critical component of independence.

The right to health explicitly imposes a government obligation, but sometimes working apart from the corruption and/or cynicism that plague many government bureaucracies is the only way to remedy inequitable access to care or to promote true community participation. As a practical matter, health NGOs in the field are often dependent on their governments for funding, certifications, institutional collaboration, advantageous tax treatments, importing supplies and equipment, and the like. NGOs are therefore understandably concerned that any criticism of or opposition to government practices will end government cooperation and may even lead to persecution. United Nations agencies are also often reluctant to alienate governments on which they depend for program implementation.

Yet, institutional and even individual discomfort often accompany challenging the powers-that-be, a lesson learned long ago by the human rights movement in Latin America. It is precisely because a human rights approach continually, consciously, and critically assesses the relationship between service delivery and the larger social and political context that it offers the possibility of real social change. Day-to-day changes may be subtle or dramatic, depending on the context. But either way, there is an underlying tectonic shift in how programming and service delivery are conceptualized (i.e., as instrumental in a broader struggle for human rights and social justice).

Conversely, applying a human rights approach to health promotion also demands innovation on the part of human rights groups. For example, in 2001, after nearly 20 years of advocacy on economic and civil rights in Peru, APRODEH (Asociación pro Derechos Humanos, or Association for Human Rights) launched a “Program on Human Rights in
Health, in which this author has participated. APRODEH is using its past strengths as an advocate for marginalized groups who may have had difficulty being heard in the public arena or seeking avenues of redress as well as the strength of the Peruvian human rights movement in general—to become an interlocutor for people whose rights to health have been or are at risk of being trampled, such as associations of people with HIV/AIDS, tuberculosis, and schizophrenia.\(^48\)

By working to transform the traditional tools used in advocating civil rights—witnessing and documentation, critique and mobilization, and litigation—to the economic right to health, the APRODEH program may achieve potentially ground-breaking results. For example, the collective nature of health rights and the lack of established judicial remedies involve creating new legal mechanisms in Peru, as well as educating judges and lawyers as part of the advocacy process. Several countries in Latin America as well as in Europe have produced cases in which NGOs and individual plaintiffs have received compensation or injunctive relief for violations of programmatic aspects of the right to health. For instance, national courts in different Latin American countries have found that unacceptable hospital conditions, lack of funding for a critical vaccine, or failure to subsidize antiretroviral medications are actionable offenses.\(^49\)

But perhaps what is most innovative about APRODEH’s nascent program is that it was not created as a stand-alone, traditional advocacy program, but as a catalyst for establishing alliances with grass-roots organizations, other NGOs, and health workers and for forming and participating in a coalition. The human rights movement in Latin America, and particularly in Peru, has historically worked with grass-roots organizations in rural and urban areas and in coalitions against poverty.\(^50\) Although APRODEH has brought this experience to the health field, it departed from the traditional, generally adversarial role of the human rights movement. Instead, it has organized workshops in different areas of Peru that have brought together government officials, international donors and agencies, NGOs offering health services, local health providers, activists from different fields, community health...
workers, and representatives of patient organizations, as well as human rights activists.

Workshops held in *sierra* and *selva* (jungle) regions, as well as in Lima are clearly just the beginning of a long process. Nevertheless, the National Coordinating Body of Human Rights Organizations (*Coordinadora Nacional de Derechos Humanos*) has formally endorsed the coalition APRODEH recently launched, which implies a long-term commitment to bringing the tools of human rights to health and will also permit the Peruvian human rights movement to assume work on health rights. One important premise behind APRODEH’s program and its investment in constructing coalitions is that health policy and programming require active, broad-based social participation and monitoring to be legitimate and for changes to be sustainable.\(^\text{51}\)

In a rights-based approach, this concept of popular participation implies that stakeholders need to translate their own interests and priorities into health programs and have the government or other entity respond with resources.\(^\text{52}\)

Therefore, APRODEH’s program has devoted much of its initial work to eliciting from multiple perspectives the priorities and needs of the different areas of the country, with respect to the four dimensions of the right to health, as set out in the ICESCR.\(^\text{53}\)

For example, initial workshops provided opportunities for community health promoters to meet face-to-face with regional health-sector officials to discuss the kinds of recognition, support, and relationships they seek from the Ministry of Health and to articulate their view of “community participation.” Difficult and controversial issues, such as providing salaries or stipends for community health workers, allocating responsibilities between the community and the government, establishing forms of decentralization and mechanisms for accountability and for practical financing, were aired and multiple perspectives (including health, human rights and rural development NGOs; representatives of the Human Rights Ombudsman, community health promoters; officials from the Health Ministry and in some cases from other sectors; local providers; and municipal officials) were shared often for the first time.

In a society that is just now emerging from an extreme-
ly autocratic regime in which civil society was not permitted a role in decision making, it is an enormous challenge to draw these disparate and often antagonistic or competitive actors together, let alone to encourage them to exchange views and debate strategies. From the outset, APRODEH clarified that its goal was not to reach a forced consensus but rather to provide a much-needed opportunity for dialogue about defining agendas and the viability of rights-based strategies.

In addition to conducting more workshops, future work will involve raising awareness and developing advocacy strategies to address the identified problems, that again will necessarily involve a variety of actors and will go well beyond the traditional “expose and denounce” model of human rights advocacy. For instance, an important conclusion that has emerged from APRODEH’s initial work is that incorporating a human rights perspective in health programs requires changes both in the working conditions of many health workers and in health education. Health workers in Peru, who have often been alleged to mistreat those seeking care, are frequently underpaid and overworked, as well as treated without respect by the system they serve. Rotations of health personnel, especially doctors, inhibit effective training and development of better community relations. At the same time, poor pay—especially for non-physicians—leads them to live in precarious conditions. If employment security and other rights of health providers themselves are not respected within the system, it will be next to impossible to persuade them to respect patients’ rights.

Similarly, workshops held by APRODEH confirmed that often physicians and other local health workers lack not only equipment and supplies but also the necessary training to resolve the health problems they encounter in many rural areas. Precisely because services should be a central component of the right to health, a fundamental axis of advocacy must be to educate current and would-be health-care professionals. Curricula and training in Peru need to be revamped so that health professionals can address the needs of rural populations and relate to patients in ways that do not reflect the racism and
inequality of the overall society.

APRODEH’s coalition-building program assumes providers can and should become allies not only in the documentation of abuses on the front lines but also in creating a more democratic society. APRODEH’s advocacy strategies therefore go beyond conventional adversarial strategies of the human rights movement to collaborate with professional societies, academics, and advocates—as well as with government agencies, which run most of the country’s large medical schools, certify all academic programs, and are Peru’s largest employer of health personnel. As straightforward or even as obvious as these strategies may seem to health professionals, they stray from those traditionally used by human rights groups to interact, for example, with police, who often work under labor conditions that are as abusive as those faced by health workers.

These challenges do not—and cannot—imply relinquishing the critical independence that has become a hallmark of the Peruvian human rights movement. But if the quality of service delivery is to change in the long term, innovative mechanisms and coalitions must be developed that encourage popular participation in decision making and constructive collaboration on structural obstacles. Obviously this will not always be possible in authoritarian contexts. Peru, however, provides an example of one of the many intermediate situations in which government and civil society urgently need to establish a true dialogue about health priorities in an effort to consolidate the country’s transition to democracy.

Understanding Health in its Social, Cultural, and Political Context and Fostering Accountability for Abuses

A framework not only determines how to go about building educational or service delivery programs; it also affects the response to the problems and abuses discovered within the health system. As shown by the work of Partners, a human rights framework overlaps with ethical and quality-of-care standards. Indeed, as many have pointed out, human rights provides a conceptual system that can
usefully be juxtaposed against the biomedical and market-oriented systems prevalent today. However, besides offering a conceptual paradigm, human rights is a body of law that imposes certain obligations on States with respect to health as well as other aspects of social well-being. Governments that ratify international treaties are therefore legally accountable to their citizens for complying with these obligations. Such accountability implies that States need to reform their laws to conform to international standards and to provide remedies when the right to health is violated. Examples from Peru’s experience with involuntary sterilization demonstrate that treating human rights as merely another set of medical ethics or quality-of-care principles excludes this dimension of rights.

The Hippocratic Oath, which physicians in many countries must take before entering practice, has traditionally informed the traditional physician-patient relationship, at least in Western countries. That oath describes the philosophical currency of the traditional physician-patient relationship as primarily one of duties as opposed to rights. In theory, the physician is the fiduciary of the patient’s well-being, having the power and responsibility to protect and promote that well-being. The patient is generally a passive recipient of expert advice. Despite variations on that paternalistic model, medical ethics are deeply rooted in a biomedical tradition that ascribes the power of defining truth to the physician and often dismisses the patient’s beliefs as “mere superstitions to be overcome with doses of factual information.” The patient’s behavior itself is generally “outside the bounds of social context.” That is, the aim of the physician-patient interaction is to secure patient compliance with the “objectively determined” course of treatment.

The rubric of “quality of care” is not a separate model in and of itself, but originally underscored the need to go beyond outcomes and examine processes in care. Although quality of care refers to the values underlying many frameworks—including human rights—in many places, including Peru, “quality of care” criteria have often been associated with evaluating health establishments’ efficiency and appeal, and it is discussed in this context here. Under this
construct, the relationship between health professional and patient is generally described as one between a “provider” and a “client” or “user.” As a result, patients are generally viewed as consumers of health services, and the services themselves are construed as commodities to be allocated according to market principles.71

In this view, social context and cultural beliefs at times can be reduced to factors considered in social marketing strategies, such as those aimed at increasing the use of health services.72 For example, an official of a large, externally financed program on quality in maternal-child care in Peru equated the government’s attempts to market Western-style birthing practices to campesina women of the Andean sierra to “trying to sell high-heeled shoes to them.”73

Again, both the quality and the cultural acceptability of care are important parts of a human rights framework (as of course are ethics), and a human rights approach proposes an understanding of these concepts that is different from a market-based one. For example, in Peru, where intercultural issues are so dominant in health interactions, it is especially important to recognize that physical and mental health cannot be detached from political, cultural, and social realities “posited as an objective state of biological being, and then treated as though the choices we make in pursuit of it are apolitical and compelled by some internal logic that derives solely from health itself.”74 However, in a human rights framework, health-system users are not simply consumers who expect quality or patients who expect ethical treatment, but rather they are holders of entitlements whose demands go beyond packages of services—beyond the health sector.75

The case of involuntary sterilizations in Peru provides a concrete illustration of how a human rights approach differs from those that are based solely on medical ethics or the prevalent quality-of-care notions. In Peru, between 1996 and 1998, a number of women’s groups documented a systematic campaign by public health institutions to sterilize primarily indigenous, rural women. The Human Rights Ombudsman’s Office later issued its own report confirming that in hundreds of cases, sterilizations were performed
without informed consent and under inadequate conditions, which at times led to serious complications and even death. Revelation of that campaign created enormous scandal, not least of all for the U.S. Agency for International Development (AID), which had funded Peru’s family-planning program. AID contracted a study by the Population Council on the issue, which analyzed it as a quality-of-care matter and concluded that there had been some instances of breaches in confidentiality, communication between doctors and patients, and, in certain cases, an inadequate standard of care. The report suggested ways that the Ministry of Health might rectify these lapses, including improving protocols and training for providers.

In contrast, the report from the Latin American and Caribbean Committee in Defense of Women’s Rights (CLADEM) conceptualized the problem as a rights issue and insisted on far broader policy and legislative changes, including revised regulations for the family-planning program and independent monitoring of informed consent for surgical contraception. But CLADEM also campaigned to provide remedies for victims and their families. APRODEH, together with CLADEM and DEMUS (Law Firm for the Defense of Women), litigated one emblematic case in which a woman died after being forcibly sterilized. After the Peruvian legal system dismissed the case, these NGOs successfully brought a petition to the Inter-American Commission on Human Rights.

On assuming office, the first Minister of Health under the new government of Alejandro Toledo, Dr Luis Solari de la Fuente, took actions that made it clear he viewed the issue of sterilizations as a problem of medical ethics—a problem of health professionals’ duty of loyalty being subordinated to the interests of the perverse politics of the former administration. For example, Solari proposed a Conscientious Objection Law, in which physicians could refuse to provide care on the basis of religious or other objections. This proposal was explicitly grounded in the understanding that under the pressures from the Fujimori administration “the health professional did not have the freedom to do what his conscience and training demanded of him.”
This bill, which has yet to be made into law, gives attending physicians untrammeled discretion, even in emergency cases where a particular physician is the only source of care available, thus jeopardizing patients’ rights.83

The medical ethics approach focused on the interference with the physicians’ independence, which had undermined the profession’s stature.84 The quality-of-care analysis conducted by the Population Council focused on making improvements for what had implicitly been a marketing disaster, not only for the family-planning program but also for AID within the U.S. Congress.85 In contrast, Peruvian women’s rights groups examined the sterilization campaign as a profound marginalization of rural, Peruvian women and undertook massive education and information projects to raise awareness about these women’s rights.86 Human rights groups also sought to make these rights a reality by seeking legal recourse domestically and internationally, as in the case of Maria Mamérita Mestanza Chávez, which is representative of the systematic campaign of discrimination and abuse that had been waged against a certain sector of the population.87

Under the current Toledo government, two commissions—in Peru’s Congress and within the Ministry of Health—were created to investigate cases of sterilizations. In July 2002, these commissions issued their findings, which were very similar to each other. They both, for example, referred to the involuntary sterilizations as “genocide,” and alleged a figure of 200,000 affected women—approximately 90 times the number of cases that women’s groups and the Human Rights Ombudsman’s Office had documented.88 All serious attempts to compensate victims and secure remedies should be applauded; however, many human rights and women’s advocates in Peru, including this author, view these ad hoc commissions as deeply flawed because of their politicized use by conservative religious elements within the government.89

These critics have pointed out, for example, that the congressional commission’s recommendation to ban voluntary surgical contraception would restrict the options and rights of Peruvian couples. Moreover, neither commission’s
recommendations made provisions to institute sanctions against institutional cover-ups or to promote transparency of information on current family-planning methods, much less to establish judicial precedents or to make the justice system more accessible in cases of health rights violations. Essentially, it seems unlikely that these commissions’ findings will be used by the government to empower users of the health system in any systemic way. Manipulating human rights rhetoric can only be countered by tying the discourse of human rights to normative principles in international law, including the need to transcend political expediency and to establish permanent mechanisms for vindicating rights.

Conclusion

In sum, frameworks matter. Understanding health as an artifact of power relations makes it apparent that societal structures that place some populations at greater risk of increased morbidity and premature death are not merely acts of divine destiny or instances of humanitarian tragedies. Rather they are injustices for which there should be accountability. Understanding health as a right makes it clear that political expediency can no longer determine social spending and policies. Instead, such decisions must be arrived at through inclusive and transparent processes that follow certain fundamental principles of equity, including gender equity. Moreover, understanding the right to health as an issue that equalizes the power people have over their own well-being, makes it clear that individuals and communities must participate in decisions about their health care and well-being and that such issues cannot be circumscribed by access to medical care, but must include living conditions and sustainable development issues. To advance work on the ground, specific criteria can be used that apply a human rights approach and are based on an understanding of health as an issue of power, over which social and governmental control can effectively be exercised. These criteria include minimum core content and adequate progress; nondiscrimination; popular participation; accountability; and multisectoral strategies. When applied to social policy and health programs, these principles can make pro-
found changes at both the macro-level of legislation and social policy as well as at the micro-level of individual institutions and providers.

The challenge for health and human rights advocates concerned with the outrageous disparities in wealth between and within countries, and in turn in health indices, is to bring these two disciplines together in the field. Partners in Health has shown that the discourse of human rights can be translated into a paradigm for designing and managing health programs that focus on remedying inequalities and promoting dignity. At the same time, APRODEH’s nascent program in Peru suggests human rights groups can play more than a conventional, purely adversarial role but rather to become a fundamental part in organizing coalitions that advocate how health is conceived and how health services are organized and delivered. Finally, the Peruvian experience with a government sterilization campaign reveals why accountability is such a fundamental part of a human rights response to abuses in a health system, and that reducing human rights to merely a conceptual discourse empties it of its normative force and may even lead to its politicized use.

Acknowledgments

The author wishes to acknowledge the contributions of both Mario Rios of APRODEH (Association for Human Rights, Peru), and Jaime Miranda, of EDHUCASalud (Association for Education in Health and Human Rights, Peru), both of whose ideas have contributed greatly to this piece. The reference to “Innovative Praxis” was inspired by the title of a workshop on reproductive rights held at the Global Center for Women’s Leadership in Rutgers, New Jersey in June 2000.

References


7. See note 6, 22.


9. See note 3, 205.

10. See note 1, Farmer, 1486.


14. See note 13, Para. 10.

15. See note 12, Para 9.

16. See note 11, ICESCR, Article 2[2].


20. See note 12, Maastricht Guidelines, Para. 11.


25. See note 22, Para. 59.
27. See note 22, Para. 59.
30. See note 11, ICESCR; see also note 6, 22.
34. See note 22, Para. 4.
35. See, for example, J. A. Auerbach and B. K. Krimgold [eds.] Income, Socioeconomic Status ,and health: exploring the Relationships (Academy for Health Services Research and Health Policy, 2001).
37. See note 22 , Paras. 12 and 17.
38. See note 1, 1490.
39. See note 1, 1490.
41. See note 1, Farmer, 1487.
42. See note 1, Farmer, 1491.
45. See note 1, Farmer, 1493.
46. Major donor institutions and aid agencies—some of which have rhetorical commitments to human rights—could do much more to promote greater equality of access, an independent civil society, participatory programs, and transparency in decision making through their financing.
47. See note 1, Farmer, 1493.
48. APRODEH is working with, among others, Life Collective (Colectivo Vida) which promotes care for HIV/AIDS patients; the Association of Tuberculosis Patients (Asociación de Enfermos de Tuberculosis), which promotes integral attention for persons with with tuberculosis; and the Association of Family Members of Schizophrenics (Asociación de Familiares de Pacientes con Esquizofrenia), which has advocated on behalf of mental health patients and their families.
51. See note 50; Partners in Health has also worked extensively with community-based organizations and associations of tuberculosis patients in Peru and elsewhere; See note 1, Farmer.
52. See note 22, Para. 54.
54. APRODEH is also working with the feminist organization Flora Tristán and the newly created Health Forum (ForoSalud), among others, to create networks of interested actors in civil society; see note 50; see also, C. Ewig, “Gender Equity and Neoliberal Social Policy: Health Sector Reform in Peru,” PhD Dissertation (Chapel Hill, NC: University of North Carolina, 2001).
55. See note 53, pp.1–5.
56. See note 53, pp. 34–79.
57. These findings confirm a 1998 investigation by the Latin American and Caribbean Committee in Defense of Women’s Rights (CLADEM), which found that women were being subjected to sexual abuse, physical aggression, and needless pain by doctors working in public health facilities. They were also denied crucial information about their sexual and reproductive health. In a joint report with the Center for Reproductive Law and Policy, CLADEM noted that there is an institutional complicity
in these actions because they go unnoticed or unsanctioned: "The cases documented . . . reflect an institutional culture that encourages and reinforces this type of behavior. This culture together with health care workers' lack of employment security, often causes them to remain silent in the face of violations of women's rights; see also, CLADEM, Silence and Complicity: Violence Against Women in Public Health Establishments in Peru [Lima: Author, 1999], p. 13.

58. See, for example, J. Anderson, Tendiendo Puentes: Calidad de atención desde la Perspectiva de las Mujeres Rurales y de los Proveedores de los Servicios de Salud or Building Bridges: Quality of Care from the Perspectives of Rural Women and Health Service Providers [Lima: Movimiento Manuela Ramos, 2001]; C. Yon Leau, Hablan las Mujeres Peruanas: Preferencias Reproductivas y Anticoncepción or Andean Women Speak: Reproductive Preferences and Contraception [Lima: Movimiento Manuela Ramos, 2000].

59. These findings confirm arguments and work done by EDHUCA Salud (Association for Education in Health and Human Rights), of which this author is an advisor, which is currently undertaking a survey of curricula in health sciences faculties around the country to assess perceptions and offerings in human rights-related topics.

60. See note 50.

61. As a first step in this direction, APRODEH, in conjunction with other human rights groups, is currently teaching a course in economic and social rights, with a large health component, at a major health sciences university in Lima, the Universidad Peruana Cayetano Heredia; see also Ewig, note 54.

62. There are beginning to be changes with respect to the police with more NGOs opening programs on citizen security. For example, the Washington, DC, office on Latin America and the Argentine Centro de Estudios Legales y Sociales (Center for Legal and Social Studies, CELS), among others, now have programs on citizen security from a human rights perspective.


69. See, for example, note 58, Anderson, p. 51, in which the author discusses quality of care from both providers and patients perspectives in a very contextualized manner which takes into account the principles of human rights.

70. M. Hernández Álvarez, Neoliberalismo en Salud: Desarrollos, Supuestos y Alternativas or Neoliberalism in Health, Premises and Alternatives” Ponencia presentada en el Seminario La falacia neoliberal. Crítica y alternativas. Centro de Convenciones Alfonso López Pumarejo, Universidad Nacional de Colombia, Sede Bogotá, 4-5 April 2002; see also note 58, Anderson.


73. See note 1, Freedman, 323; see also note 58, Anderson, pp. 121–31 and Yon Leau.


75. Defensoría del Pueblo. La aplicación de la anticoncepción quirúrgica y los derechos reproductivos II. Casos investigados por la Defensoría del Pueblo. Serie Informes Defensoriales No. 27. (Lima: Autor, 1999).

76. F. León, Peru: Providers’ Compliance with Quality of Care Norms (Lima: Population Council, 1999).


80. L. S. de la Fuente, Proyecto de Ley Que Garantiza A los Profesionales de la salud La Absoluta Libertad Profesional Para Ejercer el Derecho de Objeción de Conciencia. Proyecto No. 116/2001-CR.

81. See note 80.

82. See note 80.

83. A rural women with life-threatening complications from a self-induced abortion could, for example, be denied care under this proposal;
see also note 79, 40-43.

84. Among other things, Joseph Reese, staff director for U.S. Congressman Christopher Smith, chief counsel on International Operations of the House International Relations Committee, visited Peru to personally investigate the allegations and called for victims to testify before the Committee.

85. See note 49.

86. See note 78.


88. See, for example, Yamin, note 21, ii; and note 79.

89. See press releases from Center for Reproductive Law and Policy, “Peru’s Apology for Forced Sterilization Feared Part of a Strategy to Limit Family Planning Options,” 26 July 2002; Centro de la Mujer Peruana Flora Tristán, “El Centro FloraTristán se pronuncia sobre las investigaciones respecto a AQV,” 24 July 2002 [“The Center Flora Tristan Weighs in on the Investigation on Voluntary Surgical Sterilization”]. The author was part of a coalition of groups monitoring sexual and reproductive rights, including Flora Tristán, which is advocating changes in the current Ministry of Health’s policies (Mesa de Vigilancia de Derechos Ciudadanos en Salud).

90. See note 19, 137.

91. See note 11, ICESCR, Article 12, for definition of health.