

human rights

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Rights and the Struggle for Health

Perspectives from
Kosovo
South Africa
Ecuadorian Amazon
North Carolina
Chile
and more ...



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Neshad Asllani was born in Peja, Kosovo, and became a medical doctor in 1983. After opening the first private clinic in Kosovo in 1990, he became a member of the Council for the Defense of Human Rights and Freedoms, a Kosovar NGO, later that year. In 2000 he and other human rights activists established the Kosovo Center for Human Rights and started the Human Rights Education Project.

A physician by training, **Rony Brauman** has been a leading figure in the field of international medical assistance since 1977. Having served for several years as a physician in developing countries with Médecins Sans Frontières, he became President of the organization in 1982—a position he occupied until 1994. Dr. Brauman is currently an Associate Professor at the University of Paris XII.

A U.S. journalist who has resided in Chile since 1983, **Timothy Frasca** is a founding member of Chile's first AIDS-related organization. He is currently researching the social response to AIDS in Latin America as part of a comparative study of eight countries' experiences. He also serves as General Director of the CIPRESS Foundation in Santiago.

Nathan Geffen is a volunteer for Treatment Action Campaign, a South Africa-based NGO. His responsibilities for the organization include conducting research, producing press releases, and fundraising. When not doing activist work, Geffen teaches in the Department of Computer Science at the University of Cape Town.

Stephen P. Marks is the François-Xavier Bagnoud (FXB) Professor of Health and Human Rights at the Harvard School of Public Health and Director of the FXB Center for Health and Human Rights. Until July 1999 he was Director of the UN Studies Program and Co-Director of the Human Rights and Humanitarian Affairs Concentration at Columbia University.

Richard A. Murphy organized the FEMAville Health Care Project in North Carolina as a third-year medical student at Duke. His interest in the relationship between health, human rights, and poor communities stems from working with the North Carolina Student Rural Health Coalition, an organization that has long been making these connections in their work in the eastern part of the state. He is currently an intern in internal medicine at Columbia Presbyterian Medical Center in New York City.

Ramona Ortega is the Co-Director of the Human Rights Project of the Urban Justice Center (New York City). Her community activism is deeply rooted in her family's experience as migrant farm workers in California, where as a teenager she worked with the United Farm Workers. She began her professional career as a journalist and later worked for a public policy research organization before joining the Urban Justice Center.

Leonard S. Rubenstein has been Executive Director of Physicians for Human Rights since 1996. A graduate of Harvard Law School, Rubenstein has spent fifteen years in the field of advocacy for human and civil rights. He has lectured and written extensively on the subject of disability rights, human rights, and medical ethics.

Sarah Zaidi is the Research Director at the Center for Economic and Social Rights, one of the first organizations to challenge economic injustice as a violation of international human rights law. She has conducted research in the areas of sanctions and nutritional and environmental health in Iraq, Haiti, Ecuador, the Texas-Mexico border area, and her native Pakistan.

More than 880 million people lack access to basic health services. The absence of safe water and basic sanitation contributes to the health problems of hundreds of millions. Of the thirty-four million people worldwide who are infected with HIV/AIDS, 95 percent live in developing countries, many of which are unable to pay market prices for the only life-prolonging treatments currently available.

These facts about global health are disconcerting. But how, if at all, are these health deficits related to human rights? If the purpose of human rights norms is to promote and protect vital human interests, their relevance to health seems difficult to deny.

The relationship between health and human rights is a dynamic one. Poor health and inadequate health care are often related to human rights violations. And violation and underfulfillment of human rights are often due to poor health and lack of access to health care. The link is constitutive in the case of rights to health and health care that have been formulated in documents and treaties such as the Universal Declaration of Human Rights, the World Health Organization's Constitution, and in the national constitutions of several countries. The link is direct in the case of other basic social and economic human rights, such as the right to a standard of living adequate for the health and well-being of oneself and one's family. But poverty and lack of health protection are also indirectly linked to failures to secure civil and political human rights. People who are ill or malnourished and who lack access to medical care must struggle to survive and can often do little to resist oppression.

Why, then, have health issues been so little linked to human rights? Indeed, while both improving public health and securing human rights have long been recognized as important societal aims, they have often been thought to be tenuously connected or even in some tension with one another. This seems puzzling, especially as claims of unjust treatment and demands for institutional reform are increasingly stated in the language of human rights, and many feel that health deprivations are the result of unfair social and economic arrangements. Why do so many remain skeptical about the value of connecting the struggle for improvements in health and access to health care with human rights norms?

This issue of *Human Rights Dialogue* engages with these questions by exploring whether and how health professionals, policymakers, and activists are linking human rights norms to the evaluation of medical practices, the design of health systems, and popu-

lar struggles for improved access to health care. The picture that emerges from these essays is hopeful. As Stephen P. Marks points out in his overview of the new partnership of health and human rights, doctors, health advocates, and human rights organizations are beginning to link health concerns with human rights in ways that are having practical effects in reforming medical practices and challenging institutional barriers to improvements in health. But the articles in this issue also indicate the difficulties that practitioners and activists often have had in drawing on human rights norms to confront practical dilemmas, address difficult policy questions, and mobilize people behind their causes.

Some critics have suggested that the lack of clarity of human rights norms has limited their applicability in the field of health. The right to health (as stated in the International Covenant on Economic and Social Rights) calls on governments to create “the conditions which would assure to all medical service and medical attention in the event of sickness.” But what, these critics ask, is the content of the right to health, and what specific obligations does it entail? In his contribution, Rony Brauman criticizes the way that the right to health has been conceived, arguing that it gives little guidance to doctors in the field. Should doctors offer direct treatment to those who suffer from tuberculosis or refrain from treating for fear of contributing to significant public health problems resulting from the generation of multi-drug-resistant strains of the disease? For him, human rights might be invoked to support either option—rendering them ineffective for health practitioners in the field. And in his essay Leonard S. Rubenstein suggests that human rights norms are also unclear about how health professionals should balance their loyalties to their patients with their obligations as citizens to their states.

Nevertheless, there is reason to think that human rights concerns can become more helpfully integrated with medical practice. Rubenstein suggests that more specific guidelines that build on existing human rights standards can both improve health practices and create greater awareness of human rights among health professionals. And Neshad Asllani’s story of his treatment of Albanians who suffered under Serbian authorities illustrates how many practical dilemmas faced by physicians lead them to learn more about human rights—and even transform them into human rights activists.

Two other essays suggest that statistical indicators can be used to identify how laws and policies are undermining health protection and to empower local groups

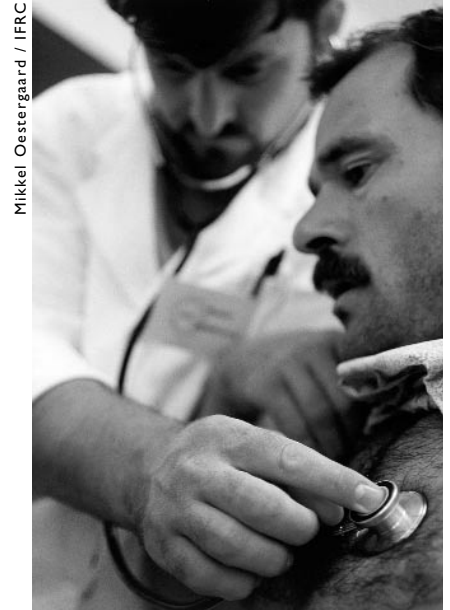
to press for their reform. Ramona Ortega describes how one group in New York City has used survey data to demonstrate that welfare reform has led to widespread discrimination in allocating health benefits and contributed to the health problems of already vulnerable populations. Sarah Zaidi discusses how her organization set out to demonstrate the relevance of human rights to the medical conditions of people living in the Ecuadorian Amazon by exposing a connection between these conditions and environmental contamination related to oil development. Both of these stories also suggest how attention to international human rights standards can motivate grassroots organizations to carry out creative statistical studies and demand relevant public information to improve the accountability of public institutions and other powerful actors.

Several of these essays indicate the power of human rights norms in people’s struggles for improvements in health. First, lack of access to health care is often the result of private conduct that, while prohibited by law, is encouraged or barely deterred by government officials. Timothy Frasca relates how a basic familiarity with human rights can lead people to demand accountability from individual staff members and institutions that deny them the care to which they are legally entitled. Second, social and economic arrangements often avoidably engender obstacles to health care access, sometimes through their contribution to extreme poverty. Richard A. Murphy discusses how local activism in rural North Carolina forced the government to remedy basic social deficits that impinged upon the health of community members. Finally, the difficulty of gaining access to expensive pharmaceuticals remains one of the greatest obstacles to health in the developing world—particularly for those infected with HIV/AIDS. Nathan Geffen’s contribution suggests how human rights activists in South Africa have overcome institutional barriers in the form of patent protection by making the government aware of the nature of the epidemic and the need for access to medicine.

The essays in this issue of *Human Rights Dialogue* add unique, local perspectives to the growing international movement to set the analysis of health concerns in a human rights framework. If the 880 million people worldwide who cannot access basic health care services, the countless poor who need adequate water and sanitation, and the millions in developing nations who are infected with HIV/AIDS are to improve their own health conditions, human rights tools may hold significant promise in helping them do so.

The Doctor as Witness

Neshad Asllani



Mikkel Oestergaard / IFRC

In 1990 the Serbian government began to limit the activity of Albanian doctors in Kosovo, imposing rules that became increasingly restrictive in the following years. A doctor was not, for example, allowed to write or talk to patients in Albanian. If he or she refused to abide by these rules, the doctor was transferred or fired. To accept these rules, many of us felt, would mean complying with the Milosevic regime. And so most of us were dismissed from state hospitals, clinics, and medical faculty, and replaced with Serb medical doctors from both Serbia and Montenegro. I applied for a position in state hospitals four times, and four times I was turned down. The last time I applied, I was accused of being an enemy of the state.

For Albanian doctors, there were two alternatives: open a private practice, or leave and find work in another country. For me, there was no choice. I decided to stay, and in 1990 I opened the first private practice in Peja, Kosovo.

Private medical practice was something completely new in Kosovo. Initially, I was surprised that patients came to my clinic, because they would have to pay me for services that were free at the hospital. I soon realized, however, that the option of visiting a private physician opened new doors to people. They were able to speak their own language. They felt safer, and they received better treatment. I started with twenty patients each day. Later, this number increased to eighty, and I was soon able to employ a colleague to work with me. We opened a lab, pur-

chased new diagnostic medical equipment, and began to provide psychiatric care as well. Every year our practice, and the care we provided, became more complete.

By 1992 I began to see signs of brutality and hear reports of abuse by Serb police from our patients. With the help of a photographer and a lawyer, I started to document the physical abuse that my patients had suffered. I also developed a cooperative relationship with two local NGOs that deal with human rights violations, the Council for the Defense of Human Rights and Freedoms (CDHRF) and the Kosovo Medical Association (KMA). My activities as a medical doctor and my documentation work in Peja were in line with the activities of CDHRF and KMA—it was a natural collaboration. Médecins Sans Frontières (MSF) and the Open Society had opened clinics in Pristina and other small towns between 1993 and 1995, and we also worked with these groups. Human rights activists throughout the region, including international organizations such as Amnesty International, referred victims and patients to my clinic. During the early 1990s I saw 4,489 patients, and in time this number increased.

I am quite sure that the local police knew about my activities, because Peja is a small town. The police came to my clinic two or three times to try to intimidate me, saying that I was not authorized to conduct such exams and document such abuse. I pointed out that I was affiliated with Amnesty

International and was authorized by their headquarters in London. Nonetheless, they threatened to shut me down. But when I asked them for documents stating that my activities were prohibited, they could show me nothing. I continued to see as many patients as I could.

I started the documentation process on my own, because I felt the abuse of my patients was wrong and needed to be recorded. While I eventually came to understand human rights, I cannot say that I knew that human rights work is what I was doing all along. After working with representatives from KMA, my colleagues and I began to understand what human rights

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are, to learn more about the legal framework and how we can protect our human rights. We were not able to articulate specific rights according to international law, such as the freedoms of expression and movement, until we worked with some of the established human rights organizations. We read—and eventually translated into both Albanian and Bosnian—Amnesty International and Human Rights Watch reports, as well as documents from the International Helsinki Federation for Human Rights. We established a cooperative relationship with all of the international institutions present in Kosovo in 1993 and 1994, an arrangement that continued up to the NATO bombing. Supporting its efforts to involve Kosovars in its work, we attended regular weekly meetings hosted by the Organization for Security and Co-Operation in Europe (OSCE). We also met with local police and authorities in an attempt to help them make their practices more transparent and to let them know that they would be held accountable for their actions.

In March of 1999, after the OSCE mission left and the NATO bombing began, Serbian soldiers came into my clinic and said in front of my patients and staff, “Where are your friends now? You are finished.” They

could have killed us all. I can’t explain why they did not. Four days later, my family and I, along with about 80,000 others, were expelled to Montenegro. In my absence, my clinic was completely destroyed and the building burned to the ground. My files—nine years of documentation of human rights abuses—were burned along with all of my other reports.

When I returned to Kosovo, my colleague and I began our work anew, but on a different track. I started to work on the exhumation of mass graves and the documentation of war crimes. People asked for our assistance in locating missing relatives, so we started the documentation process once again, taking photos and keeping records of our findings. We were aware that once winter came, the snow, rain, and soil erosion would wash all of this evidence away, so we spent July through October of 1999 exhuming war victims and working with the International Criminal Tribunal for the Former Yugoslavia and the OSCE. We exhumed around 436 bodies.

Ten years ago I worked as a doctor. My position as a doctor led me to human rights. But my involvement with human rights work was limited—it was a part-time job. Since the war it has become full-time. At first, my work involved documenting human rights violations; then it became war crimes. Now I have established an NGO called the Kosovo Center for Human Rights. We receive financial support from UNESCO and USAID for a human rights education project in Kosovo and for translating books into both Albanian and Bosnian. Our efforts are designed to include all ethnic groups living in Kosovo.

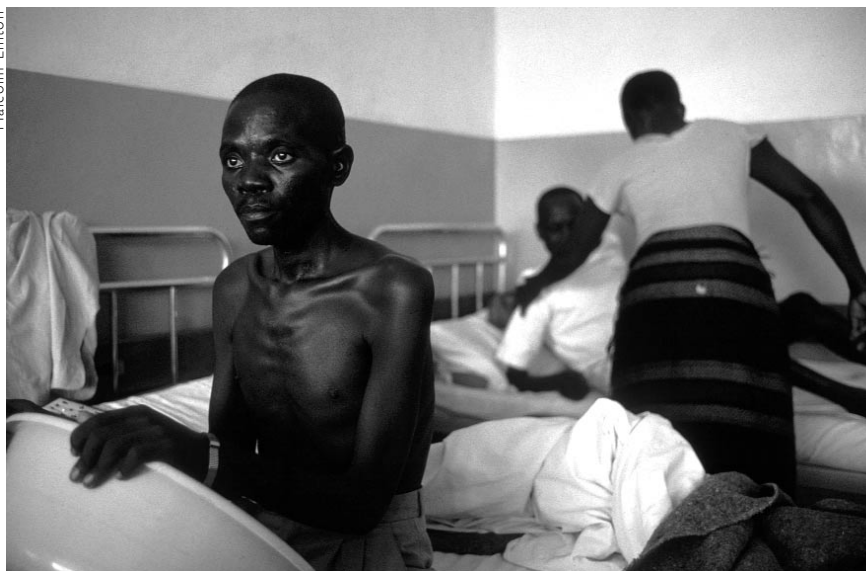
My present involvement in education stems from my belief that it is crucial to Kosovo’s future. Already, our group has hired seventeen trainers and 120 teachers to instruct about 6,000 pupils in a human rights curriculum, and our partnership with UNESCO puts us in a good position to continue this project. Only by teaching human rights to the next generation of all of Kosovo’s children can we avoid repeating the mistakes of the past.

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Questioning Health and Human Rights

Rony Brauman

Malcolm Linton



In the early 1990s the World Health Organization (WHO) decided that it wanted to eradicate tuberculosis. This would be no small task given the fact that multi-drug resistant TB (MDR-TB) was again gaining ground, primarily in Third World countries. In order to curb the spread of MDR-TB, many medical NGOs—including my own, Médecins Sans Frontières (MSF)—have become committed to WHO’s program, which instructs that no patient should be treated unless you can expect an 80 percent rate of compliance from the population to which he or she belongs. If previous evaluations lead you to think that you are unlikely to reach this high rate of compliance, then it is better not to treat. The idea behind the program was that doctors should refrain from treating patients rather than risk spreading MDR-TB—which would result in the deaths of many more people.

So in the name of this eradication program, in the cause of struggling against MDR-TB, for the sake of nice statistics, MSF and other humanitarian aid groups accepted that human beings, people of real flesh and blood, ought to be sacrificed. This is a moral and practical dilemma of a kind that medical practitioners and health professionals face all the time while working in the field. Who are we to decide who should live and who should die? For me, the terms of this dilemma ought to be posed in practical and political terms, rather than in terms of human rights. The issue of sacrifice is one that ought to be determined by the community, not by scientific

experts, and the language of human rights is too vague to help in these determinations. Human rights claims often conflict with one another; no sooner has one been evoked than another, contradictory one emerges. This is because a list of human rights is not a consistent and coherent entity. Even worse, WHO’s definition of a “right to health” is hopelessly ambiguous. I have never seen any real analysis of what is meant by the concept of “health” and “health for all,” nor do I understand how anyone could seriously defend this notion. For WHO, health does not consist of the absence of disease or handicaps; it is the state of complete physical, mental, and social well being. It has nothing to do with concrete persons, concrete diseases, or concrete explanations about health.

Nor does this definition of a “right to health” help medical practitioners make decisions in difficult cases of when to treat and how to treat, as in the MDR-TB example. Guiding these decisions are two prominent, but very different, models. The first, which one might call the “public health model,” stresses the promotion of overall public health standards. The second, which one might call the “humanitarian model,” stresses the direct treatment of existing medical conditions. There is thus a conflict of values informing the decisions of health professionals—values of general, perfect public health standards versus values of direct treatment and direct help to persons in need of medical attention.

According to the public health model, the most important factors in decision-making should be how

badly off the people affected by these conditions are in absolute and relative terms, how costly prevention or treatment would be, and how much patients would benefit from particular policies. This approach is oriented toward bringing about the best long-term health outcomes. If treatment is the best way to contribute to these long-term outcomes then one should treat, but if denying medical care to people who need it now is the best long-term strategy, then no treatment should be given. This model is generally accepted by WHO and clearly informs its policies regarding TB. Because TB patients need special follow-ups for at least eight to ten months, the public health threat is increased by so-called defaulters—a word that has moral overtones, and refers to those who abandon treatment prematurely. Defaulters threaten other members of the community because they might develop MDR-TB.

The public health model requires us to exchange corpses in the here-and-now for corpses in the future.

The humanitarian model asserts that our primary obligation is to give direct medical treatment to people who require medical attention. Essentially, we should try to treat as much as we can, regardless of what effects this may have in the future. It is the role of the medical practitioner to answer to patients' demands first, within the limits of his or her abilities. This implies that the practitioner must first seek to understand the always-complex interests of the particular patient he or she is examining. Until 1994 MSF applied this model by encouraging its medical teams to treat TB outside of the procedures promoted by WHO; growing pressure from the international aid community has made this increasingly difficult. In 1994 MSF issued a new TB guideline that referred explicitly to WHO's declaration on the eradication TB as a public health priority. This guideline appeared without any internal debate—a fact that demonstrates that a "scientific" approach to the cost of human life imposed itself as evidence, not as a question. During the last two years, fortunately, things have been slowly changing.

The humanitarian model is preferable to the public health model on both moral and practical grounds. Medical practitioners should not be understood as the representatives of society or of its *supposed* interests towards patients, as the public health model requires. Instead, their role is to deal individually and sensitively with persons who are ill. Moreover, the public health

model falsely presupposes the exactitude and validity of epidemiological predictions. I have a deep skepticism toward epidemiological prediction, insofar as it presumes that the future can be reduced to patterns. Though epidemiology certainly has value, it is often used in a scientifically unsustainable way as a "proof" that certain policies will lead to certain outcomes. One simply needs to observe the number of correlations that are insidiously supposed to indicate causal relationships, and the manner that these supposed causal relationships are then translated into policy prescriptions, to understand the empirical and moral implausibility of this model. Statistical abstractions are falsely transformed into certainties, and some modes of treatment (such as the anti-TB treatment program that should have been pursued by MSF in Angola) are rendered taboo as a result.

Epidemiological "certainties" also create the illusion that obstacles to the treatment of disease are insurmountable, when often what is really lacking is a commitment on the part of politicians and the medical community. WHO, for instance, prefers to stick with the strategy of disease eradication, even if this means embracing a policy of human sacrifice, instead of recommending resumption in TB research. Yet TB is like any other infectious disease: It evolves genetic mutations that require new antibiotics. Nobody has bothered to raise this issue because TB patients are poor and do not provide a profitable market for drugs. The public health model simply assumes these political and economic conditions.

The public health model requires us to exchange corpses in the here-and-now for corpses in the future. To me, that is a strange swap. It is morally and medically—and, I would say, humanly—unacceptable. Does taking a human rights, a "right to health," approach on the issue of MDR-TB help us adjudicate between the merits of the public health and the humanitarian model? I would say no.

A real issue, a practical one that might be defended from a human rights perspective, is the substitution of the right to health care for the right to health. I would like to see activism focus on the delivery of health care, since this can have concrete consequences for real human beings. Disease is an inalienable fact of life, but lack of access to appropriate medical care is not. Is this really a "human rights" issue? I'm not so sure. But it is at least a common concern that I think we can all agree upon.



WHO / TDR / Crump

Conflicting Interests

Leonard S. Rubenstein

Doctors, nurses, and other health workers are often on the front lines of human rights work. In many countries, they are the only outsiders with access to detained and incarcerated people and are thus in a position to report on human rights abuses committed by guards and administrators. In asylum cases, their evaluations may determine whether an individual is granted asylum or sent back to his or her country of origin.

Being on the front lines, however, means that health professionals themselves can become perpetrators of or unwitting co-conspirators in human rights abuses. The human rights movement has tended to pay the greatest attention to human rights violations by health professionals in extreme circumstances, such as where physicians participate in torture, supervise corporal or capital punishment, or misuse psychiatric diagnoses and treatment interventions to punish or control political dissidents. International bodies like the World Medical Association, in addition to many domestic medical and nursing organizations, have condemned these practices.

The problem of health professionals subordinating the interests of their patients to the interests of the state, however, goes far beyond these more serious cases. Indeed, this phenomenon, often called the dilemma of “dual loyalty,” is pervasive: the prison doctor who uses anti-psychotic medication to control a non-mentally ill prisoner for the sake of institutional security; the jail physician who fails to

record signs and symptoms of abuse in the medical record; the emergency room physician who defers to a police officer’s request to release a patient to custody rather than admit him.

The passive serving of state interests is even more common. A nurse or doctor who is the sole independent witness of abuse in a closed institution, but who remains silent concerning what she sees, elevates the protection of the state above her duties to the individuals she serves. The physician who subordinates medical judgments or interventions in the service of a discriminatory system, such as through participating in a racially segregated health care system, also chooses to serve the state rather than the patient. Even in day-to-day clinical practice, physicians or nurses may deny medical care to an individual for reasons—because of a person’s immigration status, for example—that violate a person’s human rights.

Despite the many circumstances in which the health professional actively or passively serves the state instead of the patient, the problem has received virtually no attention from the medical community (except in the extreme cases noted above). Ethical codes that govern the practice of medicine generally do not acknowledge the often-conflicting demands placed upon medical practitioners. Instead, they are replete with idealistic statements affirming the physician’s primary obligation to the patient that do not take into account the many pressures on health professionals to subordinate patient interests.

Further, these codes do not address those circumstances where subordination is both legitimate and necessary—as in cases where the health provider is obliged to breach confidentiality in order to avoid harm to innocent third parties, or to provide assistance to state-operated social programs that require medical evaluations to establish eligibility for benefits.

The absence of guidelines concerning the circumstances when breaching the duty of loyalty is legitimate and when it is not makes it very difficult for health professionals to behave appropriately and for others to hold them accountable. Indeed, it can be an invitation to abuse. For example, in a case that reached the United States Supreme Court this year, a group of doctors and nurses at a hospital in South Carolina subordinated the health and well-being of their patients—poor women—to their own political objectives. In cooperation with local police, they established a protocol requiring every

Ethical codes that govern the practice of medicine do not acknowledge the often-conflicting demands made on medical practitioners.

woman who came to the hospital for prenatal care or to give birth to be tested for cocaine. When the program started, the hospital offered treatment to women who tested positive. If a woman refused treatment, she was referred for prosecution. That policy was bad enough, for it meant that doctors and nurses became an arm of the police. Worse, as the program evolved, many women were not offered treatment at all. Some were arrested in the hospital and jailed immediately; at least one woman was shackled to the bed while giving birth.

Ultimately, the Supreme Court held that the drug tests conducted by the hospital staff violated the Fourth Amendment, concluding that the staff had become an adjunct of the police. From the standpoint of medical ethics, the more interesting issue is the hospital staff's gross violation of the duty of loyalty to these women. No physicians or nurses were charged with a disciplinary infraction, much less punished. Indeed, they appeared to lack any awareness that the ethical duty of loyalty had been compromised. Their focus on a social end—punishment of women who did not refrain from drug abuse during pregnancy—seems to have outweighed any sense of loyalty to their patients.

The South Carolina case resulted from the voluntary actions of health professionals. More commonly, health professionals face pressure from state officials to sacrifice loyalty to the patient to state interests. But they have little guidance concerning how to respond. They know that the absolutist stance taken by medical ethics codes is unhelpful, but, crucially, they do not know when to refuse state demands. Health professionals who serve in prisons, jails, and other closed institutions, as well as in agencies working with disfavored groups like refugees and immigrants, are particularly vulnerable. They often act in isolation from professional colleagues, without support from associations of health professionals, and sometimes even in an employment relationship with state officials who ask them to violate human rights.

This problem cannot be solved until there is open discussion of its existence. Guidelines are surely needed. A starting point for conduct is a rule that no health professional should subordinate the interests of a patient to the wishes of the state where doing so would violate the human rights of the patient. Guidelines can go on to address the particular circumstances in which dual loyalty problems arise. The guidelines should be accompanied by practical suggestions to professionals regarding the means by which they can protect their professional independence and their patients' human rights. There is also a role for associations of health professionals, which need to offer more support for individuals subjected to demands to violate the human rights of their patients.

An international working group on dual loyalty convened by Physicians for Human Rights and the University of Cape Town Health Sciences Faculty has begun this process. Consisting of experts in human rights and health (including human rights law), bioethicists, individuals who have experienced human rights abuses, and others, the group met in Durban, South Africa, in late 2000 to begin the process of drafting guidelines on dual loyalty. When completed, the draft will be circulated for comment, then revised and submitted to international organizations of health professionals. By bringing the problem of dual loyalty into the open and addressing it squarely, health professionals will finally be able to live up to their promise to advance and protect—rather than violate—human rights.

Transforming Practice through Activism

Timothy Frasca

Jimmy César Esparza Vegenas



Jacinto, a 39 year-old AIDS patient at the public Hospital del Salvador in Santiago, suffered an attack of herpes zoster during the winter of 2000. Although rarely serious, the painful condition, also known as “shingles,” is common among people with HIV/AIDS. The nurse in charge of the HIV program at the hospital assured him that acyclovir or an equivalent was readily available at the hospital pharmacy to treat the outbreak. “I arranged that purchase myself, so I know it’s in stock,” she told him. When Jacinto took the prescription to be filled, however, the pharmacist said no acyclovir remained. He offered no explanation and had no information on when the situation might change.

Jacinto sought help from the staff of an HIV prevention and support organization, Corporación Chilena de Prevención del SIDA, where he volunteered (and which I directed for nearly a decade). Rather than look for an alternative source for the drug, we decided to press the issue with the hospital. A staff advocate advised Jacinto to return the next day and insist that the pharmacist give him the drug. If he was denied again, he was to write down the name of the hospital pharmacist and the date and time on the prescription form, and ask the pharmacist to sign it as confirmation. If that failed, Jacinto could ask for the hospital complaint book.

Fortunately, these escalations were unnecessary. Jacinto made clear to the pharmacist the steps he was going to take, and the missing acyclovir finally appeared. “I insisted and had an organization back-

ing me,” Jacinto recalls. “But a lot of people just give up.”

There is no way of knowing whether Jacinto was the victim a simple mix-up, staff indifference, a shortage of drugs, or outright discrimination against him for his HIV status. Such problems plaguing Chile’s health care system are not exclusive to the HIV/AIDS program—nor are the frustrations they engender. “Many of the people we counsel are already beaten down by everything that has happened to them,” explains Elena Droguett, a 70 year-old caseworker who started out as the secretary of a local AIDS organization and now works for the Fundación CIPRESS in Santiago. “They don’t have the energy or the spirit to make demands on the hospital or its staff. They want to get out as fast as they can.”

Similar tales of bureaucracy, scarcity, and discrimination are repeated thousands of times throughout Chile’s troubled public health service. While some “rights” to health care may theoretically exist in Chile, such as free treatment for HIV-related illnesses, actually receiving these services is far from automatic. Whether Jacinto was in fact the victim of HIV-related discrimination, simple incompetence, or a systemic shortage, his right to the treatment he needed was violated. Jacinto’s announced intentions threatened to make the facts visible. By insisting that individual staff members assume responsibility for their actions—a technique borrowed from the human rights field—he made the refusal of treatment potentially costly to all concerned.

Droguett says she and her colleagues always believed they were defending people's human rights in their advocacy and support work. But only after hearing Argentine lawyer Susana Chiarotti from the Centro Latinoamericano de los Derechos Humanos de la Mujer describe their human rights approach during a seminar talk in 1999 did they realize that human rights advocacy could provide specific methods for improving health care delivery for their clients. Chiarotti explained that women's groups in Latin America have been taking advantage of the international agreements that emerged from UN conferences, such as the International Conference on Population and Development in Cairo in 1994 and the Fourth World Conference on Women in Beijing in 1995, to monitor and fight unjust health policies.

We learned from the human rights movement that a key element of any complaint or criticism is having unassailable facts.

Chile is now awash in human rights–related court cases—including more than 250 against former dictator Augusto Pinochet—based on information carefully compiled over the years in which no local court would grant even a habeas corpus writ. These data were assembled by groups offering direct support and services to the people affected by political repression: lawyers, doctors, psychologists, social workers, and support groups. “In Chile we have a long history of human rights work because of Pinochet and the dictatorship,” says Droguett. “But we didn't realize that these same techniques could be used to break down barriers to health care and build a case for structural changes.”

The human rights–centered approach involves identifying an entitlement and then patiently insisting that it be fulfilled. When the system breaks down, those affected are encouraged to document every detail in the process. “We learned from the human rights movement that a key element of any complaint or public criticism is having unassailable facts of specific instances,” says psychologist Valeria García, a long-time health activist in her neighborhood in the southern Santiago shantytowns. “It isn't enough to say, ‘These things are happening.’ You have to say when, where, what, and who was involved. And you have to get it right.”

Jacinto's story illustrates how individuals can learn to make effective demands on institutions unused to being held accountable for respecting people's rights. But the case-by-case resolution of patients' treatment problems does not in itself address the issue of chronic shortages. When there are not enough drugs to go around, arbitrary decisions about who receives them are inevitable. Those better able to raise the cost of refusal will be more likely to succeed in forcing the system to respond to their needs; however, as activists seeking the well-being of our clients, we who utilize human rights language and methods at the case-by-case level are aware that each “success” for one client implies that someone else will be deprived. The next step must be to push for incorporation of patient benefits in an explicit set of guarantees, based on the system's capacity to provide them.

The current government's plan for broad health-sector reform, including a package of patients' rights to improved services, provides an opportunity in this regard. Despite considerable increases in health spending since the restoration of democracy in 1990, Chile's public health system has not detected increased satisfaction among users. This fact has obvious political implications, and government leaders are interested in finding ways to transform practices, including institutional culture, to achieve better results from the budget increases. By illuminating and exposing arbitrariness and inconsistency in current practices, and by patiently placing demands on the system in one case after another, patient advocates believe we can build pressure for change. At a minimum, increasing the number and frequency of queries and complaints is likely to generate pressure throughout the system for more resources.

The human rights approach to quality of care is a promising strategy for improving the beleaguered health care system in Chile and for paving the way for individuals to take positive action. Activists will have to turn their efforts in pursuit of incremental gains or individual triumphs into solid data for policy reform. In the systematic promotion and defense of a person's right to adequate health care, Chilean activists have a multitude of opportunities both to require health care institutions to carry out their promises and to identify what new commitments can and should be made.

Applying Human Rights to the HIV/AIDS Crisis

Nathan Geffen

In the United States and Europe, people with HIV/AIDS are living longer, healthier lives primarily because of the availability of antiretroviral treatment. Yet in the developing world, we are faced with death on a scale comparable to World War II, by a disease more lethal than any since the Black Death decimated Europe's population 600 years ago. Accounting for this disparity is simple, according to Justice Edwin Cameron, formerly a judge on the South African constitutional court and himself an HIV patient: "There are people throughout Africa . . . and nearly 34 million people in our whole world who are this moment dying. And they [are] dying because they don't have the privilege that I have, of purchasing my health and life."

The Treatment Action Campaign (TAC) is a South Africa-based grassroots NGO that campaigns for access to treatment, with a focus on HIV/AIDS patients. For us, a human rights framework is not merely an academic tool, but the fundamental basis of our advocacy. Achieving social justice on the issue of obtaining the drugs necessary to sustain life requires efforts on both the domestic and the international levels. In South Africa, we have been using legal action and the threat of legal action to force the government and pharmaceutical companies to recognize and adhere to basic rights, such as the right to health care, that are enshrined in the constitution. The international community, however, must reconsider the patent abuse of pharmaceutical companies and move faster to develop a global trust fund for combating the HIV/AIDS epidemic in all developing countries.

Out of the South African revolution against apartheid emerged an internationally respected con-

stitution with a bill of rights, encompassing the rights to life, dignity, health care, and reproductive choices—the core issues underlying TAC's campaign. With the new constitution and the establishment of the constitutional court, legal action is a critical part of achieving social justice. Human rights arguments and legal action alone are, however, of limited use. It is crucial to combine them with mass mobilization, including rights awareness campaigns. In the context of HIV/AIDS, this means organizing people affected by the disease. Treatment literacy programs, protests, marches, and even civil disobedience are crucial components of grassroots pressure. This is a difficult challenge in a poor country like South Africa, which has low levels of scientific literacy, a high rate of poverty, and a high incidence of people infected with HIV/AIDS being unaware of their status.

We have already seen practical results in gaining access to medicine from this approach. Last year, TAC threatened legal action against the government for not implementing an HIV/AIDS mother-to-child transmission prevention (mtctp) program using antiretroviral medicines. The threat of action, coupled with protests and nonviolent street action, led to immediate results: The Department of Health announced the implementation of mtctp in eighteen pilot sites around the country, reaching 10 percent of pregnant mothers attending public antenatal clinics. While this was insufficient, it indicated a gradual realization of the rights being argued for. TAC halted its legal action in response to these measures. Since then, however, the government has wavered on its commitment and delayed the implementation of the eighteen sites. The



minister of health has also suggested that there are no plans to go beyond the pilot program. TAC is thus once more considering legal action on mtctp. More important, popular action demanding a countrywide mtctp program has gained momentum, which has had the effect of speeding up the implementation of the pilot sites.

Another example of combining legal action on a human rights basis with popular protest was the highly publicized court case between forty pharmaceutical companies and the South African government, which began in 1997. The pharmaceutical industry attempted to block the introduction of legislation that would substantially lower the prices of medicines. TAC joined the case as an *amicus curiae* (friend of the court) in support of the government. A number of aspects of the legislation were contested by the industry, but best known was the principle of parallel importation, which the new legislation would allow.

Parallel importation is the importation of a product under patent from a distributor in another country. This does not refer to generic versions of the product, only to the patented product sold at a lower price elsewhere. Changing the law to allow these medicines into the country is important if one considers that some essential patented drugs are sold at lower prices in countries such as Spain and India than they are in South Africa. Though the reduced cost would benefit all HIV/AIDS patients, the pharmaceutical industry sees this eventuality as a breach of their property rights, which are protected under the South African constitution. TAC's counsel argued that all other constitutional rights should be considered within the context of the rights to life and dignity—the most fundamental of all human rights.

A human rights framework is not merely an academic tool, it is the fundamental basis of our advocacy.

TAC coupled its legal action with a call to its allies around the world to participate in a global day of protest against the pharmaceutical industry's stand. The response was huge. In more than ten countries, including developing countries like Brazil, Kenya, and the Philippines (as well as South Africa), crowds gathered to protest this unjust policy. The result was a public relations disaster for the pharmaceutical industry and their swift withdrawal from the case. The industry's legal action has, however, succeeded in delaying

the new legislation from 1997 until the recent court case. Within the next two months, the legislation will be enacted.

Though important, TAC's domestic initiatives must be complemented by more concerted action on the part of the international community to get medicine to people in need. Treatment activists argue that the pharmaceutical industry is charging excessively high prices on essential patented medicines. Only competition from generic manufacturers (with royalty-based compensation for the patent-holders) offers a sustainable means of driving prices on these medicines to their marginal cost, as has happened in Brazil. The World Trade Organization Trade Related Aspects of Intellectual Property agreement, which establishes minimum standards for WTO members with regard to intellectual property law, has been partly responsible for the failure of developing countries to allow generic competition on patented medicines.

Though the agreement contains exceptions that are, in our opinion, sufficient from a legal perspective to allow the issuing of licenses for generic versions of products under patent to be produced and imported (with compensation to the patent-holder), developing countries have been fearful to act on these exceptions. This is because the agreement is poorly drafted and ambiguous, which leaves much scope for trade action by rich countries—influenced by the pharmaceutical industry—against poor ones at the WTO. Essentially, many developing countries have simply been intimidated out of pursuing generic importation or production. Furthermore, many poor country governments, though not all, cannot afford to supply HIV/AIDS drugs, even if they are sold close to their marginal cost. TAC and its allies are therefore promoting the establishment of a global trust fund financed predominantly by the United States, the European Union, Canada, and Japan. This fund would pay for medicines (including antiretrovirals), the development of health care infrastructures, and prevention programs. Such a fund is in the process of being established, but it requires a much larger financial commitment from the rich countries to be successful. If the human rights to health and medical care enshrined in Article 25 of the Universal Declaration of Human Rights—surely the most important global agreement and the one to which all bodies like the WTO should adhere—are to have meaning beyond mere platitudes, then the global trust fund for alleviating the HIV/AIDS pandemic must be given full support.

Temporary Health Care, Lasting Power

Richard A. Murphy

In the eastern third of North Carolina, racial discrimination and poverty have long impeded the development of healthy communities. Since the Civil War, counties in this region have been economically underdeveloped, racially segregated, and medically underserved. As the largely poor, African-American communities lack the political clout to organize effective opposition, irresponsible industries, including massive hog farms, chicken processing plants, and heavy industry, have established themselves here. These entities have created enormous amounts of pollution, most notably in the form of open hog waste lagoons and the disproportionately high number of Superfund sites (more than 170) in the region. When Hurricane Floyd struck eastern North Carolina in September of 1999, the storm's already extensive damage was made worse as the powerful floodwaters overflowed the numerous waste storage sites and became a frightening and dangerous effluent. The flood hit the vulnerable and dispossessed the hardest; some fifty-one people lost their lives and thousands more lost their property. Particularly affected was the historic African-American town of Princeville, a settlement built by freed slaves located on the low, flood-prone side of the Tar River.

In general, doctors and public health advocates seek to understand the spread of diseases in terms of basic pathophysiology and individual risk factors. Jonathan Mann has argued that they have, however, ignored the key role that social phenomena play in fostering ill health. As exemplified in Princeville and

many other places like it, the lack of attention to basic human rights means that factors like low levels of education, inadequate income, discrimination, and lack of safe, affordable housing have rendered one segment of the U.S. population (i.e., poor people of color) significantly sicker than the rest. Mann suggests that we use a human rights framework to address these social inequalities, since they stand as significant barriers to improving public health.

The government's response to the disaster in Princeville underscores how far we still have to go to meet Mann's suggestion. By December, after having housed disaster victims for weeks in high school gyms, the Federal Emergency Management Agency (FEMA) moved them to temporary refugee trailer camps nicknamed "FEMAvilles." The largest of these, located near Rocky Mount, had nowhere for the children to play safely and nowhere for the residents to hold religious services or even meet as a community until many months after it had come into existence. One FEMAville resident, Vernice Lyons, lamented the overcrowded conditions: "We were crammed into such small little spaces and the state did not include us at all in how the place was run. They just kept reminding us that we had only eight months before they would kick us all out." Lyons, who was taking care of her young autistic granddaughter Tomica, was repeatedly refused any additional accommodations for Tomica's needs. For many organizations that had long struggled for decent working and living conditions for the poor of

Dave Gattley / FEMA News Photo



eastern North Carolina, it was troubling to see this population, so recently traumatized, now confined to such a setting.

As the camp was being set up I met with local activist groups and helped form an ad hoc alliance called the Relief and Aid Project (RAP)—the purpose of which was to ensure that poor and working class people would not be forgotten or ignored. Despite the fact that our initial efforts to gain entry into the Rocky Mount FEMAville were confounded by the state government, we established our first FEMAville Health Clinic six months after the hurricane. Our patients' medical problems ranged from severe hypertension to post-traumatic stress disorder. At the end of the clinic days, we met with many of our patients, along with community activists, to talk about our progress and their concerns.

Camp residents, for months bullied by state officials, were thrilled to see the authorities finally answer to demands for assurance of safe living conditions.

One issue that quickly arose was the safety of the very soil upon which the camp was built. Many residents from nearby Princeville remembered that prior to its current usage, the site had been used as a dump for industrial ash. The residents themselves, while nervously watching their children play in the sandy soil, had called for state officials to investigate this charge, but their concerns went unanswered. One of my classmates, Aaron Pulver, then a student at the University of North Carolina School of Public Health, spearheaded a campaign to spread information about the potential health threat, structuring his efforts according to the concerns voiced by residents.

Weeks into the inquiry, and after further pressure from camp residents and from RAP, public officials finally agreed to carry out further testing of the soil and water. In the months that followed, it became apparent that in past years dumping had indeed taken place at that site, and that state and federal officials had not thoroughly investigated the site's safety before placing the camp there. Fortunately for the residents, the investigation showed that there was no major health threat from the industrial ash that was there. It was a significant moment for the camp residents—for months bul-

lied by state officials—to see the same authorities finally answer to their demands for assurances of safe living conditions.

At the Rocky Mount FEMAville, the collaboration of medical and public health students with residents and local activists continues to be an extremely effective tool for change. Our recent efforts have focused on the broader problem of the lack of affordable housing in eastern North Carolina, a problem that raises numerous health concerns. One man who came to the clinic this past January asked if we could test the lead levels of his four children. He explained, "There really are no good houses out there that we can afford. We moved into an old house in Tarboro for cheap, and after we had been living there for a while, the neighbors told us it was full of lead. I'm worried about my four children." Just recently, local community groups, former FEMAville residents, and student health professionals brought their latest case to the steps of the state capitol in Raleigh.

The arguments employed by the campaign have appealed to both human rights and health principles. When many existing low-rent homes are shown to contain lead, as is the case in eastern North Carolina, a health argument can easily be made and is the one to which we feel the state is most likely to respond. At the same time, to mobilize physicians and public health advocates in the struggle, it is useful to invoke human rights arguments suggesting that for the right to health to exist, governments must protect the universal right to a safe living environment.

Mann's proposal that social factors be taken more seriously in diagnosing the ills of communities seems, therefore, to be gaining some ground. In eastern North Carolina, local communities and governments recognize the language of civil rights and also that groups must be treated equally with respect to education, health care, and housing. The human rights framework motivates health care advocates—some of whom were not a part of the civil rights era—to feel like participants in a wider, global effort to assure more equitable health outcomes. It may be a long time before local officials in eastern North Carolina answer to these arguments, but until then we can frame these demands in the language of civil rights, health, and safety—something these officials already recognize.

Using Indicators to Guide Advocates

Sarah Zaidi

Andy Ryan



This article continues a discussion originally raised in *Human Rights Dialogue* (Series 2, Number 2), “Litigating Human Rights: Promise vs. Peril.” For further reading on this topic from the perspective of litigation, please see “The Story from the Oil Patch: The Under-Represented in *Aguinda v. Texaco*” by Judith Kimmerling and “The Meaning of a Legal Victory in the Ecuadorian Amazon” by Tamara Jelic and Chris Jochnick, online at www.carnegiecouncil.org/themes/hrdspring2000.html. Also see “The Other Side of the Oil Patch,” a response to the above-referenced articles, by Luis Yanza in Series 2, Number 3, online at www.carnegiecouncil.org/themes/hrdsummer2000.html.

Though the vast rainforest of the Ecuadorian Amazon is rich in oil, the eight different indigenous groups and settlers from other parts of Ecuador living there remain poor and without adequate access to health care and other services. What the indigenous people of the Amazon do know about the black crude is that it has brought continuous destruction of their lands and cultures. The new settlers spoke of problems such as leaks of a horrible-smelling gas (hydrogen sulfide), which killed their farm animals and knocked out their kids; the burning of a gas that brought “black rain” and contaminated their drinking water; oil spills in their rivers that affected fish catches and may have caused dermatitis; and the slow leakage of oil-related sludge from ponds into their farm lands, affecting their crops. These allegations were denied by both the oil companies and the government of Ecuador. Neither had ever collected data or conducted an environmental impact assessment—nor had they considered that any major economic decision that profoundly affects people’s human rights must rec-

ognize the affected population as stakeholders in the decision-making process.

Seven years ago, the Center for Economic and Social Rights (CESR) released its first report on violations of the right to health and a healthy environment in Ecuador, “Rights Violations in the Ecuadorian Amazon: The Human Consequences of Oil Development.” Our conclusions stemmed from a study we designed that sought to establish whether there was a link between the contamination of water with oil and an increased risk of cancer in the population. Starting from the premise that the right to health is scientifically measurable, the report provided a strong factual basis for claims that oil companies’ ruthless exploitation of a pristine environment and unique peoples infringed upon that basic right. Ultimately, we hoped that our efforts would draw broader public attention to environmental issues and demonstrate how human rights violations such as the ones detailed in the report might be addressed through the framework of the law. We also wanted to show how the use of

statistical indicators could empower small grassroots organizations to hold governments and other powerful actors accountable for the effects of their policies on human rights.

Despite the knowledge that contamination of the environment with microorganisms, physical agents, and toxic substances can affect health, the causal link between exposure and ill health was difficult to establish—thus making it hard to prove that the government was failing to live up to its obligations under both the International Covenant on Economic, Social and Cultural Rights and domestic constitutional law, which includes a right “to live in an environment free from contamination.” There were no population-based statistics or mortality and morbidity data from hospitals or clinics and no epidemiological studies. As a small NGO with a limited budget, we could not engage in a traditional study, which would take several years—we were going to be in the Amazon for less than ten days. In addition, the fact that environmental contaminants had been released over decades made ascertaining and quantifying their effects quite laborious.

In order to surmount these obstacles, we worked with public health experts on toxicology, environmental health, and occupational health, designing a study that would, on the one hand, measure exposure to oil-related substances in the environment and, on the other hand, ascertain whether or not health complaints might be related to oil pollution. We asked two questions: Are the residents of the Amazon exposed to levels of crude oil or toxic crude oil constituents that constitute significant health and safety risks? And are residents experiencing health effects that could be attributable to crude oil or related exposures?

To answer the first question we had to choose indicators that had clear potential for showing human exposure, intake, and harm and that were also amenable to convenient sampling, transport, and analysis. We decided to focus on exposure through bathing, drinking, and production water and to measure two classes of toxic crude oil constituents for which there were internationally recognized exposure guidelines. These two toxins were chosen also because they are associated with acute, observable health effects (e.g., dermatitis), as well as chronic and irreversible health effects (e.g., cancers).

Answering the second question was a little more difficult as indicators related to chronic adverse health

effects (such as cancers, reproductive and developmental problems, and immunological impairment) are more difficult to measure. We decided that skin disease as a result of exposure to oil was easy to observe in a physical examination. The physician recorded case histories and diagnosed only current health problems that might be related to oil spills or other exposure measurements.

Our study revealed that drinking water samples were associated with excess cancer risks from four to seven cases per millions. We also observed a higher rate of oil exposure-related dermatitis among residents near oil production facilities. These contamination-related health problems were directly linked to the government’s failure to comply with the minimum duties derived from its national and international obligations. The government failed to take reasonable precautions to avoid contaminating the environment, to regulate private actors effectively to prevent such contamination, and to provide potential victims of contamination with judicial remedies and access to information on oil development.

The CESR report concluded that the government has a legal obligation to respect and protect the health of its population. While there are no blueprints to guide human rights advocates in measuring the right to health, in our experience it is possible to construct indicators, as well as to reframe existing indicators, for human rights purposes. Ultimately, the report fulfilled our initial goals. First, it helped generate public pressure against the government’s oil policies. The findings appeared in a comic book that was disseminated widely among indigenous and settler groups. The local press and the *New York Times* reported on the government’s and the oil companies’ negligence. Second, the report led to two separate legal actions: a class action lawsuit against Texaco, and a legal petition to the Inter-American Human Rights Commission on behalf of an Ecuadorian indigenous federation protesting the activities of a private oil company. Finally, CESR, along with local groups, organized workshops on documentation, monitoring, and legal obligations and accountability for local peoples. These led to the formation of a Frente de Defensa de la Amazonia—a coalition of 300 indigenous groups, environmental groups, and “colono” communities that have joined together to resist irresponsible oil production.

Operationalizing Human Rights

Ramona Ortega



Over the last twenty years, popular opinion regarding welfare recipients has turned increasingly negative. This stigmatization of the poor means that anti-poverty advocates have found it more difficult to gain support for progressive policy initiatives that seek to eliminate poverty and advance economic justice. Decreased access to public health care has only worsened the declining health status of millions of poor people in the United States. Legal challenges to discrimination or to the restriction of access to benefits and due process have been slow to have effects—and in most cases have resulted in only minor changes to already inadequate programs. Limited access to preventative and acute health care has disproportionately affected the poor and minorities, and little has been done to eliminate the institutional barriers they face. Environmental factors such as homelessness, inadequate nutrition, lead and asbestos poisoning, and high-risk working environments only aggravate the high rates of diabetes, hypertension, and depression found in poor communities of color. Historically, public benefits such as Medicaid and welfare assisted these communities in securing care, but current reforms aimed at cutting the public assistance rolls have left them in dire straits.

In the face of a diminishing social safety net, a growing number of NGOs in the United States have drawn upon human rights standards in articulating claims to improved access to health care. Because domestic application of human rights is still relatively new, advocates must learn both how to increase public awareness of basic rights and how to opera-

tionalize the guarantees of international treaties in local contexts. The Human Rights Project (HRP) is dedicated to strengthening a human rights-based approach to public policy analysis of social welfare policies in order to promote social justice activism.

In its most recent initiative, the New York City Welfare Reform and Human Rights Documentation Project, HRP joined with five other anti-poverty organizations to monitor New York City's welfare reform policies from a human rights perspective. The survey methodology for the project was simple: We were to gather both quantitative and qualitative information from current welfare recipients, individuals who have attempted to obtain welfare benefits and failed, and those who have lost benefits because of sanctions. The project had four main objectives: document human rights abuses as they relate to welfare reform; provide quantitative and qualitative data to the media, public interest litigators, community organizations, and elected officials to progressively change public opinion and welfare policy; expand awareness among welfare advocates about human rights concepts that establish the fundamental right to basic human needs and the government's responsibility to meet those needs; and politicize social service agencies and community groups by training them to be human rights monitors.

To help capture the complexity of welfare reform, the HRP called a meeting with local grassroots, legal advocacy, policy, and service organizations that worked on issues related to social service benefits, including cash benefits, food stamps, housing, health care, and

employment. Many of these groups had already been involved in monitoring welfare reform in their own communities, and hence, they knew firsthand that people were losing benefits arbitrarily, and that the need for food and health care was increasing. In particular, people were being wrongly cut off from receiving Medicaid and Food Stamps as a result of being denied cash assistance. These administrative errors left many in need of medication, treatment, and housing (as mandated for HIV recipients). A recent lawsuit found New York City's Human Resources Administration guilty of erroneously cutting people off of Medicaid; it must now reinstate millions of recipients. Because there is so little public information—particularly disaggregated data—about the effects of welfare policies on particular populations, it is easy for politicians to sell welfare reform as an overall success based on caseload reductions. By doing so they can continue to mandate welfare-to-work programs regardless of their disastrous outcomes, rather than find appropriate supports for those bearing the brunt of the current punitive policies.

For a different perspective on human rights and welfare reform in the U.S., see Sandra Chapin's article, "The Hope of Human Rights in Combating Welfare 'Reform,'" in *Human Rights Dialogue* (Series 2, Number 3), available online at www.carnegiecouncil.org/themes/hrdsummer2000.html.

In the spring and summer of 2000 the project trained more than 175 students, social service providers, and religious congregants to be human rights monitors. They administered the survey at thirty-six service organizations, ranging from community-based welfare-to-work sites, food banks, and shelters. In spring 2001, after creating a database of more than 300 in-depth surveys, the project released the first in a series of briefs analyzing the effects of welfare reform by race. Disaggregating the statistics enabled advocates to pinpoint who was facing what type of problem within the welfare system. Analyzing the survey was useful both in identifying potential violations under the Convention on the Elimination of Racial Discrimination, in particular discriminatory patterns of diversion, and in providing data to support concrete policy recommendations for welfare reform reauthorization in 2002.

In an effort to gauge the array of effects of welfare reform, respondents were asked to describe their situation since 1998. In regard to issues of health and access to health care, the overall picture we gained is grim, illustrating the myriad barriers people living in poverty face.

More than 54 percent of the sample experienced food inconsistency, which is directly linked to a wide range of health risks associated with malnutrition. More than 40 percent faced health problems in general, and 20 percent suffered specifically from mental health problems. To make matters worse, New York City has added a complex administrative process to the relatively straightforward federal guidelines for receiving Medicaid. Health issues are particularly urgent: as welfare rolls shrink, the challenge for many people with mental and health disabilities is to become self-sufficient. Medicaid and public benefits are just one aspect of disparate health care for the poor, particularly ethnic minorities. The field of public health has been successful in using statistics to document institutionalized racism in health care, showing that minorities are sicker than whites, have higher rates of infant mortality, and make up a majority of the AIDS cases nationwide. These types of statistics have had a slow but direct influence on the formation of public health policies directed at the affected communities.

The use of surveys and qualitative methodologies serves as a tool for the process of truth-telling. It provides NGOs and on-the-ground advocates with credibility and is a built-in human rights instrument. Grassroots NGOs often lack the financial and technical support to engage in collecting and analyzing quantitative data concerning their particular communities of interest, tending instead to rely on larger research organizations and academics to provide them with the theoretical background and data. A more effective approach would involve engaging with academics, researchers, practitioners, and community members so that they may propose policy solutions informed by both research and practice.

Collecting statistics plays an important role in the struggle for human rights and must continue to be used by grassroots NGOs with technical support from research organizations and academic institutions. The ability of advocates, community members, and researchers to form strategic alliances in the generation of health-related data is an essential aspect of changing health care policies and holding governments and large institutions accountable. Moreover, the enjoyment of economic and social rights depends on the physical and mental health of individuals. Realizing the right to health and holding the government accountable for this right means working in coalition across a broad range of issues including welfare, health care, and discrimination.

The New Partnership of Health and Human Rights

Stephen P. Marks

Andy Ryan



The linkage of health and human rights (H&HR) refers to the understanding that health status is in large measure determined by the degree to which human rights are enjoyed. It also entails the application of human rights norms to policies and programs of health systems and to the conduct of health practitioners. This linkage is more than ever on the agenda of international agencies, professional associations, activist groups, public opinion, and academic research.

Building on extensive experience with HIV/AIDS, the François-Xavier Bagnoud Center for Health and Human Rights (FXB) and its team of visionary scholar-activists—Sofia Gruskin, Daniel Tarantola, and the late Jonathan Mann—drew attention to the connections between health and human rights nearly a decade ago by creating a journal devoted to that linkage (*Health and Human Rights*) and by organizing two international conferences (in 1994 and 1996). Other organizations, like Médecins Sans Frontières, Médecins du Monde, Physicians for Human Rights (PHR), Global Lawyers and Physicians, and Doctors for Global Health, as well as the American Public Health Association, have been instrumental in mobilizing professionals to investigate human rights abuses and to apply human rights norms to medical and health practices. The movement of scholars, professionals, and activists concerned with such issues is roughly a decade old and is still evolving. I will discuss four assumptions that appear to be widely shared by those who contribute to thinking and action on health and human rights.

The first assumption is that the H&HR approach includes, but is not limited to, the medical profession's commitment to the ethical treatment of patients and to the use of human rights norms to provide guidance to medical practitioners about certain aspects of their treatment of patients. The traditional role of doctors is to apply knowledge of medical science to alleviating suffering of their patients caused by disease and injury. In negotiating the doctor-patient relationship, they may face tough ethical dilemmas that are sometimes also human rights issues, like decisions concerning the right to privacy or nondiscrimination.

Tragically, the neglect of human rights norms by members of the medical profession has led to their participation in egregious violations of human rights, such as performing medical experiments on human subjects without their consent, or ensuring that torture does not result in death until the victim reveals information. These abuses of medical ethics have been prohibited by human rights texts such as the Nuremberg Code and UN texts on the treatment of detainees. The current trend is to introduce human rights language and patients' rights into the teaching of medical ethics and to expand the concerns of the profession to a broader health promotion model (concern for prevention of disease and promotion of the health of the population as a whole) rather than the biomedical model (intervention to treat a patient). Moreover, doctors have shown a growing interest in international human rights as evidenced by regular features in the *Journal of the American Medical*

Association, the *New England Journal of Medicine*, and *The Lancet*. PHR and the FXB Center are circulating a draft declaration on human rights and health practice to a wide range of individuals and associations around the world that attempts to clarify the applicability of human rights norms to the practice of all healing professions.

The second assumption is that H&HR issues are best addressed through the insights of public health, which complements the biomedical model in a vital way by looking at populations and the policies and practices that can alleviate human suffering by stemming the spread of disease and injury-inducing behavior. The H&HR approach principally builds upon the scientific discipline of public health, epidemiology, and especially social epidemiology. Multilevel approaches to understanding social determinants of health, the role of social integration, social cohesion, and social networks, and similar concerns of social epidemiology all suggest a human rights context for policies to improve the prospects for vulnerable populations to lead healthy lives. While human rights issues arise in the context of the management of health systems and other approaches to public health, the insights of social epidemiology are particularly valuable to human rights analysis because of its focus on underlying social factors.

Only in three areas—HIV/AIDS, torture, and reproductive and sexual rights—has there been significant thinking and action using the H&HR approach.

The third assumption is that the human right to health is defined as “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” and that this definition has policy implications regarding availability, affordability, nondiscrimination, participation of the population in determining priorities in health, and appropriateness of the preventive and curative strategies. This standard may require new approaches to both advanced biomedical technology and simpler and cheaper approaches to healing—including traditional modes of healing—and the most rudimentary forms of primary health care. The paradigmatic application of the linkage of H&HR has been in the field of HIV/AIDS, a disease that currently infects thirty-four million people, with five million new cases each year. Nearly half the people infected with HIV/AIDS are women, and most live in sub-Saharan Africa. Initially focused on discrimination against and stigmatization of

people with AIDS, advocates of the H&HR approach have succeeded in introducing the standards of informed consent for testing, participation of people living with HIV/AIDS in decision-making concerning policies of treatment and prevention, the right to enhanced care, and the right to information, to name the most obvious elements. The human rights approach to the HIV/AIDS pandemic has achieved a reduction in vulnerability of at-risk populations to infection. The UN guidelines on HIV/AIDS and human rights enumerate no fewer than nineteen human rights as being relevant to HIV/AIDS.

The fourth assumption is that states have specific obligations to respect, protect, promote, and fulfill the right to health. Accountability for compliance with these obligations contributes to reducing vulnerability and increasing well-being. Accountability in this context need not take the form of pointing an accusing finger. Such a confrontational approach can be reserved for a situation in which the irresponsible behavior of the state and other duty-holders is so egregious that it would be unconscionable or counterproductive to remain silent out of sensitivity to governments' claims that criticism of their policies is an illegitimate interference in domestic affairs. In most situations, the appropriate measures for securing government accountability consist of persuasion, technical assistance, dialogue, and emulation. While accountability usually refers to sanctioning an agent of the state for violating rules, the nature of the state's obligations relating to the right to health justifies cooperative means of achieving change through weaker forms of accountability. The important point is to bring about change, and the choice between confrontational and cooperative means depends on circumstances.

These assumptions characterize the approach of scholars, practitioners, and activists who identify with emerging concerns of H&HR. Only in three areas—HIV/AIDS, torture, and reproductive and sexual rights—has there been significant thinking and action using the H&HR approach. The agenda for H&HR can be fruitfully extended to other issues, such as other infectious diseases, advances in biotechnology, and social and political violence. Work is advancing in all these areas, and policies are being redefined to incorporate human rights standards. Joining in this effort has a powerful appeal, expressed well by Jonathan Mann, who said, “It is precisely through this historic effort to explore and promote values in the world for which we share responsibility, articulated in philosophy and in actions, that we express confidence in our own lives, in our community, and in the future of our world.”



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Humanitarianism Cannot be Exclusionary

The use of just war theory is a critical issue associated with humanitarian intervention. The just war tradition is predicated on the observance of certain key criteria; in the case of *ius ad bellum* (justice of war), these are right intention and the aim of peace. Given the humanitarian nature of these operations, adherence to just war criteria must be consistent with the normative considerations of a human rights-based perspective—that is, the promotion and protection of human rights, and a peace agreement that would reflect the linkages between humane governance and the maintenance of peace and stability. Yet the evocation of the just war tradition can also result in a vilification of the opponent, an effect that would seem to negate the humanitarian aims of right intention and peace.

During Operation Allied Force, the 1999 NATO bombing of Kosovo, the officially proclaimed pariah status of the Serbian regime raised the stakes of the allied campaign. If the FRY was indeed ruled by a despotic figure, and if the purpose of the intervention was humanitarian, then the international community bore some duty to alleviate the suffering of all the victims, including Serbs. The only basis for excluding them would be to argue that they were collectively responsible for the actions of the regime, and thus deserving of their fate. No NATO leader was prepared to make such an argument.

There is nothing wrong with the use of normative language to promote a cause. However, the humanitarian impulses of the international community are ill served by unexamined and unfulfilled references to just causes.

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Empowering Africans

In his article “Inconsistency and the Tragedy of Africa’s Neglect,” Pierre Antoine Louis derides the United States and other Western countries for engaging in humanitarian interventions in places such as Kosovo, while neglecting states such as Sierra Leone and Rwanda, describing this behavior as inconsistent. In doing so, however, Louis is himself inconsistent.

If the United States and other powers can be condemned for imperialist behavior during the Cold War for intervening in the less industrialized world, then how can they now be criticized for choosing not to intervene? The simple answer for people such as Louis seems to be that the lack of national interest in such conflicts makes them the most righteous places for the expenditure of this nation’s blood and treasure. The problem as I see it: the United States cannot be omnipresent; finite means can never address infinite ends.

The establishment of programs such as the African Crisis Response Initiative (the training of African troops by U.S. Special Forces units for humanitarian missions) seems to be a much better method for allowing Africans to respond to African problems. In this respect, increasing the funding of the State Department and foreign aid to develop such initiatives seems to be a more effective way of dealing with the underlying and endemic problems of poverty, disease, and famine than the deployment of a battalion or brigade of American combat troops that might only temporarily resolve problems on the ground. Unfortunately, as Chinua Achebe among others have noted, not all of the ills of sub-Saharan Africa are rooted in, or directly caused by, the action or inaction of the West.

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WHAT DO YOU THINK?

Do you have a response to “Rights and the Struggle for Health”? Share it with thousands of other *Human Rights Dialogue* readers. Send your comments before October 15, 2001, to: Jess Messer, Human Rights Initiative, Carnegie Council on Ethics and International Affairs, 170 East 64th Street, New York, NY 10021-7496, USA, fax: (212) 752-2432, e-mail: jmesser@cceia.org. We regret that we will not be able to print every response. Please limit your response to 300 words, and be sure to include your name and contact information. We reserve the right to edit text as necessary. You may also register for our new Human Rights Initiative Bulletin Board at www.carnegiecouncil.org/cchr/login.asp and tell us about your reactions to this issue of *Human Rights Dialogue*, as well as your thoughts on the emerging field of health and human rights.

human rights *dialogue*

Fall/Winter 2001

Integrating Human Rights into Peace Work

Building on a July 2001 workshop held at the Carnegie Council entitled "Bridging Human Rights and Conflict Prevention: A Dialogue between Critical Communities," the Fall/Winter 2001 issue of *Human Rights Dialogue* (Series 2, Number 7) will explore the relationships among the diverse communities of local and international actors working to advance peace, justice, and human rights in societies suffering sustained internal conflict. Even in the shared pursuit of peace and human security, organizations face difficult ethical decisions and trade-offs that can be divisive. As a result, competing perspectives arise as to how best to protect and promote human rights, which rights to give priority to, and when to pursue the chosen approaches and strategies that will advance human rights. The Fall/Winter issue will discern areas of convergence and divergence in actors' agendas, strategies, and activities. In particular, contributors will share perspectives on the relevance and legitimacy of a human rights framework for conflict resolution, prevention, transformation, and management efforts in their region of the world. The goal is to provide insight into ways to create greater convergence among human rights and peace organizations as part of an overall strategy to overcome the barriers to greater popular legitimacy for human rights.

coming soon

Visit our special online version of *Human Rights Dialogue*, featuring additional testimonies on health and human rights from Vietnam, Albania, Palestine, and Iraq. See our Table of Contents page for up-to-date information: www.carnegiecouncil.org/themes/hrdsummer2001.html.

our new look

Human Rights Dialogue has adopted a new design to highlight the contributions to our discussions. *Dialogue* continues to be a forum for individuals representing a range of views that, taken together, challenge prevailing paradigms and grapple with fundamental human rights dilemmas. In the future we will expand the use of photographs and other graphic elements to give our readers a better sense of the on-the-ground realities our contributors face.

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