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WHAT IS A HUMAN RIGHTS-BASED APPROACH TO HEALTH AND DOES IT MATTER?

Leslie London

ABSTRACT

A human rights approach to health is critical to address growing global health inequalities. Three aspects of the nature of health as a right are relevant to shaping a human rights approach to health: 1) the indivisibility of civil and political rights, and socio-economic rights; 2) active agency by those vulnerable to human rights violations; and 3) the powerful normative role of human rights in establishing accountability for protections and freedoms. Health professionals' practice, typically governed by ethical codes, may benefit from human rights guidelines, particularly in situations of dual loyalty where clients' or communities' human rights are threatened. Moreover, institutional accountability for protecting human rights is essential to avoid shifting responsibility solely onto the health professional. Human rights approaches can include holding states and other parties accountable, developing policies and programs consistent with human rights, and facilitating redress for victims of violations of the right to health. However, underlying all models is the need to enable active social mobilization, without which legal approaches to rights lack sustainability and power. Evidence from South and Southern Africa has shown that different conceptions of what is meant by human rights impact substantially on state willingness and ability to meet constitutional obligations with regard to the right to health. New approaches to health policy development, which draw on the agency of vulnerable groups, link local struggles with their global context, and explicitly incorporate rights frameworks into public health planning are needed. Models that move away from individualizing conflict over rights between health professionals as disempowered duty bearers and patients as frustrated rights holders, toward more mutual approaches to shared rights objectives may be possible and are being actively pursued through the development of a learning network to realize the right to health in South Africa.

INTRODUCTION

We live in an increasingly globalized environment, characterized by growing tensions between our technological capacities and the abilities of our social policies to meet basic health needs. While humankind stands at the cusp of mapping the human genome, with all its implications for generating wondrous new technologies for human health, less than 40% of all births in least-developed countries are attended by a skilled health professional.¹ Children in sub-Saharan Africa are four times more likely to fail to achieve full immunization than children in developed countries of the Organisation for Economic Cooperation and Development (OECD).² While genomic technologies have given us the capacity to produce drought- and pest-resistant varieties of maize and corn, the majority of the world's 830 million undernourished people will never benefit from scientific advances, because they are largely excluded from agricultural markets by factors that will not be solved by technological quick-fixes.³ Life expectancy at birth has increased in all the regions of the world over the three decades since the Alma Ata Declaration on Primary Health Care, but the absolute increase in high-income OECD countries has been 800% of that experienced in Sub-Saharan Africa,

whose newborns will, on average, look forward to a lifespan that is only slightly more than half of that enjoyed by newborns in the OECD.⁴ In short, we live in a world where inequalities in health and economic development continue to pervade our development trajectory and where exclusion from social systems remains the most fundamental obstacle to realizing human potential worldwide.

Can the integration of human rights approaches into our health and social policies offer us any opportunities for addressing these key challenges? In the field of HIV, the practice of public health has been challenged to rethink how population approaches to health can respond to public health crises based on inequalities and exclusion, and has led us to devise new ways to integrate human rights into public health.⁵ However, how fundamental are these shifts in thinking about public health practice? Is the professed commitment to human rights more than just a passing phase in a health system response increasingly desperate to meet continually unfolding and mutating health crises, ranging from infectious diseases such as HIV, malaria, and avian flu, to systemic and environmental challenges such as international terrorism and climate change?⁶ How confident can we be that the intent to “support the further mainstreaming of human rights” within the United Nations system will translate into real integration of human rights into new public health practice?⁷

The evidence may be contradictory. For example, 10 years ago, public health rhetoric around HIV testing was firmly rooted in the paradigm of combating discrimination and stigma. Since then, there has been a huge shift in discourse, partly related to the increasingly widespread availability of therapies for HIV, which has changed the ethical and human rights bases for policies. Today, this change in focus also reflects a greater willingness to elevate practical consequences above adherence to principles of protection from stigma and discrimination.

For example, Udo Schuklenk and Anita Kleinsmidt, in considering improved provision and uptake of voluntary counseling and testing (VCT) as an alternative to mandatory HIV testing, argued that:

it is not good public health policy, given resource constraints in countries with high HIV prevalence rates, to divert resources away from testing and treat-

ing people toward activities related to health promotion and counselling . . . preserving lives must take priority over counselling . . . whenever feasible, governments and other health care providers should consider mandatory testing and treatment regimes.⁸

The WHO has emerged with a policy that, while proscribing mandatory testing, offers strong support for routine (or provider-initiated) testing for HIV.⁹ This position has support from both empirical and policy grounds but has also attracted some criticism, the latter not unrelated to the increased potential for facilitating human rights violations.¹⁰ The debates/policy shifts on routine testing have opened journals and public policy fora to more radical calls for mandatory HIV testing, a development which, during the heyday of the “socio-epidemiological paradigm” of HIV programs, would no doubt have been considered an anathema to both public health practice and human rights principles.¹¹

Similarly, in relation to the growth of multi- (MDR) and extreme-drug-resistant (XDR) tuberculosis, public discourse has put firmly on the policy agenda strategies that include highly coercive interventions that prioritize population interests over those of affected patients.¹²

Responding to these developments requires evidence that, in fact, integrating a human rights approach into public health is both an essential requirement for the realization of health for all — or, for example, the MDG goals — and a sine qua non for a world based on social justice. To do so, however, first begs the question as to what is understood by a human rights approach. Definitions matter because different understandings will result in potentially flawed policy applications as well as different metrics for monitoring the success or otherwise of such policies.¹³

In examining these issues, I draw on research and policy development work conducted in South and Southern Africa, where the health crisis intersects most forcefully with issues of social justice and human rights.¹⁴

HEALTH AS A HUMAN RIGHT

The nature of health as a right has been extensively elaborated and needs no repeating. Analyses

of Southern African experiences, however, which are critical for understanding what a human rights approach can contribute to public health, reveal a number of factors.¹⁵

First, the importance of recognizing the indivisibility of civil and political rights *and* socio-economic rights means that health policy-makers need to spend as much time considering and developing health policies in terms of obligations to fulfill the right to health, as they do in developing elaborate and potentially impressive commitments to eradicating discrimination or violations of dignity, for example. This is no different from arguing that one cannot choose which rights to observe, and ignore what is inconvenient, as is the case in US foreign policy.¹⁶ In the HIV field, many governments in Southern Africa have adopted, to various degrees, policies that reflect some commitment to, at least in theory, reducing or eliminating discrimination related to HIV.¹⁷ For example, the Southern African Development Community (SADC) Code of conduct on HIV and AIDS and Employment was adopted by SADC states in 1997, representing an impressive stand against discrimination against persons with HIV in the occupational setting.¹⁸ In the parallel sphere of expanding access to ARV therapy for HIV, however, the discourse on access to health care as a right is far weaker, if visible at all. South Africa, despite having the largest ARV roll-out program in the world, had an official strategic plan for HIV for the years 2000 to 2005 that studiously avoided mention of ARV access as a right, but which shoehorned rights language into combating discrimination and stigma.¹⁹ In fact, government arguments and actions have firmly resisted being held to account over its rights obligations relating to ARV treatment. This has been evident despite a constitution regarded as one of the most progressive in the world for its extensive provisions related to human rights, and the earmarking of budgetary allocations by the National Treasury to support mass ARV treatment.²⁰ Yet, it has been a vigorous and well organized civil society that has pushed the South African Department of Health into recognizing access to health care as critical to an HIV strategy, as reflected in explicit commitments in its current strategic plan for 2007 to 2011 to “ensuring equality and non-discrimination ... challenging discrimination against groups of people who are marginalised [such that] all these groups have a right to equal access to interventions for HIV prevention, treatment and support.”²¹ This leads logically to the second consideration: without an active civil society,

paper commitments to rights mean very little. Three cases are illustrative. In 2000, a community living in an informal settlement outside Cape Town succeeded in a court action to halt its eviction by the local government authorities on the basis of a right of access to housing contained in the South African constitution.²² The case (known as the Grootboom case) made legal precedent in establishing the justiciability of socio-economic rights in the courts and was hailed beyond just the borders of South Africa as advancing popular claims to basic needs that are socio-economic entitlements in human rights law.²³ However, that particular community today remains without relief of its need for housing, and no major shifts in housing policy have followed this test case, largely because of the lack of civil society pressure or a social movement in the area of housing.²⁴ A similar example from Malawi is evident in the development of a Patient Rights Charter that had wide health worker and consumer input in its development, but whose adoption ground to a halt because it was handed over to the government and became merely a technical exercise with no accountability for delivery.²⁵

In contrast, the treatment access movement has mobilized public action very effectively to buttress court action in support of socio-economic rights claims, South Africa’s Treatment Action Campaign (TAC) being the most obvious illustration of such effectiveness.²⁶ Far from substituting for popular organization, human rights strategies have strengthened claims to ARV treatment through mutual reinforcement of civil society mobilization and simultaneous and targeted court action.²⁷ The TAC has invested substantial resources in treatment literacy training to support ARV roll-out and has ensured that its court actions are typically preceded by extensive education of its cadres before launching legal action, using both the content of the case to raise awareness and the consequence of the training to mobilize public opinion when the case arrives in court. Human rights litigation for socio-economic rights therefore creates the opportunity and space for effective civil society action but is also given legitimacy by popular discourse framed in socio-economic rights terms.²⁸ When the pharmaceutical industry was defeated in its case against the South African government’s attempts to regulate in the interest of the public’s health, its defeat was as much the result of coordinated protests on the streets of South Africa and global outrage over the industry’s greed, as it was the result of legal argument.²⁹ As Amartya Sen argues,

The implementation of human rights can go well beyond legislation, and a theory of human rights cannot be sensibly confined within the juridical model within which it is frequently incarcerated. For example, public recognition and agitation can be part of the obligations . . . generated by the acknowledgement of human rights.³⁰

What this means is that agency is critical to a human rights approach. In order to address conditions that create vulnerability, a human rights approach must seek to give voice to those who are vulnerable and enable them decision-making scope to change their conditions of vulnerability. This model is considerably different from those that frame rights as simply standards for state conduct, since it moves away from notions of benevolent handouts by state or third parties to ameliorate suffering of passive recipients of assistance. Thus, individuals, groups, and communities whose rights have been or are likely to be violated have choices and capabilities, and the extent to which a human rights approach enables them to exercise their agency in such choices is critical.³¹ Here, questions of power — who decides, who acts, and who redresses a violation — are thrown into stark relief.³²

Further, a distinction should be made between community agency reinforcing rights mechanisms and the unsavory practice of substituting government obligations with NGO or community action. Far from advancing the rights and protections of vulnerable populations, this mis-casting of human rights approaches may simply shift the burden of redress of, or protection from, violations (for example, of the right to health) onto populations already marginalized by unjust social systems.³³ For example, the doctrinaire insistence on user fees as a tool to build health systems in Africa has been shown to disguise a wide range of practices, which may afford little true agency to affected communities and have little long-term benefit on their access to decent health care.³⁴ The problem is exacerbated by the lack of political will to challenge global economic inequalities that underlie states' incapacity to maintain adequate national health systems.³⁵

These questions lead to a third consideration — that of the implications of primary state accountability under a human rights framework. In contrast to ethical standards, human rights provide a much

more powerfully normative set of criteria by which to judge right and wrong.³⁶ This is both a strength and weakness of a human rights approach. Defining who is a rights holder, who is a duty bearer, and what the nature of the obligation is, allows a much clearer opportunity to establish accountability (typically of government) for the realization of rights and creates a range of mechanisms to hold governments accountable. This is not to say that human rights standards have no ethical basis. Indeed, Sen has argued strongly that “human rights can be seen as primarily ethical demands.”³⁷ In their institutionalization, however, human rights standards can and do inform more powerful methods to establish accountability for meeting basic human needs.

What is perhaps not as well delineated by a rights-based framework is the responsibility of individual health workers toward the realization of human rights, since human rights apply primarily to states parties. There are three ways in which a responsibility falling on health professionals might be constructed: 1) if employed by a state party, a health professional may become the instrument through which the state violates the right to health and should therefore guard against involvement in such violations; 2) certain human rights obligations may have horizontal applicability among individuals, such as, for example, the prohibition against torture, or, in the South African context, the obligation on individuals not to discriminate against other people on the basis of race, gender, sexual orientation, or other factors; and 3) human rights may be viewed as an essential part of one's professional conduct. While the first two scenarios carry with them the possibility of strong legal sanction, the last example rests almost entirely on professional self-regulation and ethical compliance. Yet the strength of ethical guidelines depends entirely on the capacity of the institutional framework for professional regulation. For example, doctors shown to have participated in torture under the military dictatorship in Uruguay have largely escaped any professional sanction because of very weak accountability in that country's system for professional self-regulation.³⁸ Even in post-apartheid South Africa, with its high levels of institutional commitments to human rights, efforts to bring to account Wouter Basson, a cardiologist who presided over the apartheid military's Chemical and Biological Warfare Program, have been extremely fraught and dogged by long delays and institutional difficulties.³⁹ Despite, for example, evidence presented to the South African

Truth Commission that the program over which Basson presided was responsible for the development of offensive weapons and agents for use by apartheid death squads, he remains a practicing cardiologist and member of the national medical association.⁴⁰

Two conclusions are evident here. First, reliance on ethical frameworks alone to guide health professionals has limited effect, notwithstanding a plethora of international statements, guidelines, and ethical codes for health professionals issued by professional bodies.⁴¹ Ethical codes need to integrate stronger human rights language if professional self-regulation is to be more effective.⁴²

Second, health professionals faced with situations of dual loyalty, where the interests of their patients conflict with those of third parties, must be able to find support from their professional institutions in order to avoid actions that result in violations of their patients' rights.⁴³ Without such institutional mechanisms, we risk shifting the responsibility unreasonably onto a professional who may be entirely disempowered and subjected to coercive forces, such as a security force intimidation or the instructions of the political head of a health ministry.⁴⁴ This is not to absolve individual health professionals of responsibilities for their choices with regard to the rights of patients and communities, but it does flag the importance of recognizing the institutional factors driving health professionals to become complicit in rights violations.⁴⁵ By recognizing the range of institutions that should be intervening to prevent or remediate a dual loyalty conflict, a human rights approach locates the problem of dual loyalty, correctly, in the systemic factors that drive both health inequalities and discrimination, as well as more egregious forms of human rights violations, such as participation in torture.⁴⁶

More complicated than the individual clinical setting, however, is the question of dual loyalty faced by health professionals who work within health systems that violate the right to health. These professionals should be aware that international human rights law provides for conditions, such as population health, under which limitations of individual rights may be justified in the interest of the public good.⁴⁷ They should also know, however, that human rights law often defers to national law in determining whether such limitations might be warranted (for example,

quarantine measures in the case of XDR-TB).⁴⁸ Even here, though, national policies may be consistent with international norms in their limitations of rights, so health professionals need to be constantly vigilant as to the adequacy of the policies they are asked to implement that may limit their patients' rights.

Even more challenging, however, is the difficulty faced by a health professional in the case of a socio-economic rights violation, such as, for example, the failure of the government to fulfill its obligation regarding the right to health. Can we reasonably expect a health professional clinician to be able to interpret the core obligations of government toward the right to health in their own national or local context?⁴⁹ Probably not, but at the very least, health professionals should know where to access such public critique and need to avoid being the instrument by which a state violates the right to access to health care. For example, they can inform their patients of the kinds of treatment or preventive services that could have been available, had the government taken sufficient legislative, financial, and administrative measures to ensure the realization of that right — information that may help to spur a patient rights advocacy movement.

Furthermore, professional associations and human rights mechanisms should be used as advocacy channels to encourage health professionals to ensure adequate access to health care. For example, many health care providers were deeply uncomfortable with national policy on HIV in South Africa during the period of presidential denialism. Although they were not consciously aware of the exact nature of the rights violations, many health workers responded to the patent injustice of national refusal to provide ARV medicines through multiple routes of action in support of ARV access for their HIV-positive patients. The numerous steps that they took included testifying as expert witnesses in court actions, issuing public letters to the president, and joining protest marches.⁵⁰ Of course, health workers' lobbying against policies that violate socio-economic rights will be no less subject to state victimization than action to challenge other violations, such as torture and detention. This is illustrated by the case of a South African doctor, head of a regional hospital, who was fired for facilitating ARV access for rape survivors during the time that presidential denialism disputed the link between HIV and AIDS and branded ARV treatment as toxic.⁵¹

Health worker action to promote patients' rights of access to health care targets not only state services, but also private sector players. The rapacity of private sector health care and its prioritization of profit over patient needs remain pressing problems, whether in developing countries, such as South Africa, or high-income countries.⁵² Rights frameworks applicable to non-state actors are largely embryonic in development, despite the important and growing role of private actors and their policies in determining health and conditions necessary for health.⁵³ Yet, despite these limitations, experience in Southern Africa has been that effective civil society mobilization around explicitly rights-based demands has been a powerful driver of private sector policy shifts that have broadly enhanced rights to health care and to the determinants of health.⁵⁴ For example, public pressure coupled with state regulatory action led to legislation for the life insurance industry that precludes discriminatory testing for HIV. Moreover, TAC campaigns have forced pharmaceutical companies to agree to voluntary licensing and reduced drugs prices for ARV medication.⁵⁵

UNDERSTANDING A HUMAN RIGHTS APPROACH

So how might a human rights approach to health be conceived? Work conducted for the Network on Equity in Health in Southern Africa (EQUINET) identified four approaches to using human rights to promote health equity.⁵⁶ The most common conception of a rights approach would be one where the human rights framework is used to hold government accountable. Activities supporting accountability could range across a wide spectrum, from public critiques to litigation, although they are usually in an adversarial mode. Rarely do public servants and governments welcome being held to account — after all, who would want to be viewed as a human rights violator? Research on views of health care providers in South Africa toward a Patients' Rights Charter reveals that providers may be hostile toward rights, since they believe that rights are used as “a sword over the[ir] head[s]” when patient complaints contribute to low staff morale.⁵⁷

In many settings, however, a human rights approach offers a framework for pro-active development of policies and programs such that health objectives can be operationalized in ways that are consistent with human rights.⁵⁸ This approach begins to move away

from the adversarialist and individualist framing of rights and opens opportunities for popular input to shaping health policy. Helping governments to see how they can realize what they are obliged to do opens opportunities for win-win solutions to seemingly intractable problems.

Of course, where systems go wrong, redress of violations is another key aspect of a human rights approach. In such instances, making use of human rights machinery such as, for example, a Human Rights Commission, or a court, to secure redress of the violation represents a third notion of a human rights approach.⁵⁹ Importantly, such actions may be not only for individuals but also for groups and classes of vulnerable people.

Finally, a human rights approach may do none (or all) of the above yet still make use of human rights frameworks to mobilize civil society action to achieve the realization of the right to health. In fact, as outlined earlier, a human rights approach that lacks such social mobilization is one that loses its transformative potential. Thus, rather than offering mobilization for social justice as one model for a human rights approach, I would argue that it must underlie all approaches to human rights, such that what happens in court or in ministerial consultations is grounded in popular engagement. Without this iterative interaction, we run the risk of professionalizing rights discourse, divorcing it from its real intent — that of social change.

WHY DOES IT MATTER?

Why does it matter what kind of human rights approach is on the table? South Africa is a good example of why clear articulation of the contribution of human rights to public health makes a difference, and why inappropriate or inadequate conceptualization of what human rights are and what a human rights approach is, may have significant adverse consequences for population health.

Many of the immediate post-apartheid policies drew strongly on traditions developed in the anti-apartheid struggle that used rights language to attack the racist ideology of the apartheid government. They also evolved from a policy formation process characterized by vibrant interaction between civil society and the new government and ushered in a wave of very significant measures aimed at protecting the health of

vulnerable groups.⁶⁰ For example, policies allowing access to services for termination of pregnancy and addressing domestic violence as a rights and health concern — previously regarded by police services as a “private” matter — resulted from advocacy and lobbying by a robust reproductive health movement rooted in civil society in the mid-1990s.⁶¹ Forceful civil society demands created the space for gender activists in parliament to elevate women’s health issues in parliamentary agendas. Similarly, strong pressures to prevent discrimination relating to HIV at the workplace have resulted in legislation to restrict employers’ ability to insist on HIV testing before employment.⁶² Such an explicit protection of a civil and political right has played an important role in shaping South African employers’ awareness of the need for HIV prevention and treatment in the workplace, thereby contributing to the expansion of access to health care, a socio-economic entitlement.⁶³

Despite important steps forward, as South Africa moves further away from its 1994 miracle, fault lines have begun to emerge regarding the ways in which health is conceived of as a right. Restructuring of budgets has included substantial cuts in tertiary hospital allocations in favor of district-level services, ostensibly part of an equity-driven attempt to redress existing inequalities between and within provinces.⁶⁴ Such cuts, however, have huge implications for patient access to health care, such as prolonged waiting times for critical cancer surgery, and have been implemented without clear consideration of their impacts on patients’ and communities’ rights to health.⁶⁵ Implicit in such resource allocation decisions is the trading off of different rights (for example, to cancer treatment and rights to life versus rights to basic maternal and child health services), and inherent in the process of implementation are questions of procedural justice and evidence that those who are meant to benefit from such cuts actually do so.

These processes have nevertheless involved little consideration of the constitutional imperatives of South Africa’s Bill of Rights or of the application of analytical frameworks that integrate human rights into public health decision-making.⁶⁶ Quite unlike the days when, in an explicit recognition of South Africa’s commitment to the realization of human rights, the Mandela government introduced free health care for children and pregnant women as its first post-apartheid social policy, policy-making now has moved far away from the language of rights commitments

to one of technical efficiency.⁶⁷ For example, ANC National Executive member and Minister of Public Works, Thoko Didiza, reported that discussions at the July 2007 ANC conference identified the possibility of a basic income grant as a challenge and stated that, “if there was to be income support, it had to be linked to ‘work activity’ to avoid creating dependency.” These comments echoed those of the Minister of Finance in 2004: “People must learn to work instead of living on handouts.”⁶⁸

Indeed, a deep skepticism reigns within the ruling party regarding the role of civil society proponents of social justice and is reflected in a reluctance to acknowledge the socio-economic rights dimensions of claims to health services or to conditions needed for health.⁶⁹ The increasing emergence of social movements and civil society aggregations challenging government on its service delivery record, while met with derision by those holding power, points to very real difficulties in translating political struggles against apartheid into a meaningful and sustained commitment to pro-poor and human rights-based policies beyond the immediate transition period.⁷⁰

The consequence for health is that, rather than acknowledging health as a right, policy-makers frame health policy decisions as service delivery issues, requiring technical inputs to reach the best “evidence-based” decisions, a public health phenomenon gaining increasing popularity worldwide.⁷¹ In doing so, the state is relieved of its burden of having to answer to its constitutional obligations for progressive realization of socio-economic rights, and its public servants are able to retain their own identities as servants of a social good, keeping up the tradition of being part of a movement for social justice.⁷² Such reframing of health away from its nature as a socio-economic right strips health policy-making of its inherent elements of power and the contestation that goes with the recognition of power. For that reason, it absolutely does matter what is understood by a human rights framework.

This is not to say that evidence is not important to a human rights analysis for health. On the contrary, evidence is critically important to informing how a rights approach tests, motivates, and informs the best policy decisions, but it does so within a framework that recognizes health as a right, rather than as merely a service, or worse still, a product of state beneficence or an element instrumental to economic devel-

opment.⁷³ Policy development and analysis based on a rights framework makes explicit what the values are that inform decisions about the weighting and relevance of various pieces of evidence, and how uncertainty should be dealt with where evidence is weak or lacking.⁷⁴

A second consideration is that, for rights to be made real, mechanisms are needed at local, national, and international levels to foster public participation and enable meaningful agency on the part of those most affected by policies that limit or violate rights. Aspects of procedural justice have, to a large extent, been overlooked both in the development of health policy and in the health and human rights literature.⁷⁵ For example, South Africa's National Health Act provides for statutory community participation structures in health care, yet only a handful of provinces have passed legislation to provide the infrastructure for implementation.⁷⁶ Furthermore, no monitoring of implementation is in place, as evidenced in a South African Human Rights Commission investigation into the right of access to health care.⁷⁷ It is through organized community action, however, that the hard work of realizing rights is best effected. If adopting a human rights approach to health is to impact on lives "on the ground," much more needs to be done to put in place mechanisms to elevate procedural rights (such as public participation mechanisms, recourse to appeals processes, and administrative justice safeguards) to greater importance in policy development and to ensure that their implementation is adequately monitored.

A third component to the way a human rights framework should give recognition to questions of power relates to challenging injustice at all levels, local and global, micro- and macro-. Challenging governments and their public servants to meet their obligations relating to the right to health can be a complex task requiring a broad understanding of power networks. For example, anti-retroviral access for poor rural women in KwaZulu-Natal province, where antenatal HIV prevalence rates exceeded 30% in 2006, has as much to do with global inequalities in trade and intellectual property regimes as with the failure of lawmakers and public servants to recognize an obligation to address the needs of the most vulnerable and most marginalized in their society.⁷⁸ This is because global trade rules shape the context in which national policies and programs operate and therefore

constrain national and local decision-makers who are caught between conflicting forces. Even with the best will possible, national policy-makers, especially in developing countries, cannot alone find the resources to challenge global inequalities that are the underlying determinants of health.⁷⁹

MODELING HUMAN RIGHTS AS A SHARED OBJECTIVE

Here is where new thinking about the relationships between civil society and governments can be generated by a human rights framework that recognizes joint interests in realizing the right to health. The example of the Doha round of negotiations on trade and intellectual property rights illustrated how NGO interventions were able to support developing country governments to achieve better outcomes for the agreement.⁸⁰ Thus, invoking a human rights framework does not, of itself, inevitably mean a conflictual relationship between civil society and the state.

Two areas merit exploration — that of health care and that of the determinants of health.

Research on patients' rights conducted with South African health care providers have revealed deeply ingrained negative feelings about rights, with health workers perceiving that patients' rights can jeopardize those of the providers.⁸¹

There had been a feeling from the staff, some of the staff that everybody had been concentrating on the patients' rights and not on the patients' responsibilities. . . . make sure that the staff are being protected as well and I think quite often that has been the gripe of staff, is that, you know 'what are our rights?' Certainly that has come up very clearly from the nursing staff and sometimes from the medical staff.

The fact is that front-line health workers are frequently unable to provide adequate access to care because of systemic factors outside their control and because of management systems that disempower them from acting independently and effectively.⁸² Such a scenario sets up a fruitless antagonism between the aggrieved rights holder and the disempowered duty bearer without recognizing the structural constraints imposed by a health system poorly geared to respond

to a human rights demand. Resort to rights claims in such a situation frequently makes little headway and gives a human rights approach a bad name.

Rather than turning the accountability inherent in human rights constructs into individual claims against individual health professionals, however, patients' rights mechanisms, such as patients' rights charters, need to build collective claims of users and potential users of health services into claims against health systems. These mechanisms also need to enlist the support of health professionals to achieve these objectives as part of their professional practice. Using rights language to build local consensus among health care providers, their professional managers, and user and community groups around what are acceptable core standards of quality of care means that rights standards become shared objectives, and the health workers cease to be the gatekeepers for health claims. Moreover, organizing to change the constraints limiting affordable and available local services becomes part of a joint exercise between communities and health professionals in realizing the right to health. For example, the use of a community score card, jointly developed and interpreted by users and providers, was shown to improve access to and quality of health services for rural residents in Malawi.⁸³

Similarly, NGOs were extensively involved in the implementation of abortion services for women in South Africa following adoption of ground-breaking abortion legislation, which was itself a product of extensive state-civil society engagement.⁸⁴ These implementation activities focused not only on raising community awareness (demand-side) but also on empowering providers (supply-side) by co-hosting values-clarification workshops to enable health professionals conflicted by personal, religious, or moral concerns to avoid acting as impediments to service provision.⁸⁵ These programs have been run cooperatively with government health services so as to maximize the opportunity provided by abortion legislation for the realization of women's reproductive health rights. The fact that a women's legal advocacy NGO developed materials to clarify the provisions for conscientious objection contained in the South African legislation is a further example of how rights objectives can be mutually shared and operationalized between government and civil society.⁸⁶ These case studies in health are also supported by accounts from other contexts that provide evidence that such

approaches can work and point to the importance of reinforcing procedural rights (such as access to information, community participation in policy decisions) as instrumental to making these approaches work.⁸⁷

These lessons apply not only to the delivery of health care but also to health more generally, since the determinants of health are largely social and lie substantially outside of the health sector.⁸⁸ In the formulation of public policy, social movements can utilize the fact that governments have obligations in terms of recognized international human rights standards not only in advocacy, but also as a framework for program analysis. Rights commitments can be used to analyze the system-building programs undertaken to enable governments to meet their obligations to citizens.⁸⁹ Experience in South Africa has shown that NGOs whose primary mandate was to promote ARV access have very successfully used mobilization around broader health systems issues and even advocacy for social welfare interventions to build a significant social consensus around health equity issues.⁹⁰ For example, the TAC, while focused primarily on issues of ARV access, has initiated and spearheaded a broad network lobbying for a national social security grant, campaigned for improvement in health worker conditions of service, and mobilized civil society input to a National Health Charter being developed by the government.⁹¹ All of these strategies are seen as health systems interventions needed to create the institutional and social infrastructure to better deal with the prevention and treatment of HIV.

Whether focused on health care or on policies and services to generate the conditions for health, organized civil society is key to effecting the right to health. Pilot studies in the Western Cape province of South Africa highlight the importance of building learning networks around health and human rights to provide information to those most marginalized to effect the changes needed to reduce their vulnerability.⁹² Inviting front-line health workers to join these networks in deliberating on how best to realize the right to health offers a different model that could perhaps overcome the intractable conflicts between providers and users of health services.

CONCLUSION

Unless we recognize 1) the programmatic and policy indivisibility of civil and political rights *and* socio-

economic rights; 2) the critical importance of agency on the part of civil society in realizing rights; and 3) the complementarities and differences in ethical and human rights standards, particularly acute in the problems of dual loyalty faced by clinicians, providers, and policy-makers, we will make insufficient use of rights-based approaches to impact the health of the most vulnerable in society. This article has argued that civil society mobilization must underlie all the different modalities by which a human rights approach can work for health, whether it involves holding government accountable for delivery on the right to health, pro-actively developing policies and programs, or securing redress for those whose rights have been violated. South Africa's experience of translating the constitutional promise of human rights for all its peoples has shown that definitions of what constitutes human rights and a rights-based approach do matter, because framing access to health care and the conditions for health as a matter of service delivery is a political choice that demobilizes effective rights advocacy. Indeed, for rights to be made real, there have to exist mechanisms that both foster public participation and enable meaningful agency on the part of those most affected by policies that limit or violate rights. Such agency has to be exercised at local, national, and international levels, where many of the antecedents for health violations, manifested in disparate power, may be traced.

This article has also argued that relationships between civil society and governments require new thinking. A human rights framework is needed that recognizes joint interests of the state and its parties, on the one hand, and users, communities, and civil society, on the other, in realizing the right to health. Rather than imprisoning the accountability inherent in human rights constructs in individualized claims against individual health professionals, we need to shift focus to health systems and build local consensus among health care providers, their professional managers and users, and community groups around shared objectives for the realization of the right to health. In that way, we can best achieve outcomes that make a difference for those most affected by violations of their right to health.

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