

Editorial

Promoting Equity in Health: What Role for Courts?

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I AM PARTICULARLY delighted to introduce this special issue on health rights litigation on the 20th anniversary of the launch of *Health and Human Rights*. The last 20 years have witnessed an extraordinary growth and evolution in the "health and human rights movement," and this journal, which has also evolved, has often played an important role by providing a forum for robust interchange of ideas among practitioners, scholars, and activists in both the public health and human rights communities.

One of the most significant transformations to occur in the landscape of struggles for health justice since this journal was originally launched relates to the increasing judicialization of health-related rights, and economic, social, and cultural rights (ESC rights) more broadly. Indeed, the articles in this issue go far toward debunking outdated conceptions about health rights as merely "programmatic rights," which are not justiciable. Over the last 20 years, and increasingly in the last decade, we have seen that health and related rights are in fact being enforced by courts around the world, from South America to South Asia, Eastern Europe to East Africa. And increasingly, even in low-income countries, important demands for health-related entitlements are being framed in terms of legally enforceable claims.

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In many ways, the advent of effective anti-retroviral medications (ARVs) in the mid-1990s spawned much of the early health rights litigation. Clear linkages to the right to life, coupled often with issues of discrimination against marginalized groups, and the existence of a clearly defined remedy all contributed to the framing of enforceable legal claims. The existence of important social movements strengthened demands for ARVs in terms of rights, as well as implementation of judgments, when many political branches of government had previously shown indifference or resistance to providing treatment for People Living with HIV/ AIDS. Since then, however, health rights litigation has expanded to many other topics, and has begun to have a substantial impact in countries across the world, affecting tens of thousands of individual entitlements to medications and treatments a year in some countries, but also rewriting intellectual property rules, ensuring regulation of laws, causing changes in policies of various kinds, and influencing health priority-setting processes and budgetary allocations.

In certain countries in Latin America, where individual litigation of health rights has been most intense, many (but not all) public health policy makers have reacted negatively to an expansive role by the courts, viewing judicialization as distorting priorities and even overstepping separations of power to make public policy. In the rest of the world, however, public health professionals by and large continue to pay relatively little attention to this emergent activity, and its implications—for good and ill—for the achievement of universal health care and, ultimately, the construction of more equitable and responsive health systems. I hope this issue can contribute to bridging that gap.

The impact of courts on social justice generally has long been hotly debated. In 1985, Upendra Baxi argued, "The future of law in India is partly, but vitally, linked to the future of social action litigation because, through it great and unending injustices and tyranny begin to hurt the national conscience and prod at least one major institution of governance to take people's miseries seriously." At the other end of the spectrum, Gerald Rosenberg famously argued about the US in Hollow Hope that

courts only produce significant social reform under very defined conditions. With regard to abortion rights in the US, for example, Rosenberg writes, "if Court influence exists, it is of the subtlest nature. And while subtlety has its virtues, relying on it may not be the best use of scarce resources in important battles for significant social change."²

The truth—insofar as health rights litigation is concerned—seems to lie somewhere in between. Moreover, as courts are approaching these challenges differently in different countries, it may not be so revealing to analyze the judicialization of health rights in the abstract, untethered to specific social and legal contexts. For example, some courts assert an immediately enforceable minimum core content, others emphasize judging the reasonableness of government actions. Moreover, the assessment of "reasonableness" varies with more and less deference to legislatures and political branches of government, extending in some cases to an examination of the design or of the design and implementation of policies, and in some to the "effective enjoyment of rights"or "until the medicine is in the patient's hand." 3 It is not just a matter of variations in approaches to doctrine, though, but conceptions of the purpose and function of courts, together with the design of the Constitution and legal system which play a role in how courts approach enforcing health and other ESC rights. Moreover, we also know that not only do the legal opportunity structures and the political role that courts play within specific societies affect both the forms and impacts of health rights litigation, but also that the nature of the health system and its reaction to litigation can have equally important impacts on equity.4

In disentangling the many elements of this complex topic, the diverse articles in this issue suggest certain themes to consider both for legal practitioners and public health professionals, and for scholars interested in evaluating the impacts of health rights litigation.

1. Litigation regarding discrimination, and rights in health care, continues to be critical to protecting health rights and human dignity

Blatant violations of basic human dignity in

health care settings continue to occur across all development levels, despite constituting obvious violations of well-established international human rights standards. In their piece, Brett Dignam and Eli Adashi write about the horrifying practice in the US of perinatal shackling "prior to, during, and after labor and delivery." Despite violating the Convention Against Torture and the International Covenant on Civil and Political Rights, continuous reproach from the UN, domestic legal challenges, and rebuke from the medical community, perinatal shackling continues in the US without an end to the practice foreseeable in the near future.

Open Society Foundations (OSF) and Human Rights Watch continue to document and advocate against torture and ill treatment in health care settings more broadly. For example, OSF has documented instances of denial of basic pain relief; refusal to treat persons with disabilities in addition to overriding refusals to consent to treatment; and low-quality, abusive, or negligent care for women seeking reproductive health care, as well as persons diagnosed with HIV/AIDs, among others.⁵

With support from OSF and Open Society Initiatives of East Africa, the FXB Center for Health and Human Rights has collaborated with the Center for Health, Human Rights, and Development (CEHURD) in Uganda to create a network for health rights litigation in East Africa relating to such basic rights as patient access to information and medical records which, in addition to being a basic right per se, is also critical for vindicating rights through litigation, as Namusobya Salima's perspective essay demonstrates.⁶

Not only does litigation in relation to guarantees of basic human dignity in health care settings continue to be critical, Mikhail Golichenko and Freddie Arps' article highlights how discrimination and social stigma affect access to quality health care. These authors write that current laws in Russia leave "sex workers stigmatized, vulnerable to violence, and disproportionally affected by HIV and other sexually transmitted infections." Indifferent and abusive health systems then reinforce the socially determined nature of health risks that sex workers face.

2. When health rights litigation centers around individual entitlements, it poses the greatest challenges to equity, but claims regarding judicial activism need to be nuanced

The civil law, or mixed civil-common law jurisdictions in Latin America, where thresholds for standing and bringing claims are extremely low, produces high levels of individual litigation for treatments and services, which as a general matter exploit the system but do not attempt to transform it. At the outset however, it is important to note that much of this litigation involves services and treatments that claimants are entitled to under obligatory insurance plans. Colombia's Ombuds Office noted in its recently released 2013 report that 70% of tutelas (protection writs) in health were for treatments, drugs, appointments, surgeries or other services that should have been provided under the obligatory health plan (El Plan Obligatorio de Salud (POS)).7 This situation, which is not unique to Colombia, speaks more to "quality skimping" in health—a refusal by the mostly for-profit insurance companies and providers to give the services and treatments to which their clients have the rightmore than judicial activism. Moreover, the pattern is not limited to health. Almost half (48.11%) of tutelas in Colombia relate to the right to petition, that is involving the judiciary to get bureaucrats to do what they are supposed to do.8

Yet, as Daniel Alzate's perspective piece and other articles in this issue suggest, as well as outside research, there are very significant transaction costs to such "routinization," to use Paola Bergallo's term—in addition to undermining the legitimacy of judicial mechanisms, such as the tutela.9 And in relation to health care in particular, there are also potentially perverse equity implications of the overuse of litigation. For example, in his work on judicialization in Brazil in 2009, Octavio Ferraz found that individual litigation is generally used by those who are better off, thus compounding social inequities. He cites a recent study that determined that 74% of health rights claimants in São Paulo resided in three areas within the city that had the lowest social vulnerability rates overall. 10 In this issue, Ana Paula de Barcellos notes the same phenomenon in Brazil. And studies of litigation in Colombia and Argentina have also found that it is the middle class who generally claim entitlements, far more than the poor, thus compounding background inequities.¹¹

In the Colombian context, the Constitutional Court's T 760/08 decision, which called for a restructuring of the health system along rights principles, was in part a response to the overuse of litigation. Issued after literally thousands of *tutela* cases involving individual claims for health services or medications, as well as years of reiterating constitutional requirements regarding health policies (admissibility criteria, non-discrimination, progressive funding requirements), the Constitutional Court addressed regulatory failures in 22 illustrative cases, but then went much farther in issuing orders regarding structural problems in the health system.¹²

3. Consideration of equity impacts in health goes beyond socioeconomic status

Ole Frithjof Norheim and Bruce Wilson's review of Costa Rica's health rights jurisprudence surfaces the important insight that equity in health is a complex and multivalent topic, which requires more than attention to socioeconomic disadvantage. Equity requires consideration of prioritization of the sickest versus attention to a greater number of people with less serious diseases; it requires consideration of what treatments are cost-effective as well as clinically effective. And the role that cost-effectiveness should have in judicial decision-making has not been well sorted out to date.

In the Costa Rican context, where there have also been high levels of litigation, Norheim and Wilson provide empirical evidence to argue that judges are not well-suited to adjudge evidence of clinical effectiveness and cost-effectiveness, which are also critical to equity of treatment for patients with different conditions. As a result, the authors argue some judicial decision-making in individual entitlement cases may actually undermine equity in allocation of resources for health. Their analysis revealed that more than 70% of successful cases involved low-priority medications and of the 37 cases analyzed, only three medications requested were on WHO's essential drugs list. The emphasis

on court-mandated provision of new and expensive medications, more than essential or generic medications, leads the authors to conclude that litigation for medications did not lead to more fairness in access to medicines. Norheim and Wilson's piece points to a clear issue in the way courts had been functioning in Costa Rica. In Costa Rica, the court took a different route from Colombia in acknowledging problems with overuse of litigation by choosing to participate in the Cochrane Collaboration, which provides training to judges on evidence-based medicine and also grants access to the Cochrane Network, a network of over 33,000 individuals, which provides independent information and evidence on medicines.¹³

Colleen Flood and Aeyal Gross's article, which is based upon a recent comparative study of 16 countries, also concludes that individual litigation for provision of high-priced drugs and treatments with limited effectiveness undermines the ability of governments to run "fair and efficient health care systems." They contrast such decisions with the benefit of litigation to address barriers to access to health care including co-payments or limited health care coverage for vulnerable groups.

4. Innovative structural remedies may allow courts to create opportunities for public learning about health rights, but implementation also poses challenges

As Bruce Porter has noted, when courts are unwilling to recognize social demands as justiciable, it may in fact be that they feel that their capacity is limited, thus blurring the lines between constitutional competence questions and institutional capacity issues.14 However, innovative remedies with respect to health-related rights, which appear to follow Mark Tushnet's notion of strong rights and 'weak' or softer remedies, can allow courts to preserve their legitimacy.¹⁵ In these remedies, courts do not attempt to define policies but rather force the political branches of government to come up with policies and programs and institutional designs that meet certain criteria. This role for courts, as Keith Syrett argued, can also afford public learning relating to health. Syrett points, for example, to the important role that the South African Constitutional Court played in requiring the government to come up with a justifiable plan of action with respect to prevention of mother-to-child transmission of HIV, in the context of the national health emergency that HIV/AIDS represented in the country at the time:

It is essential that there be a concerted national effort to combat the HIV/AIDS epidemic. The government has committed itself to such an effort. We have held that its policy fails to meet constitutional standards...This does not mean that everyone can claim access to such treatment, although the ideal...is to achieve that goal. Every effort must, however, be made to do so as soon as reasonably possible. The increase in the budget which we have referred will facilitate this. We consider it important that all sectors of society, in particular civil society, should co-operate in the steps taken to achieve this goal. In our view that will be facilitated by spelling out the steps necessary to comply with the Constitution.¹⁶

Similarly, in Colombia, the T 760/08 decision did not define the contours of the right to health, beyond for example excluding 'experimental treatments' or cosmetic procedures. Rather, it called for a participatory process through which to update the obligatory health plan, or POS, and unify the two benefits schemes (subsidized and contributory). However, as there are some 'harder' orders in the judgment, such as impositions of strict deadlines for compliance, the justice who authored the T 760/08 decision, Manuel José Cepeda Espinosa, has characterized the T 760/08 decision as one of 'biting substantive progressiveness.' 17

The T 760/08 decision is but one example of a structural remedy relating to health requiring supervision over time. In various judicial systems, we see courts remaining seized of a health-related matter and issuing orders over time. This is the case, for example, in India, Argentina, and Colombia, where courts have remained involved in overseeing decisions relating to: the right to food; pollution affecting, among other things, the right to health; and the structural reform of the health system (as

well as conditions, including health, for internally displaced persons), respectively.

Nevertheless, the kinds of structural orders in decisions issued by the courts in these cases require rigorous scrutiny and close follow-up over an extended period of time, and there is no question that such monitoring has proven to be a challenge in various contexts, precisely because of indifference or open hostility to the judgment by the political branches charged with implementation, as well as the highly technical nature of health. No doubt, exuberance for the possibilities of enhancing deliberative democracy through fostering dialogue between branches of government and civic participation should be tempered with not just the evidence of the ultimate impact on the effective enjoyment of health rights in practice, but also with some understanding of the complexity of health as both a sector and a subject matter. The health sector, perhaps more than any other, contains enormous asymmetries of both power and information between the pharmaceutical or insurance industries, or even providers, and ordinary patients.

Thus, the record is mixed. After eight years, very little improvement in contamination in the Mantanza-Riachuelo River Basin in Argentina has taken place, following a structural decision establishing multiple lines of responsibility among different agencies and levels of government, despite creating public discourse and opening spaces for participation. After 13 years of ongoing public interest litigation on the right to food resulting in over 50 interim orders, India continues to rank desperately poorly in food security and under-nutrition, although it has seen several major legislative advances and programmatic interventions.18 And more than six years after T 760/08, meaningful health reform that would diminish the demand for individual complaints against providers and insurers remains elusive in Colombia, despite important impacts on oversight, a more willing and proactive ministry of health under the Santos Administration, and a new framework law on health.

In short, nuanced rather than blanket appraisals of the effects of litigation, as well as such structural remedies, are more likely to be valid. Moreover, as Cesar Rodriguez and others have asserted, they require varied approaches to measuring and attributing distinct impacts over time, including the possibilities of creating public, attitudinal change regarding fundamental rights issues.¹⁹

5. Pro-equity health rights litigation should extend to claims beyond medical care

To the extent that judicialization leads to an over-emphasis on health care, and medical care in particular, it is unlikely to be pro-poor in contexts of egregious inequalities in social determinants of health. For example, Ferraz writes in his work that the Brazilian model of judicialization "is characterized by a prevalence of individualized claims demanding curative medical treatment (most often drugs) and by an extremely high success rate for the litigant [where] ... the right to health is an individual entitlement to the satisfaction of one's health needs with the most advanced treatment available, irrespective of costs."20 As noted above, litigation that promotes placing a priority on curative treatments for the middle and upper classes, as opposed to basic preconditions, or underlying determinants, of health which would inure to the benefit of the poor, may indeed exacerbate inequity, as well as likely being less cost effective in terms of health outcomes.

On the other hand, in Barcellos' article in this issue regarding the right to sanitation in Brazil, she points to the possibility of turning toward the courts for aspects of the right to health that relate to preconditions as opposed to specific health care. This potential use of litigation in Brazil would go far toward responding to critics that see it as an avenue for the middle class to exploit the system to obtain expensive medications that are not offered through the unified health system, thereby exacerbating inequities in access to health with inequities in access to justice.21 Barcellos' study found that there have already been 258 decided lawsuits in Brazil seeking sanitation services and of these cases, 47% deal with requests for sanitation services for communities. While sanitation services are generally collective goods compared to many health system provisions like pharmaceuticals which are private goods thus each relating to inequalities differently, Barcellos found that "litigation has dealt so far with less than 7.09% of the 2,495 Brazilian municipalities that lack both sewage collection and treatment systems and lawsuits tend to be concentrated in the richer cities, not in the poorest ones." Barcellos argues that the courts' amenability to granting sanitation claims provides a "window of opportunity for the advancement of public health conditions" and "can help introduce sanitation in the list of political priorities."

6. Health rights litigation involves regulation of public and private actors, including of the pharmaceutical industry

Elsewhere, Brinks and Gauri have empirically analyzed and shown that the regulatory function of litigation may indeed have greater pro-poor impacts than ESC rights litigation relating heavily to the direct provision of services to certain individuals or groups.²²

In their article in this issue, Luisa Cabal, Monica Olaya, and Valentina Robledo provide Colombia's jurisprudence on conscientious objection as an example of how states can balance the individual provider's right to conscientious objection while still imposing an institutional obligation to ensure that women can access abortion services. Cabal et al. argue that Colombian jurisprudence achieves this balance through 11 specific health system regulations, including limiting the right to conscientious objection to directly involved health workers, implementing referral procedures, and establishing sanctions for non-compliance. It is important to note that regulation of conscientious objection is required with respect to both public and private providers, as in Colombia, as well as in many contexts—from the US to India to East Africa—women often obtain reproductive health services through private facilities.

The pharmaceutical industry poses particular challenges and requirements for regulation, and has proven to be both an object and subject of health rights litigation. Carolijn Terwindt's article highlights the role of health rights litigation in India to protect subjects of clinical trials of drugs including a pending case before the Supreme Court.

Past litigation has resulted in increased regulation on behalf of the state, but Terwindt explains that a ruling in the pending case could establish legal obligations of trial sponsors and manufacturers for the protection of research participants and would open up additional possibilities for individuals to claim their health rights against those private actors.

Allan Maleche and Emma Day's examines intellectual property rules relating to the pharmaceutical industry, in light of a recent constitutional challenge in Kenya that argued that access to affordable and generic ARVs was limited by the 2008 Anti-Counterfeit Act. That Act "included essential medicines in the definition of 'counterfeit' goods, making it an offense to sell or purchase such medicines ... [and which] presented a significant threat to parallel importation." The Kenyan court's landmark ruling suspended the provisions of the Act that impeded parallel importation, thereby reinstating access to generic ARVs. Maleche and Day's article points to the international dimensions of pharmaceutical industry lobbying regarding the rules of the game in specific countries, as well as the potential impact of judicial decisions beyond borders. They note that this decision has also had implications in East Africa, beyond Kenya, for example, being used by Ugandan civil society to influence the Ugandan Parliament to order revision of the Anti-Counterfeit Bill proposed in 2010.

But pharmaceutical companies also play a role in bringing some health rights litigation cases, and the extent to which there is pharmaceutical regulation often affects the budgetary, and in turn equity, impacts that judgments have in practice. While it may be an oversimplification of what is happening in Brazil or Argentina or Colombia to argue that litigation for expensive drugs is predominantly driven by pharmaceutical companies, it is unquestionably true that some is. Moreover, a key issue with respect to the litigation in Colombia, and elsewhere, has involved the lack of pharmaceutical regulation, which has meant that the prices of court-ordered medications not included in the obligatory plan are reimbursed at exorbitant prices. In 2014, the Colombian government took significant steps to increase pharmaceutical regulation. Nevertheless, implementation of health reform in Colombia still faces tremendous obstacles, in part due to the clout exercised by the pharmaceutical industry. Indeed, the Colombian and other South American cases illustrate why it is fallacious to look at costs produced by judicial orders in the absence of what may be deemed "exogenous factors" such as pharmaceutical regulation and pricing. Many of the most litigated medicines (which are primarily for non-communicable diseases) are from companies that hold a significant market share, or dominate the market.²³

7. Litigation needs to be placed in a broader context and used with other strategies

Litigation is never the beginning or the end of struggles for more health justice, as many of the articles in this issue highlight. A positive decision is often just the beginning of a long struggle for implementation, which can extend far beyond the passage of legislation or regulations. Conversely, a negative decision can lead to impact in unexpected ways through, for example, political mobilization. Nor is litigation a tool that must be used in isolation from other strategies. For example, Ayman Sabae's article discusses strategic considerations of human rights organizations seeking to redress health and human rights abuses through litigation, among other tools, using case examples from Egypt. Coming from a prominent civil society organization, the author reflects upon the opportunity structures that factor into strategic decision making, but argues that these options should be seen as complementary, and not incompatible. These include, for example, proposing new legislation to policy makers, participatory formulation of new laws from the ground up, public advocacy, coalition building, and litigation.

Ciara O'Connell's article comes to some of the same conclusions, but starts from a very different vantage point in a wholly different context, analyzing the impacts of litigation in the Inter-American System on reproductive rights at the national level. She argues that, while reproductive health rights litigation at the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights has been successful in some cases, it often fails to have sustained impact because cases

do not afford sufficiently structural remedies, nor do they connect broadly enough with other actors. O'Connell posits that: "Successful and sustainable implementation of reproductive health rights law requires incorporation of non-repetition remedies in the form of legislation, education, and training that seeks to remodel existing social and cultural practices that hinder women's enjoyment of their reproductive rights. In order for a reproductive health rights case to ultimately be a 'winner,' case recommendations and decisions emerging from the Commission and Court must incorporate perspectives provided by members of civil society, with the ultimate goal of developing measurable remedies that address underlying obstacles to domestic implementation."

In short, the judicial enforcement of health and other ESC rights must be seen as part of a broader process of reform regarding health and related rights, which necessarily implicates—even in implementation of decisions—wider social struggles. Moreover, struggles for more responsive and equitable health systems and health rights generally, including in relation to social determinants of health, cannot be divorced from questions of democratization and substantive equality more broadly.

Concluding reflections for this issue

While health has been established as justiciable in many countries, a legal entitlement to care and the preconditions of health remains a distant dream in too many others. Moreover, there continue to be many open questions around how to best promote practices that lead to greater equity in health systems, and in our vastly unequal societies more broadly. There are various initiatives in the Latin American region and elsewhere now, including Saluderecho led by the World Bank Institute, to foster 'multi-stakeholder dialogues' with respect to judicialization in health, among health policy makers, judges, economists, academics, and other actors. Harvard's FXB Center for Health and Human Rights offers an annual global school intensive course for practitioners regarding health rights litigation, aimed specifically at building coalitions across communities of practice, and strategically considering equity impacts.²⁴ There are many other projects aimed at capacity-building among judicial and other actors as well. These kinds of initiatives will undoubtedly spread, as increasingly actors from different domains are concerned with both enhancing the equity of judicial decision-making in health, and the capacity of health systems to regulate themselves, while still finding ways to guarantee access to effective remedies in the event of violations.

Further, at the global level, the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, which entered into force in 2013, ushers in new possibilities for the UN Committee of Economic, Social and Cultural Rights to set standards relating to reasonableness of States parties' steps toward the progressive realization of the right to health, and other ESC rights, under international law. Moreover, as Universal Health Coverage (UHC) is poised to become embedded in global Sustainable Development Goals, post 2015, judicial enforcement of health rights has implications for choices made along the path toward UHC, with respect to balancing the inclusion of more people, extending new treatments and services, and protections against financial loss.25

It is therefore an ideal time to glean lessons from what courts at the national level are doing, as well as some of the challenges and questions that remain to be addressed if we are concerned about how to promote patterns of judicialization to best foster more social justice through legal enforceability of health and related rights. The diverse pieces in this issue provide important insights.

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