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English Edition

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Access to medicines and intellectual property in Brazil: reflections and strategies of civil society



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## PRESENTATION



With the aim of seeking out different perspectives and dealing with subjects of a specialized nature, Conectas Human Rights has been creating partnerships with non-governmental human rights organizations in diverse parts of the world. In this issue of *Sur – International Human Rights Journal*, which is principally focused on access to medicines, a new cooperative partnership was formed with the Brazilian Interdisciplinary AIDS Association – ABIA.

Founded in 1987, it is the mission of ABIA to promote access to treatment and assistance to persons living with HIV and AIDS. Along these lines, ABIA has been monitoring public policies and developing projects regarding education, prevention, and access to information about HIV/AIDS. ABIA has also been coordinating the Working Group on Intellectual Property of the Brazilian Network for the Integration of Peoples – GTPI – REBRIP, in order to enrich and enlarge the debate over the harmful impacts of the rigid rules regarding intellectual property in the area of access to essential medicines, in addition to contributing to the construction of alternatives to the present model.

This eighth issue of the *Sur Journal* is divided into two parts: the first specifically examines access to medicines, while the second deals with questions that evaluate the present state of human rights in general.

Beginning with the discussion over access to medicines, the main problems related to the often conflicting interaction between human rights and international trade are debated. Those questions deal with the conflict between the human right to health and the protection of pharmaceutical innovations; efforts at making businesses responsible and breaking away from the protective framework initially confined to the sphere of the State; and the developing of the public debate over the political use of judicial power.

In the article by Chaves, Vieira and Reis the system for the protection of intellectual property is discussed, taking as a starting point the situation in Brazil. The relevance of the Brazilian case is based on Brazil's adoption of a policy of universal access to medicines for the treatment of AIDS as well as its recent adoption of a compulsory license for the supply of antiretroviral medicines. The model of universal access and the adoption of a compulsory license represent important benchmarks for the recognition of the preference of human rights over economic interests. The article also presents the main action strategies adopted by a Brazilian group of activists that has had a profound effect on the area. The description of these strategies is important because it enhances the possibility of exchanging experiences with other activist groups in the South.

In the article by Pogge, the author discusses the argument that patents stimulate pharmaceutical innovation. For the author, this system strengthens monopolies and the

concentration of research on the symptoms, and not the causes, of chronic illnesses. At the same time the treatment of specific illnesses of poorer populations is relegated to a secondary position because it is less profitable, thus increasing the rate of avoidable deaths. The author goes beyond simply spelling out the problem. He presents a proposal that would complement the patent system: a Health Impact Fund, financed by governments. This Fund would stimulate the development of new medicines with the promise of re-compensating successful innovators in proportion to the impact of the medicine on the global burden of illness.

The article by Hunt and Khosla deals with the responsibility of pharmaceutical businesses, along with the presentation of normative guidelines for health rights. In this sense, the article written by the Rapporteur of the United Nations on the right to health could be interpreted almost as “soft law”, assisting in the structuring of this right in regard to the access to medicines.

In the last article of this first part of the Journal, which was authored by Contesse and Lovera, the question of access to medicines is analyzed beginning with individual cases that depict the perspective of those that lack access to medicines in Chile. The authors show how the litigation process can be used politically to create a public debate to sensitize the executive and legislative branches of the government to enact new public policies.

In the second part of this issue of the Sur Journal, the following issues are discussed: the justiciability of economic, social, and cultural rights (Cavallaro and Brewer); the growing consolidation of sexual rights as autonomous rights (Mattar); the participatory preparation and adoption of a new international treaty on rights of persons with disabilities (Dhanda); and the challenges that have to be overcome by non-governmental human rights organizations (Abregu).

We would like to thank the following professors and partners for their contribution in the selection of articles for this issue: Alejandro Garro, Bernardo Sorj, Carlos Correa, Denise Hiraó, Frans Viljoen, J. Paul Martin, Jeremy Julian Sarkin, Juan Amaya, Julieta Rossi, Mustapha Al-Sayyed, Richard Pierre Claude, Roberto Garretón, Roger Raupp Rios, and Vinodh Jaichand.

Finally, we would like to announce that the next edition of Sur Journal will be a special issue in commemoration of the sixtieth anniversary of the Universal Declaration of Human Rights. The next issue will be published in partnership with the *International Service for Human Rights*.



## MARTÍN ABREGÚ

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## ABSTRACT

The human rights and citizenship movement has been a key agent in the processes of democratic consolidation that have taken place in the Andean Region and the Southern Cone over the last two decades. Yet civil society organizations need to change their strategies in new post-dictatorial contexts. In this article, some of the central challenges that confront these organizations will be identified. I would especially like to thank all my colleagues at the Ford Foundation Office for the Southern Cone and Andean Region for their valuable feedback on earlier versions of this article. The suggestions of Alex Wilde and Michael Shifter were also extremely useful.

Original in Spanish. Translated by Benjamin Chaffin.

## KEYWORDS

Civil society organizations – New modes of action – Democracy – Latin America – Public policies



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# HUMAN RIGHTS FOR ALL: FROM THE STRUGGLE AGAINST AUTHORITARIANISM TO THE CONSTRUCTION OF AN ALL-INCLUSIVE DEMOCRACY - A VIEW FROM THE SOUTHERN CONE AND ANDEAN REGION

Martín Abregú<sup>1</sup>

## Introduction

The human rights movement has been a key agent in the processes of democratic consolidation that have taken place in the Andean Region and the Southern Cone over the last two decades. In the Southern Cone, the claim of human rights violation victims to obtain truth and justice made up one of the axes around which post-dictatorial transitions revolved; in the Andean Region, the role of civil society organizations that reported heinous crimes perpetuated or backed by agents of the State has also been a central component of the political agenda of the region. Beginning with those first steps, human rights organizations were expanding their original sphere of influence, actively taking part in issues as diverse and current as the struggles against poverty and corruption.

Such leadership has been accompanied by a transformation of organizations dedicated to the protection of rights—organizations which ceased to be basically dedicated to the reporting of sponsors of systematic and unacceptable violations so that they could shape a movement much more diverse in its composition and aims. In its early years, the human rights movement was fundamentally made up of organizations of victims and relatives—especially in the countries of the Southern Cone—and of organizations of attorneys that supported the demands of these groups—with greater development in the Andean Region.

Beginning with the restoration of democracy in the countries of the Southern Cone and with processes of larger rights awareness which are being

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*Notes to this text start on page 37.*

developed in the majority of the countries of the continent, especially from the nineties onward, the world of civil society organizations, which are organized in demand to fundamental human rights, has been expanding in different directions.<sup>2</sup>

On the one hand, civil movements begin to organize themselves to take aim at not only the safeguarding of rights to life and physical integrity, but additionally aspire to the consolidation of a democratic system that ensures the participation of the larger majorities in the public agenda. At the same time, organizations that defend the rights of some group in particular, such as those that unite women; indigenous peoples; persons with disabilities; racial, religious, or ethnic minorities; as well as minorities of sexual orientation, amongst others, are achieving a new level of development. Many of these organizations form part of social movements that, in many cases, predate the formation of groups for the defense of human rights (such as those linked to indigenous peoples); however, what is new about these organizations in recent decades is that they have additionally assumed a perspective of rights in their principles and actions.

Similar to the diversification process that continues to change the landscape of civil society organizations, the recognition of human rights in new, post-dictatorial contexts, and in general, in all countries of the region, has been accompanied by a growing “officialization” in the field: the governments themselves, that were previously declared enemies of human rights, are beginning slowly but systematically to promote the defense of these principles.<sup>3</sup>

While in many cases this promotion is primarily rhetorical, it is without doubt that this new situation, in and of itself, is an advance and has led civil society organizations to alter their strategies in order to go beyond the mere defense of a value (which appears now to be socially shared). In this new scenario, human rights organizations needed to revise their traditional paradigm of work which was primarily designed to confront heinous crimes and unacceptable crimes sponsored by State agents acting to suppress the enemies of an authoritarian government. It should be emphasized, at any rate, that this crisis of the traditional paradigm, which has directed human rights work, is not a phenomenon limited to Latin America but instead assumes in this geography traits specific to the region while at the same time responding to a context at a global level. This situation, which has been classified as a “midlife crisis,”<sup>4</sup> reflects the important challenges that the human rights movement must confront in order to preserve levels of impact and relevancy that it had in the past.

One of the most important consequences of this appropriation of the discourse of human rights on the part of democratic governments has been to open up the opportunity for working toward the inclusion of a rights perspective in the formulation, designing, and application of public policies. This endeavor,



however, has not been exempt from difficulties. A context of complex, and in some cases, conflicting, issues confronts the organizations with a reality in which there are high levels of poverty and social exclusion, fragility with regard to the institution of democracy, and the growing leadership of different social agents which take to the streets in carrying out politics. In addition, questions of an internal nature linked to the history and current situation of civil society organizations also present significant challenges for the realization of goals and have propelled a process of reflection on goals, priorities, and responsibilities of human rights organizations launched in the Southern Cone and Andean Region, which give account for this new scenario.<sup>5</sup>

With that in mind, this article will identify some of the central challenges that must be confronted by human rights and citizenship organizations,<sup>6</sup> like the question of the representativeness of these organizations, their relation to the State, the construction of alliances with other national and international agents, the development of a revised communications strategy and the need for designing impact indicators that allow for an assessment against achieved benchmarks. In order to tackle these issues, this article has been structured in two parts, in addition to this introduction: a first part dedicated to the work of human rights and citizenship organizations as it relates to public policies and a second part that analyzes the challenges that these organizations must confront for the carrying out of these endeavors.

## **I. The work of human rights and citizenship organizations in public policy**

Human rights and citizenship organizations have come to work in an increasingly systematic way with regard to the incorporation of the rights perspective in public policies, conscious that only these types of actions will allow for the maximizing of the outcome of their efforts in achieving a larger and more diverse world for society. In some cases this work can have a quantitative goal: to arrive at advances for a minority sector or in individual cases to reach a significant part of society (which some have called “the challenge of quantity”). In other cases, by contrast, they are attempting to secure access to benefits enjoyed by the majority for minority groups who have, historically speaking, been postponed access.

In search of these goals, civil society organizations have organized their work around four benchmarks:

- i. To render a law or public policy invalid:** the human rights movement has traditionally attempted to stop the State in its designing and application of policies, practices, or laws that directly result in the violation

of fundamental rights. The basic tool for this type of action is litigation, alleging that these laws or practices are unconstitutional.

**ii. To contribute to the designing of public policy:** in other cases, civil society organizations are invited by the executive or legislative branch to participate in the designing of a policy that involves human rights issues. In the majority of these cases, the initiative to invite civil society organizations belongs to the government or congress, but in general, those organizations have previously communicated their proposals and sent the message that they have “something to say.” With many opportunities, a previous stage for this kind of work involves campaigns that hope to create consciousness about an issue in particular, with the object in mind that it is correctly nurtured by the appropriate public official. In these cases it could be said that the organizations are helping to create the political desire necessary for the formulation of a public policy but the designing itself of the policy is necessarily a collaborative endeavor (when those in authority decide to involve those who originally propelled the issue). It is necessary to point out, at any rate, that this is the assumption when the relationship between the State and civil society is friendlier, in the sense that they would seem to pursue the same goal. In point of fact, in this situation it is very rare that advances can be particularized through the path of litigation (which is a route of a confrontational nature). A partially distinct situation appears when organizations promote the approval of an international human rights treaty. In these cases, organizations contribute to the designing of an international norm that eventually must be implemented as an internal policy within the States.

**iii. To promote the revision or correction of a law or practice:** perhaps the greater part of the actions of civil society organizations around public policies can be included in this entry. It involves those cases in which a public policy does not violate human rights or citizenship *per se* (as can be the case with laws that grant impunity). In confronting problems of this nature, the actions of civil society tend to be greatly varied, for example going ahead with a communications campaign that compels the State to revise a law, or through the gathering of information demonstrate the consequences of a specific practice. The decisions of supranational agencies for the protection of human rights (such as the United Nations Human Rights Committee and the Inter-American Court of Human Rights of the Organization of American States) are also able to play a fundamental role in achieving these kinds of changes. In the case of litigation, it is interesting to see that they are not only observed in those instances in which a judicial decision compels the

revision of a law or practice, but are taking the initiative to promote collaborative meetings between civil society and the State beginning with the premise of an “unconstitutional state of things.”

**iv. To participate in the implementation of a policy:** in some cases, agencies of the State invite civil society organizations to participate in the application of a specific public policy. In these situations it may be that the invitation is for the going ahead of tasks of a more operative nature like, for example, collaborating on a food distribution plan in order to ensure the arrival of the largest amount of necessities possible. It is difficult to consider these endeavors as similar to those that have been analyzed at previous points, in that the contribution of organizations is not necessarily at the level of ideas but is limited to the carrying out of definite activities by state agencies. However, in many other cases the invitation is not for the carrying out of actions of an operative nature but actions that will have a direct impact on the way in which policies are put into practice. For example, training activities for government officials who will be expected to comply with a specific law undoubtedly will directly impact the ultimate form that a public policy takes. When an institution is invited to carry out the follow-up to a specific State action it also contributes to ensuring the protection of fundamental rights. In many cases it is impossible to draw a clear dividing line between more operative activities and those that have a more substantive end, inasmuch as during the design and application of any policy civil society organizations will probably be called on to perform both types of work.

In order to achieve these benchmarks, civil society organizations have gone ahead with different actions and strategies for “impact,”<sup>7</sup> such as lobbying, litigation and legal assistance, international advocacy, training and education, producing of information, and organizing of alliances and communications. This list is not exhaustive with regard to all the actions that human rights and citizenship organizations carry out but is limited to just those organizations whose ultimate objective is participation in the development and implementation of public policies. Other fundamental work that these organizations undertake, such as psychological assistance to victims of torture and sexual aggression, have not been included in this description owing to the fact that they do not aspire (at least in an immediate way) to change public policy but achieve reparation (although it is partial) for the damage caused.<sup>8</sup> It is necessary to keep in mind that to have an impact on public policies it is not enough to undertake one of these activities but that more than one of them must be coordinated and, often, it will be necessary to carry out a strategy that

includes all of them or at the least most of them (in the identifying of these examples that are offered in the descriptions below, the inclusion of a case of one action or another is many times arbitrary owing to the multifarious nature of actions that are called for; the same example could have been included in another category.)

At any rate, it has been opted in this article to organize the presentation of these activities and strategies into seven areas:

- i. **Lobbying:** these actions for impact are those that involve these organizations in a direct dialogue with the authorities of the executive branch and congress. In the early years of human rights work this task was almost non-existent due to the openly hostile policies of the authoritarian governments against this sector; however now human rights and citizenship organizations direct an important amount of economic and human resources at informing those in authority of the positive and negative consequences that the eventual sanctioning of a law or decree would have, preparing, for example, documents for discussion or conducting interviews with those directly involved.
- ii. **Strategic litigation and legal counsel:** the work of litigation and legal assistance was that which, in a certain way, gave rise to a human rights movement in the region in the decade of the seventies (together with the gathering of information, which is analyzed farther on). From their inception, many human rights organizations dedicated themselves to assisting victims of State terrorism and, when it was possible, sponsored them in the courts. If in the early years the formation of these organizations responded in part to a kind of immediate reaction of solidarity with the victims and a quest for justice in the face of the atrocities that were being committed, with the passage of time this work gave way to actions of assistance and strategic litigation. Thus, today it is possible to prove that legal assistance work is more focused on relieving a sponsor of violations or developing pilot experiences that, in one way or another, may provide an answer to the serious situation of lack of access to justice that can be observed in all the countries of the region. In many cases, assistance work is becoming a “cable to the Earth,” with regard to the daily reality of organizations that are performing at a more superstructural level, or in a way in which they manage to identify eye-witness cases that create an inquiry against the sponsors of serious human rights violations. In litigation work, from the onset, in which the largest amount of possible cases was sponsored, among other reasons for documenting grave and systematic human rights violations that were committed on a daily basis

by agents of the State (or with their acquiescence), a more selective policy of sponsorship came to pass, in which the selection of a case for its presentation before the courts conformed to a series of requisites linked to its possible social impact.<sup>9</sup>

**iii. International advocacy:** the work of local or national organizations with international counterparts is also found at the origin of many institutions. The human rights movement in the Andean Region and the Southern Cone was established over the foundation of a fundamental alliance with international organizations such as Amnesty International or Human Rights Watch, looking to take maximum advantage of the international instances of human rights protection by international agencies belonging to the United Nations (UN) or the Organization of American States (OAS). In this context, the national organizations looked to the exterior for the attention and protection they were not receiving from their own countries.<sup>10</sup> From that background, human rights and citizenship organizations have acquired experience and developed expertise in the area that is still one of their greatest assets, taking advantage of the concern of governments in presenting a favorable international image in a global scenario that is increasingly more interconnected.

**iv. Training and education:** numerous human rights and citizenship organizations carry out important work in human rights education, for example, pushing forward the incorporation of modules on discrimination into the official curriculum of public schools. However, this section will not tackle this type of work in education but that work which organizations carry out with the immediate aim of participating in the application of public policy. This is the case, for example, for training activities for judges and public prosecutors carried out by some organizations with the purpose of advancing in the proper setting the progress of specific legislation. The tasks of training and education look to ensure the proper application of a law and, in this way, participate in the execution of a specific public policy linked to questions of human rights. Other types of training and education activities associated with this objective are those directed at journalists, for example, for achieving better coverage in areas of justice, with the aim of securing a more informed public opinion and instigating a better debate of public policies.

**v. Producing of information:** from their inceptions, the production of information has been the principle tool for human rights organizations.<sup>11</sup> Probably more so than for any other type of civil society organization, where in the case of human rights violations the phrase “information is power” is appropriate. Beginning with this certainty, human rights and

citizenship organizations assign a significant proportion of resources to the production of reports and other types of documents that register fundamental rights abuses. The most notorious of these is the production of annual reports on the state of human rights. Additionally, annual reports on specific questions (that is to say, without claiming to tackle the entire spectrum) are prepared. In addition to these reports, civil society organizations are constantly generating information that is even not always designed for general diffusion (at least in the short term). It is beyond doubt that the task of gathering information has become increasingly sophisticated and therefore civil society organizations have often needed to draw upon the counsel of experts, a tendency that is still incipient and will probably make itself known with more force in the years to come.

**vi. Organization of alliances:** one of the strategies which have generated major benefits for work in human rights and citizenship is collaboration with other social agents. During their early years, scarce, existent organizations were working in a very united way and were searching for the support of other agents in the exterior or in their respective countries, according to the available possibilities. (The case of the Catholic Church is one example. In countries like Chile, it played a fundamental role in the reporting of human rights violations during the military dictatorship,<sup>12</sup> while in Argentina it turned its back on the calls of victims, although its own members were involved.<sup>13</sup>) More recently, civil society organizations have searched for other forms of collaborative organization as well as new allies. One alternative is the construction of a formal network that would even adopt its form to a new organization. However, such jointures do not establish permanent institutions in all cases but, dependent on the opportunity, involve specific or temporary alliances for the achievement of changes in some area in particular.

**vii. Communications:** without doubt the most effective communication activity for impacting public policy are campaigns that are carried out by organizations or alliances of organizations for the moving forward of a proposed law or, more largely, for calling attention to the need to change a practice or regulate a right. Beyond these massive campaigns, civil society organizations in the last few years have looked to develop a larger capability for mapping out more sophisticated communication strategies beginning with the recognition of the multifarious nature of the audiences they need to reach. Some organizations are designing increasingly more diverse communication products, with the object of drawing the attention of some specific sector. Organizations have often incorporated professional journalists into their staff for taking over what is now the communications



policy in general, or in particular, the organization's relationship with mass media, which has been reflected in a larger media coverage of their activities.

## II. Challenges in human rights work on public policy

Carrying out these activities and achieving the goal of influencing public policies brings coupled with it new challenges for organizations that aspire to make this qualitative leap in their work. In so far as activity in human rights and citizenship moves away from humanitarian defense to dedicate itself to strategic litigation and advancement of initiatives for a larger participation of the citizenry to a more democratic designing of public policies, civil society organizations must confront a series of new problems associated with this revised leadership.

### *1. The question of representativeness and legitimacy*

The journey from work at a local level or assistance work, for example, to the formulation and design of a public policy means, among other things, a change of scale: organizations that involve themselves in these kinds of endeavors work to change living conditions of a significant fraction of the population. In this context, a question often appears: who do those organizations represent? And connected to that: what legitimacy do they have for carrying out this kind of work? While in many cases these inquiries are made with a "lack of faith," by those who are interested in quieting organizations, they really involve questions that deserve an answer, especially because the organizations allege to work in favor of a greater (or better) democracy.<sup>14</sup>

In their beginnings, human rights organizations did not have to confront these types of questions. The fact that in many cases the organizations were made up of victims or those who represented them was enough to grant a legitimacy of "origin," in the sense that they were representing a collective of which they formed a part. Nevertheless, the passing of time and above all an enlargement of the agenda have necessarily caused a crack in that historical legitimacy. Especially coming from sectors closer to the political parties, there is a tendency to allege that while representatives or senators are legitimate representatives of the interests of those who have voted for them, civil society organizations defend the sectorial interests of minorities, conflicting with those of the majority. In some countries especially, the fact that civil society organizations are financed principally with contributions from the international community adds to these questions the issue of the supposed defense of outside interests.

With respect to this, in the first place it is necessary to point out that

while legitimacy and representativeness of the organizations is often a narrow link, the issue involves two kinds of questions which must be differentiated. In this sense, questions related to the lack of an electorate that tenders support seem to demand that the only legitimacy possible for public agents is a democratic legitimacy, that is, one supported by voting. In the face of these types of criticisms, organizations tend to insist on the special nature of the position that they defend—in favor of human rights and citizenship—and do not necessarily need to have the majorities of a society behind them, and that in general values are involved that must be especially protected from the majorities or their representatives, as they are exactly those who can put them at risk.

Associated with the above, another possible answer to challenges concerning legitimacy is related to the capability of the organizations and their demonstrated expertise in the issues in which they intervene. In this sense, it would involve a legitimacy rightly “acquired” by the worth of their interventions—similar to, for example, the means of communication open to prestigious persons whose opinion can be very influential, even when they do not “represent” any sector in particular. Organizations would act in this case as “experts” that defend universally recognized values (of human rights and citizenship).

While these lines of argument—for quality of work and the defense of universal values—adequately address the mentioned questions, it should not be inferred by the above that human rights organizations do not have to worry about their legitimacy. A question associated with their legitimacy and that has come to generate a growing preoccupation in recent years is the accountability of these institutions. For some years, civil society organizations have occupied a privileged position in the public arena, and as a consequence, the natural result has been the emergence of demands for better mechanisms of control and that they answer to certain specific sectors. This does not mean that those said mechanisms must be similar to those that oversee government bureaus or that the workers of these organizations have to be treated as public officials, but it becomes clear that the question of the responsibility of these organizations, or their accountability, has come to acquire an importance directly proportional to the growth of their influence, and becomes a central issue when the situation involves their participation in the gestation of public policy (a task that fundamentally lies in the hands of the representatives of the people.)<sup>15</sup> The ways in which this accountability must be adopted are still found in discussion and it is hoped that the organizations themselves are the leaders for this design. On the one hand, it is necessary to advance the defining of control mechanisms on the part of the State so that they address the current relevancy of these organizations, at the same time not imposing arbitrary or unnecessary



restrictions to their action. On the other hand, it also seems necessary to design standards with transparent rationales, so that whatever legitimately interested person can access relevant information about the organization. Those levels of transparency, however, must be adapted to the needs of the civil society organizations, for example, not putting at risk their representatives.<sup>16</sup> Some organizations are taking the initiative to begin the development of objective and transparent criteria for their own accountability, and the advances that are achieved in this area in the short term will prove crucial for the off-setting of potential challenges.<sup>17</sup>

Another challenge to the legitimacy of these organizations is related to the enlargement of the agenda for work in human rights and citizenship and the inclusion of new groups of human rights violation victims and for defense organizations of some rights in particular. The growing leadership of those movements which promote rights in a particular sector or one type of right not only enlarge the horizon of human rights work to areas unexplored up to that moment, but, in turn, indirectly question traditional organizations. Some of the new actors in the area maintain that, while their claims are circumscribed by a group or theme in particular, this is not distinct from the work that original agencies for human rights adopted from their inception, a work that was focused on the sponsors of human rights violations and reached only a reduced group of the population—in comparison with other practices that affected, for example, an indigenous majority. The activist conception of women's rights demonstrates a tendency to incorporate special charters (for women, indigenous peoples, minorities of sexual orientation, persons with disabilities, etc.) to declarations of rights; this necessity of making additions demonstrates that the “universal” declaration was in reality a rights declaration for white heterosexual males without disabilities.<sup>18</sup>

In light of this situation, the legitimacy of civil society organizations that work in the defense of human rights and the promotion of citizenship depend, in a large way, on the capability they have to band together with other agents and in that way ensure a true universality for human rights work that incorporates all sectors. The legitimacy of the work in these issues is directly linked to their representativeness: those who aspire to participate in the designing of public policies that effect specific groups must not do it without a direct association with those directly interested. This means, especially for original organizations at the present moment, learning to act not as representatives of their own interests but as part of an alliance that requires the endorsement of those directly affected in its daily application. It is for this reason that these organizations must develop proactive strategies to ensure the necessary mechanisms that will safeguard the narrow link between their work and the interests of those that they aspire to represent.<sup>19</sup>

## *2. The relationship with the State*

Human rights work began in this region with the intention of putting a stop to the heinous crimes that, during the decades of the seventies and eighties, were being sponsored by the States (dictatorships in the Southern Cone and weak democracies in the Andean Region). In this scenario, especially in the countries of the Southern Cone, the concept of the State that was employed during these first years was, without doubt, that of an enemy-State.<sup>20</sup>

The re-establishment of democracy in the Southern Cone re-opened an opportunity for rethinking this relationship; however, the process was not simple nor was it devoid of tension. On the one hand, the confrontation between the new governments and human rights organizations, which resulted in an almost immediate way from policies of truth and justice, was an insurmountable obstacle for settlement on positions. The official policies of reparation in general did not satisfy the demands of the victims and the organizations that represented them, leading to the delay of a shift in mutual perception that lasted longer than was expected. Many of the more traditional human rights organizations continued working with a concept of the enemy-State even in the context of democratically-elected administrations.<sup>21</sup>

At the same time, the very nature of political action supposed work in constructing agreements and mutual commitments that was often resisted by civil society organizations, resulting in distrust toward the public sector which in some cases persists up to the present. The Chilean transition to democracy proves very interesting as well when seen from this perspective, inasmuch as the human rights movement became divided between those who, coming from human rights organizations, started to form part of the blocks of the government administration and politically negotiated the nature of the democratic transformations and those who opted to continue in civil society organizations and self-relegate themselves from these conversations.

At any rate, the greater acceptance of human rights throughout the region has permitted civil society organizations to search for their own place in a continuum that moves away from the conception of an enemy-State to that of an ally-State or even friend-State. This enlargement of territory led to the creation of different organizations, more or less radical, that would find their own place in the tension. On the one hand, it is possible to identify organizations that even today perceive the State as a kind of leviathan, which it is necessary to confront with all available force. While it becomes difficult on occasion to harmonize this point of departure with the need to deepen

the democracy, these organizations assume that their contribution is reporting on a government institution which is by nature abusive. On the other extreme, there are organizations that, operating from the recognition of the State as a friend, wind up losing their independence and become enveloped in a confusion of roles.

On the other hand, the reconfiguration of the States of the region, especially from the decade of the nineties onward (although in some cases, like Chile, it begins earlier, during the dictatorship of Augusto Pinochet) also resulted in a responsive modification to the scenario. With the processes of privatization, the reduction of the influence and presence of the State in numerous sectors and with globalization, the bureaucratic apparatus has lost some of its territory as an exclusive agent and, instead, begins to be perceived often as a regulating entity which now must not only worry about the legality of its own actions, but also as a monitor of increasingly powerful third parties. This is the case, for example, with the role of the State in monitoring private security agencies or in protecting the rights of the less-favored with regard to the supply of essential public services (like potable water). Other actors such as transnational businesses and international financial institutions are acquiring growing importance and the accusatory finger of human rights organizations now has more than one target. At the same time, other sectors begin to make systematic challenges toward the State, inasmuch as it is asserted that the State does not necessarily respond to the interests of society in general but is controlled by a specific group that does not represent those excluded. Movements vindicated by indigenous ancestral traditions, from *Zapatismo* in Mexico to mobilizations in Ecuador and Bolivia, bring into question the State-Nation such as it has been known in Latin America. The case of the *piqueteros* (or “picketers”) in Argentina, especially in their more radical sectors at the worst moment in the crisis of 2002, have also been transitioning toward this type of establishment beginning with a practice that aspires to make them independent from official policies and construct their own community—which includes its own schools, hospitals, policies of revenue distribution, etc. In the rural sphere, perhaps the most notorious case is the Landless Workers’ Movement (MST) in Brazil.

It is in this changing scenario that the necessity to contribute to the development of the State as a protector of human rights has begun to develop with more force among civil society organizations. In the last few years, the crises which numerous governments of the region experienced, and which included the anticipated departure of democratically-elected presidents in many of those countries, have wound up painting a new landscape in which human rights and citizenship organization have been obliged to commit

themselves more forcefully to the strengthening of democracy. In this sense, there are already few of those that deny the necessity of collaboratively working with the State, at the same time that many of those governments, given their weaknesses, produce among others, reasons for a crisis of representativeness, and have begun to invite these organizations into the process of formulating and putting into motion public policies in a way that is significantly more systematic if compared to the past.

However, there is no necessary, clear understanding with respect to the way in which the State and civil society must collaborate with each other on this issue. As partially results from the absence of an ideal State at the heart of organizations, as well as an inefficiency of administrations and inexperience on both sides, the intentions of working together have not always been fruitful. These difficulties have become more manifest recently, with the rise in functions of several governments regarding the human rights movement that have adopted for their lines important benchmarks for this movement and have established more systematic work relationships with civil society organizations.

A principal challenge for the collaboration between governments and civil society around the construction of a State protector of human rights is the inefficacy of many of the administrations of the region. One of the serious shortcomings of the democracies of the Andean Region and the Southern Cone is their incapacity to provide their inhabitants with essential goods and services. For this reason, the promotion of a State protector of human rights clashes with a reality of administrations incapable of achieving expectations. There are repeated cases of administrations with an unquestionable commitment to human rights (at least in some issues) that, regardless, have been incapable of deterring unacceptable practices. The case of torture in police commissaries is probably one of the most notorious examples of these failures, seeing as many governments, especially at a national level (and federal, according to the cases to which they correspond) have made efforts to eradicate this practice, but the political will is insufficient for disarming bureaucracies entered in supporting these types of isolated onslaughts.<sup>22</sup> In the same sense, administrations (or governmental agencies) that have proposed confronting the corruption were in the majority of cases overcome by those same bureaucracies or even by the structures of their own political parties.

The role of activists and intellectuals of civil society in a public function is a question rarely studied in Latin America. This lack of attention is contrasted with the fact that these experiences result in a great usefulness for reflecting on the relationship between civil society and the State and the democratization of the process of defining public policies. Such

experiences bring into question one of the principal reasons that generally is wielded as an obstruction to the participation of civil society organizations in the formulation and putting in practice of public policies: those that have developed a diligent manner of reporting and follow-up are recognized but are criticized by those who believe that they lack the necessary credentials for actively participating in the process of designing the policies.

There are many civil society leaders that have accumulated valuable experience in the formulation and execution of public policies that is as much linked with their interaction with the State as with their previous work in non-governmental organizations.<sup>23</sup> Taking advantage of this expertise will probably be of great help for developing the know-how necessary for strengthening the relationship between the State and civil society.

### *3. Collaboration with other agents*

If the different activities and described strategies above are analyzed it can be concluded that human rights organizations today do more or less the same as they did at their beginnings: influencing the government, litigating, gathering information and diffusing it, and mobilizing the international community for a “rebound effect” in the internal setting. The difference in their work does not seem to rest so much on the nature of the actions that they undertake but in the way in which they are carried out.

One of the differences in the way in which these activities are undertaken is the possibility of building alliances with other social agents or actors. Work in human rights began as an isolated action to confront authoritarian governments, so that its discourse was destined to be inevitably marginalized. With the passage of time, the changes in the political context, and the growing legitimacy which human rights organizations have achieved has stimulated a situation of varying correspondence.

However, the strong isolation of their origins has had consequences up to the present: the human rights movement was built around a nucleus of original organizations proud of their work that constitute a selective group which proves hard to enter.<sup>24</sup>

That sealed-off nature of the organizations also functions in the direction of an interior movement, with often loses sight of other agents and is concentrated too much on its own vicissitudes,<sup>25</sup> in the worst examples, in a kind of “autism.” Such an attitude has implicated in the loss of valuable opportunities, by human rights organizations, for advancing toward their objectives on a base of alliances with larger sectors.

Organizations that promote citizen participation, and which did not suffer the same isolation that more traditional human rights organizations

did, worked from their inceptions with a more diverse network of agents. However, apart from some exceptions, it can be demonstrated that even in these cases collaboration with other protagonists is limited. In these cases, it is observed that the organizations have a greater capability for coordinating amongst each other and working together; but these relationships continue being in some way a kind of interbreeding in the sense that they are limited to other civil society organizations with similar characteristics.

Nevertheless, the work in formulating and putting into action of public policies requires collaboration with other, different agents from these organizations. In this sense, the lack of an exertion in democratic negotiation on the part of civil society leaders is notorious, and has, in many cases, been an insurmountable obstacle for these organizations. The best experiences of participation in public policies are observed in the context of alliances between different civil society organizations and other fundamental agents. Working with other organizations and being able to arrive at agreements with them is the first step in achieving an impact on a larger scale. However, the possibility of politically influencing and being persistent pursuant to those ends will depend not just on this “internal” coordination amongst civil society organizations but must include a larger group of counterparts.

In this sense, if human rights and citizenship organizations aspire to participate more actively in the formulation and execution of public policies, it becomes necessary to develop strategic alliances with at the least three sectors (there are many other agents with whom these organizations should formalize more stable alliances, like, for example, the business sector; however, it has been preferred in these pages to highlight three possible allies which have become fundamental for participation in public policies):

- i. Social movements and grassroots organizations:** especially in the way that civil society organizations at the current moment do not represent their own interests but a public interest and in many cases their actions are directly linked to the situation of specific sectors, it becomes fundamental to ensure channels of communication and situations of permanent representation with those other agents. Among social movements and grassroots organizations it is common to hear criticisms of “non-governmental organizations” that are often described as being merely intermediate or non-representative. Such criticisms are accentuated when they are augmented by related ethnic and racial questions. As much between indigenous peoples as between Afro-Latinos it is common to assert that they will only be able to build medium to long-term alliances with human rights organizations when these include



representatives of their peoples in their staff hierarchy and in structured guidelines.

**ii. Universities and centers for study:** considering that the participation in the development of political policies requires a given level of expertise that in general is lacking among civil society organizations, the formulation of alliances with this sector has a strategic character. However, it is possible to demonstrate that these types of relationships are still significantly precarious. In effect, in many cases it is the universities themselves that are involved in the area of public policies, without the need for a stable link with civil society organizations; in other cases, centers for study have become marginalized in the discussion of public policies. None of these situations is ideal, inasmuch as, in the first case, the direct collaboration of universities in the designing of public policies can transform the debate to a technocratic dialogue or one for only experts, and even conspires against the participation of civil society organizations; in the second case, it is a waste of expertise that is invaluable for the ensuring of the eventual achievement of the sought goals.

**iii. Political parties:** the relationship between human rights and citizenship organizations and political parties is one of “love-hate.” Sometimes the political parties are erroneously assimilated into the apparatus of the State, and thus the tension between these two sectors has relatively the same characteristics as in the description of the previous apparatus. In other cases, the concerns of civil society organizations with respect to political parties are reduced to two preoccupations: the risk of being co-opted and the dream of their own party. On the one hand, organizations tend to be alert in the face of whatever possible interest political parties might have by incorporating them into their lines and in this way rendering them harmless. While it would be naive to dismiss this motivation in many approaches, it calls attention to the fact that this involves a risk of immobilization. On the other hand, in the face of the crisis of representativeness of those parties, some organizations have proposed the possibility of creating their own space of political participation through the creation of an alternative electorate. Experiences such as that of the Workers’ Party (Partido dos Trabalhadores), which has infiltrated the government in Brazil, nourish these hopes. While the possibility of forming a political party that invites some sector of organized civil society always appears as an attractive option, it becomes worrisome that these organizations might not be able to exit this dual role which limits their possible alliances with a fundamental agent for the construction of a solid democracy.

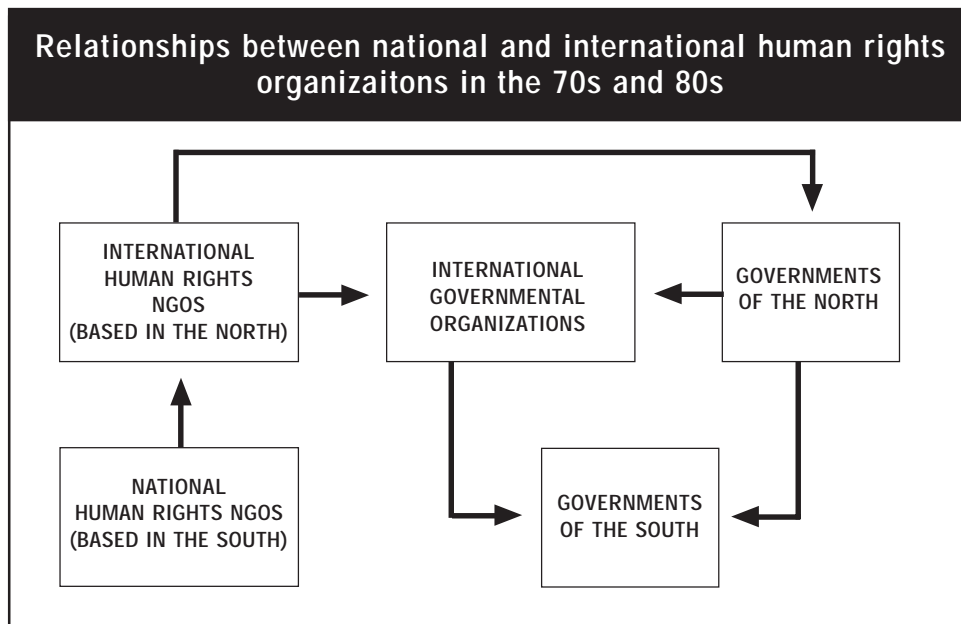
## Collaboration with international organizations

One of the key alliances that human rights organizations built from the very moment of their creation was with international organizations and supranational agencies for the protection of human rights. This society continues to be fundamental for local organizations. However, after more than three decades of ties, it seemed that a reinvention of this cooperation might be necessary, and is a product of changes that have been observed at national and international levels, as much as a result of what is referred to as the acceptance of the discourse of human rights, as the diversification and larger development of key agents in the field.

For a better understanding of these changes perhaps it is helpful to examine the relationships between international and national organizations in Charts 1 and 2, which respectively describe these connections in the past and then the present.

This chart shows what is probably a very accurate description of the way in which international and national human rights organizations were inter-related during the seventies and eighties: human rights organizations that worked at a national level collected information that non-governmental international organizations used to make an impact on governmental international organizations (such as the United Nations or the Organization of American

Chart 1



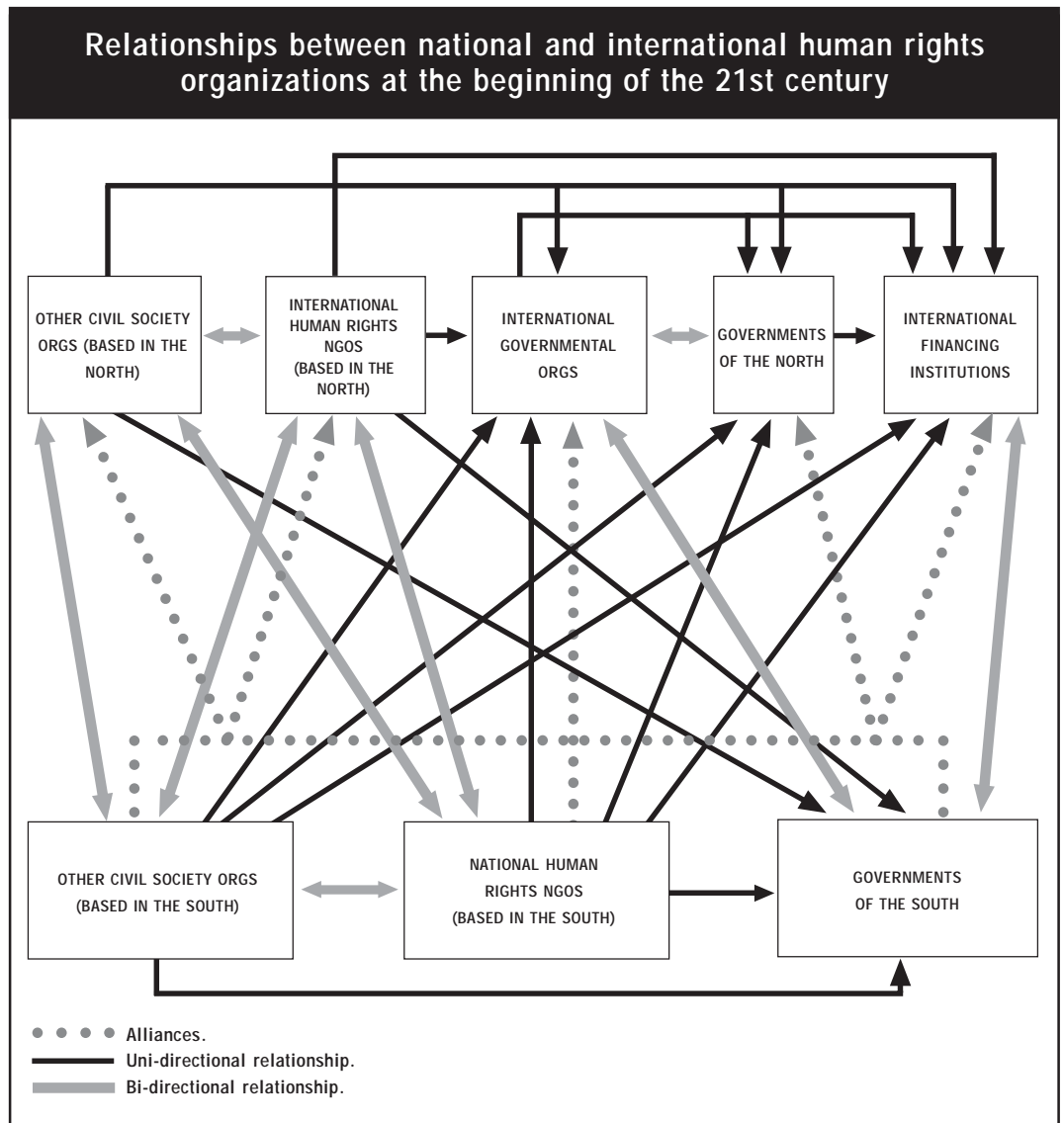
Source: Elaboration based on Keck and Sikkink.<sup>26</sup>



States) and in view of the governments of other countries that defended the cause of human rights, who, by their turn, would take the opportunity to pressure the government in question.

This system is still utilized in many cases and especially with relation to some (few) governments of the region that still today ignore the demands of human rights at a local level, though they listen more attentively to challenges from the international community. In this sense, such interaction is not only still practiced but sometimes continues to be very effective.

Chart 2



Source: Original elaboration.

However, by looking at the following chart, which tries to reflect the current nature of the relationships among national and international human rights organizations, it is possible to appreciate that this type of interaction is very far from being the only form of collaborative work between the two.

As can be seen in Chart 2, the relationships between national and international human rights agencies are much more intricate at the present moment. Various forms of interaction are recognized, represented by the lines of the chart. On the one hand, the simple, solid lines with one arrow describe classic unidirectional relationships in which one actor attempts to influence the other. The solid lines, with two arrows, on the other hand, describe channels of two-way or bi-directional communication, in which the two parties give and receive. Finally, the dotted or segmented lines map out a new form of alliances, which have arisen in the last few years and which will be examined farther on.

Different from Chart 1, the relationship between international and national organizations is at the present moment bi-directional. This means that even when in some cases the organizations that work at a national level continue to provide information to international organizations, there are also other types of exchanges in which, for example, national organizations provide their expertise to each other, try to design impact strategies together and even aspire to influence the agendas of international organizations. The relationship between national and international organizations is itself nearing an exchange which is much more one of “equals”—even when some international organizations are still unaware of the situation. While it is true that there are still enormous differences between the national and international organizations (among them, a significant difference in levels of financing), at least between organizations which carry out similar tasks there is a much more equitable relationship. One of the reasons for this leveling out is that national organizations often now do not require international organizations to be heard by their own governments. As it has been examined, human rights organizations that work at a local level have achieved during the last ten years a level of exposure and unchecked influence which creates a situation in which their governments are unable (or do not want) to continue ignoring their demands.

At the same time, non-governmental organizations that operate at a global level might sometimes not need national organizations or international governmental organizations to exercise influence in specific countries. To cite an example, the leadership that Human Rights Watch or Amnesty International has achieved in Colombia as agents in the internal process is qualitatively distinct from the traditional role of original international organizations as “processors” of information gathered by third parties.

In this more complex scenario, it is common to encounter some paradoxes. For example, in the case of the campaign for the ratification of the International Criminal Court, it was very difficult during the first few years to actively involve organizations that worked at a local level, in spite of the principal benefits of a court of this kind which was undoubtedly going to directly impact national situations. In that first stage, international organizations were the ones who worked arduously for the creation of this Court, while the national organizations had other priorities, associated with their urgencies and pressing contexts. That which makes this case particularly interesting as well is that on the part of the governments there was seen an unusual situation. Even though some governments of the South had in times past been tenaciously opposed to an initiative of this kind, they became here key allies of non-governmental international organizations, which instead were seen confronted by a traditional ally like the United States.

Another relevant characteristic of the new schema of relationships between national and international organizations is the appearance of other agents. While all these are seen included in the context of the second chart under a single category of “Other civil society organizations”—because of their difference from traditional human rights organizations—they represent a great diversity in new agents. This involves, in the case of development organizations that work at a local or international level on the anti-globalization movement, to mention just a couple of examples. Amongst international governmental organizations, the growing leadership of international financing institutions has also come to responsively change the issue of human rights. In this new context there are many more opportunities for the coordination of alliances and the identification of membership strategies for specific questions. In fact, toward the middle of the nineties, when many national organizations wanted more actively to promote the defense of economic and social rights, in light of the scarce receptivity that they encountered from international human rights organizations, they opted for partnering themselves with other types of international agents.

Among these new possible alliances true forms of South-South collaboration are outlined in Chart 2 (with dotted lines), in which organizations that work at a national level collaborate with their own government for the advancement of initiatives that are often resisted by governments historically friendly to human rights (and even resisted by some non-governmental international organizations). This is the situation that has been observed, for example, in the negotiations surrounding the World Trade Organization (WTO)—in which human rights organizations and governments of the South have promoted a common agenda on issues such as commercial barriers and intellectual property rights.

In light of this new situation, it is possible to infer some preliminary conclusions:

- The agendas of national and international organizations are increasingly different. This does not mean at any rate that the agenda of one is better than the other, but it is reasonable to predict more tension in the relationship between the two. The construction of an international agenda that represents all the actors involved will probably be an increasingly complex process if it hopes to enlarge the participation level of traditionally secondary actors. However, this will depend not only on the attitude that is taken on by international organizations in favor of the participation of other agents but also, such as occurred in the mentioned case of the debate process for the approval of an International Criminal Court, it will also depend on the capability of organizations that act at a national level to develop a work agenda at an international level—even in the context of complicated scenarios at a national level. The capability of organizations to act at a national level to collaborate with similar organizations in other countries will determine the increase in their capability of influence at an international level.
- A progressively larger leadership of local organizations will mean a relative loss of relevancy at a national level for traditional international actors, which in many cases will have to attend to the initiatives of their national counterparts and, for others, filling some vacancies that the local actors have not taken care of.<sup>27</sup> At the same time, non-governmental organizations that act at a global level will probably continue their creeping change of focus away from work on the situation in other countries in order to concentrate on strictly international issues (such as the strengthening of international governmental institutions) and on foreign policy with regard to the issue of human rights in developed countries. At a national level, it can be expected that international non-governmental organizations will go on performing a key role in those cases in which there are still no strong organizations in the local terrain (a situation which is presented in a few of the countries in Latin America) and in situations where conditions for those organizations to carry out their activities are absent. A partially distinct case is that of international organizations that have specialized in an area of work in particular, as for example, the International Center for Transitional Justice (ICTJ). The role at a local level of these kinds of expert organizations will continue to be of special fundamental relevancy in what is referred to as the national construction of capabilities in their areas of expertise.

#### *4. Strategic communications*<sup>28</sup>

Communicating the message in favor of respect and vigilance toward human rights has been one of the central goals of this movement. In as far as making visible a human rights violation is the first step in remedying it, civil society organizations have concentrated the greater part of their effort in this direction. In point of fact, the formula “naming and shaming”<sup>29</sup> was and continues to be one of the most powerful tools in human rights work.

However, in the way that the actions in defense of human rights become more complex, the mere identification of those responsibilities is insufficient for the attaining of new goals as in many current structured violations of human rights the way of rectifying the situation is not simple. If when Amnesty International was created it was obvious that the problem of prisoners of conscience ended with the liberation of whoever was detained, the necessary means for remedying the lack of access to healthcare or, even, police brutality, is significantly more complex, in the sense that those responsible are more diffuse, injustices usually have an endemic origin and the solution implies numerous variables.

In this context, although the task of organizations monitoring human rights situations and exposing the more serious violations, for example, in annual reports, is still a basic activity, there is a marked consensus concerning it—that it does not provide for achieving the objective of rectifying the situation. In spite of that acknowledgement, the attention that the human rights movement has discharged to this problem is still disparate. While some of these institutions undertake excellent work in this area and have managed to position themselves very well in mass communication media or have developed their own very successful tools for diffusion, many others today have great difficulties in making their message reach its audience just as in the significantly adverse contexts under dictatorships or authoritarian governments.

These difficulties, at any rate, increase when it is an issue of influence on public policies. In order to achieve this goal it is not sufficient to develop a systematic means of dissemination, but it becomes necessary to count on strategic communications that “clear the path” of obstacles and enable movement toward the formulation of policies respective of human rights. A strategy of this kind should move away from an evaluation of the context in which it wants to exercise influence, including an analysis that identifies possible allies, adversaries to neutralize, and conceivable scenarios. Simply working off of an analysis of this nature will make it possible to identify the audience which needs to be sensitized and develop the appropriate message for reaching each one of them. The last step, in this schema, will be to specify the activities essential for diffusion, through the most appropriate channels.

However, it can be demonstrated that civil society organizations are in general far from a work scheme similar to the one proposed. The strategy in this area for many civil society organizations depends in a large way on individual desires and the personal intuition of some of their members. While in many cases the “nose” of those who are in charge of these issues proves skillful, it would be helpful to develop more solid institutional capabilities if there is a desire to participate in a more active way in the debate on public policy.

Many civil society organizations even have difficulty in determining key audiences: determiners of policy, public opinion, other civil society organizations that are working on the issue and other social groups directly involved (including, depending on the issue at hand, unions, grassroots organizations, business sectors, ethnic and racial groups, other minorities, etc.); and, among all of these, differentiating potential allies from adversaries. In general, civil society organizations have enormous difficulties in developing appropriately communicative materials for each one of these publics. While these problems are understandable in light of a lack of human and economic resources, they continue to be a large disadvantage for organizations that prepare their pieces for diffusion, producing too many sectors at which to direct themselves or prioritizing one over another.

Another challenge for the participation of human rights organizations in the designing of public policies is preparing the appropriate message. In as far as it is not sufficient to simply identify the situations with violations of human rights, these organizations must develop the necessary institutional capacities to present a discourse which, together with reporting, includes the proposal of the actions that would be able to modify the situation. The participation of organizations in tasks of this kind requires a larger or better capability to communicate, as well as routes for solving the problems that are reported.

Finally, it is also important that the organizations, at the moment of planning the actions of dissemination, develop strategies for working with the different media of communication, without ignoring the advantages and disadvantages that each one represents. It can be demonstrated that many organizations prioritize in almost an exclusive way the work with mass communication media.<sup>30</sup> While it is beyond doubt that the access to the major media becomes a fundamental tool for the discussion of political policies and that, in addition, transplanting and maintaining the debate in this arena guarantees a reasonable level of transparency, this strategy can also entail important costs. On the one hand, in this model the message of the organizations arrives to those who design public policies through an intermediate; on the other, the rules of the political debate in the public opinion are distinct from those that rule the discussion of determiners of policy and, in this context, the

discourse on media has in general a bipolarity that does not facilitate the construction of agreements.

Considering then the limitations of mass media, for participating in the designing of public policy, civil society organizations should explore, for example, the development of tools of communication aimed especially at the public sector, thereby accessing it by alternative routes and lowering the degree of interference with the message. In the same sense, the focusing of the field on mass media communication commercials is necessarily sufficient either for reaching audiences identified above as fundamental for the discussion of public policies.

### *5. The measurement of impact*

“There are few tasks more important, and few more difficult, than adequately measuring advances in the field of human rights and evaluating the impact of human rights organizations.”<sup>31</sup> The humanitarian character of human rights work in many cases means that results can be measured by the number of lives saved. However, these types of indicators prove insufficient for evaluating the general situation of human rights in the context of the current democracies in Latin America.

This difficulty in measuring the current application of fundamental rights has been acquiring growing relevance in the last few years. On the one hand, there are an increasing number of cases in which a diagnostic on the human rights situation in a specific country described by a civil society organization was challenged by governmental authorities. In contrast to what was occurring during the authoritarian government regime who questioned the “ideology” of human rights defenders (who they directly accused of inventing their records), today the governments question the methodology utilized by the organizations and say that the numbers are not representative of the reality. The Colombian case, where there is a virtual “war of statistics” between state authorities and non-governmental organizations is the clearest example of this tendency.

But, in addition, the necessity of designing appropriate mechanisms for measuring advances in the human rights situation is also fundamental for evaluating the impact of civil society organizations. In the section referring to the legitimacy of human rights and citizenship organizations, it is pointed out that one of the possible answers for these growing challenges is linked to the quality of the work carried out. In this sense, the backing of tools for the measurement of outcomes is without doubt a great help in reaffirming the importance of the work developed by these organizations.<sup>32</sup>

Among civil society organizations references to the need for an evaluation



of impact gives rise to many doubts. In the midst of a very demanding daily work dynamic, numerous organizations resist undertaking the task of taking an “inventory of results.” International cooperation has been in this issue part of the problem, in that there is a track record of frustrated initiatives on the part of cooperative agencies, those which promoted the use of a series of indicators (in their majority quantitative) that were difficult to adapt to the needs of civil society.

One of the reasons human rights and citizenship organizations have brandished for explaining the difficulties that must be confronted for the employing of these measurements is that an often changing context impedes the forward movement of profound processes of planning that, by the time which they have been completed have already become noncurrent. This constitutes, without a doubt, a large challenge for civil society organizations, especially in the context of political instability that persists in the region. A very tedious planning process, for example, could conspire to take advantage of unexpected opportunities, which are frequently the only method which participating organizations have in the process of defining policies. The changing context and the lack of a rational discussion between the actors involved that can make their decisions based on sectorial pressure or faced with the necessity of giving quick answers, renders the designing of political policies a process sometimes random and sometimes with an aspect of heteronomy.<sup>33</sup> In this context, it is argued, the identification of benchmarks and indicators can become more of a disadvantage than a tool.

In a manner partially conflictive with the above, another of the repeatedly seen obstacles for an appropriate measuring of impact is that the outcome of human rights work can only be observed in the long term and that to aspire to indicators of success over a couple of years can be counterproductive because it requires the search for immediate achievements that by their nature are more difficult to sustain over time. In this line of argument, the work of human rights and citizenship aspires in the last instance to a cultural change that, as such, requires several generations for its achievement. The advances in the short term must only be understood as small steps on a longer road and thus their immediate impact should be in relative terms.

This relationship between the short term and the long term is fundamental for the evaluation of the work in public policies. In effect, being alert to taking advantage of opportunities that this context offers is indispensable if one wants to advance in the protection of rights and verify that these achievements are preserved over time it is something that can only be evaluated in the long term. This interaction and partial conflict between both levels of work requires a complex approach that often surpasses the experiences of the involved organizations. Especially in the context of instability that predominates in the



political scene of several countries of the region, the unpredictability of the process of designing political policies makes it so that those decisions are fragile and that policies can be revised—and even reversed—with relative ease. It is because of this nature that it becomes necessary to differentiate with more clarity the work in this context surrounding the structural causes of human rights violations. Only in as far as sporadic opportunities are taken advantage of for the advancing of goals in the long term can results be obtained that endure over time.

Perhaps the process that best exemplifies work regarded in a coordinated context with the quest for long-term goals is the work of original human rights organizations in the search for truth and justice for human rights violations committed during the military dictatorships. In this case, human rights organizations took advantage of each opportunity that the situation gave them, even in the adverse context of military regimes, not only for the saving of the lives of persons at risk, but also for avoiding what would have consolidated impunity for these serious crimes. Throughout thirty years of struggle, at the same time that immediate results were pursued (often in response to urgent problems), strategies were designed that were not necessarily going to give rise to advances in the short term, such as lawsuits initiated during the dictatorships and that had to be resolved by judges in the majority of cases associated with *de facto* regimes (and which in many recent cases are beginning to bear fruit.)<sup>34</sup>

Another additional challenge for the evaluation of work in human rights and citizenship is the lack of reliable indicators that not only make the measurement of the results difficult but can also be an additional obstacle for evaluating the human rights situation. On enlarging the work in areas such as social rights, organizations require other instruments of measurement in that the description of the situation on the foundation of eyewitness accounts is not always the best formula. The development of human rights indicators not only would help to measure the impact of the organizations but would also serve as a powerful tool for applying pressure to governments and others possibly responsible for action or omission.

In a world in which there is more and more data for the measuring of political and social situations, with novel indicators that measure the distribution of revenue (as with the Gini index) or the quality of the democracy,<sup>35</sup> to cite a couple of examples, human rights work still appears too much devoted to monitoring on the basis of cases and sponsors that clearly become insufficient for evaluating the much more complex nature of rights violations that are seeking reversion.

At any rate, the difficulties associated with this challenge must not be underestimated. The fact of it is that the carrying out of these tasks requires

a qualification and special training based on relevant data. Few issues have confronted the “old” and “new” generations of human rights defenders like the subject of measuring impact. Many of the activists that initiated the work believe that the development of indicators is a techno-bureaucratic question that does not justify attention. This posture is explained by the fact that, in its beginnings human rights work had very clear, immediate objectives whose achievement was easily verifiable. In a context in which the issue was saving lives and stopping atrocities that were committed on a daily basis, the results were “in sight.” More recently, in as far as the human rights field is becoming more complex with the incorporation of new themes and sponsors of human rights violations, that does not only have to be a state desire, a new generation of professionals has incorporated new work tools such as strategy planning and the development of strengthening schemata, opportunities, weaknesses and threats, that are often strongly resisted by their predecessors.

These differences, which are explained by the training that they have received and the experience of work in the field, is often translated as a confrontation between the more “political” sector, integrated by those who created the organizations and other leaders that, being younger, also have had a personal trajectory of this kind, and others, more technical, who conform to the idea of “professionals of non-governmental organizations.” On the one hand, then, it would be those who do not lose sight of foundational objectives and know how to achieve them without the necessity for “framed logic” (and which, in fact, often have been highly effective); on the other hand, professionals that manage a sophisticated variety of tools that, however, often move away from the political arena.

The scenario seems to indicate the presence of a crossroads at which it is necessary to decide between one of the two options that confront each other instead of going together: activists and strategists versus professionals and managers. Building alternatives among these two possibilities becomes fundamental for the human rights movement in the region, if one wants to maintain levels of historical impact. In the context of an enlargement of the field of work, that makes it much more complex. Only the development of leadership with necessary technical capacities but also backed by the quality of developing effective strategies ensures the necessary capabilities for directing these organizations at a level of systematic change and the obtaining of results on a larger scale.

In order to analyze the role of organizations in the designing of public policies, the measurement of impact can be approached on two levels: on the one hand, evaluating if the participation of these organizations achieved or did not achieve the modification of a specific public policy (in whatever of the four

ways described earlier: rendering invalid a law or public policy; contributing to the designing of a policy; promoting the revision of a law or practice; and participating in putting it into effect); and, on the other hand, demonstrating the effects that these transformations had on the level of the protection of human rights. It should be emphasized that at any rate the change in a policy can mean an advance in of and itself for the protection of rights. This would be the situation, for example, with a law that recognizes mechanisms for the exertion of the right to the accessing of information. Beyond the eventual problems that can exist in the application of a normal dictum, their mere sanction constitutes an advance.

At the first level—if the participation of these organizations achieved or did not achieve a specific public policy—the manual *Advocacy Funding*,<sup>36</sup> identifies three classic ways of measuring the success of initiatives of this nature. The first of the more basic is the evaluation of the process, which should determine if the campaign of impact resulted in the activities and products planned. A second way is the evaluation of the outcome which aspires to evaluate the effect which the campaign produced on the identified targets. The third alternative is more ambitious and refers to the measurement of the impact, that is, determining what effects those activities produced in the process of formulating the policies.

The distinction between advances in the process and the measurement of the outcomes, however, has generated certain confusions. Among civil society organizations it is common to hear that it is convenient to concentrate efforts on the evaluation of the process, in that this would permit a qualitative analysis (which might include, for example, a growing level of collaboration among the organizations), while the measurement of the outcomes would be more limited by including a quantitative perspective. For their part, there are those who point out that the evaluation of the process indicates how rights are to be protected, while the measurement of the outcomes reflects the levels of the effective protection of those rights (Hines, 2005)<sup>37</sup> – a criterion that, applied to work in public policies, would mean the measurement of the impact of the organizations in the changing of a public policy would be the evaluation of the process, while the effects of that policy on the population affected would be the evaluation of the outcome.

The need to strengthen the capabilities for impact measurement in human rights and citizenship, however, does not mean the involvement of reproducing or replicating forms of evaluation imported from other areas. The identification of the measured outcomes, of the realized contribution<sup>38</sup> or of the type of indicators utilized, must necessarily respond to the special characteristics of the work. To illustrate, some of the questions that organizations should ask could include: should we measure the outcome of specific cases or of the

situation in general? Is it possible that improvement in one area of work signifies a worsening in another? Is a lesser advance in a priority area more important than a major advance in an area of secondary concern?

As it has been indicated, many organizations feel uncomfortable with the use of quantitative indicators and prefer to utilize qualitative mechanisms. While whatever systematic evaluation of the impact must include both types of analysis, there is no doubt that qualitative indicators can be a very useful tool for the measurement of outcomes; however, it is essential that those who work in human rights and the promotion of citizenship organize in a more systematic way this information in a way that can dislodge its more general conclusions.

At any rate, without goals and clearly-defined benchmarks<sup>39</sup> or a coherent theory of social change that links both levels of work, the actions of civil society organizations will find it difficult to instigate a responsive improvement in the protection of rights and, although it is possible that they will achieve certain advances, it will be difficult to sustain them over time. The distinction between short term and long term work is the only way to be able to evaluate, to the same extent, the advances in the process as well as the attainment of the outcomes and to be able to check if there are differences between the two levels of analysis.

In summary, in as far as the leadership of human rights and citizenship organizations continues growing and these participate more actively in the designing of public policies, the measurement of impact will be increasingly more relevant. The demonstration of the outcome of their work will be the best defense against attacks that they are already receiving for a supposed lack of legitimacy and representativeness. In some cases, the measurement of the impact will allow presenting a less debatable way of achieving advances and at the same time, will favor the recognition of true government allies for the cause; in others, the verification that nothing has improved or that the situation has gotten worse will mean that organizations should radicalize their critics and, in some cases, revise their actions. As it has been pointed out, there are many good reasons and possible benefits for the human rights movement to develop these indicators of success, but for which it is fundamental that it abandons the position “of the defensive” that it has assumed on this issue and proactively goes after achieving advances in this area.<sup>40</sup> At any rate, organizations must be conscious that if they do not take on the challenge of measuring impact, others will take the initiative.

## NOTES

1. This article was originally published in VARAS, A. et al. *The citizen proposal. A new civil society-State relationship*. Santiago, Chile: Catalonia, 2005. I would especially like to thank all my colleagues at the Ford Foundation Office for the Southern Cone and Andean Region for their valuable feedback on earlier versions of this article. The suggestions of Alex Wilde and Michael Shifter were also extremely useful.

2. SABA, R. El movimiento de derechos humanos, las organizaciones de participación ciudadana y el proceso de construcción de la sociedad civil y el estado de derecho en Argentina. In: PANFICHI, A. (coord.). *Sociedad civil, esfera pública y democratización en América Latina: Andes y Cono Sur*. Mexico – D. F.: Catholic Pontific University of Peru, Cultural Economic Fund, 2002.

3. IGNATIEFF, M. Human Rights: the Midlife Crisis. *The New York Review of Books*, 20 May 1999.

4. Ibid.

5. Some of the conclusions on these reflections can be read in BASOMBRÍO, C. ¿... Y Ahora Qué? *Desafíos para el trabajo por los derechos humanos en América Latina*. Lima: Diakonía Acción Ecueménica Sueca, 1996; ZALAQUETT, J. (coordinator of content). *Temas de derechos humanos en debate. Grupo de reflexión regional*. Lima: Legal Defense Institute, Center of Human Right, School of Law, University of Chile, 2004; and YAMIN, A. *Facing the 21st Century: Challenges and Strategies for the Latin American Human Rights Community*, a rapporteur's report based on July 1999 Conference Organized by The Washington Office on Latin America and the Instituto de Defensa Legal, WOLA.

6. Several people that read a preliminary version of this text insisted on the need to emphasize that human rights organizations and citizenship organizations "are not the same." In effect, at least in Andean Region and the Southern Cone there is a strong dividing line between the identities of these groups. As has been pointed out in the principal text, human rights organizations were created prior, they are led by victims or their representatives and tend to be more intransigent and concentrate their efforts on the reporting of state abuses. In contrast, citizenship organizations have a larger view of the public interest; they may have greater technical or professional expertise and were created in the context of democratic governments and wager more on the proposal than the report. However, the division between both groups continues to be capricious. On the one hand, it is probable that no human rights or citizenship organization is feeling entirely comfortable with the description made regarding these lines and probably would reproach the suggestion that they "do a little of both;" on the other hand this distinction that seems so "obvious" in this region becomes difficult to understand in other parts of the world. In this article the existence of important difference between human rights organizations and those of citizenship are not refuted; however, the similarities between both are also considerable, especially in reference to their participation in the formulation of public policies, and as a consequence, one and the other can be combined in the analysis.

7. The word "impact," or "incidencia" in the original Spanish, has several meanings. María Moliner defines it as an "action to incite: slamming one thing into another at which it is directed" (Dictionary of Spanish Usage, Editorial Gredos, Madrid, 20a reprinting, 1997), while the Royal Spanish Academy maintains in its first entry that it is an "occurrence of what survives in the course of an issue or negotiation and has with it some connection" (<http://www.rae.es/>). However, civil society organizations have come to generalize it as something distinct from any of these. Thus, a manual on the subject explains that "political impact is the effort of the organized citizenry to influence the formulation and implementation of public policies and programs, through persuasion and pressures against state authorities, international financial agencies, and other institutions of power. They are activities directed

at gaining access and influence over persons that have the power of decision in issues of importance for a group in particular or for the society in general." WOLA and CEDPA. *Manual para la facilitación de procesos de incidencia política*, Washington Office for Latin American Issues. (WOLA) and the Center for the Development of Population Activities (CEDPA), March 2005, p. 21. Available online at: <[http://www.wola.org/publications/atp\\_manual\\_para\\_facilitacion\\_jun\\_05.pdf](http://www.wola.org/publications/atp_manual_para_facilitacion_jun_05.pdf)>. Last access on: April 1, 2008.

8. For a description of many other invaluable activities that human rights organizations carry out and have carried out, see GARCÉS, M. and NICHOLLS, N. *Para una Historia de los D.D.H.H. en Chile. Historia Institucional de la Fundación de Ayuda Social de las Iglesias Cristianas FASIC 1975-1991*. Santiago: LOM. Editions, Human Sciences, 2005.

9. FORD FOUNDATION. *Rompiendo la indiferencia. Acciones ciudadanas en defensa del interés público*, Ford Foundation, LOM Ediciones, Santiago, 2000; Idem, *Caminando hacia la justicia. El trabajo en el área del derecho de los donatarios de la Fundación Ford en el mundo*, Ford Foundation, Alfabetar Artes Gráficas, Santiago, 2001; GONZÁLEZ, F. (ed.). *Litigio y Políticas Públicas en Derechos Humanos. Cuadernos de Análisis Jurídico*, Santiago, Series of Special Publications n.14 School of Law, Diego Portales University, 2002; GONZÁLEZ, F. and VIVEROS, F. (eds.). *Defensa jurídica del interés público. Enseñanza, estrategias, experiencias. Cuadernos de Análisis Jurídico*, Santiago, Special Publications Series n. 9, School of Law, Diego Portales University, 1999.

10. KECK, M. and SIKKINK, K. *Activists Beyond Borders: Transnational Advocacy Networks in International Politics*. New York: Cornell University Press, Ithaca, p. 227, 1998.

11. IGNATIEFF, M. Human Rights and the Measurement Revolution, field document presented at the conference *Measuring Progress, Assessing Impact*, Cambridge, Mass., May 2005. COHEN, S. Human Rights Violations: Communicating The Information, Discussion Paper From an International Workshop Oxford 1995 and Related Papers, London, 1995.

12. LOWDEN, P. *Moral Opposition to Authoritarian Rule in Chile, 1973-90*. New York: St. Martin's Press, p. 216, 1996.

13. MIGNONE, E. F. *Iglesia y dictadura*. Buenos Aires: Colihue Editions, reedited, p. 272, 2006. VERBITSKY, H. *El silencio*. Buenos Aires: Editorial Sudamericana, p. 256, 2005.

14. Peruzzotti has written a very interesting analysis on the relevancy but also the misunderstanding that explain many of these challenges. PERUZZOTTI, E. (en prensa). *Civil Society, Representation and Accountability: Restating Current Debates on the Representativeness and Accountability of Civic Associations*. In: Jordan, L. y Van Tuijl, P. (eds.). *NGOs rights and Responsabilites*. London: Erthscan, 2006.

15. PERUZZOTTI, en prensa, op. cit.

16. RAINE, F. (en prensa). The Measurement Challenge in Human Rights. *Sur – International Journal on Human Rights*, n. 4, year 3, São Paulo, 2006.

17. *Corporación Transparencia por Colombia* and *Comisión Colombiana de Juristas* have pushed forward a reflection among civil society organization on the ensuring of their legitimacy. Among the various activities that can be mentioned as steps in the correct direction include the producing of information on activities in a more systematic way (for example, through anual reports that are distributed amongst diverse audiences) or making public sources of financing and accounting on the webpages of organizations.

18. VÁSQUEZ, 2005, op. cit.

19. The issue of the representation of outside interests is especially sensitive in the case of work in strategic litigation. For a debate on the need for those who move ahead this kind of litigation, respecting and learning how to accompany the leadership of those directly affected, see ABRAMOVICH, V. La enseñanza del derecho en las Clínicas Legales del Interés Público. Materiales para una agenda temática. In: GONZÁLEZ, F. y VIVEROS, F. (eds.). Defensa jurídica del interés público. Enseñanza, estrategias, experiencias. *Cuadernos de Análisis Jurídico*, Santiago, School of Law, Diego Portales University, Special Series Publications n. 9, 1999.

20. TISCORNIA, S. Límites al poder de policía. El activismo internacional de los derechos humanos y el caso Walter Bulacio ante la Corte Interamericana de Derechos Humanos. In: TISCORNIA, S. y PITA, M. V. (eds.). *Derechos humanos, tribunales y policías en Argentina y Brasil*. Buenos Aires: Estudios de Antropología Jurídica, Social Anthropology Collection, School of Philosophy and Letters, 2006.

21. For an experience of the difficulties that were confronted by traditional human rights organizations in order to change their relationship with the State even in the middle of the nineties, see ABREGÚ, M. *Democratizando la lucha por los derechos humanos*. Buenos Aires: mimeo, presented at LASA, 1996.

22. SOARES, L. E. La experiencia de la inadecuación: contradicciones y complementariedad entre academia, activismo cívico y militancia política. In: BASOMBRÍO I., C. (ed.). *Activistas e intelectuales de sociedad civil en la función pública en América Latina*. Lima: Institute of Peruvian Studies, 2005.

23. BASOMBRÍO I., C. I. (ed.). *Activistas e intelectuales de sociedad civil en la función pública en América Latina*. Lima: Institute of Peruvian Studies, p. 480, 2005.

24. For many years it was customary among original human rights organizations to question other civil society organizations with the catch-phrase: "And where were you guys during the difficult years?" This is a question that is systematically repeated even at the present in the dialogue between the human rights movement and the feminist movement in Peru (VÁSQUEZ, R. Los un@s y las otr@s: feminismos y derechos humanos. *Filosofazer*, year XIV, n. 26, Brasil, Instituto Superior de Filosofía Bertier, 2005.).

The relationship between human rights organizations and organizations that have been mentioned in this article when referring to "citizenship" were also confronted at their beginnings by these types of questions.

25. IGNATIEFF, 2005, op. cit.

26. KECK and SIKKINK, 1998, op. cit., p. 13.

27. These openings are in general related to certain "invisible" elements or even histories of prejudice in a specific country that reproduce themselves at the interior of civil society organizations. For example, the work of international organizations was fundamental for promoting the inclusion in the human rights agenda of issues of gender as well as ethnicity and race.

28. I would like to especially thank Alex Wilde for his insightful comments on the first version of this section, while acknowledging that the text is the exclusive responsibility of the author.

29. This expression is used to describe the strategy carried out by human rights organizations of identifying the country or individual human rights violator and exposing them in view of public opinion in order to force them to modify their behavior.



30. In point of fact, in many cases communication media are mentioned as one of the sector that civil society organizations must establish strategic alliances with. In this article it has been preferred not to include them as possible counterparts and to consider them only as a channel for disseminating their work. This approach avoids considering the communication media as an ally because it means describing them as a corporate entity in a sector that only exists around particular issues (such as freedom of expression or access to information).

31. IGNATIEFF, 2005, op. cit., p. 1.

32. RAINE, 2006 (en prensa), op. cit.

33. There are very few endeavors that analyze the context in which civil society organizations attempt to influence public policies. A recent study on the work of think tanks at a regional level sheds a certain amount of light on this area (BRAUN, M.; CHUDNOVSKY, M.; DUCOTÉ, N. y WEYRAUCH, V. *A Comparative Study of Think Tanks in Latin America, Asia and Africa* (working Paper from the second phase of the project Global Development Network's Bridging Research and Policy). Center for the Implementation of Policies Promoting Equity and Growth - CIPPEC, 2005.); however, even it involves insufficient information and tackles this question in an incidental and non-central manner. Lamentably, this article suffers from the same deficit.

34. ABREGÚ, M. Apostillas a un fallo histórico. *Cuadernos de Jurisprudencia y Doctrina*, Buenos Aires, year IX, n. 16, Editorial Ad-Hoc, 2003, p. 39 onward.

35. VARGAS CULLELL, J.; VILLARREAL, E. and GUTIÉRREZ, M. Auditorías ciudadanas sobre la calidad de la democracia: una herramienta para la identificación de desafíos democráticos. In: O'DONNELL, G.; IAZZETTA, O. and VARGAS CULLELL, J. *Democracia, desarrollo humano y ciudadanía. Reflexiones sobre la calidad de la democracia en América Latina*. Sante Fe-Argentina: HomoSapiens Ediciones, United Nations Program for Development, Regional Direction for Latin America and the Caribbean, 2003.

36. GRANTCRAFT. *Advocacy Funding. The Philanthropy of Changing Minds*. GrantCraft Practical Wisdom for Grantmakers, 2005. Available online at: <[www.grantcraft.org](http://www.grantcraft.org)>. Last access on: March 31, 2008.

37. HINES, Andrew. What Human Rights Indicators Should Measure. Measurement and Human Rights: Tracking Progress, Assessing Impact. (working paper) A Carr Center Project Report. Summer 2005. Available at: [www.hks.harvard.edu/cchrp/pdf/Measurement\\_2005Report.pdf](http://www.hks.harvard.edu/cchrp/pdf/Measurement_2005Report.pdf).

38. The advances in any area of human rights work can only with great difficulty be the product of the actions of a specific organization, and therefore the level of contribution in a context with many actors can be an additional complexity in measurement of impact. For this reason it has been proposed to prefer the impact of a field instead of the impact of an organization in particular.

39. The author is aware that the concepts of "goals", "benchmarks" and outcomes can have more than one meaning and that often the translation of the English to Spanish has been a cause for confusion. This is not the place to pursue that discussion. These assertions are generally valid with any of the accepted meanings that have been attributed to the terms among civil society organizations and cooperating agencies.

40. RAINE, 2006 (in the press), op. cit.



## RESUMO

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O movimento de direitos humanos e cidadania foi um ator-chave nos processos de consolidação democrática que ocorreram na Região Andina e no Cone Sul durante as últimas duas décadas. No entanto, as organizações da sociedade civil precisam modificar suas estratégias nas novas conjunturas pós-ditatoriais. Neste artigo, serão identificados alguns dos desafios centrais que essas organizações devem enfrentar.

### PALAVRAS-CHAVE

Organizações da sociedade civil – Novos modos de atuação – Democracia – América Latina – Políticas públicas

## RESUMEN

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El movimiento de derechos humanos y ciudadanía ha sido un actor clave en los procesos de consolidación democrática que han tenido lugar en la Región Andina y el Cono Sur durante las últimas dos décadas. Con todo, las organizaciones de la sociedad civil necesitan modificar sus estrategias en las nuevas coyunturas post-dictatoriales. En este artículo se identificarán algunos de los desafíos centrales que deben enfrentar esas organizaciones.

### PALABRAS CLAVES

Organizaciones de la sociedad civil – Nuevos modos de actuación – Democracia – América Latina – Políticas públicas



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#### ABSTRACT

The Article examines the Convention on the Rights of Persons with Disabilities, which is the first human rights instrument of the millennium to understand how the disability rights discourse has been altered, and to contribute to human rights jurisprudence. This is because the Convention alters the lexicon of disability rights and offers fresh insight on the way to resolve some perennial human rights dilemmas.

Original in English.

#### KEYWORDS

Persons with disabilities – Welfare – Discrimination – Autonomy –  
Indivisibility - Participation



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# CONSTRUCTING A NEW HUMAN RIGHTS LEXICON: CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Amita Dhanda

## I. Introduction

The emergence of a unipolar world has resulted in traditional understandings of international law to be challenged. This challenge has included the raising of queries on the relevance of the United Nations system, which was founded on the power dynamics of the post war world. The United Nations it has been contended is not in harmony with the hopes and aspirations of the global south and operates much more like the hand maiden of the first world countries.<sup>1</sup> Further the human rights instruments which were a mechanism to obtain accountability from States have yielded meager benefits to the people on the ground; instead these Charters of universal values have become a convenient stick in the hand of the first world with which to batter the third world. These criticisms along with others have prompted some of the structural reform efforts that engage the attention of the World body. Amongst them being a reconstitution of the permanent members of the Security Council; and the effort to restructure and reform the treaty implementation bodies.<sup>2</sup>

It is in this environment of growing skepticism, which the reform efforts have in no way curbed, that the United Nations has adopted the Convention on the Rights of Persons with Disabilities. A new human rights convention may not arouse optimism, especially when the convention addresses the concerns of a special group as is the case with the United Nations Convention on the Rights of Persons with Disabilities (hereinafter CRPD), which was adopted by the General Assembly on the 13<sup>th</sup> of December, 2006 and was opened for

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*Notes to this text start on page 37.*

signature by State parties on 30<sup>th</sup> March, 2007. The Convention required 20 ratifications to come into force and the last of these instruments was deposited with the UN Secretariat on 3<sup>rd</sup> of April 2008. The Convention thus came into force on the 3<sup>rd</sup> of May.<sup>3</sup>

Insofar as international human rights law goes, the process of negotiating, drafting, adopting and enforcing the CRPD has been a relatively quick one. Despite these happy developments, persons with disabilities are continually informed that their expectations from the United Nation system were naive and unreal.<sup>4</sup> Studies documenting the impact of the Women's Convention<sup>5</sup> and the Child Rights Convention are often mentioned in order to establish this point. As already mentioned the CRPD has just obtained the last of the ratifications that was required to bring it into force. As the CRPD is just about ready to come into force, it is neither empirically possible nor normatively desirable to assess whether or not it will change the situation of persons with disabilities on the ground. It is important to note that the CRPD is a human rights instrument and hence universal law. Though the explicit provisions of CRPD enunciate the rights of persons with disabilities; the philosophy informing these rights, as also the procedure followed for arriving at the text of the CRPD cannot be limited to disability alone. The CRPD can thus be appropriately introduced as the most recent member of the human rights family. In this capacity, it is necessary to obtain acquaintance with the CRPD not just to understand what it promises to persons with disabilities; but also to comprehend what it contributes to human rights jurisprudence. Consequently in this article I examine the CRPD in order to highlight and analytically describe what the Convention does for disability rights and how it contributes to human rights jurisprudence. Before I undertake this analysis, primarily to provide a socio-political context to the adopted text I briefly describe the developments which informed the movement for a special convention for persons with disabilities.

The present move to persuade the United Nations to adopt a human rights convention for persons with disabilities was not the first of its kind. Efforts to obtain a disability rights convention had been earlier made by Sweden and Italy but without success. The previous initiatives were turned down on the reasoning that disability was in no way excluded from general human rights instruments; consequently there was no need to adopt a special convention on disability rights. Despite these claims of normative inclusion the ground level experience of persons with disabilities was one of deprivation. These rejections in effect, invisibilized both persons with disabilities and the disability experience. As the lived experience of persons with disabilities in no way matched the reasoning used to shoot down a special convention, an effort to persuade the world body was made yet again by Mexico.

It is significant to note that even as the international community did not accede to the claims of persons with disabilities for a special convention it admitted to the ground level difficulties encountered by persons with disabilities by adopting Standard Rules on the Equalization of Opportunities for Persons with Disabilities<sup>6</sup> and the World Program on Action. Prior to the adoption of these implementation supporting documents the world body also proclaimed the UN Declarations on the Rights of Mentally Retarded Persons<sup>7</sup> Rights of Disabled Persons<sup>8</sup> and the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental HealthCare.<sup>9</sup> These soft law instruments which were adopted without the participation of persons with disabilities signify how the non disabled world perceive disabilities and hence create a lower standard of rights for persons with disabilities. It is significant that whilst the CRPD recognizes the efforts made through the World Program of Action and the Equalization Rules<sup>10</sup> it maintains a total silence on the two Declarations and the MI principles. This silence has been maintained because persons with disabilities were highly critical of the pejorative and patronizing tone of these soft law instruments. A comparison of these instruments and the CRPD, which is not the objective of the present article, illuminates the differences between the welfare and the rights approach.<sup>11</sup> These instruments which had no binding legal force are being mentioned primarily to highlight the paradigm shift that the CRPD makes in enunciating the rights of persons with disabilities. It is to those ideational changes that we now turn.

## **II. What has the CRPD done for persons with disabilities?**

It is my view that the CRPD has done the following for persons with disabilities: it has signaled the change from welfare to rights; introduced the equality idiom to grant both same and different to persons with disabilities; recognized autonomy with support for persons with disabilities and most importantly made disability a part of the human experience.

### ***From welfare to rights***

The CRPD is not the first international instrument that has engaged with the issue of disability. The Declarations and Equalization Rules have already been mentioned. An examination of soft law instruments and especially the Equalization Rules shows how the Rules were almost an exclusive engagement with social economic rights. Thus in the preconditions for equal participation the CRPD mentions awareness raising;<sup>12</sup> medical care;<sup>13</sup> rehabilitation<sup>14</sup> and support services.<sup>15</sup> In the target areas for equal participation the Equalization

Rules refer to accessibility;<sup>16</sup> education;<sup>17</sup> employment;<sup>18</sup> income maintenance and social security;<sup>19</sup> culture;<sup>20</sup> recreation and sports;<sup>21</sup> and religion.<sup>22</sup> Except for Rule 9 which speaks of family life and personal integrity the Equalization Rules, only engaged with policy rights<sup>23</sup> that made good the developmental deficits faced by persons with disabilities. There was an ominous silence on civil political rights in all these instruments.

Thus no need was felt to guarantee to persons with disabilities the right to life, right to liberty and security, the freedom of speech and expression or the right to political participation. The absence of a regime of civil political rights for persons with disabilities significantly contributed to the welfarist approach because international human rights law has conferred the qualities of immediacy and justiciability to civil and political rights. Social economic rights are progressively realized subject to availability of economic resources. The gradualness of realization renders these rights constantly negotiable. The characteristics of immediate availability and justiciability contribute to the non-negotiable visage of civil and political rights, and enable the bearers of these rights to assert them without defensiveness or shame.<sup>24</sup> In the absence of a civil and political rights regime, persons with disabilities were unable to assertively claim their rights; they had to continually negotiate for the same.

The CRPD recognizes that persons with disability have right to life on an equal basis with others.<sup>25</sup> This affirmation in itself without more challenges the belief that a disabled life is a less valued life and hence it does not need to be protected. The right to life is an assertion that difference of disability contributes to richness and diversity of the human condition and is not a deficit that has to be selected out.

The value of the disability perspective is reinforced by other civil and political rights such as the right to liberty and security,<sup>26</sup> freedom of speech and expression;<sup>27</sup> physical and mental integrity.<sup>28</sup> The right to political participation is an acknowledgement that the lives of persons with disabilities cannot be organized by non-disabled others<sup>29</sup> and there is a disability dimension to every law and policy hence such laws and policies should not be finalized without the full participation of persons with disabilities.<sup>30</sup>

### ***Equality and non-discrimination***

The CRPD is sworn to the objective of non-discrimination evidenced in the right to equality. However the recognition of this right has caused to surface the age old questions which surround the discourse of equality. What do persons with disability want: Do they want the same as non-disabled world or do they want different? Do all persons with disabilities want the same or do they want different? This conundrum of sameness and difference has haunted every

excluded group in its journey of inclusion. The CRPD has avoided this interminable debate by seeking both same and different. Thus whilst persons with disabilities are entitled to the same respect and dignity as the rest of the humanity;<sup>31</sup> they are also entitled to reasonable accommodation<sup>32</sup> of their difference in order to obtain the outcome of inclusion and full participation.<sup>33</sup>

The issue of sameness and difference is not only relevant in the context of the disabled and the non-disabled world. It holds as much significance whilst determining the relationship between different segments of the disabled world for example how should the question of inclusion in education be addressed, when there are disadvantages in ghettoizing persons with disabilities in special schools and yet there are special skills that persons with disabilities need to learn for their own capability development. The convention has once again not opted for an either or choice but has chosen to allow both same and different. Thus for example article 24(3) requires states parties to “enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community”. And 24 (3) (c) then requires states parties to ensure “that the education of persons and in particular children who are blind, deaf or deafblind is delivered in the most appropriate languages and modes and means of communication for the individual and in environments which maximize academic and social development”.<sup>34</sup>

### *Autonomy and support*

The third issue on which the CRPD significantly contributes in altering the accent of the rights of persons with disabilities is the issue of autonomy and support. An examination of the legal systems across the world shows that if there is one body of persons who has not been recognized as people who have the ability or capacity to be able to manage their own lives – it is persons with intellectual and psychosocial disabilities.<sup>35</sup> This belief in the incapacity of persons with psychosocial and intellectual disabilities has been accorded legislative recognition through laws that deny legal capacity to persons with disabilities. These laws disqualify persons with disabilities from taking their own life decision in matters of treatment, marriage or residence and prevent them from managing their own affairs by a blanket denial of contractual capacity. The CRPD has tried to remedy this deep discrimination by firstly recognizing that all persons with disabilities are persons before the law.<sup>36</sup> However this recognition is not confined to only reaffirming the legal identity of persons with disabilities as subjects of right. The Convention is also according to persons with disabilities the agency to manage their own affairs.<sup>37</sup> This agency is not grounded in the paradigm of independence but in that of



interdependence. The interdependence paradigm lays down that capacity and support can be co-terminus. A person with disability does not have to pronounce himself incapable in order to obtain support. Consequently the CRPD recognizes that a person with disability may need support to exercise capacity,<sup>38</sup> yet the obtaining of the support is no reason to conclude that capacity does not exist. This paradigm of interdependence which allows both autonomy and support to co-exist is a major advance that the Convention has made in establishing rights regime for persons with disabilities. In recognizing autonomy with support the CRPD has given voice to persons with disabilities, made persons with disabilities an integral part of the polity and thus accorded space to the disability perspective on the world.

### **III. Contribution of CRPD to human rights jurisprudence**

The CRPD is the first human rights convention of the new millennium. To that extent its normative jurisprudence is not just of relevance to persons with disabilities but also important to all advocates of human rights. The convention requires special attention because it has what I term the wisdom of a straggler. By this, what I mean is that the CRPD gains from the mistakes made or the obstacles discovered in the working of the other human rights conventions. It is important to examine this convention for the fresh perspective it provides on the basic dilemmas of human rights advocacy.

#### ***Indivisibility of human rights***

It has been long recognized that international human rights law has created a false dichotomy between civil and political rights, by one side, and social and economic rights, by the other. The Universal Declaration of Human Rights was a composite document incorporating civil, political, social and economic rights. However the succeeding conventions<sup>39</sup> introduced a divide between two sets of rights and further provided that whilst civil and political rights shall be immediately available; social and economic rights shall be progressively realizable. The logic for this difference of enforcement was situated in the manner in which the two sets of rights were classified. Thus whilst civil and political rights were termed negative; social and economic rights were seen as positive in their content. The presumption being that whilst States need to expand resources to uphold social and economic rights, no such correlative obligation needed observance in order to respect civil and political rights.

Henry Shue in his study on basic rights has exploded this myth.<sup>40</sup> It is Shue's thesis that it is incorrect to classify rights as positive or negative. He convincingly demonstrates that both civil and political rights and social and

economic rights give rise to positive and negative duties. The right to security for example is not realized just by the State observing its duties of avoidance whereby the citizen is not arbitrarily deprived of his right to life and liberty. The recognition of this civil right also requires the State to perform active duties of protection. And if it fails in providing protection it would need to extend aid be it to riot victims or civilian victims of war. For example the right to security cannot be guaranteed to citizens unless the state creates adequate infrastructure to protect the right. Hence Shue holds that the rights to subsistence and security should be guaranteed to all persons without quibbling on availability of resources; this is because without these basic rights it would not be possible to guarantee any of the other rights be they civil, political, social or economic. Unfortunately, despite its great logical and moral coherence Shue's thesis has not won the day in international law and the artificial dichotomy between civil and political rights and social and economic rights continues to be reiterated. The CRPD provides human rights advocates an opportunity to revisit this false division and once again set up a case for the indivisibility of rights.

The process of recognizing the rights of persons with disabilities mandated the creation of hybrid rights. For example the recognition of the right to speech and expression for persons with disabilities, provision has to be made for alternative and augmentative modes of communication, as without such provision the right would be meaningless. This connection that the CRPD makes between civil and political rights and infrastructure development is not unique to persons with disabilities; it is required for all persons. However by reason of the special needs of persons with disabilities this connection had to be made explicitly in CRPD. And as civil and political rights are immediately available, such like infrastructure development would have to be provided for contemporaneously and not progressively. Human rights advocates especially in the developing countries would be well advised to take note of this new development in the international law which could strengthen grass root advocacy for infrastructure development.

The indivisibility of civil and political rights, by one side, and social and economic rights, by the other, needs to be addressed not just when civil and political rights are provided for but also when provision is made for social and economic rights.<sup>41</sup> Illustratively state programs in furtherance of the right to food can be planned and executed without participation of the beneficiary of the program. Such non-consultative upholding of rights undermines dignity and negates the choice of the beneficiary. Thus whilst the programs carry the label of rights the beneficiaries cannot assert these rights as claims without defense or shame. In fact such like programs are a continuous affront to the self respect of the beneficiaries. The CRPD has useful learnings on participation

rights in so far as it makes the right to participation a general obligation of the States. The States are required to consult with persons with disabilities on all policies and laws affecting them. This incorporation has transformed the slogan 'nothing about us without us' from a campaign anthem to a non-negotiable principle of disability rights. Yet again it would be appropriate for human rights advocates to learn from the CRPD and analogically extend the learnings of the convention to sites other than that of disability rights.

### *Human interdependence*

The CRPD has not just reopened the issue of indivisibility of rights; it has also revisited the construction of the human. An examination of human rights instrument shows that the human has been constructed as a self-reliant and self-contained being who does not need anybody else. Feminist theory has convincingly demonstrated that this perception of self reliance and independence is a patriarchal myth.<sup>42</sup> It is a patriarchal myth because the support which is obtained by the so called self reliant persons can be obtained without recognizing or acknowledging it in any manner. The public private divide allows men to make claims of self-reliance in the public domain as they can bank on the women behind the scene, to address their human neediness.

Persons with disability on the other hand possibly because of their impairments need to seek support in a more open and forthright manner. This explicit seeking of support makes possible the recognition of human interdependence. This recognition of interdependence is not a declaration of incapacity, but an honest acknowledgement that persons with disabilities may require support to exercise their capacities. This model is emancipatory not just for person with disabilities but for all of humanity. The model is emancipatory because it allows a person to admit deficits without feeling diminished. The model acknowledges the fact that we human animals are in need of each other.<sup>43</sup> The veracity of this proposition is borne out if a life course approach to the human life is adopted. There are very few stages in life that support the myth of self reliance. Childhood, adolescence, old age, and illness are obvious examples of human vulnerability and neediness. Humans have to and continually need to support each other in various kinds of ways but this mutual support in real life finds no juridical recognition. Consequently our jurisprudence continues to talk about independence. By setting up the paradigm of supported decision making, the CRPD unequivocally declares that it is possible to obtain support without being lessened or diminished. This paradigm of interdependence should be empowering and emancipatory for all of humanity and not just persons with disabilities.

### *Double discrimination*

Another question which has constantly dogged human rights jurisprudence revolves around the issue of double discrimination. How should human rights jurisprudence address the vulnerability of those who are disadvantaged on more than one parameter? Be it gender combined with race or disability combined with ethnicity or age or gender. It is possible to come up with multiple formations of discriminated groups.<sup>44</sup> The question is how this double and multiple discrimination should be addressed. The issue of double discrimination came to the fore when the Women Convention had been negotiated. However at that juncture it was felt that any acknowledgement of multiple discrimination would dilute CEDAW's challenge of sex discrimination. Consequently except for a notional mention of rural women,<sup>45</sup> CEDAW constituted women as a universal category with this understanding that questions of double discrimination shall be addressed at the point of implementation.<sup>46</sup> Even as the Women's Committee has issued a General Comment on the rights of women's with disabilities<sup>47</sup> these promises relegated to the arena of implementation have been far from realized. The Convention on the Rights of the Child (CRC) answered the question of double discrimination a trifle differently in so far as a dedicated article on children with disabilities was included in the CRC.<sup>48</sup> This article was included in the CRC with the understanding that while the children with disability would be entitled to all the rights guaranteed in the CRC, their special interests would be taken care of in the dedicated article. Unfortunately the concern of children with disabilities was ghettoized in the dedicated article.<sup>49</sup> The CRPD was also required to engage with the issue of multiple discrimination. However, possibly because of the learnings from both the CEDAW and the CRC, the CRPD has devised a new strategy to address the issue of double discrimination, which can be termed the twin track approach.

This twin track approach guarantees to women and children both same and different. Thus whilst dedicated articles have been included in the convention to address the concerns of women<sup>50</sup> and children with disabilities,<sup>51</sup> gender and age concerns have also been incorporated in several general articles of the CRPD on issues of special concern to these constituencies. Thus for example the article on liberty of movement and nationality explicitly mentions that children with disability shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and cared for by their parents.<sup>52</sup> And the right to health expressly requires State parties to provide for health services that are gender sensitive.<sup>53</sup>

With the adoption of twin track approach CRPD has devised a new strategy to address the issue of multiple discrimination. This approach requires that the

special concern of the vulnerable group be addressed in a dedicated article and simultaneously the general articles also take on board the distinct concerns of special groups. And thus the doubly discriminated should be doubly compensated. In so far as such discrimination is not only encountered by persons with disabilities, it would be appropriate for human rights advocates to engage with this new precedent in international human rights jurisprudence.

### *Right to participation*

International law is an agreement between State parties; hence people have little role in the making of this law. In the more recent past efforts are being on to enhance peoples participation to curb this obvious disadvantage of international law. Ironically this induction of the perspective of the people is largely controlled by the will of the State. The negotiation of the CRPD as also the text which has emerged from these negotiations has put in place a new paradigm of people's participation.

The General Assembly resolution that setup the Ad Hoc Committee to negotiate the CRPD expressly required the State parties to arrive at the text of the Convention in consultation with civil society i.e. people with disabilities, organizations of people with disabilities, human rights institutions and other civil society associations.<sup>54</sup> This resolution of the General Assembly received the most liberal interpretation from the various Chairpersons of the Ad Hoc Committee. This resolution, interpretation and practice have established a new precedent on people's participation in the making of the international law. Even as these developments have occurred in the field of disability rights, their application need not be so confined. For wider application and analogical use it is important that human rights advocates closely study the manner in which the civil society participation was ensured during the negotiation for CRPD. A brief narration is hereby made in order to whet the advocacial appetite.<sup>55</sup>

The setting up of a working group, to produce a working text was amongst the first decisions that the Ad Hoc Committee undertook towards its duty of reaching an agreed text for the CRPD. Insofar as the States as a whole would be reacting to the Working Group text, in the first place it was this working text which would form the basis for the proposed Convention. It is significant that organizations of people with disabilities along with human rights institutions were full members of this Working Group and optimally utilized this opportunity to educate State parties on issues and concerns of persons with disabilities. More significantly the working text which emerged from this process bore the indelible stand of civil society participation. This advantage obtained in the base text by organizations of people with disabilities,

significantly influenced the tone and tenor of negotiations in the Ad Hoc Committee. The participative right wrested by the organizations of people with disabilities in the Working Group was not surrendered by them at any juncture of the subsequent negotiations.

Ordinarily negotiations for international legal texts are undertaken in informal sessions and in order to aid flexibility and consensus no formal records are maintained of the deliberations in the informal sessions. Early in the negotiations for the CRPD it was resolved that civil society organizations will not have the right to speak in informal sessions. The informal sessions for CRPD occurred in the same room which was allocated for the formal meeting of the Committee. Thus though they did not have a right to speak, civil society organizations were allowed to remain present during the informal deliberations between States parties. Moreover as deliberation on any major article was concluded between States parties in the informal sessions, chairpersons took to convening formal sessions in order to provide opportunity to civil society organizations to express their views on the article under discussion. This near seamless switchover from informal to formal enabled the views of the people with disabilities and their organisations to be given full voice. On some of the controversial issues of the Convention thematic groups were constituted, wherein the views of people with disabilities and their organisations were generally sought and provided.

Ordinarily, even when civil society participation has been inducted during the making of international law; the negotiation of final texts has always occurred between State parties. The opinion of civil society has not been determinative of the process. The negotiations for CRPD have altered this practice of international law. As already mentioned the directive of the General Assembly was liberally construed in order to obtain inputs from people with disabilities and their organizations. To allow for efficient induction of the perspective of organizations of people with disabilities, persons with disabilities started to convey their opinion to the Ad Hoc Committee through an international caucus. The International Disability Caucus was a loose network formed at the United Nations by more than 70 international, national and regional disability organizations which were registered with the Department of Economic and Social Affairs (DESA). The unification of the disability voice substantially contributed the leverage acquired by people with disabilities and their organizations in the negotiation for the Convention. It is this leverage alone that explains why State parties towards the end of the process were unwilling to moot any textual proposal without obtaining the prior approval of people with disabilities and their organizations. The right to participation as constructed during the negotiations for the CRPD constitutes a precedent in international law which merits close study and replication.



### *The way forward*

CRPD was opened for signature on 30<sup>th</sup> of March, 2007. A record 82 signatures were appended to the document on the inaugural day. Now that the CRPD has obtained the required 20 ratifications for the Convention and shall soon come into force, the Convention has become operative international law for the ratifying countries. The present international situation can be stated to be as follows: countries that have signed the CRPD; countries that have both signed and ratified and countries that have neither signed nor ratified the Convention.

This gap between signature and ratification also subsists because countries differ in the approach towards ratification and in the procedure by which countries induct norms of international law into municipal law. A number of countries do not ratify a convention till they have modified all domestic laws and policies and brought them into conformity with the international convention. For these countries the deposit of the instrument of ratification is no more than a formality as they would have fulfilled all their commitments emanating from the international instruments. Other countries take stock of the domestic situation and if they believe there is nothing in the international instrument with which they have disagreement they go ahead and ratify the instrument. It is important for civil society organizations to distinguish between the two processes of ratification and devise their advocacial strategies accordingly.

It is an established proposition in international law that a State is bound by the provisions of an international treaty only after it deposits the instrument of ratification. It is this proposition that causes organizations of people with disabilities to press early ratification by their respective countries. Even as the impatience of people with disabilities and their organization is understandable, it would rather unfortunate if this impatience may cause them to sacrifice the advantage obtained from the signature of the Convention. When a State party signs an international convention it undertakes that it shall not carry out any activity which is opposed to the mandate of the convention. Thus whilst ratification brings in a positive obligation signature inducts a negative duty. It would be unwise to accord no significance to this negative duty. At the very least this duty places an embargo on any other laws and policies which diminish the rights of persons with disabilities.

In conclusion I wish to refer to those kinds of tasks which disability rights activists can undertake to ensure that the promises of the CRPD are in fact be realized for persons with disabilities. International human rights law is arrived by consensus, and in the bid to obtain consensus, State parties perforce accept and agree to open textured language. This open textured



language then tends to create the impression that the demands of international human rights law are rather meager. A close study of the preparatory papers will show the various alternatives that were considered by the State parties, before consensus on the final text was reached. The open texture of the text masks this process. It is important therefore for disability rights activists to be aware of the various alternatives that were on offer, and use advocacy to lobby that the more aspirational interpretation be inducted in the national law. In this manner civil society can help raise the bar and prevent international law from being just an agreement on the least common denominator.<sup>56</sup>

On another note the Convention has given birth to hybrid rights. Hybrid rights are those rights which have components of both civil and political rights, by one side, and social and economic rights, by the other. The creation of these rights has strengthened the indivisibility of rights discourse in human rights jurisprudence. The question is how would these rights be interpreted? Would they be dictated by the jurisprudence of civil and political rights? Or would they be guided by the theories surrounding social and economic rights? The ambiguous text of Article 4 (2) of the CRPD allows for either kind of interpretation.<sup>57</sup> It is therefore necessary that disability rights activists are quick on the draw and generate sufficient literature which would guide the policy and law thinking on rights of persons with disabilities.

Lastly the CRPD has provided new answers to some of the questions which have been dogging human rights jurisprudence for long. Illustratively questions on the entitlements of persons with psychiatric disabilities have been raised in the context of the Convention against Torture. It would be appropriate if instead of seeking answers all these questions in the Torture Convention alone, efforts were made to build bridges between the Torture Convention and the CRPD especially as the CRPD provides for rights to liberty, integrity, and legal capacity to all persons with disabilities. These rights can be employed to reinforce the mandate of the Convention against Torture. This strategy cannot be confined to the Convention against Torture similar initiative can be launched to strengthen the jurisprudence of the Women's Convention and the Child Rights Convention.

The unrelenting advocacy of persons with disabilities and their organizations has resulted in the adoption of the CRPD by the United Nation in record time. It goes without saying that this text shall greatly inform disability rights discourse from here on. However it would be unfortunate if normative and institutional innovations devised by the Convention are restricted in their application to disability alone. The Convention reconstructs both "human" and "rights" in human rights, it is therefore appropriate that human rights advocates engage with and draw on the learnings of this first human rights convention of the new millennium.

## NOTES

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1. For a bibliography of writings on reforming the United Nations see <<http://www.un.org/Depts/dhl/reform.htm>>. Last visited on: 12 Apr. 2008.
2. MORIJN, J. *UN Human Rights Treaty Body Reform Towards a Permanent Unified Treaty Body*. Available at: <<http://www.civitatis.org/pdf/untreatyreform.pdf>>. Last visited on: 12 Apr. 2008.
3. Article 45(1) of the Convention on the Rights of Persons with Disabilities (CRPD) lays down that the Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.
4. BYRNES, A. *Convention on Rights of Persons with Disabilities*, presentation made at the Critical Legal Studies Conference at NALSAR Hyderabad India 1<sup>st</sup> to 3<sup>rd</sup> Sep. 2006.
5. For a comprehensive analysis of women's engagement with the United Nations see JAIN, D.. *Women development and the UN - A sixty year quest for equality and justice*. Hyderabad: Orient Longman Hyderabad, 2005.
6. Adopted by General Assembly resolution 48/96 of 20<sup>th</sup> Dec. 1993.
7. Proclaimed by General Assembly Resolution 2856 (XXVI) of 20<sup>th</sup> Dec.1971.
8. Proclaimed by General Assembly Resolution 3447 (XXX) of 9<sup>th</sup> Dec.1975.
9. Adopted by General Assembly Resolution 46/119 of 17<sup>th</sup> Dec. 1991.
10. CRPD. *Preamble*, paragraph f.
11. Illustratively Paragraph 5 of the Declaration on Mentally Retarded Persons declares that a mentally retarded person has a right to a guardian and article 12 of the Convention speaks of universal legal capacity and support to exercise capacity.
12. Standard Rules on the Equalization of Opportunities for Persons with Disabilities, rule 1.
13. *Idem*, rule 2.
14. *Idem*, rule 3.
15. *Idem*, rule 4.
16. *Idem*, rule 5.
17. *Idem*, rule 6.
18. *Idem*, rule 7.
19. *Idem*, rule 8.
20. *Idem*, rule 10.
21. *Idem*, rule 11.
22. *Idem*, rule 12.
23. Rights theorists make an important distinction between respect and policy rights. Whilst the first are absolute and non negotiable the latter are linked with resources and subject to negotiation. Socio-economic rights are generally referred to as policy rights in such categorization. Henry Shue

with his thesis on basic rights and SEN, A. Development as Capability Expansion. In: FUKUDA-PARR; S. & SHIVA KUMAR, A. K. (eds.). *Readings in human development*, 2003 and NUSSBAUM, M. *Frontiers of justice disability, nationality species membership*. New Delhi: Oxford University Press, 2006 with the capabilities approach are two efforts to attempt to promote at least some social – economic rights in a more unequivocal manner.

24. Henry Shue (SHUE, H. *Basic rights subsistence affluence and US foreign policy*. Princeton: University Press Princeton, 2<sup>nd</sup> ed., 1996) relies on Joel Feinberg (FEINBERG, J. *Social Philosophy*. Englewood Cliffs: Prentice Hall Inc., 1973) posits that the ability to demand it without shame is an integral component of a claim right. And it is because of this dignity that they confer on the rights holder that such rights are viewed as integral for promoting the innate respect of human beings.

25. CRPD, article 10.

26. Ibid, article 14.

27. Ibid, article 21.

28. Ibid, article 17.

29. Ibid, article 29.

30. Ibid, article 4(3).

31. Ibid, article 5(2) which requires states parties to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds”.

32. Ibid, article 2 defines reasonable accommodation to mean necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others all human rights and fundamental freedoms.

33. Ibid. article 5(3).

34. For information on the state of the law on legal capacity see DHANDA, A. Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future. *Syracuse Journal of International Law and Commerce*. New York, v. 34, n.2, 2007, p. 429-462,

35. CRPD, article 12 (1).

36. Thus article 12 (2) states that “states parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”.

37. Article 12 (3) which requires states parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”.

38. That is the International Covenant on Civil Political Rights adopted and opened for signature, ratification, and accession by General Assembly Resolution 2200 A (XXI) of 16<sup>th</sup> Dec. 1966. The Convention entered into force on 23<sup>rd</sup> Mar. 1976 and the International Covenant on Economic, Social and Cultural Rights adopted and opened for signature, ratification, and accession by General Assembly Resolution 2200 A (XXI) of 16<sup>th</sup> Dec. 1966. The Convention entered into force on 3<sup>rd</sup> Jan. 1976.

39. SHUE, supra note 24.

40. On the importance of the right to dignity see Nussbaum, *supra* note 23.
41. See especially YOUNG, I. M. *Justice and the Politics of Difference*. Princeton: Princeton University Press, 286 p., 1990.
42. For an extended treatment of this dimension of humanness see NUSSBAUM. *Frontiers of Justice*, *supra* note 23.
43. On a complex articulation of the phenomenon of double discrimination see FRASER, N. & HONETH, A. *Redistribution or recognition: A political philosophical exchange*. Verso, 2003.
44. Article 14 of Convention on the Elimination of Discrimination Against Women.
45. JAIN, *supra* note 5.
46. General Comment 18 was devoted by the Women's Committee on Women with Disabilities.
47. Article 23 on the Convention on the Rights of the Child.
48. Testimonies to this effect were made before the *AD Hoc* Committee on the CRPD by child rights advocates who had served on the Child Rights Committee. ( Personal Notes on file with Author).
49. CRPD, article 6.
50. *Ibid*, article 7.
51. *Ibid*, article 18 (2).
52. *Ibid*, article 25.
53. GENERAL ASSEMBLY. Res 56/1681, 4 UN Doc A/RES/56/168 (26 Feb. 2002).
54. The following narrative has been written on the strength of the notes that I have maintained as a NGO delegate from the 3<sup>rd</sup> to 8<sup>th</sup> Meeting of the *Ad Hoc* Committee that is from June 2004 to Aug.2006.
55. Interestingly article 4 (4) of CRPD expressly allows States Parties to recognize more than the Convention.
56. Section 4(2) provides with regard to economic, social, and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed within the framework of international cooperation with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

## RESUMO

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O artigo examina a Convenção sobre os Direitos das Pessoas com Deficiências, que é o primeiro instrumento de direitos humanos do milênio a entender como o discurso dos direitos das pessoas com deficiências tem sido alterado e a contribuir para a jurisprudência sobre direitos humanos. Isso ocorre porque a Convenção altera o léxico dos direitos das pessoas com deficiências e oferece um novo insight sobre o modo de resolver alguns dilemas perenes dos direitos humanos.

### PALAVRAS-CHAVE

Pessoas com deficiências – Assistência social – Discriminação – Autonomia – Indivisibilidade – Participação

## RESUMEN

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Este artículo examina la Convención sobre los Derechos de las Personas con Discapacidad, que es el primer instrumento de derechos humanos del milenio en comprender cómo el discurso de derechos de personas con discapacidad tiene sido alterado, y cómo el contribuye a la jurisprudencia de derechos humanos. Esto se debe a que la Convención modifica el léxico de derechos de discapacidad y ofrece un entendimiento novedoso sobre la manera de resolver algunos dilemas perenne de derechos humanos.

### PALABRAS CLAVES

Personas con discapacidad – Asistencialismo – Discriminación – Autonomía – Indivisibilidad – Participación



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#### ABSTRACT

This article explores the reasons why legal recognition for reproductive rights is out of step with legal recognition for sexual rights, through an analysis of three perspectives: historical; religious moral, notably Roman Catholic; and, finally, legal. The article concludes by presenting the advances for democracy and for the citizenship of homosexuals (gays and lesbians) and heterosexual women that would come from legal recognition for sexual rights.

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#### KEYWORDS

Human rights – Reproductive rights – Sexual rights – Gender – Sexuality



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# LEGAL RECOGNITION OF SEXUAL RIGHTS – A COMPARATIVE ANALYSIS WITH REPRODUCTIVE RIGHTS

Laura Davis Mattar

## I. Introduction

This article will demonstrate the importance of legal recognition for the sexual rights of homosexuals (gays, lesbians and bisexuals) and women. It will, therefore, explore and discuss the reasons why reproductive rights enjoy more recognition from the standpoint of positive law than sexual rights. The relevance of this comparison centers on the frequent conceptual confusion between these rights and its consequences, a confusion that has arisen from the inherent connection between sex and reproduction that has endured for so long.<sup>1</sup> Reproductive rights refer, briefly, to the right to decide freely and responsibly on the number, spacing and timing of one's children, and the right to have the information and means to make this decision. Sexual rights, meanwhile, deal with the right to exercise sexuality and reproduction free from discrimination, coercion and violence. If on the one hand these rights are interrelated – since, as we shall see, the free and safe exercise of sexuality is only possible if the sexual act is detached from reproduction – on the other hand, setting them apart for different legal treatment is the way to guarantee full citizenship for women and homosexuals.

The importance of this study is due primarily to the recognition that the positivization of rights,<sup>2</sup> given the way domestic and international jurisprudence is currently structured, affects public policies and, subsequently, the lives of numerous people, the majority women, lesbians and gays. It should be noted, however, that the legal recognition of rights does not necessarily

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*Notes to this text start on page 79.*



result in their full and immediate efficacy, although it is considered at least a step in the right direction.

The focus of this paper will be on international human rights law. This is because the constitution of reproductive rights and the signalization<sup>3</sup> of sexual rights has occurred on the international stage, that is, in the increasingly more democratic forums of international conferences of the United Nations. Women from across the developed and developing world, whether part of national delegations or representing non-governmental organizations, used these international forums to raise, in an articulate and provocative manner, fundamental questions of female citizenship and its consequences.

It is true that the Declarations and the Programmes and Platforms for Action of international conferences, regardless of which – for example on Population and Development or on Women – are considered soft law, i.e. they are not legally binding like human rights treaties and conventions. They are, in fact, moral commitments made by signatory states and do not imply automatic integration into domestic law.<sup>4</sup> These commitments result in external pressure to comply with a given agreement and, ultimately, political embarrassment for states that fail to comply. They are intended, therefore, while offering no guarantees, to promote enforcement inside national borders of the provisions of the international consensus.<sup>5</sup>

Nevertheless, since these soft law incentives are often insufficient, the academic community has tried to identify rights enshrined in human rights treaties that are related to sexual and reproductive rights, in a bid to lend them more legal clout. Since these treaties are legally binding, they place a legal obligation on states to enforce sexual and reproductive rights – albeit through indirect legal argument.

In order to explore these issues, this paper is divided into three parts. The first presents a brief historical retrospective of reproductive and sexual rights as they have developed on the international stage. The second part takes a look at the reasons why reproductive rights enjoy a greater degree of formulation and legal recognition compared to sexual rights. The third and final part draws the conclusion that a clear definition of sexual rights, and their subsequent positivization, would benefit society at large.

## **II. The current formulation of reproductive and sexual rights**

In 1948, the General Assembly of the United Nations (UN) adopted and proclaimed the Universal Declaration of Human Rights (UDHR), the first step towards establishing an international human rights law and a global system of human rights protection within the UN framework. This system

embraces all human beings in all their abstraction and generality.<sup>6</sup> The construction and recognition of human rights has, since then, evolved and expanded into areas of vital importance for the preservation of human dignity. This process, which we might call the “specification of subjects with rights”, took into account the specific characteristics of individuals and groups, shifting from the abstract figure of man to attend to the differences existing between genders, races, generations, etc.<sup>7</sup>

It was this process that led to the emergence of human rights for women and, later, sexual and reproductive rights – contemporary formulations that took shape in the final decade of the 20th century.

### *a) Reproductive rights*

The term “reproductive rights” was coined at the 1<sup>st</sup> International Meeting on Women and Health in Amsterdam, Holland, in 1984. There was, at the time, a global consensus that this designation would convey a more complete and adequate concept than “health of women” for the broad agenda of women’s reproductive self-determination.<sup>8</sup> The definition of reproductive rights, therefore, began to be formulated in a non-institutional framework, one of dismantling maternity as a duty through the struggle for the right to legal abortion and contraception in developed countries.<sup>9</sup>

From here, legal academics began to refine the concept of reproductive rights, in an attempt to give them a more precise definition. This is the case with Lynn Freedman and Stephen Isaacs, who identified the importance of reproductive choice as a universal human right.<sup>10</sup> Rebecca Cook, meanwhile, defends the idea that laws that deny, obstruct or limit access to health services violate basic human rights protected by international conventions. She claims that for international human rights law to be truly universal, it must require states to take preventive and curative measures to protect women’s reproductive health, affording them the possibility to exercise their reproductive self-determination.<sup>11</sup>

The expression “reproductive rights” was enshrined in the International Conference on Population and Development (ICPD), held in Cairo, Egypt, in 1994, and was again used in the 4<sup>th</sup> World Conference on Women, in Beijing, China, in 1995. According to paragraph 7.3 of the Cairo Programme of Action:

*[R]eproductive rights embrace certain human rights that are already recognized in national laws, international human rights documents and other consensus documents. These rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of*

*their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents.*

### ***b) Sexual rights***

Sexual rights, meanwhile, began to be discussed towards the end of the 1980s, following the outbreak of the HIV/AIDS epidemic, primarily by the gay and lesbian movement, which was joined by part of the feminist movement.<sup>12</sup> According to Sonia Corrêa and Maria Betânia Ávila, the term “sexual rights” was introduced as part of a bargaining strategy at the ICPD, in 1994, to guarantee a place for reproductive rights in the final text of the Cairo Declaration and Programme of Action – the inclusion of the term “sexual” radicalized the language, and negotiations for its removal involved keeping the expression “reproductive rights”.<sup>13</sup> As a result, the term “sexual rights” does not appear in the final document of the Cairo Programme of Action.

Nevertheless, these rights were broached again in discussions at the 4<sup>th</sup> World Conference on Women. According to paragraph 96 of the Beijing Declaration and Platform for Action:

*The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behavior and its consequences.*

As we can see, this is still not a definition *per se* of sexual rights. It refers to the rights that supposedly comprise sexual rights, while pleasure as an objective in itself remains absent from the discourse of the UN’s International Conferences.

Rosalind Petchesky points out that the emergence, albeit still incipient, of the concept of sexual rights has only occurred from a negative approach, i.e. expressing the right to not be the object of abuse or exploitation, in the corrective sense of combating violations. She asks, then: “why is it so much easier to assert sexual freedom in a negative way, and not in an affirmative, emancipatory sense? Why is it easier to reach a consensus on the right not to be abused, exploited, raped, trafficked or mutilated in one’s body, but not the right to fully enjoy one’s own body?”. The author goes on to say that the development of sexual rights needs to expand and move towards an affirmative concept, going beyond combating the discrimination and abuse committed

against sexual minorities, which includes women that do not fit into the conventional role of their gender. These rights should, therefore, embody the so-called “affirmative entitlements”, since affirmative and negative entitlements are two sides of a coin: I cannot enjoy my sexual body if I am subjected to constant fear of, say, battering.<sup>14</sup>

Bearing in mind the current formulation of sexual and reproductive rights, we shall now move on to an analysis of the obstacles and challenges to legal recognition of sexual rights in the international arena.

### III. Historical perspective

The historical perspective behind the construction of sexual and reproductive rights is by far the most revealing. By examining scientific data on masculine and feminine from a medical point of view, the understanding of the human body and the evolution of the theories of sexuality grow clearer because even today it is difficult, first of all, to separate the act of sex from the task of reproduction and, second, to alter our gender models, with their corrupt power structures.

According to Wilza Villela and Margareth Arilha, “until the 17th century, humans were represented by men, and women were forms of intermediary corporality and existence between humanity and animality”. There was, then, only the masculine sex, as women were considered an undeveloped male body.<sup>15</sup>

It was only from the 18th century, during the Renaissance, that the existence of a model of two distinct biological sexes began to be considered. It was the egalitarian environment of the French Revolution that overhauled the way of thinking about the existence of men and women, taking into account the need, on the grounds of equality, to change the perception of women as inferior human beings. Consequently, “in the cries for equality, liberty and fraternity, women shift from being a feeble version of man and acquire a sex and corporality of their own.”<sup>16</sup>

However, in virtue of the phenomena that constantly transformed women’s lives, such as pregnancy and “periodic hemorrhaging”, men viewed women as strange beings whose inherent instability could upset the world order. Women appeared to be more susceptible to outside influences, since they were ostensibly more fragile and vulnerable – physically, morally and intellectually.<sup>17</sup> Intelligence was associated with the masculine and sensitivity with the feminine, since biological characteristics determined physical and mental capabilities and, therefore, the roles that each gender could play in society.<sup>18</sup> Accordingly, the primary function of women was procreation, and God had endowed them with the necessary characteristics to perform this task well.<sup>19</sup>

An interesting point, raised by Fabiola Rohden, is that the prevailing idea at the time was that nature had bestowed basic differences on men and women, although these would be operationalized and crystallized throughout their lives. The consolidation of these differences required the good governance by woman of their bodies – with culture (as opposed to nature), therefore, being fundamental. In other words, the development of society hinged on women's prudent and effective administration of their bodily development and their reproductive capacity.<sup>20</sup> And this, therefore, justified the control and subordination of women.

However, in the words of Wilza Villela and Margareth Arilha, “in the recently inaugurated world of two sexes, [it was] the differences imprinted by nature on the bodies of men and women that led [them] to occupy different social positions and functions. Women were endowed by nature with bodies and sentiments suited to the task of gestating, breastfeeding and caring for fragile human babies through their development – such an important task that they became almost incapable of performing any other social function. Men, since they had not been molded for any specific function, were entrusted with all the other functions necessary for human reproduction, namely social, political, cultural and economic activities”.<sup>21</sup>

The importance of reproduction as the ultimate purpose of the sexual relation is not shaped only by the discourse on women and their role in society. It is also linked to the discourse on sex, as a means not only of restricting sexual relations between people of the same sex, since this does not produce children, but also restricting the exercise of sexuality by women outside marriage. As a result, “any sexual expression associated with obtaining pleasure, not reproduction, is rejected.”<sup>22</sup>

The accepted norm, then, based on this link between sex and reproduction, could be none other than heterosexuality. This was (and still is) considered the ‘natural’ form of sexual relation,<sup>23</sup> which was only possible as a result of the repression against other forms of sexual expression.<sup>24</sup>

It can be concluded, then, that the norms concerning the exercise of sexuality are not predetermined, but rather learned socially: “each culture, in each historical era, constructs symbols and signs of what is acceptable and desirable in sexual terms.”<sup>25</sup>

And it is drawing on this far-off historical overview that we shall make our analysis of the historical construction of sexual and reproductive rights. It is important during our examination of the evolution of these rights to bear in mind that (1) woman at the dawn of science was a less developed masculine body; (2) once the existence of two sexes was “understood”, each one had social purposes determined by biological characteristics, woman's being procreation; (3) for a long time, there was (and there still is for some)

a necessary link between sex and reproduction, which, finally, (4) determines that heterosexuality, since it is the only one that can lead to reproduction, is the natural form of sexual relations, resulting in the social condemnation of all others that pursue only pleasure, such as homosexuality or sex outside marriage.

The construction of reproductive rights as human rights was achieved historically by two distinct movements: the population movement and the women's movement. For this reason, Lynn Freedman and Stephen Isaacs call it a "schizophrenic history", since it is split.<sup>26</sup>

The population movement in the 1960s, called neo-Malthusian,<sup>27</sup> predicted that if the population growth curve were not reversed, the world would self-destruct. There emerged, at the time, studies on ways of reducing fertility, which led to the introduction of contraception, such as the pill and IUDs, which are widespread nowadays. Third world countries that discouraged the use of contraception became a threat to the human race itself, making external interference necessary, i.e. international.

The only purpose of this interference was to reduce population growth; it was never concerned with women, the primary agents of reproduction. Contraceptive methods, which could have been tools of female liberation, since they separated the sexual act from reproduction, were actually viewed as devices for controlling women.<sup>28</sup>

Therefore, the history of reproductive rights as human rights – that is, focused on reproductive autonomy exercised primarily by women – supposedly began at the first International Conference on Human Rights, held in Tehran (Iran) in 1968. This Conference adopted, for the first time, what would become the essence of reproductive rights: "parents have a basic human right to determine freely and responsibly the number and the spacing of their children and a right to adequate education and information in this respect".<sup>29</sup>

Some years later, in 1974, at the World Population Conference in Bucharest, Romania, developing nations defended the idea that population growth was linked to a country's level of development.<sup>30</sup> They claimed that the priority of governments of the North to control population growth was a ruse to assure their supremacy on the international stage, not a "humane" plan to address population issues in less developed countries. The Conference ended up reaffirming the right to reproductive choice, although it broadened its definition to include couples and individuals. Furthermore, it established that people should have the information, education and means to exercise their reproductive right.

The International Conference on Population and Development, held in Mexico in 1984, however, at the suggestion of the United States, discussed



population growth as a neutral phenomenon. Nevertheless, its final document stuck to the same language that was adopted in Bucharest and also included the obligation of governments to make family planning programs universally available.

After that, there came a fundamental shift in the agenda at the International Conference on Population and Development, held in Cairo in 1994. Women, the main victims of the population control programs, were elevated from the object to the subject of the population and development programs. This was the occasion when an actual definition of reproductive rights – given earlier – was achieved.

The women's movement, meanwhile, not unlike the population movement also drew on reproduction for one of its central themes, but with a different focus: women's control of their own body, their sexuality and their reproductive life. The feminist slogan of the 1970s, "our bodies, our choice" was in direct opposition to the interference of the Church and the State.<sup>31</sup>

The United Nations Decade for Women began with the 1<sup>st</sup>. World Conference on Women, held in Mexico in 1975. This meeting drew people from across the world (practically 70% were women) who successfully managed to include in the Declaration of the Conference the right to reproductive autonomy. And they achieved more: the declaration provided for the right to reproductive choice grounded on the notion of bodily control and integrity.<sup>32</sup>

In 1979, the UN adopted the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). According to Flávia Piovesan, CEDAW is based on the "twin obligation to eliminate discrimination and assure equality".<sup>33</sup>

Article 16 of CEDAW sets the obligation for all States Parties to take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular ensure, on a basis of equality of men and women, the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

However, it was only in 1993, at the 2<sup>nd</sup>. World Conference on Human Rights in Vienna, that the sexuality of women was invoked for the first time. Paragraphs 18 and 38 of the Vienna Declaration and Programme of Action call on states to eliminate gender-based violence and all forms of sexual harassment and exploitation.

In December of the same year, the UN adopted the Declaration on the Elimination of Violence against Women, which condemns, in its second paragraph, the various forms of physical, sexual and psychological violence suffered by women, noting that these rights and principles are enshrined in



international instruments. It should be noted that this declaration was the basis for the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, approved by the Organization of American States in 1994 and legally binding for the countries that ratified it.

It was also in 1994, at the Cairo Conference on Population and Development that the feminist movement managed to definitively remove demographics from the scope of reproductive rights. It was explicitly defined at the Conference that population policies should be guided by human rights.<sup>34</sup>

Although it was not possible to define sexual rights in Cairo, there are countless references to “sex” and “sexuality”. Petchesky claims that the inclusion of sexual health as a right to be protected can be attributed to the efforts of delegations from Sub-Saharan Africa, where the consequences of the HIV/AIDS epidemic were, and still are, devastating.<sup>35</sup>

The Platform of Action drawn up at the 4th World Conference of Woman, in Beijing in 1995, reaffirmed the advances made in relation to reproductive rights – by this point definitively incorporated into the human rights language – and also made some progress in formulating sexual rights as part of human rights. According to Petchesky, it was a “notable” consensus, since for the first time in history women were recognized as not just reproductive, but also sexual beings.<sup>36</sup>

One key point to emphasize in this historical retrospective is that the correlation between population and development clearly expedited the positivization of reproductive rights that, in the words of Norberto Bobbio, as human rights, “arise from [...] conditions characterized by the embattled defense of new freedoms against old powers”.<sup>37</sup>

Furthermore, the fact that reproductive rights emerged as a demand made solely and exclusively by the feminist movement made them more cohesive and, as such, they acquired more clout. In defense of sexual rights, however, were gay and lesbian groups, and also part of the women’s movement. The failure of these groups to develop the necessary liaison to come up with effective strategies undermined their claims for these rights.

We shall now move on to address the moral perspective obstructing the recognition of sexual rights, when compared to reproductive rights.

#### **IV. Moral perspective, focusing on a Catholic religious perspective**

Morally imposed obstacles to the recognition and the positivization of sexual (and reproductive) rights will be discussed from a religious angle, exemplified here by the Roman Catholic Church. This does mean that there are no impediments to this recognition in other religions, such as Islam or Judaism;

these also view the exercise of sexuality as a taboo. However, the Catholic Church, represented by the Vatican, has, with its status and its available resources, played a more active and visible role opposing sexual rights, making it a clearer example of the existing obstacles.

For the Roman Catholic Church: (i) there is only one ideal family structure which is the nuclear family, formed by a man, a woman and their offspring; (ii) sexuality should only be exercised for purposes of reproduction and, even then, only inside marriage; (iii) all kinds of contraception are wrong, and (iv) provoked abortion, even to save the life of a woman, is always immoral. A person's sex life has, in the eyes of this Church, no purpose in itself other than procreation. And, finally, (v) women may not be ordained into the priesthood, and they are excluded from all decision-making functions.<sup>38</sup> These were the precepts of the Code of Canon Law and they continue today as Catholic Christian doctrine. It is fair to say, therefore, that Catholicism naturalizes gender roles and that the institution strives to keep them ingrained in our culture.

This view is radicalized in the spheres of sexuality and reproduction. Their naturalization and crystallization over time, claim Sonia Corrêa and Maria Betânia Ávila, implies that it is not possible to apply the rationality of law to these realms of human life. The authors affirm that “an ongoing challenge in the theorization of reproductive and sexual rights has been to question this persistent naturalization [...], based on a new paradigm in which reproduction and sexuality are considered phenomena of social construction [...]. A first step in this direction is to demonstrate that the discourses that naturalize reproduction and sexuality do indeed constitute an ideological stratagem to conceal the many rules of regulation and discipline to which sexuality and reproduction were and continue to be subjected”.<sup>39</sup>

Bearing this in mind, we shall now take a look at the role of the Catholic Church, represented by the Vatican, throughout the process of constructing sexual and reproductive rights on the international stage.

In both the Cairo and Beijing conferences, the feminist movement was pitted against fundamentalist religious groups, population groups and conservative governments – all far more powerful. According to Rhonda Copelon and Rosalind Petchesky, one of the challenges in Cairo was, therefore, to confront the coalition of religious fundamentalists, united with the Vatican and some Muslim states, that was trying to impose a strictly pronatalist agenda and objected to any language that might imply the acceptance of abortion or sexual pleasure, education and services for adolescents, the existence of gays and lesbians and their rights, or any form of family or union other than the traditional heterosexual form.<sup>40</sup>

This group tried persistently to establish in the final document of the Cairo Conference religion and traditional cultures as possible restrictions to the implementation of human rights, drawing on the terms of paragraph 22 of the Vienna Declaration – which stipulates that culture should not be invoked to deny women human rights. In this paragraph, all states are invited to put into practice the provisions of the UN's 1981 Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief.

This Declaration states, in its preamble, that “it is essential to promote understanding, tolerance and respect in matters relating to freedom of religion and belief and to ensure that the use of religion or belief for ends inconsistent with the Charter of the United Nations [...] is inadmissible”. It goes on to say that “the expression ‘Intolerance and Discrimination Based on Religion or Belief’ means any distinction, exclusion, restriction or preference based on religion or belief and having as its purpose or as its effect nullification or impairment of the recognition, enjoyment or exercise of human rights and fundamental freedoms on an equal basis”. Intolerance and discrimination were exactly what the Vatican, together with fundamentalist religious groups, was proposing. In view of this, the Cairo Programme was flawed insofar as it did not reaffirm that human rights have preference over traditional cultural and religious conflicts.<sup>41</sup>

At the end of the Cairo Conference, dissenting delegations registered their reservations to the final Programme of Action. Particularly relevant is the written statement of the Holy See, which reads: “with reference to the term ‘couples and individuals’, the Holy See reserves its position with the understanding that this term is to mean married couples and the individual man and woman who constitute the couple”.<sup>42</sup> It is clear, though, that underneath the aversion to sexual rights lurks the taboo against homosexuality, bisexuality and alternative family forms.<sup>43</sup>

Nevertheless, the positive affirmation of the value of “a satisfying and safe sex life” without limitations based on sexual orientation or age can be considered a partial victory in view of the document's silence concerning sexuality.<sup>44</sup>

Negotiations at the Beijing Conference were also complicated: on one side, women and, on the other, the Vatican and its allies. The latter, also represented by a group of American women called the “Coalition for Women and the Family”, as Rosalind Petchesky reports, distributed a flier entitled *Sexual Rights and Sexual Orientation: what do these words really mean?*, associating “these words” not only with homosexuality, lesbianism and sexual relationships outside marriage and among adolescents, but also with “pedophilia”, “prostitution”, “incest” and “adultery”. Added to this organized

effort was the *coincidental* release, just months before the Conference, of the encyclical *Evangelium Vitae* in which “the pope condemns ideas and practices asserting reproductive and sexual autonomy by associating them with ‘a hedonistic mentality unwilling to accept responsibility in matters of sexuality’ and ‘a self-centered concept of freedom’”.<sup>45</sup>

This, therefore, explains the disappearance from the final version of the Beijing Platform for Action of the expression “sexual rights”, which was in the draft, and the fact that the terms “sexual orientation” and “lesbians and gays” never even emerged.<sup>46</sup> In spite of this, however, it was possible to approve the historic paragraph 96, with reservations from the Holy See, which did not commit to its implementation.

Given the position of the Catholic Church in these International Conferences, it is possible to understand the obstacles to the legal recognition of sexual rights and also reproductive rights. There is a sexual morality and a security in the institution of the nuclear family that will be preserved as a reflection of a negative and decidedly discriminatory vision of women and the exercise of sexuality. The Church ends up transforming a person’s sexual activity into their moral yardstick, making their character and their morality subordinate to their condition as a homo or heterosexual, married or not, bound or not by rules concerning sex.<sup>47</sup>

This, therefore, poses a threat to the universality of human rights, since there are still voices calling for a concept of human rights that is sensitive to cultural and religious values.<sup>48</sup> These voices clearly make political use of religion, culture and tradition to oppress not only women, but also sexual minorities, denying them the full exercise of their citizenship. But arguments of religious conviction, as argued by Lima Lopes, cannot be legitimately used in a democracy when they are purely religion-based. In other words, the religious beliefs of others, given the protection afforded to the freedom of religious belief to all, may not deprive of their rights a social group that does not refuse to observe the general duties of citizenship.<sup>49</sup>

## V. Legal perspective

The legal perspective is the broadest of the perspectives addressed here, since it embodies a series of issues. First, the fact that human rights in their origin, as we shall see, have been formulated by men, based on their own needs. Second, there is the traditional distinction between the regulation and application of the law in the public and private spheres, which affected the legal recognition of sexual rights in relation to reproductive rights. Finally, this section of the article will also address the important connection between reproductive rights and the right to health, which has facilitated their

recognition. Sexual rights, on the other hand, whose link to health came later, remained, as we shall see, further on, associated with so-called liberal rights. Hence, the preference for their non-regulation by the state undermined their legal recognition.

Since the start of the contemporary conception of human rights, after the 2<sup>nd</sup> World War, a broad range of rights have been accorded legal recognition. But, despite having evolved significantly, this branch of the law, as Henry Steiner and Philip Alston point out, still has in the human rights of women one of its “blind spots”.<sup>50</sup> The same can be said about the rights of homosexuals.

According to Katherine Bartlett, analyzing laws from a feminine viewpoint means examining how they fail to take into account the experiences and values that are more typical of women than men or how they actually disadvantage women.<sup>51</sup> Rebecca Cook, meanwhile, says feminists have stressed the indeterminacy of law and the extent to which, despite its claim to neutrality and objectivity, it masks hierarchies and distributions of power.<sup>52</sup> In other words, you cannot study the law without examining the power relations between the sexes, classes and ethnicities present in the society that formulated it. Evidently, it has a tendency to reflect the dominant group, which consists of white heterosexual males.

In view of this, the feminist movement built its agenda on discrimination, i.e. seeking equality between men and women. Discrimination, in this case, means the denial, non-recognition or infringement of human rights by women in virtue of distinction, exclusion or restriction on the basis of sex. But which human rights have been hardest for women to claim? According to Florence Butegwa,<sup>53</sup> those that do not have masculine equivalents, that is to say, that address needs that men do not have.

With no “exclusive” human rights for their gender, it took time for the state to regulate the fundamental human rights of women,<sup>54</sup> such as reproductive rights, concerning the reproduction that occurs within their bodies.<sup>55</sup> For women to prove that their rights had been violated, they had to prove, without any equivalent in the masculine world, that they had been discriminated against and that the state failed to provide them with the same protection as men.

In view of this, Margaret Schuler believes that while the discriminatory discourse is indeed a powerful instrument for claiming rights, the rights discourse is extremely important, since women (and also homosexuals) have characteristics that differ from men (heterosexuals), and that require a specific rights structure.<sup>56</sup>

Given this legal vacuum, the feminist movement started to reinterpret the rights that were not traditionally thought up to be applied to women.

This is the case with the right to life, embodied in article 6(1) of the International Covenant on Civil and Political Rights and traditionally understood to be the obligation of States Parties to observe the due process of law before capital punishment is imposed. The UN Human Rights Committee, linked to this Covenant, considers this interpretation restrictive and claims that protection of the right to life requires the adoption of positive measures, such as those aimed at reducing the infant mortality rate and raising life expectancy.

Women's right to life, or to survival, assures them access to healthcare services; therefore, any restriction to this access should be considered a violation of international human rights law. According to Rebecca Cook, the traditional application of the right to life is male-oriented, since men associate the violation of the right to life more easily with capital punishment than with death from pregnancy, ignoring the historic reality of women.<sup>57</sup>

This reinterpretation of rights has widened the responsibility of the state and, more recently, increased the power of the committees that monitor state actions/omissions related to the rights of women. And yet women, and homosexuals, enjoy less recognition as part of the system and as full subjects of human rights, since the protection of the law is often found to be lacking.<sup>58</sup>

And to this lack of protection of the law for the specific issues of women (and, even more of homosexuals) can be added the supremacy of the regulation and application of law in the public sphere. Karen Engle, when addressing the distinction between public and private, criticizes public international law presenting two positions: one that claims it is flawed because by excluding the private – the domestic sphere, where women are more present – it is not truly universal; and the other that claims that it uses the division between public and private conveniently to avoid issues related to women. According to the advocates of the first position, public international law should be re-conceptualized to include women and the private sphere. For those on the other side, it already exist the doctrinaire instruments in human rights necessary to accommodate women in international law, although their application is made inconsistently – a good example is the possible intervention to end “private” forms of violence, such as cannibalism or slavery.<sup>59</sup>

This analysis by Engle clearly indicates that it was not in the interest of the state to regulate what occurred in the domestic sphere, and that it was more convenient to remain detached from what went on there. This is why reproductive rights remained so long without state regulation.

The regulation of sexuality, meanwhile, is still found in the interface



between public and private. If on the one hand the exercise of sexual rights is in the scope of privacy and sexual liberty relating to the way we obtain pleasure, on the other hand state protection is needed for this liberty to be fully exercised, without discrimination, coercion or violence. The balance between state regulation and deregulation – that is, between freedom and protection – is, to borrow from Sonia Corrêa and Maria Betânia Ávila, an “inconclusive” matter. In particular because breaking the barriers of the private sphere, where abuses involving sexuality (and reproduction) frequently occur, can pave the way to an exaggerated state intervention that ends up restricting the freedom of the individual.<sup>60</sup> When looking to strike this balance, there is a risk of opening the door to abuse of discretion by the state.

It is evident, then, that the supremacy of the regulation and application of the law in the public sphere contributes to women and sexual minorities not having the necessary protection of the law to exercise their citizenship in the domestic context. Democracy, as Pitanguy tells us, refers not only to the full exercise of citizenship in the public sphere, but also to everyday life relations, in the workplace, in the family, in health, in education.<sup>61</sup>

In view of this, how did the feminist movement manage to bring its demand for reproductive and sexual rights into the realm of law? The formulation of reproductive rights, and their subsequent positivization, occurred after their association with the right to health. As a human right, health first appeared in the UDHR of 1948 and it later acquired more specific definitions in countless other international human rights protection documents. Article 12 of the International Covenant on Economic, Social and Cultural Rights of 1966, for example, phrases the right to health as “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”, and it goes on to exemplify the steps to be taken to achieve its full realization.

CEDAW, from 1979, in article 12, also establishes the right to health as a right of women, emphasizing the importance to “ensure, on a basis of equality of men and women, access to healthcare services, including those related to family planning”. Paragraph 2 of the same article stipulates that States Parties must provide women appropriate and free services during pregnancy, confinement and the post-natal period. These are examples of the conceptual evolution of the right to health on the international stage.

Drawing on these provisions, the feminist movement began to fight in the 1970s for reproductive rights, calling for the decriminalization of abortion. Abortion, as an obstacle to women’s exercise of human freedom,<sup>62</sup> is a public health problem. This is because many are performed unsafely, putting the



health of women at risk and sometimes even causing their death. According to Rebecca Cook, “the WHO estimates that 500,000 women die each year from pregnancy-related causes, between 25% and 50% of which result from unsafe abortion”.<sup>63</sup> From a healthcare point of view, these are clearly avoidable deaths.

To demonstrate the negligence of the state in relation to women, the feminist movement used statistical data to help bring into the public debate the need for recognition of the reproductive rights and of the positive duty of states to provide full healthcare assistance to women – which requires the formulation and execution of public policies.

Nevertheless, at the time, the same connection between health and sexual rights was not possible. Associated instead with sexual freedom, privacy and the right to not suffer discrimination, coercion and violence, the state declined to regulate sexual rights to safeguard the private life of the individual, primarily from its own interference.

Note once again that sexuality was absent from international human rights discourse until 1993.<sup>64</sup> Moreover, human rights discourse accepts sexual life only implicitly and, even then, when it is restricted to reproduction and, therefore, heterosexual marriage. Suffice to say that not even CEDAW mentions the sexual freedom or rights of lesbians. As Wilza Villela and Margareth Arilha remind us, there is no point isolating a category for “lesbians” in the political discussion on the sexual oppression that all women suffer, regardless of their sexual orientation.<sup>65</sup>

But as history has shown, there are “dimensions to the private autonomy of the human person that are so important to their dignity that they need to be protected even from the lawmaker, the incarnation of the will of the majorities”.<sup>66</sup> Sexual rights, although primarily negative in character – as state abstention – require positive action by the state to guarantee their realization.

This claim, however, has not been enough to bring about the regulation of sexual rights. It was only with the outbreak of the AIDS epidemic, in the 1980s, that for health reasons sexuality was incorporated into the international public debate. This association with the right to health was, once again, decisive in achieving rights, in this case for gays and lesbians.

In developing countries, the connection with the right to health is still very important. It is through an efficient public healthcare system that women, gays and lesbians “manage” to fully exercise their citizenship, provided that their freedom and autonomy is protected.<sup>67</sup>

It is clear, therefore, that the connection with the right to health has prompted the formulation and positivization of reproductive rights and, eventually, and still only in a preliminary way, sexual rights.

## VI. Conclusion

In this paper, we have seen that the formulation and legal recognition of sexual rights is less developed than the formulation and recognition of reproductive rights. It has presented the motives for this imbalance: (i) the historical perspective, which demonstrated a connection between population concerns and reproductive rights, causing these rights to be discussed earlier on the international stage; (ii) the Catholic moral perspective, which attempted to conceal sexual diversity, presenting it as amoral; and, finally, (iii) the legal perspective, which identified the “masculine” formulation of international human rights law and the distinction between the application of the law in the public and private spheres. Furthermore, it has presented the strategy of both the feminist movement and the gay and lesbian movement to link these rights to the right to health, with a view to securing their legal recognition. Now it is necessary to illustrate the importance of this recognition for democracy and for the citizenship of homosexuals and women.

According to Lima Lopes, the rights of recognition are based on some presumptions: (a) that there are groups in society that are stigmatized; (b) that stigmas<sup>68</sup> are institutional and historical products; (c) that stigmas do not necessarily have any scientific, rational or functional grounding for society; (d) that people belonging to stigmatized groups suffer from the “usurpation” or denial of an asset that is immaterial, which is respect and self-respect; (e) that the social perpetuation of stigmas is, therefore, an injustice, causing unnecessary pain, suffering, violence and disrespect; and (f) that members of a society have the right to have their demeaning stigmas removed.<sup>69</sup>

In this context, homosexuals are clearly not recognized in our societies. The consequences of this denial, as Lima Lopes goes on to say, are manifold. The first is physical violence, i.e. the prevention of someone being physically safe in the world. Then there is non-physical violence, which can be split into two forms: the first – and the most important here – is exclusion from the sphere of rights, denying a person social autonomy and the possibility to interact; and, second, the negation of respect for a way of life or a way of being, which can explain the degrading and insulting treatment of people and groups.<sup>70</sup>

Based on Lima Lopes’ point of view that the denial of rights, coupled with the traditionalism of the “status quo”, is what maintains and fuels the most evident forms of physical violence, and that this in itself is an offence against the democratic regime of equal liberties, we should not be surprised by his conclusion that “under the silence of the legal system [...] an intolerance is cultivated”.<sup>71</sup>

Accordingly, non-regulation by the law – the rules in place – helps

naturalize the differences and inequalities common in the culture. Regulation by the law, claims Lima Lopes, can promote change and remove historically consolidated injustices against stigmatized groups, namely homosexuals.<sup>72</sup> Added to this is the fact that these groups will start to fully exercise their citizenship and to feel like they belong to a society that values diversity and plurality instead of simply tolerating it.

In the words of Maria Betânia Ávila, “[s]exual rights, by placing sexual relations on a par with social relations in the realm of citizenship and allowing their needs to be mediated and guaranteed through rights, establish heterosexuality and homosexuality as sexual practices that are equally free”.<sup>73</sup> The value of legal recognition for the sexual rights of homosexuals, in fact, signs the importance of the sexual dimension in human life<sup>74</sup> and in the protection of human dignity. Only through such recognition, everyone will enjoy the rights and fundamental freedoms that characterize democracy.

However, legal recognition for sexual rights also has important consequences for the daily life of women, especially heterosexual women. This is because, besides suffering from sexual repression, they also experience the abuse and violence rooted in a culture that still does not recognize their sexual freedom. In this vein, the recognition of reproductive rights for women, as opposed to sexual rights, was possible since they are linked to the supposed feminine “function” or “nature”, which is reproduction. But, what about sexual pleasure? Does a woman have the right to enjoy her own body?

With legal recognition of sexual rights, it is finally possible to say yes. This recognition consolidates the separation of sex from reproduction, making it definitively clear that women are indeed sexual beings, not just reproductive beings. To put it another way, legal recognition of the sexual rights of women comes with an emancipatory and libertarian perspective, since it accepts the sexual pleasure of women as positive and desirable. Making a “safe and satisfactory sex life” a right of everyone, but especially women (and homosexuals), represents an enormous step forward in their quality of life, since they can freely seek and experience sexual pleasure with the partner of their choice, exercising their citizenship both in the public sphere and, also, in the private, intimate, domestic context.

It should be emphasized, however, as stated earlier, that the mere positivization of rights is no guarantee of their enforcement. Much reflection is still needed on how to enforce human rights with a view to their enjoyment by everyone and their social and cultural acceptance and recognition. Whatever the case may be, the current panorama points to the importance of expanding the frontiers of the debate on human rights, including new rights, such as sexual rights, that guarantee, at least formally, the human dignity of vulnerable groups, such as women and homosexuals.

## NOTES

1. It is not only sex that has detached itself from reproduction. Reproduction nowadays is also separate from sex, considering the scientific progress that has led to *in vitro* fertilization, among the other methods currently available.
2. The relationship between positivization of rights and their implementation as public policies is not automatic. We know that positivized rights may have no social efficacy, nor even cause the State to earmark the resources for their enforcement. Nevertheless, this paper works on the premise that positivization is a significant step in the process of implementing and enforcing rights. This is because, specifically in the case of sexual rights, as we shall see in this paper, positivization to some extent removes the moral considerations that represent obstacles to the recognition of homosexuals and transsexuals, for example, as individuals with rights.
3. Signalization ( *sinalização*) is the term used by Miriam Ventura for the incipient formulation and recognition of sexual rights (VENTURA, M. (org.). *Direitos Sexuais e Direitos Reprodutivos na Perspectiva dos Direitos Humanos: síntese para gestores, legisladores e operadores do direito*. Rio de Janeiro: ADVOCACI, 2003, p. 14.)
4. CORRÊA, S. and ÁVILA, M.B. Direitos Sexuais e Reprodutivos – Pauta Global e Percursos Brasileiros. In: BERQUÓ, E. (org.). *Sexo & Vida: Panorama da Saúde Reprodutiva no Brasil*. Campinas, SP: Editora da UNICAMP, p. 17-78, 2003, p. 23.
5. Nevertheless, we should not fail to mention the frequent difficulties transferring the consensus to the domestic arena.
6. PIOVESAN, F. Os Direitos Humanos da Mulher na Ordem Internacional. In: PIOVESAN, F. *Temas de Direitos Humanos*, 2<sup>nd</sup> ed., São Paulo: Max Limonad, p. 205-219, 2003, p. 205-206.
7. PITANGUY, J. O Movimento Nacional e Internacional de Saúde e Direitos Reprodutivos. In: GIFFIN, Karen and COSTA, Sarah H. (orgs.). *Questões da Saúde Reprodutiva*. Rio de Janeiro: FIOCRUZ, p. 19-38, 1999, p. 37.
8. CORRÊA, S. and ÁVILA, M.B., op. cit., p. 20.
9. CORRÊA, S. Saúde Reprodutiva, Gênero e Sexualidade: legitimação e novas interrogações. In: GIFFIN, K. and COSTA, S.H. (orgs.). *Questões da Saúde Reprodutiva*. Rio de Janeiro: FIOCRUZ, p. 39-50, 1999, p. 41.
10. FREEDMAN, L.P. and ISAACS, S.L. Human Rights and Reproductive Choice. *Studies in Family Planning*, v. 24, n. 1 p. 18-30, 1993.
11. COOK, R. International Human Rights and Women's Reproductive Health. *Studies in Family Planning*, v. 24, n. 2, p. 73-86, Mar-Apr. 1993.
12. The segment of the feminist movement that joined in the fight for the sexual rights of gays and lesbians (who suffer oppression for being women like any other) is the part that considers sexuality a crucial realm for understanding and transforming gender inequality (CORRÊA, S. and ÁVILA, M.B., op. cit., p. 21).
13. CORRÊA, S. and ÁVILA, M.B., op. cit., p. 21.
14. PETCHESKY, R.P. Direitos Sexuais: um novo conceito na prática política internacional. In:

BARBOSA, Regina M. and PARKER, Richard (orgs.). *Sexualidades pelo Averso: direitos, identidades e poder*. Rio de Janeiro: IMS/UERJ; São Paulo: Ed. 34, p. 15-38, 1999, p. 16, 24-25.

15. VILLELA, W.V. and ARILHA, M. Sexualidade, Gênero e Direitos Sexuais e Reprodutivos. In: BERQUÓ, Elza. (org.). *Sexo & Vida: Panorama da Saúde Reprodutiva no Brasil*. Campinas, SP: Editora da UNICAMP, p. 95-150, 2003, p. 95 and 102.

16. Ibid, p. 102-103.

17. RÖHDEN, F. A Construção da Diferença Sexual na Medicina. In: *Cadernos de Saúde Pública*, Rio de Janeiro, 19(Sup. 2):S201-S212, 2003, S206.

18. Ibid.

19. VILLELA, W.V. and ARILHA, M., op. cit., p. 95.

20. RÖHDEN, F., op. cit., nS205-S206.

21. VILLELA, W.V. and ARILHA, M., op. cit., p. 103.

22. VILLELA, W.V. *Mulher e Saúde Mental*. Thesis (doctorate in preventative medicine), FMUSP, USP, São Paulo, 1992, *apud* VILLELA, W.V. and ARILHA, M., op. cit., p. 104.

23. It is precisely this moral view of what is natural that the gay and lesbian movement is fighting against, since this is a central issue in configuring their citizenship.

24. ÁVILA, M. B. Direitos Sexuais e Reprodutivos: desafios para as políticas de saúde. In: *Cadernos de Saúde Pública*, Rio de Janeiro, 19 (Sup.2):S465-S469, 2003, S466.

25. VILLELA, W.V. and ARILHA, M., op. cit., p. 98.

26. FREEDMAN, L.P. and ISAACS, S.L., op. cit., p. 21.

27. Thomas R. Malthus (1766-1834), a 19th century British economist, defended in his treatise "*An Essay on the Principle of Population*" his theory that while populations grow at geometric rates, food supplies to sustain these populations tend to increase at an arithmetic rate. Therefore, Malthus predicted the collapse of the human population if birth rates were not voluntarily reduced.

28. ÁVILA, M.B. Direitos Reprodutivos: o Caos e a Ação Governamental. In: SOS CORPO – Grupo de Saúde da Mulher. *Os Direitos Reprodutivos e a Condição Feminina*. Recife, PE: SOS CORPO, p.17-25, 1989, p. 18.

29. FREEDMAN, L.P. and ISAACS, S.L., op. cit., p. 20.

30. Ibid, p. 22.

31. CORRÊA, S. and ÁVILA, M.B., op. cit., p. 19.

32. Note, as Freedman and Isaacs observe, the contrast between this declaration and those of Tehran and Bucarest, which resolved nothing concerning women's integrity and control of their body.

33. PIOVESAN, F. Integrando a Perspectiva de Gênero na Doutrina Jurídica Brasileira: Desafios e Perspectivas. In: PIOVESAN, F. *Temas de Direitos Humanos*, 2<sup>nd</sup> ed., São Paulo: Max Limonad, p. 221-235, 2003, p. 207.

34. BARSTED, L.L. As Conferências das Nações unidas influenciando a mudança legislativa e as decisões do Poder Judiciário. In: *Seminar: Human Rights: Towards a Jurisprudence of Equality*, Belo Horizonte, 14-17 May 1998, *apud* PIOVESAN, F. and PIROTTA, W.R.B. A Proteção dos Direitos Reprodutivos no Direito Internacional e no Direito Interno. In: PIOVESAN, F. *Temas de Direitos Humanos*, 2ª ed., São Paulo: Max Limonad, p. 237-276, 2003, p. 241-242.
35. PETCHESKY, R.P., *op. cit.*, p. 19.
36. *Ibid*, p. 21.
37. BOBBIO, Norberto. *A era dos direitos*. Rio de Janeiro: Campus, 1992, p. 5.
38. KISSLING, F. Perspectivas Católicas Progressistas em Saúde e Direitos Reprodutivos: o desafio político da ortodoxia. *Cadernos de Saúde Pública*, Rio de Janeiro, 14 (Supl.1), 1998, p. 135-137.
39. CORRÊA, S. and ÁVILA, M.B., *op. cit.*, p. 58.
40. COPELON, R. and PETCHESKY, R.P. Toward and Interdependent Approach to Reproductive and Sexual Rights as Human Rights: Reflection on the ICPD and beyond. In: SCHULER, M.A. (ed.). *From Basic Needs to Basic Rights*. Washington D.C.: Women, Law and Development International, p. 343-368, p. 1995, p. 348-349.
41. *Ibid*, p. 355-356.
42. According to the Report on the International Conference on Population and Development. United Nations, 1994, Cairo, 5-13 September.
43. PETCHESKY, R.P., *op. cit.*, p. 22.
44. COPELON, R. and PETCHESKY, R.P., *op. cit.*, p. 355.
45. PETCHESKY, R.P., *op. cit.*, p. 23.
46. *Ibid*, p. 20-21.
47. WEEKS, J. *Sexuality and its discontents: meaning, myths and modern sexualities*. London: Routledge & Keagan Paul, 1985, *apud* VILLELA, W.V. and ARILHA, M., *op. cit.*, p.105.
48. BUTEGWA, F. International Human Rights Law and Practice: Implication for Women. In: SCHULER, M.A. (ed.). *From Basic Needs to Basic Rights*. Washington D.C.: Women, Law and Development International, p. 27-39, 1995, p. 33.
49. LIMA LOPES, J.R. de. The Right to Recognition for Gays and Lesbians. In: *Sur – International Journal on Human Rights*, v. 2, p. 61-91, 2005.
50. STEINER, H.J. and ALSTON, P. *International Human Rights in Context: law, politics, morals. Text and Materials*, 2<sup>nd</sup> Edition. New York: Oxford University Press Inc., 2000, p. 158.
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52. COOK, R., *op. cit.*, p. 76.
53. As mentioned by Margaret Schuler SCHULER, M. Introduction. In: SCHULER, M. (editor.)

*From basic needs to basic rights. Women's claim to human rights.* Washington D.C.: Women, Law and Development International, p. 1-24, 1995, p. 10.

54. The same occurred with the rights of lesbians and homosexuals.

55. BUTEGWA, F., op. cit., p. 31.

56. SCHULER, M.A. From Basic Needs to Basic Rights (Introduction). In: SCHULER, M.A. (ed.). *From Basic Needs to Basic Rights.* Washington D.C.: Women, Law and Development International, p. 01-24, 1995, p. 10.

57. COOK, R. *Women's Health and Human Rights.* Geneva: World Health Organization, 1994, p. 24.

58. SCHULER, M., op. cit., p. 3.

59. ENGLE, K. After the Collapse of the Public/Private Distinction: Strategizing Women's Rights. In: DALLMEYER, DORINDA G. (Ed.). *Reconceiving reality: women and International Law.* Washington D.C.: American Society of International Law, 1993, p. 143.

60. CORRÊA, S. and ÁVILA, M.B., op. cit., p. 60-61.

61. PITANGUY, J., op. cit., p. 21.

62. CORRÊA, S. and ÁVILA, M.B., op. cit., p. 38.

63. Safe Motherhood Conference Conclusions. 1987. *Lancet* I:670 (COOK, R., op. cit., p. 83).

64. PETCHESKY, R.P., op. cit., p. 17-18.

65. VILLELA, W.V. and ARILHA, M., op. cit., p. 131.

66. SARMENTO, D. *Direitos Fundamentais e Relações Privadas.* Rio de Janeiro: Editora Lúmen Júris, p. 173-220, 2004, Capítulo V, p. 190.

67. According to General Comment No. 14 of the ICESCR committee, item 8: "The right to health is not to be understood as a right to be *healthy*. The right to health contains both freedoms and entitlements". CESCR, *General Comment 14*, UN ESCOR, 2000, Doc. No. E/C.12/2000/4.

68. The term stigma, according to Goofman, is used in reference to a significantly discrediting attribute. GOOFMAN, E. *Estigma: Notas sobre a Manipulação da Identidade Deteriorada.* Rio de Janeiro: LTC Editora, 4a. Ed., 1988, p. 13-14.

69. LIMA LOPES, J.R. de. The Right to Recognition for Gays and Lesbians. In: *Sur – International Journal on Human Rights*, v. 2, p. 61-91, 2005, p. 69.

70. Ibid, p. 70-71.

71. Ibid, p. 74.

72. Ibid, p. 69.

73. ÁVILA, M.B., op. cit., S467.

74. VILLELA, W.V. and ARILHA, M., op. cit., p. 136.



## RESUMO

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Este artigo sistematiza as razões que levaram a um descompasso entre o reconhecimento jurídico dos direitos sexuais e dos direitos reprodutivos, por meio da análise de três perspectivas: a da História, a da moral religiosa, especialmente a Católica Romana e, por fim, a do Direito. O artigo conclui apresentando os ganhos para a democracia e a cidadania pública de homossexuais (gays e lésbicas) e mulheres heterossexuais caso haja o reconhecimento jurídico dos direitos sexuais.

### PALAVRAS-CHAVE

Direitos humanos – Direitos reprodutivos – Direitos sexuais – Gênero – Sexualidade

## RESUMEN

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Este artículo sistematiza las razones que condujeron a un descompás entre el reconocimiento jurídico de los derechos sexuales y el de los derechos reproductivos mediante el análisis de tres perspectivas: la de la historia, la de la moral religiosa, especialmente la Católica, y por último, la del derecho. El artículo concluye presentando los beneficios para la democracia y la ciudadanía pública de homosexuales (gays y lesbianas) y mujeres heterossexuales del reconocimiento jurídico de los derechos sexuales.

### PALABRAS CLAVES

Derechos humanos – Derechos reproductivos – Derechos sexuales – Género – Sexualidad



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The views expressed in this piece are solely those of the authors.

## ABSTRACT

This article contends that efforts to expand the justiciability of economic, social, and cultural (ESC) rights before supranational tribunals may not always be the best way to increase respect for these rights on the ground. In the Inter-American System, the authors maintain that human rights lawyers will best advance social justice and ESC rights when they use supranational litigation as a subsidiary tool to support advocacy efforts led by domestic social movements, a role that may often entail litigating ESC claims strategically within the framework of civil and political violations.

Original in English.

## KEYWORDS

Inter-American – ESC rights – Justiciability – Social movements – Strategic litigation



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# THE VIRTUE OF FOLLOWING: THE ROLE OF INTER-AMERICAN LITIGATION IN CAMPAIGNS FOR SOCIAL JUSTICE

James L. Cavallaro and Stephanie Erin Brewer

## **The virtue of following: the role of Inter-American litigation in campaigns for social justice**

For two decades, human rights lawyers have sought to advance the enjoyment of economic, social, and cultural (ESC) rights by establishing the justiciability of these rights before domestic and supranational human rights tribunals. However, in the race to make ESC rights justiciable before courts, the human rights movement has failed to consider thoroughly whether expanding the ability of courts to render decisions on ESC rights per se is always the best way to increase respect for these rights and promote social justice on the ground. We contend that advocacy of ESC justiciability as an end in itself fails to appreciate the instrumental nature of litigation in advancing human rights.

Thus, in certain contexts, the most successful strategies for promoting social justice through litigation will not necessarily emphasize making ESC rights justiciable. Instead, we maintain that human rights lawyers will best advance ESC rights when they use supranational litigation as a subsidiary tool to support advocacy efforts led by domestic social movements, a role that may often entail litigating ESC claims strategically within the framework of civil and political violations. This is often the case, we argue, for litigation before the Inter-American Court of Human Rights.<sup>1</sup>

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*Notes to this text start on page 93.*

## Introduction

In an earlier piece published in the *Hastings Law Journal*,<sup>2</sup> one of the authors of this piece together with Emily Schaffer set out what we believed to be the wisest path forward for advocates seeking to advance ESC rights through Inter-American litigation, specifically litigation before the Court. That piece, based in significant part on its authors' combined experience working with rights defenders and social justice movements in Latin America for two decades and litigating scores of matters in the Inter-American system, challenged some of the conventional wisdom regarding the expansion of the justiciability of ESC rights. In particular, it questioned the wisdom of alleging direct violations of article 26 of the American Convention (referring to progressive implementation of ESC rights). The piece argued that given the Court's reluctance to recognize alleged violations of article 26, litigating direct ESC claims under this article was an approach unlikely to convince the Court and even less likely to be implemented by states. We also set out a range of alternative ways that litigants might seek to advance social justice by litigating in the Inter-American system. These included, for example, invoking the ESC rights protected in the American Declaration before the Commission. Before the Court, we emphasized litigation strategies that focus on ESC elements in civil and political rights, frame cases in terms of the non-discrimination principle, and invoke the economic and social rights for which clear access to the Court is recognized in the San Salvador Protocol.<sup>3</sup>

In a piece published last year in the *N.Y.U. Journal of International Law and Politics*,<sup>4</sup> human rights attorney Tara J. Melish responded to these arguments, contending that article 26 is a viable path for alleging ESC rights violations provided that litigators limit their claims to individual-oriented, conduct-based duties on the part of states. Melish maintains that so long as human rights lawyers conscientiously fulfill all of the other legal requirements of an admissible case before the Inter-American system, the Court can recognize article 26 claims to the same extent as traditional civil and political claims.<sup>5</sup>

Much of the debate between us and Melish focuses on the technical viability – from a litigator's perspective – of alleging direct ESC rights claims before the Court. In this regard, the present authors continue to have serious doubts about the prospects of success under this approach and to advocate that litigators within the system bear in mind the legal and practical limits of article 26 when framing their cases. However, in evaluating this debate, we have come to place increasing emphasis on a much broader question: rather than asking how litigators can persuade the Court to expand the justiciability of ESC rights under article 26, practitioners must ask themselves whether aiming for such declarations is the best means of improving enjoyment of ESC rights in practice. Answering the latter question, in turn, requires human rights lawyers to ask themselves what role a given Inter-American Court case can and should play in advancing human rights and social justice on the ground. We take this opportunity to refine and reiterate what we believe this role to be.

As an initial matter, practitioners must come to terms with the limited access that the Inter-American system provides in real, numerical terms. In the last three years, for instance, the Inter-American Court has resolved an average of 15 cases annually<sup>6</sup> - less than one case per year for each country that has recognized the Court's contentious jurisdiction.<sup>7</sup> In light of the system's limited capacity to address directly the vast majority of rights violations in the Americas, we assert that any litigation strategy that does not seek to produce or at least encourage effects beyond the individual litigants is rendered inefficient at best and misguided at worst.

Moreover, as argued in the Hastings piece, the on-the-ground impact of the Court's determinations has not correlated directly with the merits of those determinations, but rather has varied in relation to parallel organization, media mobilization, and civil society strategies.<sup>8</sup> As a consequence of this broader context, we call on practitioners to promote social justice through well grounded litigation that plays a secondary, supporting role to the broader advocacy efforts of domestic social movements and organized civil society. We contend that listening to social movements and working to support them have real consequences for the framing of litigation and for the ways in which supranational bodies are best deployed. For instance, domestic social movements may prefer that litigation before the Court be grounded in civil and political rights as part of a broader strategy to advance a given ESC right. In this regard, we emphasize the strategic importance of cases that involve violations of the right to life.

### **Listening to social movements and civil society**

Rather than relying on litigation as the primary means to advance a given human rights agenda, we maintain that human rights practitioners must recognize and support the key role of social movements, civil society, and media advocacy in developing campaigns to foster social justice. Many if not most human rights advocates already recognize that litigation has a larger impact when it occurs in conjunction with advocacy by social movements, media coverage, and other forms of domestic and international pressure. However, human rights lawyers often operate under the assumption that litigation should drive the advocacy strategy and that the other elements mentioned above should support it. We argue that the reverse is true. That is, broader advocacy campaigns may include litigation in the Inter-American system, as appropriate, but supranational litigation preferences should not, as a general rule, impose limits on advocacy for social justice. Social justice advocacy strategies, however, may lead to restrictions or modifications of methods of litigation.

Under this view, the relationship between litigation and other strategies will have real consequences for the nature of petitions submitted to the Inter-American system as well as the way they are framed and litigated. In practice, social movements are often more interested in the Court as an avenue for raising the profile of particular agendas rather than as a forum in which the justiciability of ESC rights may be

advanced. Moreover, in light of the extremely limited access to the Court in numerical terms, these two objectives often come into conflict. The Commission and Court adjudicate a handful of cases per year. For example, since 1979, ninety-two contentious cases have been resolved by the Court, leading to 167 determinations; the Court has resolved an additional seventy-six requests for precautionary measures, and has issued nineteen advisory opinions.<sup>9</sup> If one measures from 1986, the year the first contentious cases were forwarded to the Court, this yields an average of just over four contentious cases per year. While these numbers have increased dramatically in recent years, particularly after the reforms of 2001, the Court continues to address an average of less than one case per country per year.<sup>10</sup> Based on these severe limits, we argue that petitioners must rethink their understanding of the system. With such remarkable limits on its access, the system cannot reasonably be viewed as capable of responding to every injustice in the Americas.<sup>11</sup> Instead, it should be seen as a tool that must be used to magnify a very, very limited universe of cases. Which universe of cases, we argue, is the fundamental question. If deployed intelligently, litigation before the system may provide opportunities for thoughtful practitioners to promote social justice more broadly. At the same time, the bottom line is very often one that involves real tradeoffs. Should the one case in any given year that the Court addresses from Ecuador focus on extending the justiciability of protections against forced eviction or on the killing of an indigenous leader seeking control of resources on traditional lands? Should the one case that proceeds to the Court against Brazil in a given year address the concerns of persons with mental health issues, through the prism of a patient beaten to death in a closed mental hospital, or on efforts to encourage the Court to recognize an article 26 claim to the right to food? Admittedly, these questions are not presented in absolute terms to any individual petitioner, but they flow directly from the extremely limited capacity of the system and, in particular, the Court.

If, as we argue, the main objective of supranational litigants in the Inter-American system should be to place issues before supranational bodies in conjunction with other advocacy strategies, then it should not matter whether the Commission or Court addresses a particular question from the framework of civil and political or ESC rights. More important, we contend, is which issues are addressed and what broader efforts are included in the advocacy campaign. If the civil and political rights frame offers greater opportunity for advocacy and promotion of change, then this frame, rather than the ESC frame, should be given priority.

#### ***A. Working with social movements to promote agrarian reform: the Corumbiara and Eldorado dos Carajás cases***

One case that demonstrates the utility of working with social movements and litigating strategically within the framework of civil and political rights is *Corumbiara v. Brazil*.<sup>12</sup> The case involved the violent forced eviction of over 500 families from a parcel of

land called the Santa Elina ranch. To remove the families from the land, Brazilian military police stormed the ranch in a surprise nighttime attack, using grossly excessive force and leaving 11 settlers dead and 53 wounded. The case therefore presented several possible angles from which to argue that Brazil was liable for violations of the settlers' human rights. For instance, advocates could have framed the case primarily as a violation of the right to housing. However, the petitioners in the case decided instead to focus their arguments on the brutal violence used by the military police during the eviction.<sup>13</sup>

For advocates of expanding the justiciability of ESC rights, Corumbiara may appear as a missed opportunity given that the petitioners focused on civil and political rather than economic or social rights.<sup>14</sup> In Brazil at the time, however, the vision of those working with landless and human rights leaders was quite different. Indeed, the extreme violence employed by the police, particularly after seizing control of the Santa Elina ranch, was an issue that helped to catapult the land reform debate—in its many dimensions—to national prominence in Brazil.

The choice to emphasize conflicts involving extreme violence was important for the broader land reform strategy. A similar strategic decision was made the following year when police attacked a group of landless squatters pressing for expropriation in Pará state. In that April 1996 incident (known as the Eldorado dos Carajás massacre), the squatters were occupying the main road connecting the south of Pará state with the capital, Belém, when military police opened fire on them and attacked the squatters with their own hoes and machetes, killing nineteen and wounding scores of others.<sup>15</sup>

In both cases, the advocacy agenda focused on highlighting the violations of the right to life in an effort to mobilize domestic and international public opinion against the use of police violence to resolve land conflicts. This, rather than a pronouncement by the Inter-American system on forced evictions, was the main goal of the litigation strategy. Moreover, such a focus made sense in light of the domestic advocacy strategy at the time. Brazil's landless movement, most probably Latin America's best developed social movement, regularly deployed a range of strategies designed to end forced evictions and to bring about change in land tenure patterns. These included pressure for legislative change, litigation within Brazil, and, primarily, land occupations. Because the last element was so central to its overall strategy, reducing the threat of future massacres by police was vital to the landless movement.

At the same time, framing the Inter-American litigation in terms of violations of the right to life did not prevent ESC rights from playing a prominent role in the advocacy campaign. First, the submissions to the Commission focused on the context of gross inequality in which the killings occurred. At the time of the initial Corumbiara case (October 1995), the Eldorado dos Carajás massacre (April 1996) and filing (September 1996), and the litigation of the two cases (for the next several years), those engaged in promoting land reform routinely addressed the underlying ESC claims in a range of fora (including domestic courts, the Brazilian parliament,



international debates, etc.). The advocacy campaign thus addressed the issues of forced eviction, as well as questions related to land distribution, financing, and credit for land reform, even beyond the scope of what could have been presented to the Inter-American Commission.<sup>16</sup> Media sources, as well, in their coverage of the Corumbiara matter, routinely analyzed the broader context of land reform, squatter occupations, the demand for land settlement, and respect for housing rights.<sup>17</sup>

Interestingly, the record demonstrates the partial success of this strategy. While land conflicts still continue to dominate rural Brazil, incidents of multiple deaths caused by police firing at squatters virtually ceased after the Corumbiara and Eldorado massacres. Likely in response to this mobilization and joint strategy, after the killings of twenty-eight people in the Corumbiara and Eldorado incidents in a period of just eight months, the number of people killed by police in rural land conflicts decreased dramatically. Over the next four years, police killed a total of eight civilians in this context. All but one of the conflicts involved a single victim; the bloodiest caused two<sup>18</sup> fatalities.<sup>19</sup> One of Brazil's leading weekly magazines, *IstoÉ*, reported months after the Eldorado massacre that the State Government in Pará—the epicenter of Brazil's most violent rural clashes—expressly ordered its military police to avoid all situations that might lead to violent conflicts similar to that in the Eldorado massacre.<sup>20</sup>

At the same time, as multiple killings by police in rural conflicts practically ceased, land occupations intensified, leading to the settlement of hundreds of thousands of squatters.<sup>21</sup> According to official data, in relation to the preceding twenty-five years, between 1995 and 1999 the average number of families settled per year increased by all accounts. By some, the surge was as much as five hundred percent.<sup>22</sup> According to the Landless Movement, the number of land occupations more than doubled from 1995 to 1999, compared to the previous five years.<sup>23</sup> Official figures demonstrate that more families were settled from 1995 through 1999 than in the twenty-five years preceding that period.<sup>24</sup> As for land expropriation (*desapropriação*)—areas ordered redistributed for land reform purposes—more than double the number of hectares were expropriated in the 1995 through 1999 period than in either of the two previous five year periods.<sup>25</sup>

Notably, among the areas expropriated by the federal government was the Macaxeira fazenda, the focus of the highway occupation and brutal police response that resulted in the killing of nineteen squatters in the Eldorado case.<sup>26</sup> In addition, in response to the domestic and international outrage over the Corumbiara and Eldorado massacres, federal authorities implemented a range of other measures, including expediting expropriations for land reform and providing additional funding for landless settlements.

The Corumbiara and Eldorado cases underscore the importance of understanding that social movements, not international human rights lawyers, should take the lead in designing social change strategies. Human rights lawyers, of course, play a prominent role in litigation, applying legal rules and developing arguments before supranational

tribunals. But they should do this in a way that supports the objectives of those directly affected by grave social injustice, rather than in ways that promote particular jurisprudential agendas. The Corumbiara case is one example among many in which the need for litigants to work more closely with social movements shapes the legal strategies adopted. This case also underscores that advocacy strategies that do not place the Inter-American system at their center often demonstrate greater promise to promote social justice than strategies that rely primarily on supranational litigation.<sup>27</sup>

Such an approach – in which supranational litigation plays a secondary and supporting role – stands in contrast to campaigns in which litigants rely upon an Inter-American Court case to drive social change. For instance, in the case of *Yean and Bosico v. Dominican Republic*,<sup>28</sup> the Inter-American Court considered the Dominican Republic's discriminatory failure to provide two children of Haitian descent with the nationality certificates necessary for their enrollment in school. The case occurred against a backdrop of entrenched prejudice against individuals of Haitian descent in the country; indeed, the opinion in *Yean and Bosico* notes testimony regarding the unpopularity of the issue of equal rights for these Dominicans.<sup>29</sup> In contrast to the experience of the landless movement in Brazil, activists in the Dominican Republic had encountered severe difficulties in mobilizing widespread pressure by the public and media for the equal treatment of children of Haitian descent. This resulted in the Inter-American Court case becoming, at key moments, the most visible element of the advocacy strategy. Unsurprisingly, the Court's finding of violations in the case met with backlash in the Dominican Republic,<sup>30</sup> where this outcome did not resonate with the majority of the population and drew criticism from the government. In general, we argue that supranational litigation in controversial areas such as this – when not well supported in the domestic agenda – is unlikely to produce social change.<sup>31</sup>

Other cases before the Court have been developed as part of broader advocacy strategies. These cases have generally led to greater compliance pressure on states and change on the ground. One such case was decided by the Court in mid-2006. The case, *Ximenes Lopes v. Brazil*,<sup>32</sup> concerned a killing within a psychiatric clinic operating pursuant to a contract with Brazilian authorities in Ceará state. Initially filed by the sister of the victim before the Commission, the *Ximenes Lopes* case attracted the support of the Ceará state legislature's human rights commission, a major Brazilian human rights organization, psychiatric professionals and progressive insiders within the Brazilian government, as well as favorable media. While the case was framed in terms of civil and political rights, it provided an important vehicle for addressing the broader situation of persons with mental health disabilities, particularly those in closed institutions in Brazil. The discussion fostered by the supranational litigation occurred both within the terms of the litigation and in the broader debate within Brazil.

After finding that the death of the victim was attributable to the State, the Inter-

American Commission recommended that Brazil take necessary measures to avoid the recurrence of such violations in the future. By this time, efforts by domestic stakeholders including patients' relatives, health professionals, and local and national health commissions had already triggered an ongoing shift from an internment model of mental healthcare to a system focused on outpatient care and respect for patients' rights.<sup>33</sup> This context of domestic reform encouraged greater discussion of the underlying issues of mental health policy before the Inter-American Court in the Ximenes Lopes case. For instance, Brazil presented testimony regarding steps it had taken to reduce the frequency of confinement of persons with mental health problems and to restructure its national mental health program.<sup>34</sup> The Court case, in turn, fostered fresh debate within Brazil about national public health policy. The Ximenes Lopes case thus exemplifies, among other things, how an issue framed legally in terms of civil and political rights may address questions of social justice, including ESC rights.

### **Jurisprudence and integrated advocacy meet: framing cases using the right to life**

As emphasized above, litigation in the Inter-American system, by its inherent, limited nature, excludes the overwhelming majority of victims of rights abuse in the Americas and will continue to do so until the system is radically overhauled. Until that time, cases should be designed carefully and, we argue, jointly with social movements and organized civil society. We take this opportunity to highlight briefly a pattern that emerges from following this approach: namely, when practitioners follow the lead of social movements, they will often place priority on violations of the right to life due to the strategic value of petitions involving this right.

Over the past several years, the Court has developed an increasingly broad understanding of the right to life, including in cases involving underlying ESC rights violations. In the Sawhoyamaya case,<sup>35</sup> for instance, the Court found the state of Paraguay responsible for the deaths of nineteen indigenous community members (including eighteen children) due to the state's failure to provide adequate conditions to ensure their well being.<sup>36</sup> This line of jurisprudence opens opportunities for many advocates litigating cases of ESC violations to frame the underlying violations in terms of the right to life. Such an approach avoids the riskier strategy of relying on article 26 of the American Convention and offers a well-established body of caselaw from which to draw support.

More importantly, the advocacy value of a claim involving the right to life goes to the core of what gives an issue salience for media campaigns, grassroots organizing, and networking with civil society. Violations of the right to life—whether in the context of urban police killings, prison revolts, conflicts over land, failure to treat HIV patients, or failure to prevent precarious housing from flooding—tend to carry more weight than violations that do not threaten life. Recognizing this is part and

parcel of working with advocacy groups (social movements, NGOs, etc.) and taking one's cues from them as a litigator. For example, if one is listening to these groups, one will often hear a preference for focusing on those who have died in their struggles, rather than all those who, on a daily basis, suffer other rights abuses. Not surprisingly, social movements tend to value quite highly the sacrifices made by their members whose lives are lost in the course of their struggles for social justice. Supporting this civil and political rights frame—rather than fighting against it—makes good sense from the perspective of a legal practitioner focused on social justice rather than jurisprudential development. The key is to find ways to use this right to life focus to advance other aspects of social justice campaigns—including ESC rights.

## Conclusion

In thinking about future avenues of litigation in the Inter-American system, we urge practitioners to avoid the assumption that increased justiciability of ESC rights alone will lead to increased social justice on the ground. We call on litigators to consider instead strategies such as employing expansive constructions of civil and political rights to embrace ESC rights elements or filing petitions that involve violations of both civil and political and ESC rights. Most importantly, we urge practitioners to work closely with social movements, organized civil society groups, and the media in the countries involved. By taking their cue from these groups and recognizing the subsidiary role of supranational litigation in advocacy campaigns, human rights lawyers can help to ensure that efforts to deploy the Inter-American system maximize its potential to advance not merely the justiciability of ESC rights, but the enjoyment of these rights in practice.

## NOTES

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1. Much of this piece is based upon a previous article published last year in the N.Y.U. Journal of International Law and Politics. See CAVALLARO, J. L. & SCHAFFER, E.. Rejoinder: Justice Before Justiciability: Inter-American Litigation and Social Change. *New York University Journal of International Law & Politics*, p. 345, New York, v. 39, 2006.

2. CAVALLARO, James L. & SCHAFFER, Emily J. Less as More: Rethinking Supranational Litigation of Economic and Social Rights in the Americas. *Hastings Law Journal* p. 217, v. 56, 2004. In the text, we refer to this piece as *Less as More* or as the Hastings piece.

3. The San Salvador Protocol is the Inter-American treaty that deals specifically with economic, social, and cultural rights. It explicitly provides for petition to the Inter-American system to enforce the right to education, protected in Article 13, and of certain labor rights, established in Article 8, clause (a). *Additional Protocol*

to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights “Protocol of San Salvador”, Inter-Am. C.H.R. 67, OEA/ser. L.V./II.82, doc. 6 rev.1 (1992).

4. MELISH, Tara J.. Rethinking the “Less as More” Thesis: Supranational Litigation of Economic, Social and Cultural Rights in the Americas. *New York University Journal of International Law & Politics* p. 171, v. 39, 2006.

5. See id. p. 205 (asserting, “direct litigation in the Inter-American system of economic, social, and cultural rights presents no greater justiciability or legitimacy problems than does direct litigation of classic civil and political rights”).

6. INTER-AMERICAN COURT OF HUMAN RIGHTS. *Jurisprudence*. Available at <<http://www.corteidh.or.cr/>>. Last visited on 29 Sept. 2007.

7. More than twenty states have now recognized the Court’s competence to adjudicate contentious cases. See INTER-AMERICAN COURT OF HUMAN RIGHTS, B-32, American Convention on Human Rights (“Pact of San José, Costa Rica”). Available at <<http://www.cidh.org/Basicos/English/Basic4.Amer.Conv.Ratif.htm>>. Last visited on 29 Sept. 2007.

8. CAVALLARO & SCHAFFER, *supra* note 2, p. 240, 251.

9. INTER-AMERICAN COURT OF HUMAN RIGHTS. *Jurisprudence*. Available at <<http://www.corteidh.or.cr/>>. Last visited on 7 Nov. 2007.

10. Ibid.

11. We cannot underscore this point enough. Our analysis of litigation strategies is entirely contextual. If the Inter-American system were expanded and were provided with greater resources and state support, we would support expansion of litigation of all types. However, given that very, very few cases are able to proceed to the Court, we argue for great care in selecting cases to be petitioned.

12. *Corumbiara Massacre*, Petition no. 11.556, Inter-Am. C.H.R., Report No. 32/04. Available at <<http://www.cidh.org/annualrep/2004eng/Brazil.11556eng.htm>>. Last visited on 28 Feb. 2008.

13. James L. Cavallaro, at the time, director of CEJIL/BRASIL and Brazil office director of Human Rights Watch, was one of several petitioners in both the Corumbiara case and the Eldorado dos Carajás matter, discussed below.

14. Indeed, in her critique of the *Hastings* article, Tara Melish argued that the petitioners in the Corumbiara massacre erred in not framing the case primarily in terms of ESC rights violations. MELISH, *supra* note 4, p. 315-323.

15. *Admissibility El Dorado dos Carajás*, Petition no. 11.820, Inter-Am. C.H.R., Report No. 4/03. Available at <<http://www.cidh.org/annualrep/2003eng/Brasil.11820.htm>>. Last visited on 28 Feb. 2008.

16. OSAVA, MARIO. *Brazil: Fear of Social Unrest Revives Land Reform*. Rio de Janeiro: IPS – INTER PRESS SERVICE, 28 September 1995; see Corumbiara: Deadly Eviction. *Time*, v. 146, n. 9, 28 Aug. 1995, p. 8; Land Question Develops into Crisis: Military Fear Conflicts May Lead to Guerrilla Violence, *Latin American Weekly Report* p. 447-48, London, 1995.

17. OSAVA, M. op. cit. Corumbiara: Deadly Eviction, op. cit.; Eleven Die in Land Conflict: Lula Claims Cardoso Has No Interest in Agrarian Reform, *Latin American Weekly Report*, p. 374-75, London, 1995  
SCHEMO, D. J.. Brazilian Squatters Fall in Deadly Police Raid, *N.Y. Times*, 19 Sept. 1995, p. A1.

18. It is possible to interpret this figure as three. According to CPT data, military police and gunmen killed two civilians on March 2, 2001 in the municipality of Confresa, state of Mato Grosso. Two days later, they killed another civilian in the same municipality. It is unclear whether these should be considered two separate conflicts. See COMISSÃO PASTORAL DA TERRA, *Conflitos no Campo: Brasil 1997*, 1998, p. 10-11. After 2001, CPT stopped including information on the identity of murder suspects.

19. Nevertheless, despite the reduction in the numbers of landless squatters and protesters killed by police after Corumbiara and Eldorado dos Carajás, rights groups in Brazil have documented an increase in other forms of repression. For instance, according to Landless Movement (MST) data, instances of arrests of landless peasants vastly increased in the years after 1996, suggesting a displacement in repressive techniques and highlighting the continued need for advocacy related to civil and political rights that would allow the landless movement to continue its land reform push. See MOVIMENTO DOS TRABALHADORES RURAIS SEM TERRA, *Prisões – 1989 a 2003*. Available at <<http://www.mst.org.br/mst/pagina.php?cd=1501>>. Last visited on 28 Feb. 2008.

20. According to *IstoÉ*, “[t]he Government of Pará, after the massacre of Eldorado dos Carajás, ordered the Military Police not to involve itself in any situation that might result in confrontation”. (The original in Portuguese reads: *O governo do Pará, após o massacre de Eldorado do[s] Carajás, determinou ao comando da Polícia Militar paraense que não se envolva em nenhuma situação que possa resultar em confronto.*) See CHIMANOVITCH, M.. Tensão permanente: Relatórios reservados informam que os sem-terra pretendem criar versão nacional de Chipas no Pará, *IstoÉ*, 7 Aug. 1996. Available online at <<http://www.zaz.com.br/istoe/politica/140112.htm>>. Last visited on 28 Feb. 2008 [hereinafter *Tensão permanente*]

21. According to the MST data, from 1990 until 1995, the number of land occupations [*acampamentos*] fluctuated from a low of 78 in 1991, with 9,203 families, to a high of 214 in 1993, with 40,109 families. Then, from a low, in 1995, of 101 land occupations representing 31,619 families, the number of occupations grew each year to 538 with 69,804 families in 1999. (A participação da polícia em assassinatos e chacinas não é novidade, mas ela vem crescendo nos últimos anos.) COMISSÃO PASTORAL DA TERRA, *Conflitos no Campo: Brasil 1995*, 1996, p. 5.

22. According to the government, an average of 11,870 families were settled per year from 1970 through 1984. That figure increased modestly to 15,013 over the next ten years. From 1995 through 1999, the average number of families settled each year, according to government reports, surged to 74,644. See INSTITUTO NACIONAL DE COLONIZAÇÃO E REFORMA AGRÁRIA. *Relatório de Atividades INCRA 30 Anos*. Available at <<http://incra.gov.br/arquivos/0173400476.pdf>>. Last visited on 28 Feb. 2008 [hereinafter *Relatório de Atividades*]. Different INCRA reports provide somewhat contradictory figures, though all affirm the stated trend of increasing settlements from 1995 through 1999, in varying degrees. Another INCRA report released some time after the thirty-year retrospective, asserts that only 218,000 families were settled from 1964—the year of the passage of the Land Statute [Estatuto da Terra]—until 1995. Then, from 1995 through 1999, 372,866 families were reported settled. See INSTITUTO NACIONAL DE COLONIZAÇÃO E REFORMA AGRÁRIA. *O Futuro Nasce da Terra*. Available at <<http://www.incra.gov.br/arquivos/0173500477.pdf>>. Last visited on 28 Feb. 2008 [hereinafter *O Futuro Nasce da Terra*].

23. MOVIMENTO DOS TRABALHADORES RURAIS SEM TERRA, *Acampamentos – Total dos Acampamentos, 1990-2001*. Available at <<http://www.mst.org.br/mst/pagina.php?cd=897>>. Last visited on 28 Feb. 2008.

24. In its thirty year retrospective, the Instituto Nacional de Colonização e Reforma Agrária (INCRA)

reported that while 316,327 families were settled from 1970 until 1995, in the five years that followed, a total of 373,220 families were settled. See *Relatório de Atividades*, *supra* note 22.

25. According to the government, 4,191,147 hectares were expropriated from 1985 through 1989, falling to 3,858,828 hectares from 1990 through 1994 before jumping to 8,785,114 hectares from 1995 through 1999. See *O Futuro Nasce da Terra*, *supra* note 22

26. See *Tensão permanente*, *supra* note 20.

27. As demonstrated in *Less as More* through an assessment of several case studies, instances in which litigation before the Inter-American system occurred in relative isolation from domestic activism were least likely to produce significant change. See CAVALLARO & SCHAFFER, *supra* note 2, p. 240-251.

28. *Yean and Bosico Case v. Dominican Republic*, Inter-Am. Ct. H.R. (ser. C) No. 130, 8 Sept. 2005.

29. *Id.*, p. ¶¶ 85-86.

30 See PINA, Diógenes. *Acatamiento Parcial a Corte Interamericana*, *Inter Press Service News Agency*, 23 Mar. 2007. Available at <<http://ipsnoticias.net/interna.asp?idnews=40469>>. Last visited on 28 Feb. 2008 (citing a document released by the Dominican Secretary of Foreign Relations in which the government challenged both the procedural integrity and the outcome of the Court case); DÍAZ, J. B.. ¿Haitianos, dominicanos ó domínicohaitianos?, *El Diario Hoy*, San Salvador, 16 Oct. 2005. Available at <[http://www.clavedigital.com.do/Portada/Articulo.asp?Id\\_Articulo=6231](http://www.clavedigital.com.do/Portada/Articulo.asp?Id_Articulo=6231)>. Last visited on 28 Feb. 2008 (reporting that most Dominicans who knew of the Court sentence had strong negative reactions to it); *Consideran política, excluyente y discriminatoria, sentencia de la Suprema Corte de Justicia Dominicana*, *AlterPresse*, Port-au-Prince., 19 Dec. 2005. Available at <<http://www.alterpresse.org/spip.php?article3809>>. Last visited on 28 Feb. 2008 (reporting a decision by the Dominican Supreme Court (issued 14 Dec. 2005) that contradicted the Inter-American Court's holding in *Yean and Bosico* that children born in the Dominican Republic cannot be denied Dominican nationality based on their parents' immigration status).

31. To be sure, we do not counsel an absolute rule against using litigation as one's central advocacy strategy. Rather, we suggest that practitioners assess the political context in which they operate and reach out to other actors and social movements in designing mobilization and litigation strategies. There may well be instances in which no other mobilization strategies besides international pressure, and by extension, international litigation are viable. However, litigating a case before the Inter-American Court in these circumstances should be the result of a deliberative process, rather than an instinctive, legalistic response to a perceived violation of human rights law.

32. *Ximenes Lopes v. Brazil*, Inter-Am. Ct. H.R. (ser. C) No. 149 (July 4, 2006).

33. See *id.*, p. ¶ 46.2. (summarizing documentary evidence regarding Brazil's ongoing reform efforts aimed at reducing confinement of mental health patients and "humanizing" the mental health care system with input from patients, their relatives, and healthcare professionals).

34. One of the witnesses presented by Brazil was Pedro Gabriel Godinho Delgado, National Coordinator of the Mental Health Program of the Ministry of Health. Godinho Delgado's testimony focused on measures taken by the state to increase outpatient care, as opposed to confinement, as well as measures designed to promote and respect human rights within the mental health system. See *id.*, p. ¶ 47.3.b.

35. *Sawhoyamaya Indigenous Community v. Paraguay Case*, Inter-Am. Ct. H.R. (ser. C) No. 146, 29 Mar. 2006.

36. See *id.*, p. ¶¶ 151, 153, 178.



## RESUMO

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Esse artigo defende que os esforços para expandir a justiciabilidade dos direitos econômicos, sociais e culturais (ESC), perante tribunais supranacionais, possivelmente não venha a ser sempre a melhor forma para aumentar concretamente o respeito a esses direitos. No Sistema Interamericano, os autores deste artigo afirmam que os advogados de direitos humanos serão mais capazes de promover a justiça social e os direitos ESC quando usarem a litigância supranacional como uma ferramenta subsidiária, destinada a apoiar esforços de mobilização já promovidos por movimentos sociais internos. Esse papel coadjuvante pode com frequência implicar, como uma medida estratégica, a litigância de casos relacionados a direitos ESC dentro da estrutura própria das violações a direitos civis e políticos.

### PALAVRAS-CHAVE

Sistema Interamericano – Direitos ESC – Justiciabilidade – Movimentos sociais – Litigância estratégica

## RESUMEN

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Este artículo sostiene que el esfuerzo por expandir la justiciabilidad de los derechos económicos, sociales y culturales (DESC) ante tribunales internacionales no siempre puede ser la vía más adecuada para mejorar el respeto efectivo de estos derechos. En el sistema interamericano, según los autores, los abogados de derechos humanos lograrán más avances en materia de justicia social y de DESC cuando utilicen el litigio internacional como una herramienta subsidiaria para apoyar esfuerzos de incidencia sostenidos por movimientos sociales locales, una función que a veces puede requerir plantear violaciones de DESC con la perspectiva de violaciones a derechos civiles y políticos.

### PALABRAS CLAVES

Sistema Interamericano – DESC – Justiciabilidad – Movimientos sociales – Litigio estratégico



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## ABSTRACT

This article considers the component of the right to the highest standard of health that relates to medicines, including essential medicines. Using the right-to-health analytical framework that has been developed in recent years, the first section focuses on the responsibilities of States. The second section provides a brief introduction to the responsibilities of pharmaceutical companies.

Original in English.

## KEYWORDS

Medicines – Right to health – Human rights – TRIPS – WHO



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# THE HUMAN RIGHT TO MEDICINES

Paul Hunt and Rajat Khosla

## A. Introduction

Almost 2 billion people lack access to essential medicines.<sup>1</sup> This deprivation causes immense and avoidable suffering: ill health, pain, fear, loss of dignity and life.<sup>2</sup> Improving access to existing medicines could save 10 million lives each year, 4 million of them in Africa and South-East Asia.<sup>3</sup> Besides deprivation, gross inequity in access to medicines remains the overriding feature of the world pharmaceutical situation.<sup>4</sup> Average per capita spending on medicines in high income countries is 100 times higher than in low-income countries: about US\$ 400 compared with US\$ 4. WHO estimates that 15 per cent of the world's population consumes over 90 per cent of the world's production of pharmaceuticals.<sup>5</sup>

Existing national and international policies, rules and institutions give rise to these massive deprivations and inequalities. National supply systems for medicines often do not reach those living in poverty. If they do, the medicines are often unaffordable. Historically, research and development have not addressed the priority health needs of those living in poverty. Alternative arrangements are feasible and reforms are urgently required. Indeed, they are demanded by legal and ethical duties, including those arising from international human rights law.

Millennium Development Goals, such as reducing child mortality, improving maternal health, and combating HIV/AIDS, malaria and other diseases, depend upon improving access to medicines. Indeed, one of the Millennium Development Goal targets is to provide, "in cooperation with pharmaceutical companies, access to affordable essential drugs in developing countries".<sup>6</sup> Crucially, implementation

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*Notes to this text start on page 112.*

of the right to the highest attainable standard of health can help to achieve the health related Goals.

Medical care in the event of sickness, as well as the prevention, treatment and control of diseases, are central features of the right to the highest attainable standard of health (the terms the “right to the highest attainable standard of health” and “right to health” are used as a convenient abbreviation for the more accurate formulation of the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health”).<sup>7</sup> These features depend upon access to medicines. Thus, access to medicines forms an indispensable part of the right to the highest attainable standard of health. Numerous court cases, as well as resolutions of the UN Commission on Human Rights, confirm that access to essential medicines is a fundamental element of the right to health.<sup>8</sup> Some of the cases also confirm that access to essential medicines issues are closely connected to other human rights, such as the right to life.

This article briefly examines the medicines component of the right to health. While the article focuses upon the responsibilities of States, it also provides a brief introduction to the responsibilities of pharmaceutical companies. The article is offered as a preliminary contribution to far-reaching human rights issues of the first importance.

### **The right-to-health analytical framework**

In recent years, the UN Committee on Economic, Social and Cultural Rights, WHO, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, civil society organizations, academics and many others, have developed a way of “unpacking” or analysing the right to health with a view to making it easier to understand and apply to health-related policies, programmes and projects in practice. The analytical framework that has been developed is made up of ten key elements and has general application to all aspects of the right to health, including the underlying determinants of health: this has been demonstrated by the Special Rapporteur in his use of the framework throughout his work.

While the analytical framework is set out in more detail elsewhere,<sup>9</sup> its key elements may be very briefly summarized as follows:

- (a) Identification of the relevant national and international human rights laws, norms and standards;
- (b) Recognition that the right to health is subject to resource constraints and progressive realization, requiring the identification of indicators and benchmarks to measure progress (or the lack of it) over time;

- (c) Nonetheless, recognition that some obligations arising from the right to health are subject to neither resource constraints nor progressive realization, but are of immediate effect, for example, the obligation to avoid de jure and de facto discrimination;
- (d) Recognition that the right to health includes freedoms (e.g. freedom from non-consensual treatment and non-consensual participation in clinical trials) and entitlements (e.g. to a system of health care and protection). For the most part, freedoms do not have budgetary implications, while entitlements do;
- (e) All health services, goods and facilities shall be available, accessible, acceptable and of good quality;
- (f) States have duties to respect, protect and fulfil the right to the highest attainable standard of health;
- (g) Because of their crucial importance, the analytical framework demands that special attention is given to issues of non-discrimination, equality and vulnerability;
- (h) The right to health requires that there is an opportunity for the active and informed participation of individuals and communities in decision making that bears upon their health;
- (i) Developing countries have a responsibility to seek international assistance and cooperation, while developed States have some responsibilities towards the realization of the right to health in developing countries; and
- (j) The right to health requires that there are effective, transparent and accessible monitoring and accountability mechanisms available at the national and international levels.

By way of illustration, this article briefly applies elements of this analytical framework to access to medicines.

## **B. The responsibilities of States**

### ***Ensuring medicines are available, accessible, culturally acceptable and of good quality<sup>10</sup>***

States have to do all they reasonably can to make sure that existing medicines are available in sufficient quantities in their jurisdictions. For example, they

might have to make use of the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) flexibilities by passing and using compulsory licence legislation, thereby ensuring that medicines reach their jurisdictions in adequate quantities. Historically, research and development have not addressed the priority health needs of low-income and middle-income countries. Thus, within a framework of international assistance and cooperation, States are required to take effective measures to promote the development and availability of new drugs, vaccines and diagnostic tools for those diseases causing a heavy burden in developing countries.<sup>11</sup> States therefore are required to resort to a variety of economic, financial and commercial incentives in order to influence research and development into specific health needs.

In short, States not only have a duty to ensure that existing medicines are available within their borders, they also have a responsibility to take reasonable measures to ensure that much-needed new medicines are developed and thereby become available.

In addition to being available, medicines must also be accessible. Accessibility has four dimensions. First, medicines must be accessible in all parts of the country (for example, in remote rural areas as well as in urban centres). This has major implications for the design of medicine supply systems, including outreach programmes. Second, medicines must be economically accessible (i.e. affordable) to all, including those living in poverty. This has major implications for medicine funding and pricing arrangements. It may also mean that a State has to revisit import duties and other taxes on medicines if they are helping to take medicines beyond the reach of the poor. Third, medicines must be accessible without discrimination on any of the prohibited grounds, such as sex, race, ethnicity and socio-economic status. As discussed in the next section, the principle of non-discrimination may require a State to take measures to ensure equality of access for all individuals and groups, such as disadvantaged minorities. Fourth, reliable information about medicines must be accessible to patients and health professionals so they can take well-informed decisions and use medicines safely.

As well as being available and accessible, medicines and associated issues must be culturally acceptable and respectful of medical ethics. For example, national measures should support the proper use of traditional medicine and its integration into health-care systems, while clinical trials must ensure the informed consent of research subjects.

Medicines must also be of good quality. If rejected in the North because they are beyond their expiry date and unsafe, medicines must not be recycled to the South. Because medicines may be counterfeit or tampered with, States must establish a regulatory system to check medicine safety and quality.

### ***Combating discrimination, inequality and vulnerability***

The right to health requires a national medicines policy to be designed to ensure access for disadvantaged individuals and groups, including women and girls, ethnic minority and indigenous populations, people living in poverty, people living with HIV/AIDS, internally displaced people, the elderly, people with disabilities, prisoners and others.

This preoccupation with vulnerability and disadvantage arises from two of the most fundamental principles of international human rights law: non-discrimination and equality. Importantly, these twin principles do not always demand equal treatment; on the contrary, they sometimes require a State to take measures in favour of disadvantaged individuals and communities. Although closely linked to the ethical concept of equity, the principles of non-discrimination and equality have the advantage of being reinforced by law and accountability mechanisms.

In relation to access to medicines, non-discrimination and equality have numerous implications. For example, a State is obliged to establish a national medicine supply system that includes programmes specifically tailored to reach the vulnerable and disadvantaged. It is also required to tackle the cultural, social and political factors that inhibit vulnerable groups' access to health care generally and to medicines in particular. So far as possible, data must be disaggregated to identify vulnerable groups and monitor their progress towards equal access.<sup>12</sup>

### ***In relation to medicines, how is progressive realization to be measured and monitored? What are the obligations of immediate effect?***

The right to the highest attainable standard of health — and thus access to medicines — is subject to progressive realization and resource availability, in accordance with article 2 (1), of the International Covenant on Economic, Social and Cultural Rights. Put simply, progressive realization means that a State is required to be doing better in two years time than it is doing today, while resource availability means that what is required of a developed State is of a higher standard than what is required of a developing State.

This has a number of important implications. For example, States need appropriate indicators and benchmarks so they know whether or not they are progressively realizing the right to health.<sup>13</sup> But it also has an important qualification: the right to health includes some core obligations of immediate effect, without which the right would be largely deprived of its *raison d'être*.<sup>14</sup>



For example, States have an immediate obligation to avoid discrimination and also to make certain pharmaceuticals — known as “essential medicines” — available and accessible throughout their jurisdictions.<sup>15</sup> These core obligations of immediate effect are not subject to progressive realization.

Guided by the WHO Model List of Essential Medicines, a State is required to prepare a national essential medicines list, by way of a participatory inclusive process. If a State declines to prepare its own national essential medicines list, the WHO model list will apply, subject to any obvious contextual revisions. A State has a core obligation of immediate effect — not subject to progressive realization — to make available and accessible throughout its jurisdiction the essential medicines on its national list.<sup>16</sup>

In summary, the right to health encompasses access to non-essential and essential medicines. While a State is required to progressively realise access to non essential medicines, it has a core obligation of immediate effect to make essential medicines available and accessible throughout its jurisdiction. This article encompasses non-essential and essential medicines.

### ***Duties to respect, protect and fulfil***

States have duties to respect, protect and fulfil the right to the highest attainable standard of health.<sup>17</sup> For example, the *duty to respect* obliges a State to ensure that its medicines policy does not discriminate against women, ethnic minorities, or other disadvantaged groups. The *duty to protect* requires a State to ensure that third parties do not obstruct enjoyment of the right to health, for example, a State is required to ensure that privatization in the health sector advances, and does not hinder, the realization of the right to health. The *duty to fulfil* requires a State to provide those living in poverty with essential medicines if they would otherwise be unable to access them.

In other words, while a State may contract the delivery of health services to a private company, it does not contract out of its right-to-health obligations. A State always retains residual responsibility for the proper regulation of its health and medicines systems, as well as for the well-being of the most disadvantaged in its jurisdiction.

### ***Participation in health policymaking***

The active and informed participation of individuals and communities in health policymaking that affects them is an important feature of the right to the highest attainable standard of health. In most cases, a local community will have a keen sense of its health priorities; it is entitled to participate in the identification

of priorities and targets that guide the technical deliberations underlying the policy formulation that will affect its members.

When formulating its national medicine policy and programmes, a State is required to take steps to ensure the active and informed participation of all those affected, not only professional associations and universities, but also rural communities, non-governmental organizations, patients and consumer associations, and representatives of disadvantaged groups.

### *International assistance and cooperation in health*

The primary obligation for implementing the right to health falls upon the national authorities in the State in question. However, States have the obligation to take steps individually and through international assistance and cooperation towards the full realization of various rights, including the right to health.<sup>18</sup>

In the context of medicines, this responsibility means that no rich State should encourage a developing country to accept intellectual property standards that do not take into account the safeguards and flexibilities included under the TRIPS Agreement.<sup>19</sup> In other words, developed States should not encourage a developing country to accept “TRIPS-plus” standards in any bilateral or multilateral trade agreement.<sup>20</sup> They should help developing countries establish effective, integrated, inclusive health systems that include reliable medicine supply systems delivering quality affordable medicines for all, and support research and development into the priority health needs of developing countries.

### *Monitoring and accountability*

The right to health brings with it the crucial requirement of establishing accessible, transparent and effective mechanisms of monitoring and accountability. Those with right-to-health responsibilities must be held to account in relation to the discharge of their duties, with a view to identifying successes and difficulties; so far as necessary, policy and other adjustments can then be made. There are many different forms of monitoring and accountability mechanisms. While a State will decide which are most appropriate in its particular case, all mechanisms must be effective, accessible and transparent.

A national medicines policy should therefore be subjected to appropriate monitoring and accountability. This requires that the policy set out: the Government’s right-to health obligations in relation to medicines; an implementation plan that identifies objectives, timelines, duty holders and their responsibilities, indicators, benchmarks, and reporting procedures. From time to time, a suitable national body (e.g. a health ombudsman) will have to consider the degree to which those responsible for the implementation of the national

medicines policy have fulfilled their duties — not with a view to sanction and punishment, but with a view to establishing which policies and institutions are working and which are not, with the aim of improving the realization of the right to medicines for all.

### *A selection of specific, practical issues regarding access to medicines*

Ensuring access to medicines for all gives rise to a wide range of specific, practical and important issues. By way of illustration, this section briefly introduces four of these issues, keeping in mind the analytical framework signalled in the preceding paragraphs.

#### **A reliable system for the supply of good quality affordable medicines**

Whether it chooses a supply system that is public, private or mixed, a State has a legal obligation to ensure that there is a reliable, efficient, transparent system for the supply of quality affordable medicines throughout its jurisdiction. The supply system must be attuned to current needs, obtain good value for money, minimize waste and avoid corruption. Crucially, it must be designed to serve those living in poverty and isolated communities, as well as wealthy urban elites.

Of course, this obligation is subject to the resources available in a particular country: Canada is obliged to ensure better access to a wider range of medicines than Chad. However, the obligation of both developed and developing States is subject to progressive realization: all States are required to ensure better access to a wider range of medicines in two years' time than exists today.

To measure this progressive realization (or lack of it), States must develop disaggregated indicators and benchmarks for a reliable, efficient medicine supply system.<sup>21</sup> These indicators have to reflect human rights features, for example, the degree to which the system ensures equal access for disadvantaged groups (hence the need for disaggregated indicators), and provides effective monitoring and accountability mechanisms.

#### **Quality of medicines**

International human rights standards are clear: a State has a legal obligation to ensure that medicines of good quality are available throughout its jurisdiction. Thus, effective medicine regulation is required to ensure the safety, efficacy, and quality of medicines available in both public and private sectors, as well as

the accuracy and appropriateness of medicine information available to health professionals and the public.

While the safety and quality of medicines is a problem in many developed and developing States, the magnitude of the problem is much greater in developing countries, where poor quality medicines may be the only ones to reach the poor. In recent assessments carried out by WHO, 50-90 per cent of anti-malarial drug samples failed quality control tests, while more than half of antiretrovirals did not meet international standards.<sup>22</sup> The sale of counterfeit and substandard medicines remains a global concern.

One third of States have either no medicine regulatory authority or inadequate capacity to regulate the medicines market.<sup>23</sup> The absence of such an authority is clearly inconsistent with the right to the highest attainable standard of health. In line with their human rights responsibility of international assistance and cooperation, developed States should actively help developing countries establish appropriate medicine regulatory authorities.

### **Financing of medicines**

Whether a medicine is affordable depends upon many factors, including financing (i.e. how they are paid for) and pricing. There are different ways of financing medicines, including by way of public or private health insurance, patients' fees, donations, loans, and so on. These are complex issues and here the Special Rapporteur confines himself to one point. Whatever the chosen financing arrangement, a State has a human rights obligation to ensure that medicines are economically accessible (i.e. affordable) to all.

In many high-income countries, over 70 per cent of medicines are publicly funded whereas in low- and middle-income countries public expenditure does not cover the basic medicine needs of the majority of the population. In these countries, patients themselves pay for 50 to 90 per cent of medicines. Where the cost of medicines is borne by households, it can further impoverish already disadvantaged populations, and inhibit equitable access to medicines.

In developed countries, a course of antibiotics for pneumonia may be bought for the equivalent of two or three hours' wages; in developing countries, a course may cost one month's wages.<sup>24</sup> In developed countries, one year's HIV treatment may consume the equivalent of four to six months' salary and, in most cases, will be covered by health insurance; in many developing countries, one year's HIV paediatric treatment may consume the equivalent of an adult's income for 10 years. Such striking inequalities are deeply repugnant and underscore the importance of developed States' responsibility for international assistance and cooperation.

For present purposes, however, the crucial point is that in developed

countries most medicines are paid from public funding, whereas in developing countries the majority of households buy their medicines with money from their own pockets. In developing countries, inadequate public funding in the health sector makes medicines less affordable, especially for those living in poverty.

### **Corruption**

In some medicine supply systems, corruption is endemic. Products are diverted; unofficial “fees” are required for customs clearance; counterfeit medicines are permitted to circulate and so on. Corruption can be deadly. As Dora Akunyili, head of Nigeria’s Food and Drug Authority, put it: “drug counterfeiting, facilitated by corruption, kills *en masse* and anybody can be a victim”.<sup>25</sup>

Those living in poverty are disproportionately affected by corruption in the health sector because they are less able to afford small bribes for services that are meant to be free, or to pay for private alternatives where corruption has depleted public health services.

The right to health includes participation, access to information, transparency, monitoring and accountability. Each of these features helps to establish an environment in which corruption cannot survive. In short, a right-to-health policy is also an anti-corruption policy. Thus, the application of the right to health can help to reduce corruption in health systems in general, as well as medicine supply systems in particular.

### ***Conclusion***

It is crucial for all States to have an up-to-date national medicines policy and detailed implementation plan. The policy should include a national list of essential medicines. At the turn of the century, almost 100 States did not have a national medicines policy.<sup>26</sup> Two thirds of those with a policy did not have an implementation plan.<sup>27</sup> Under these circumstances it is difficult to argue how any State can be in conformity with its right-to-health obligations if it does not have an up-to-date and appropriate national medicines policy, implementation plan and essential medicines list, prepared by way of a participatory inclusive process.<sup>28</sup>

### **C. The responsibilities of pharmaceutical companies**

The previous section emphasized the primary responsibility of States to increase access to medicines. But, of course, this is a shared responsibility. If there is to be an increase in access to medicines, numerous national and

international actors have an indispensable role to play. The Millennium Development Goals recognize that pharmaceutical companies are among those who share this responsibility. Goal 8, a global partnership for development, has a number of targets, not least: “*in cooperation with pharmaceutical companies, provide access to affordable, essential drugs in developing countries*” (emphasis added).

A few years back, a British Government policy paper on access to medicines elaborated on this point: “responsibility for increasing access to essential medicines rests with the whole international community. Progress depends on everyone working in partnership to build health systems in developing countries, increase financing, make medicines more affordable, and increase the amount of new medicines developed for diseases affecting developing countries”.<sup>29</sup> Significantly, the paper continued: “in this context there is a particular role for pharmaceutical companies. As the producers of existing, and developers of new, medicines they can — and do — make a difference within their sphere of influence”.

The pharmaceutical sector has a profound impact on the implementation of the right to the highest attainable standard of health. States and others have criticized the pharmaceutical sector for setting prices too high, erratic drug donations, imbalanced research and development, lobbying for TRIPS plus standards, inappropriate drug promotion, problematic clinical trials, and other practices that are seen to obstruct a State’s ability to discharge its right to health responsibilities.<sup>30</sup> However, States and others have also commended some significant progress in recent years, such as the more widespread use of differential pricing, predictable and sustainable drug donations, and a renewed commitment to research and development into neglected diseases.<sup>31</sup>

There is congruity between corporate responsibility, good practices and the right to health. While the right-to-health analytical framework (as outlined before) is primarily designed for States, its application can help to identify policy interventions that a pharmaceutical company can — and should — take to improve access to medicines. The right to health can be promoted and protected without recourse to the courts, by shaping good policies. While it is commendable that some of the companies have joined corporate responsibility self-reporting initiatives, they fall short of the independent accountability mechanisms anticipated by human rights. (Some independent accountability mechanisms are non-judicial, for example a Health Ombudsman.)

Although a number of pharmaceutical companies report on their corporate citizenship or corporate responsibility activities, few make specific references in their corporate mission statements to human rights in general, or the right to health in particular. Even fewer appear to have carefully examined their policies through the lens of the right to the highest attainable

standard of health. This is a missed opportunity because all pharmaceutical companies, whether large or small, research based or generic, and whether or not their reach is global, would find it beneficial to adopt a rights-sensitive approach to their businesses, as outlined in the excellent joint publication of the Global Compact, Business Leaders Initiative on Human Rights and OHCHR.<sup>32</sup>

In recent years, the general understanding of economic, social and cultural rights has deepened. If this momentum is to be maintained, it is necessary to move from general discussions about economic, social and cultural rights to consideration of specific rights, in relation to specific sectors, actors and issues. This is the point that has now been reached in relation to pharmaceutical companies and the right to health. Today, general statements about pharmaceutical companies and economic, social and cultural rights provide the indispensable foundation for a more detailed examination of specific right-to-health issues arising in the pharmaceutical sector. In short, it is time to explore further the right-to-health responsibilities of pharmaceutical companies that were acknowledged in general terms by the UN Committee on Economic, Social and Cultural Rights in its general comment 14, paragraph 42.

For this reason the UN Special Rapporteur has embarked on a process of preparing draft Guidelines for States and pharmaceutical companies on access to medicines.<sup>33</sup> The draft Guidelines for pharmaceutical companies consider specific issues, such as differential pricing, donations, research and development for neglected diseases, public-private partnerships, drug promotion, clinical trials, and corruption.<sup>34</sup> As observed by the UN Special Representative of the Secretary-General on the issue of human rights and transnational corporations and other business enterprises: “it is essential to achieve greater conceptual clarity with regard to the respective responsibilities of States and corporations [...] In doing so we should bear in mind that companies are constrained not only by legal standards but also by social norms and moral considerations.”<sup>35</sup>

### *Conclusion*

A consensus is emerging that business enterprises, like all actors in society, have some legal and ethical human rights responsibilities. According to its Preamble, the Universal Declaration of Human Rights gives rise to some human rights responsibilities for “every organ of society”, which must include business enterprises.<sup>36</sup> The United Nations Global Compact, with more than 2,300 participating companies, affirms that businesses should support and respect the protection of international human rights.<sup>37</sup> The Organization for



Economic Cooperation and Development's Guidelines for Multinational Enterprises require businesses to "respect the human rights of those affected by their activities consistent with the host Government's obligations and commitments".<sup>38</sup> While holding that the draft Norms on the Responsibilities of Transnational Corporations and Other Business Enterprises with Regard to Human Rights of the Sub-Commission on the Promotion and Protection of Human Rights had no legal standing, the Commission on Human Rights found that the Norms contained "useful elements and ideas".<sup>39</sup> Some national courts have recognized the impact of pharmaceutical company pricing policies on the human rights of patients.<sup>40</sup> Significantly, some companies have prepared their own guidelines and other statements explicitly affirming their human rights responsibilities.<sup>41</sup>

Today, the key issues include, *first*, clarifying the scope and content of these human rights responsibilities and, *second*, identifying which are legal and which are ethical. The draft Guidelines are a modest endeavour focusing on the first of these issues in the specific context of pharmaceutical companies. As for the second, it is inconceivable that some human rights do not place legal responsibilities on business enterprises.<sup>42</sup>

## D. Conclusions

Today, the content of the right to the highest attainable standard of health is becoming clearer. In 2000, the UN Committee on Economic, Social and Cultural Rights developed a general framework that unpacked the right to health in terms of freedoms and entitlements; health care and underlying determinants of health; non-discrimination; participation; monitoring and accountability, and so on.<sup>43</sup> This article endeavours to apply the framework to medicines, a health issue encompassed by the Millennium Development Goals.

The right to health makes a number of important contributions to the struggle to improve access to medicines. It sharpens analysis of the causes, as well as the responsibilities of various stakeholders. Policies informed by the right to health are likely to be more equitable, sustainable and effective. This contribution is already recognized in the context of some health policies and programmes.<sup>44</sup> In relation to policy making about medicines, there is also a growing appreciation of the positive contribution that can be made by taking into account the right to the highest attainable standard of health.

Additionally, experience confirms that traditional human rights techniques, including "naming and shaming" and taking court cases, continue to have an indispensable role to play in the realization of various elements of the right to health, not least access to medicines.

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## RESUMO

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O presente artigo analisa o acesso a medicamentos, em especial aqueles considerados essenciais, como parte do direito a desfrutar do mais elevado nível possível de saúde. A partir da estrutura analítica do direito à saúde elaborada nos últimos anos, a primeira parte deste artigo concentra-se nos deveres atribuídos aos Estados. A segunda parte procura nos introduzir à responsabilidade das empresas farmacêuticas.

### PALAVRAS-CHAVE

Medicamentos – Direito à saúde – Direitos humanos – TRIPS – OMS

## RESUMEN

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Este artículo analiza el componente del derecho al disfrute del más alto nivel posible de salud que se relaciona con el acceso a los medicamentos, incluyendo los medicamentos esenciales. Utilizando el marco analítico del derecho a la salud que ha sido desarrollado en los años recientes, la primera sección se concentra en las responsabilidades de los Estados. La segunda sección provee una breve introducción a las responsabilidades de las compañías farmacéuticas.

### PALABRAS CLAVES

Medicamentos – Derecho a la salud – Derechos humanos – TRIPS – OMS



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#### ABSTRACT

Pricing advanced medicines beyond the reach of the poor and encouraging neglect of diseases concentrated among them, the TRIPS Agreement produces avoidable death and disease on a massive scale. This injustice can be remedied through a Health Impact Fund that gives patent holders the option to price any new medicine at cost in exchange for annual reward payments based on this medicine's global health impact.

Original in English.

#### KEYWORDS

Advance Market Commitment — Disease — Health Impact Fund — Incentives — Justice — Medicine — Monopoly — Patent — Poverty — Public good — Research — Rights — TRIPS



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# MEDICINES FOR THE WORLD: BOOSTING INNOVATION WITHOUT OBSTRUCTING FREE ACCESS

Thomas Pogge

## Background

In an earlier essay for *SUR Journal*,<sup>1</sup> I have described the radical inequality blighting our world. At current exchange rates, the poorest half of the world's population — some 3,400 million people — has less than 2% of global income as against 6% of global income received by the most affluent one percent of US households which consist of only 3 million people.<sup>2</sup> The bottom half of humankind owns about 1% of all global wealth as against 3% owned by the world's 946 billionaires.<sup>3</sup> These inequalities among individuals are staggering. And they continue to increase rapidly, not only globally,<sup>4</sup> but also within most countries. In the US, for example, the bottom half of the population saw its share of national income decline from 26.4% to 12.8% during 1979-2005, while those in the top one percent of the income hierarchy expanded their share from 9% to 21.2%.<sup>5</sup> In China during 1990-2004, the income share of the bottom half declined from 27% to 18%, while that of the top tenth increased from 25% to 35%.<sup>6</sup> In recent decades, income inequality has been clearly declining in only four countries. Brazil is one of these four, but still among the most inegalitarian societies with the bottom half earning only 14% of all household income as against 45% for the top tenth.<sup>7</sup>

Such huge inequalities are especially remarkable when those at the bottom lack not merely pocket money, denying them the toys of the rich,

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*Notes to this text start on page 137.*



but access to the most basic necessities of human life. And this is actually the case, both globally and in most countries. The poverty endured by the bottom half of humankind poses serious dangers to their health and survival. The poor worldwide face greater environmental hazards than the rest of us: from contaminated water, filth, pollution, worms and insects. They are exposed to greater dangers from people around them: through traffic, crime, communicable disease, and the cruelties of the more affluent. They lack means to protect themselves and their families against such hazards: through clean water, nutritious food, good hygiene, ample rest, adequate clothing, and safe shelter. They lack the means to enforce their legal rights or to press for political reform. They are often obliged by dire need or debt to incur additional health risks: by selling a kidney, for instance, or by accepting hazardous work in prostitution, mining, construction, domestic service, textile and carpet production. They lack financial reserves and access to public sources of medical knowledge and treatments, and therefore face worse odds of recovering from disease. Mutually reinforcing, all these factors ensure that the poor bear a hugely disproportional burden of disease — especially of communicable, maternal, perinatal and nutritional conditions — and a hugely disproportional share of premature deaths: One third of all deaths each year, 18 million, are from poverty-related causes. These much greater burdens of morbidity and premature mortality in turn entail large economic burdens that keep most of the poor trapped in lifelong poverty.

This cycle of mutually reinforcing poverty and disease can be broken by reducing or eradicating severe poverty. I have argued that this can be done effectively by reforming various features of existing global institutional arrangements that — beneficial to the affluent and maintained by them — contribute greatly to the persistence of poverty.<sup>8</sup> But it is also possible to make substantial progress against the global burden of disease (GBD) more directly: existing huge mortality and morbidity rates can be dramatically lowered by reforming the way the development of new medical treatments is funded. I will sketch a concrete, feasible, and politically realistic reform plan that would give medical innovators stable and reliable financial incentives to address the diseases of the poor. If adopted, this plan would not add much to the overall cost of global health care spending. In fact, on any plausible accounting, which would take note of the huge economic losses caused by the present GBD, the reform would actually save money. Moreover, it would distribute the cost of global health care spending more fairly across countries, across generations, and between those lucky enough to enjoy good health and the unlucky ones suffering from serious medical conditions.

## The Problem

Medical progress has traditionally been fueled from two main sources: government funding and sales revenues. The former — given to universities, corporations, other research organizations and governmental research facilities such as the US National Institutes of Health — has typically been *push* funding focused on basic research. Sales revenues, usually reaped by corporations, have mostly funded more applied research resulting in the development of specific medicines. Sales revenues, by their nature, constitute *pull* funding: an innovation has to be developed to the point of marketability before any sales revenues can be realized from it.

The fixed cost of developing a new medicine is extremely high for two reasons: it is very expensive to research and refine a new medicine and then to take it through elaborate clinical trials and national approval processes. Moreover, most promising research ideas fail somewhere along the way and thus never lead to a marketable product. Both factors combine to raise the research and development (R&D) cost per new marketable medicine to somewhere around half a billion dollars or more. Commencing manufacture of a new medicine once it has been invented and approved is cheap by comparison. Because of this fixed-cost imbalance, pharmaceutical innovation is not sustainable in a free market system: competition among manufacturers would quickly drive down the price of a new medicine to near its long-term marginal cost of production, and the innovator would get nowhere near recovering its R&D investment.

The conventional way of correcting this market failure of undersupply is by awarding innovators intellectual property rights that entitle them to bar competitors or to charge them licensing fees. Either way, the result of such monopolies is an artificially increased sales price that enables innovators to recoup their R&D expenses through selling products that, even at prices far above marginal cost, are in heavy demand.

Monopolies are generally denounced by economists as inefficient and by ethicists as an immoral interference in people's freedom to produce and exchange. In the case of patents, however, many believe that the curtailment of individual freedom can be justified by the benefit, provided patents are carefully designed. One important design feature is that patents confer only a temporary monopoly. Once the patent expires, competitors can freely enter the market with copies of the original innovation and consumers need no longer pay a high mark-up over the competitive market price. Temporal limits make sense because additional years of patent life barely strengthen innovation incentives: At a typical industry discount rate of 11% per annum, a 10-year patent life delivers 69%, and a 20-year patent life 90%, of the profit (discounted to present

value) that a permanent patent would deliver.<sup>9</sup> It makes no sense to impose monopoly prices on all future generations for the sake of so slight a gain in innovation incentives.

During the life of the patent, everyone is legally deprived of the freedom to produce, sell and buy a patented medicine without permission from the patent holder. This restraint hurts generic producers and it also hurts consumers by depriving them of the chance of buying such medicines at competitive market prices. Still, consumers also benefit from the impressive arsenal of wonderful medicines whose development is motivated by the prospect of monopoly rents.

It may seem obvious that this benefit outweighs the loss of freedom. But we must consider that not everyone is either affluent enough to buy advanced medicines at monopoly prices or fortunate enough to need them only after patent expiration. Many human beings are trapped in severe poverty. Most of them derive little or no benefit from that marvelous arsenal because they cannot, at prevailing prices, get access to the medicines they need. These people — and they number in the billions — have a powerful objection to the use of monopoly patents for incentivizing pharmaceutical innovation: “if the freedom to produce, sell and buy advanced medicines were not curtailed, then the affluent would need to find another (for them possibly less convenient) way of funding pharmaceutical research. But advanced medicines would then be available at competitive market prices, and we would have a much better chance to get access to them through our own funds or with the help of national or international government agencies or nongovernmental organizations. The loss of freedom imposed through monopoly patents thus inflicts on us a huge loss in terms of disease and premature death. This loss cannot possibly be justified by any gain that monopoly patents may bring to the affluent”.

This objection was less pertinent until the 1990s, when strict patent rules were mostly confined to the affluent states, which allowed the less developed countries to have weaker patent protections or none at all. This exemption of poor countries had little effect on innovation incentives because, in these countries, those able to afford advanced medicines at monopoly prices are few, relative to the one-billion population of the high-income countries. But the exemption brought relief to many poor residents of poor countries: to all those who obtained at competitive market prices advanced medicines they would not have been able to obtain at the much higher profit-maximizing monopoly price.

This diversity of national regulations was destroyed in the 1990s when a powerful alliance of industries (software, entertainment, pharma, and agribusinesses) pressured the governments of the richest states to force uniform intellectual property rules upon the world. Acceptance of this regime, enshrined in the Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement

of 1994, was made a condition of the World Trade Organization (WTO) membership which, it was then promised, would allow the poor countries to reap large benefits from trade liberalization. This promise was broken as the high-income countries continue to sabotage the export opportunities of poor countries through a variety of protectionist measures. But the globalization of uniform intellectual property rights is prosecuted relentlessly — with devastating effects, for instance, on the evolution of the AIDS epidemic.

The world responds to the catastrophic health crisis among the global poor in a variety of ways: with the usual declarations, working papers, conferences, summits, and working groups first and foremost, of course; but also with efforts to fund delivery of medicines to the poor through *intergovernmental initiatives* such as 3 by 5,<sup>10</sup> through *governmental programs* such as the US President's Emergency Plan for AIDS Relief (PEPFAR), through *public-private partnerships* like the Global Alliance for Vaccines and Immunization (GAVI) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), and through medicine donations from pharmaceutical companies; and with various efforts to foster the development of new medicines for the diseases of the poor, such as the Drugs for Neglected Diseases Initiative (DNDi), the Institute for One World Health, the Novartis Institute for Tropical Diseases, and various prizes as well as advance purchase commitments and advance market commitments.<sup>11</sup>

Such a busy diversity of initiatives looks good and creates the impression that a lot is being done to solve the problem. And most of these efforts are really doing good by improving the situation relative to what it would be otherwise. Still, these efforts are not nearly sufficient to protect the poor. It is unrealistic to hope that enough billions of dollars will be devoted to neutralizing the cost imposed on the world's poor by the globalization of monopoly patents. And it is even more unrealistic to hope that such billions will reliably and efficiently be spent year after year. It makes sense then to look for a more systemic solution that addresses the global health crisis at its root. Involving institutional reform, such a systemic solution is politically more difficult to achieve. But, once achieved, it is also politically much easier to maintain. And it preempts most of the huge and collectively inefficient mobilizations currently required to produce the many stop-gap measures, which can at best only mitigate the effects of structural problems they leave untouched.

The quest for such a systemic solution should start from an analysis of the main drawbacks of the newly globalized monopoly patent regime.

**High prices.** While a medicine is under patent, it will be sold at the profit-maximizing monopoly price which is largely determined by the demand curve of the affluent. When wealthy people really want a drug, then its price can be raised quite high above the cost of production before increased gains from

enlarging the mark-up are outweighed by losses from reduced sales volume. With patented medicines, mark-ups in excess of 1000% are not exceptional.<sup>12</sup> When such high monopoly prices prevail, the poor can have access only through the charity of the affluent.

**Neglect of diseases concentrated among the Poor.** Under a monopoly patent regime, such diseases — no matter how widespread and severe they may be — are not lucrative targets for pharmaceutical R&D. This is so because the demand for such a medicine drops off very steeply as the patent holder enlarges the mark-up. There is no prospect, then, of achieving high sales volume *and* a large mark-up. Moreover, there is the further risk that a successful research effort will be greeted with loud demands to make the medicine available at marginal cost or even for free, which would force the innovator to write off its R&D cost as a loss. In view of such prospects, biotechnology and pharmaceutical companies predictably prefer even the trivial ailments of the affluent, such as hair loss and acne, over tuberculosis and sleeping sickness. This problem of neglected diseases is also known as the 10/90 problem, alluding to only 10% of all pharmaceutical research being focused on diseases that account for 90% of the GBD.

**Bias toward symptom relief.** Medicines can be roughly sorted into three categories: curative medicines remove the disease from the patient's body; symptom-relieving medicines improve well-being and functioning without removing the disease; preventative medicines reduce the likelihood of contracting the disease in the first place. Under the existing monopoly patent regime, symptom-relieving medicines are by far the most profitable, with the most desirable patients being ones who are not cured and do not die (at least until after patent expiration). Such patients buy the medicine week after week, year after year, delivering vastly more profit than would be the case if they derived the same health benefit from a cure or vaccine. Vaccines are least lucrative because they are typically bought by governments, which enjoy a strong bargaining position. This is highly regrettable because the health benefits of vaccines tend to be exceptionally great as vaccines protect from infection or contagion not merely each vaccinated person but also their contacts.<sup>13</sup> Once more, then, the present regime guides pharmaceutical research in the wrong direction — and here to the detriment of poor and affluent alike.

**Wastefulness.** Under the present regime, innovators must bear the cost of filing for patents in dozens of national jurisdictions and then also the cost of monitoring these jurisdictions for possible infringements of their patents. Huge amounts are spent in these many jurisdictions on costly litigation that pits generic companies, with strong incentives to challenge any patent on a successful medicine, against patent holders, whose earnings depend on their ability to defend, extend, and prolong their monopoly rents. Even greater costs are due

to the deadweight loss (DWL) “on the order of \$200bn” that arises from blocked sales to buyers who are willing and able to pay the competitive market price but not the much higher monopoly price.<sup>14</sup>

**Counterfeiting.** Very large mark-ups also encourage the illegal manufacture and sale of medicines. Even when such illegal drugs are pharmacologically fully equivalent, they reduce innovator profits and thereby undermine R&D incentives. When they are not fully equivalent (e.g., diluted, adulterated, inert, or even toxic), they endanger patient health.

**Excessive marketing.** When pharmaceutical companies can maintain a very large mark-up, they find it rational to make extensive special efforts to increase sales volume by influencing physicians’ prescription patterns. This produces pointless battles over market share among similar (“me-too”) drugs as well as gifts that induce doctors to prescribe medicines even when these are not indicated or when competing medicines are likely to do better. With a large mark-up it also pays to fund massive direct-to-consumer advertising that persuades people to take medicines they don’t really need for diseases they don’t really have (and sometimes for invented pseudo-diseases).<sup>15</sup>

**The last-mile problem.** While the present regime provides strong incentives to expose affluent people to patented medicines they do not need, it provides no incentives to ensure that poor people benefit from medicines they do need. Even in affluent countries, pharmaceutical companies have incentives only to sell products, not to ensure that they are actually taken, properly, by patients whom they can benefit. This issue is compounded in poor ones, where the infrastructure is severely lacking to distribute, prescribe, and supervise the proper consumption of medicine. In fact, the present regime gives pharmaceutical companies the opposite incentives. To profit under this regime, a company needs not merely to develop and patent a medicine that is effective in protecting paying patients from a disease and/or its detrimental symptoms. It also needs this target disease to thrive and spread because, as a disease waxes or wanes, so does market demand for the remedy. A pharmaceutical company making a morally motivated effort to allow the poor to benefit from its patented medicine would be seriously undermining its economic position: by paying for the effort to make its drug competently available to poor patients, by curtailing a disease on which its profits depend, and by losing affluent customers who find ways of buying, cheaply, medicines meant for the poor.

Contemplating these seven problems together, we see another reason to aim for a comprehensive solution in preference to the many stopgap measures that have been proposed and sometimes (at least partially) implemented: The practical value of efforts to mitigate one of the seven problems may be greatly reduced by one of the other problems that remains unaddressed; and efforts to mitigate one problem may aggravate another. For example, a drug donation



for the benefit of the poor, intended to mitigate the problem of high prices, may actually do more harm than good because of the weak health infrastructure (last-mile problem) in the recipient countries. Lacking competent medical instruction and package inserts in their own language, poor patients may fail to take the medicine in the right doses, at the right times, or for the appropriate length of time. Such patients may not merely remain sick; they may also develop and spread drug-resistant strains of the disease which (as in the case of MDR and XDR tuberculosis) can pose grave dangers to people everywhere.

Another example of counterproductivity is compulsory licenses that some governments have issued or threatened in order to gain for their populations cheaper access to patented medicines. Though specifically permitted by the TRIPS Agreement as reaffirmed in the Doha Declaration,<sup>16</sup> compulsory licenses are energetically resented by pharmaceutical companies, and governments daring to issue such licenses are routinely censured and penalized by these companies and by the rich-country governments doing their bidding. By issuing a compulsory license, a government authorizes the production and marketing of a cheaper generic version of a patented medicine on condition that the authorized generic firm pays a small license fee to the patent holder. Such a license, and even the mere threat of one, will typically cause the price of the relevant medicine to fall substantially in the relevant country. But this welcome relief from the problem of high prices also aggravates the neglect of diseases concentrated among the poor. Pharmaceutical companies spend less on the quest for vital medicines — especially ones needed mainly by the poor — when the uncertainties of development, testing, and regulatory approval are compounded by the additional unpredictability of whether and to what extent successful innovators will be allowed to recoup their investments through undisturbed use of their monopoly pricing powers.

## Reasoning

Counterproductive effects notwithstanding, the moral appeal of compulsory licensing is compelling. Consider a life-saving medicine whose patent-holding producer sells it at \$100, of which \$10 constitutes the long-run marginal cost of production and distribution. The high sales price effectively excludes poor patients many of whom, if the sales price were near cost, could gain access to the medicine, with the help of some international organization, perhaps, or on their own. What do we say to these patients who are suffering and dying even though they could obtain the medicine at the competitive market price? We tell them that, to merit access, they must pay not merely for the physical medicine but also for the intellectual property embodied in it: for the innovative idea or discovery or invention. But how can we impose such a huge mark-up



for intellectual property on them, and thereby effectively exclude them from the medicine, when the cost to them of exclusion is sickness and death?

This question becomes even more pressing when we realize that including the poor adds nothing to the cost of innovation. It is a wonderful thing about the products of thought that their cost is independent of the number of beneficiaries. The intellectual labors of composing a novel are exactly the same, regardless of whether it has millions of readers or none at all. Likewise for the labors of producing music, composing software, developing a new breed of plant or animal, and discovering a new medically effective type of molecule. Millions can benefit from such intellectual efforts without adding at all to their cost.<sup>17</sup> And this renders morally irresistible the conclusion that poor people, when their lives are at stake, must not be prevented from buying medicine from willing suppliers at competitive market prices. A compulsory license secures this freedom for the poor.

But what about the person or company that has put in the effort and expense to achieve the innovation? Doesn't the innovation belong to him or her or it — to give or withhold or sell at will? Many believe that there is such a natural right of first appropriation, analogous to the right of someone who takes possession of unowned objects such as apples or wood or water in a state of nature as Locke has described. But the analogy is deeply flawed: the person who appropriates some apples does not thereby deprive others of the opportunity to do likewise. To be sure, no one else can eat the particular apples she has eaten. But, if she leaves “enough and as good” for others (as Locke and Nozick require) then others can collect and eat other apples.

As Nozick emphasizes, a medical researcher who synthesizes a new medicine from widely available materials and refuses to share this medicine with others or to show them how to make it, such a researcher is also leaving enough and as good. He does not interfere with the freedom of others to acquire the same materials and chemically to transform them into the lifesaving medicine if they can. He merely refuses to help them.<sup>18</sup>

Nozick's argument may be sound, but it is of no help in the defense of intellectual property. Here the question is whether the medical researcher is entitled also to veto production of the medicine by others who learn how to make it later. Demanding such veto power, the medical researcher asserts a natural right of ownership not over object *tokens* he has produced, but over an object *type*: a whole species of medically effective molecule. In doing so, he is like someone who, based on having first conceived the idea of eating apples, claims ownership of this idea and thus asserts that it is up to her to give or withhold or sell at will her permission to the apple-eating of others. This appropriation of a *type* is not supported by Locke's view. On the contrary, it clearly goes against Locke: enforcing an innovator's exclusive property right

over all objects of a class necessarily fails to leave enough and as good for everyone else and partially expropriates others who lose the freedom to use their own apples for eating or the freedom to transform their own materials in a certain way. It necessarily deprives others of the freedom the innovator claims for himself: the freedom to eat apples legitimately acquired, or to produce certain molecules out of legitimately acquired materials, without another's permission. Far from supporting monopoly rights in pharmaceuticals, the philosophical tradition most friendly to property rights thus refutes such intellectual property rights. Generic producers have a natural right to do what the innovator did before them: to produce, if they can, medicine from ingredients they legitimately own and to offer such medicine for sale. And patients have a natural right to purchase such medicine from generic suppliers on mutually agreeable terms.<sup>19</sup>

But is not such freedom on the part of patients and generic producers destructive of innovation? Does it not deprive us of the wonderful new medicines pharmaceutical innovators keep on producing? These questions constitute a change of venue, suggesting a defense of monopoly patents not in the courtroom of natural rights but in the courtroom of mutual advantage. Does this defense succeed? It is indisputable that wonderful new medicines whose development was motivated by the hope for profits have greatly benefited some patients — namely those affluent enough to buy them at monopoly prices or fortunate enough to need them after patent expiration. If all human beings were so affluent or fortunate, then monopoly patents might be defensible as in everyone's best interest: it would then be rational for all of us to accept the cost of laying down our rights to produce, sell, and buy a new medicine invented by another in exchange for the much greater benefit of having available a broad and powerful arsenal of pharmaceuticals.

In fact, however, many human beings are trapped in severe poverty. Most of them derive little or no benefit from the marvelous arsenal of available medicines because they cannot, at prevailing prices, get access to them. For these people — and they number in the billions — it would be highly irrational to agree to lay down their freedom so that the affluent can more successfully use monopoly patents to stimulate pharmaceutical innovations.<sup>20</sup> In the real world, the poor do not give such highly irrational consent. The often devastating cost is imposed on them by others who, for their own advantage, interpose the barrier of monopoly patents between poor people and the generic companies willing to supply the medicines they urgently need. This interposition is a grievous injustice that kills millions of poor people each year.<sup>21</sup>

This injustice is manifest in national legislation — in India, for instance, where the poor have recently lost their legal freedom of access to medicines at competitive market prices. It is also manifest in international trading rules such as the TRIPS Agreement, which required India to implement the legislative

changes as a condition of the limited access WTO membership affords Indian exporters to the markets of the affluent countries. Perhaps the governments of India and other less developed countries made a reasonable choice when they imposed unjust pharmaceutical access rules upon their poor for the sake of gaining a little more fairness in international trade.<sup>22</sup> But the powerful affluent countries devising and imposing the present WTO regime have no such excuse. They are acting most unjustly by pressing weaker countries to inflict this injustice on their poor. If rich countries and their citizens desire medical innovation, then they must find ways of funding it that either leave the freedom of the poor unreduced or else adequately compensate the poor for the loss of freedom imposed upon them.

Because adequately compensating poor people for disease and death is more costly and often impossible, let us consider ways of funding pharmaceutical innovation that do not deprive the poor of their freedom of access to existing medicines at competitive market prices. This freedom is inconvenient for the affluent by making it difficult to collect monopoly rents from anyone. Though the affluent are often willing to buy advanced medicines at prices far above the marginal cost of production, many of them prefer to buy cheaper, even illegally. And clever brokers and smugglers, too, stand ready to exploit any substantial differential between the monopoly price charged the rich and the competitive market price charged the poor. Split markets with large price differentials thus generate unfairness as smugglers and selfish affluent patients benefit at the expense of honest affluent patients and innovators. More to the point, allowing the poor their freedom of access at competitive market prices substantially reduces the monopoly rents that can be extracted from affluent patients and thereby also the incentives of pharmaceutical companies to undertake expensive R&D efforts in the first place. To avoid all these problems with large price differentials, it is best then to level pharmaceutical prices in the opposite direction: instead of unjustly imposing monopoly prices also on the poor (which effectively excludes most of them from advanced medicines), we should grant open access at competitive market prices also to the affluent. In this way, we avoid the problem of high prices in an efficient way. We also eliminate high mark-ups entirely and thereby avoid the problems associated therewith: wastefulness, counterfeiting, excessive marketing, and the bias toward symptom relief.

Because pharmaceutical R&D is urgently needed, loss of funding from monopoly patents must be replaced somehow – with public funds – to ensure a reliable flow long-term. As we will see, such public funding can be designed to overcome the two last remaining problems of the present regime: the neglect of diseases concentrated among the poor and the last-mile problem.

Mechanisms of public financing are usually categorized under the labels

of “push” and “pull”. A push program selects and funds some particular innovator — a pharmaceutical company, perhaps, or a university or a national health agency — to undertake a specific research effort. The intent here is that, with adequate funding, the selected innovator will develop the desired innovation, which can then be made freely available for production by competing pharmaceutical manufacturers so as to ensure wide availability at competitive market prices.

A pull program, by contrast, is addressed to many potential innovators, promising to reward whoever is first to achieve a valued innovation. Pull programs have two interrelated advantages over push programs: they avoid paying for failed research efforts and they generate strong financial incentives for innovators to work hard toward early success. The flip side of these advantages is that, in order to elicit such a serious research effort, the reward must be large enough to compensate for the risk of failure. This risk is twofold, as a research effort may fail either because the sought medicine proves elusive or because some competing innovator succeeds first. Potential innovators have incentives to try to develop a new medicine only if the reward for success, discounted by the probability of failure, is substantially greater than the expected cost of the R&D effort. In these respects, a pull program is similar to the current patent regime.

Despite this extra cost, pull programs can nevertheless be more effective than push programs, for three reasons: push programs are more likely to fail because they get only one rather than several competing innovators to work on the problem.<sup>23</sup> Push programs are more likely to fail because the innovator is chosen on the basis of some outsider’s confidence in it whereas in pull programs each innovator’s decision to try is based on *its own*, more competent and better motivated assessment of its capacities. Push programs are more likely to fail because the chosen innovator has much weaker incentives to work hard and cost-effectively toward early success. This higher probability of failure is compounded by the fact that such failures are paid for — in contrast to pull programs, which pay nothing for failed efforts. Given this contrast, pull programs are more easily sustainable, politically, in the long run.

Most prominent among pull programs are prize competitions that promise a reward to the innovator who is first able to produce a medicine that meets certain specifications. This reward can be specified as some monetary amount or as an APC or AMC (note 11). Such rewards have been described with considerable ingenuity.<sup>24</sup> They clearly can be a valuable complement to existing patent rewards and have the potential of stimulating the development of medicines for currently neglected diseases.

Nonetheless, such ad hoc prize competitions have four drawbacks. First, politicians, bureaucrats, or experts play a crucial role by deciding which diseases

should be researched, how the sought remedy should be specified, and how large a reward should be promised for a remedy meeting these specifications. Determining the direction research will take, these decisions are likely to be associated with substantial inefficiencies due to incompetence, corruption, gaming, and lobbying by companies and patient groups. Ideally, the relevant planners should aim to stimulate the most cost-effective innovations. But their own incentives to make this aim paramount are weak. And their information about the cost of specific research efforts to innovators is likely to be of poor quality, as potential innovators have reason to exaggerate both the costs and the potential utility of their efforts.<sup>25</sup> Given weak incentives and poor information, the planners' design of prize competitions would likely be seriously suboptimal.

The second problem arises from the fact that ad hoc rewards involve excessive specificity. Each reward must define a precise finish line, specifying at least what disease the medicine must attack, how effective it must minimally be (magnitude and duration of the improvement, percentage of patients), how bad its side effects may be (severity and frequency), and how convenient the medicine must minimally be (stability at various temperatures, frequency and mode of intake). Such specificity is problematic because it presupposes the very knowledge whose acquisition is yet to be encouraged. Since the sponsors lack this knowledge ahead of time, their specification is likely to be seriously suboptimal even if they are single-mindedly devoted to the goal of improving public health. Such suboptimality can take two forms. The specification may be overly demanding in at least one dimension, with the result that innovators give up the effort even though something close to the sought solution is within their reach. And the specification may be insufficiently demanding in some dimension(s), with the result that innovators, to save time and expense, deliver products that are just barely good enough to win the prize even when they could have done much better at little extra cost.<sup>26</sup>

The third disadvantage of ad hoc rewards is that the funding they depend on is likely to be haphazard and case-by-case. This is so because arbitrary factors and political contingencies will invariably enter into the choice of specific diseases and types of intervention around which prize competitions are organized. It is also likely that overall fund allocations will be erratic: when encountering budget problems, governments will tend to skip or to postpone planned reward competitions, and the conduct of other sponsors is also likely to be unduly influenced by extraneous factors (e.g., by their public-relations needs or by how much money they must spend in the current year to retain their tax-deductible status).

A fourth serious defect of ad hoc rewards is that they fail to address the "last-mile" problem, which is especially severe in the context of currently

neglected diseases that mostly affect the poor. The fact that a new vital medicine is available in large quantities, or can be produced very cheaply by generic producers, does not yet give poor populations real access to it. The reward pulls innovators to the invention of a new safe and effective medicine or even to its production in large quantities. But it does not pull this medicine the rest of the way to the patients who need it. It may seem that AMC's can get around this problem by making the reward conditional on the innovator finding willing buyers. But I am skeptical. If — as in one of Michael Kremer's numerical examples — a \$14 subsidy (up to 200 million doses) is promised for each dose the innovator can sell for \$1 or more, then the innovator has powerful incentives to induce or entice or bribe buyers regardless of how they intend to dispose of the medicine. If it must be used, as a condition of the subsidy, it may well be prescribed to patients irrespective of whether they need it or not.

## Solution

The basic idea for solving all these problems now lies open before us: pharmaceutical innovation should be encouraged through publicly funded rewards that are tied to actual health impact. This incentive should be specified in general terms, as a promise to reward *any* new medicine that works, in proportion to how well it works. The combination of these two elements has been described as creating a new, *comprehensive* AMC.<sup>27</sup>

An important third element of the solution is that the funding mechanism should be global (rather than national) in scope. The reasons that make the reform compelling in any one country or region make it compelling everywhere. Moreover, global scope avoids the problems associated with large price differentials. And global scope also brings huge efficiency gains by diluting the cost of the scheme without diluting its benefits. No matter how many beneficiaries we may add, the cost of achieving an innovation remains the same even while its aggregate benefit increases with the number of beneficiaries.<sup>28</sup> Pharmaceutical innovation is therefore best encouraged by promising to reward any safe and effective new medicine in proportion to its *global* health impact. Such a promise constitutes an AMC that is *fully* comprehensive: by including not merely all diseases but also all patients.

As all human beings are included in the benefits of pharmaceutical innovation, so its cost can be dispersed worldwide through an international agreement that reinforces the commitment of individual countries to the scheme. The agreement might create a *Health Impact Fund* (HIF) that offers a reward for any new medicine based on its health impact during its first decade or so.<sup>29</sup> To receive this reward, the innovator must make a concession affecting its price. This concession may be specified in two ways or as a disjunction of both. The



innovator might be required permanently to waive claims to market exclusivity on a medicine worldwide, enabling generic competition that would drive the medicine's price down to near marginal cost of production.<sup>30</sup> Or the innovator might be required, during a specified reward period, to turn over all revenues worldwide from the sale of its medicine, inducing the innovator to lower the price of the medicine to the point where the marginal health-impact reward from selling additional units just equals the marginal cost of producing such units. Either way, innovators would gain for each of their new medicines the option of forgoing monopoly rewards in favor of an alternative path that would provide ample rewards for the development of a new high-impact medicine without excluding the poor from its use.

To provide stable incentives, member states must guarantee funding some 15 years into the future to assure pharmaceutical innovators that, if they fund expensive clinical trials now, they can claim a full decade of health-impact rewards upon market approval. This guarantee might feature fixed annual pools to be shared among registered medicines in proportion to their respective health impacts or it might feature a fixed monetary amount per QALY.<sup>31</sup> The former solution makes the cost of the HIF predictable and may therefore be more attractive to governments. The latter solution makes the reward per QALY predictable and would therefore be more attractive to potential innovators. A simple compromise would fix each annual reward pool in proportion to the square root of the QALYs gained by all registered medicines that year, subject to a \$/QALY ceiling. For example, in its start-up phase the Health Impact Fund might promise annually to reward the health impact of each registered medicine at \$1000 per QALY if the health impact of all registered medicines is at or below the limit of 4 million QALYs. If the total health impact is above 4 million QALYs in any year, then the HIF promises to pay out more than \$4 billion but at a reduced reward rate per QALY. If the health impact of all registered medicines is 6.25 million QALYs in some given year, for instance, then governments face an increased payment of \$5 billion and innovators face a decreased reward rate of \$800 per QALY (the contribution of governments is increased by a factor of 1.25 and the reward for registered medicines is reduced by the same factor).

This kind of funding mechanism has important advantages. It achieves reasonable predictability for both governments and pharmaceutical innovators. It puts pharmaceutical innovators in a competitive position, inducing them to check one another's activities and health impact claims (if one company illicitly inflates its measured health impact, then other companies are short-changed through a reduced \$/QALY rate). It establishes an observable, market-based \$/QALY rate in pharmaceutical innovation. And it is scalable, allowing governments to scale up the HIF if it proves successful (downscaling is



constrained by the 15-year guarantee). Such scaling-up could take three forms: when governments find that even the maximum per-QALY rate of \$1000 elicits little innovation, they can raise this ceiling. They can also increase (beyond the initial 4 million QALYs) the limit to which this maximum rate holds. And they can reduce the steepness of the drop in the \$/QALY rate beyond this limit. Any such scaling-up can be financed through an increased commitment by the member states and/or through the accession of new members.

The establishment and scaling-up of the HIF would be facilitated by a rule that divides the cost of the HIF in proportion to the member states' respective gross national incomes (GNIs). Thus, if one member state's GNI is 3.7 times that of another, than the contribution assigned to the former will be 3.7 times that assigned to the latter. Such rigidity has three main advantages. First, the contributions of the various countries are automatically adjusted in a way that tracks their shifting fortunes — fast-growing countries automatically assume a larger share while countries in recession (declining GNI) find their burden alleviated. Second, such rigidity pre-empts protracted struggles over contribution proportions such as have marred the United Nations. Third, rigidity assures each country that any extra cost it agrees to bear by supporting an increase in the contribution schedule, say, is matched precisely by a corresponding increase in the contributions of all other member states. Getting a state to agree to commit an extra \$20 million is much easier if this agreement expands available rewards for pharmaceutical research by a much larger amount than if (as in conventional governmental research allocations) it adds merely \$20 million to the available funds.

If all countries of the world were to agree to join the effort, each would contribute less than 0.008 percent of its gross national income for the first 4 million QALYs. As citizens, we would all pay an additional 0.008 percent of our gross income in taxes (\$1 for every \$12,500 in gross income) and, by agreeing to do so, gain the equivalent of 4 million years of healthy life against the GBD. If countries representing only half the sum of GNIs were willing to participate, their citizens would contribute 0.016 percent of their gross incomes for the first 4 million QALYs — still a trivial amount relative to its impact and mitigated, of course, by the much greater affordability of HIF-registered medicines.

The solution is then to create — parallel to the existing patent regime — a Health Impact Fund that gives pharmaceutical innovators a standing option to forgo exploitation of their monopoly powers on any medicine worldwide in exchange for a guaranteed payment stream proportioned to this medicine's impact on the GBD. Let us recapitulate how this parallel track would provide a full systemic solution to the seven problems described at the outset.

**Diseases concentrated among the poor**, insofar as they substantially aggravate the GBD, would no longer be neglected. In fact, the more

destructive ones among them would come to present some of the most lucrative R&D opportunities for biotechnology and pharmaceutical companies. This would happen without undermining the profit opportunities such companies now enjoy.

**Bias toward symptom relief** would be absent from HIF-encouraged R&D. The HIF assesses each registered medicine's health impact in terms of how its use reduces mortality and morbidity worldwide — without regard to whether it achieves this reduction through cure, symptom relief, or prevention. This would guide firms to deliberate about potential HIF-track research projects in a way that is also optimal for global public health — namely in terms of the expected global health impact of the new medicine relative to the cost of developing it. The profitability of research projects would be aligned with their cost effectiveness in terms of global public health.

**High prices** would not exist for HIF-registered medicines, and innovators would typically not even wish for a higher price on their HIF-registered medicines. The reason is that a higher price would greatly reduce a drug's health impact rewards by impeding access to this drug by the very poor who make up about half the human population. On the HIF track, health benefits to the poorest of patients count equally with health benefits to the richest.

**Wastefulness** would be dramatically lower for HIF-registered medicines. There would be no deadweight losses from high mark-ups. There would be little costly litigation as innovators would welcome generic competitors who, by increasing access to the medicine, would boost the innovator's health impact reward. Given this situation, innovators might often not even bother to obtain, police and defend patents in many national jurisdictions. To be eligible for rewards proportioned to the global health impact of a new medicine, an innovator would need to show *only once* that it has a patentable product.

**Counterfeiting** of HIF-registered medicines would be much less attractive: with the genuine item available near marginal cost of production, much less profit can be made from producing and selling fakes.

**Excessive marketing** would also be much reduced for HIF-registered medicines. Because each innovator is rewarded for the health impact of its addition to the medical arsenal, innovators get no reward for switching patients over to a new drug that is no better than its predecessor and would consequently never register it with the HIF. Innovators would have incentives to urge a HIF-registered drug upon doctors and patients only insofar as such marketing results in measurable therapeutic benefits for which the innovator would then be rewarded.

**The last-mile problem** would be mitigated because each HIF-rewarded innovator would have incentives to ensure that patients are fully instructed and properly provisioned so that they make optimal use (dosage, compliance,

etc.) of its medicines, which will then, through wide and effective deployment, have their optimal public-health impact. Rather than ignore poor countries as unprofitable markets, pharmaceutical companies would, moreover, have incentives to work together toward improving the health systems of these countries in order to enhance the impact of their HIF-registered medicines there.

## Conclusion

This essay describes and justifies a complement to the existing monopoly-patent regime that would generate a flow of pharmaceutical innovation without depriving the poor of their freedom to buy new medicines at competitive market prices. In response one might ask why the Health Impact Fund here described should be confined to new medicines. There are other means for reducing the GBD, such as access to safe drinking water, adequate nutrition, clean sanitation, proper hygiene, protections (such as mosquito nets) against disease-carrying animals, off-patent medicines, and many more. Why reward only new pharmaceutical remedies when there are alternative, perhaps more cost-effective ways of averting the same diseases?

A partial answer is that the efforts encouraged by HIF rewards would not be neatly confined to new medicines. Once a firm has registered a new drug, its reward will depend on how this drug affects the evolution of mortality and morbidity attributable to its target disease (the disease for which it is indicated). This impact will depend on many factors some of which — for example, the quality of health-care delivery in poor countries — the firm can affect. By helping to improve such health-care delivery, an innovator can magnify its medicine's impact, which is strongly affected by the extent to which doctors and nurses are locally available, know about the medicine, have it on hand, prescribe it, ensure that patients have access to it in the best dosage and in sufficient quantity, and instruct patients in its proper use.

The answer I have given does not fully overcome the objection. There are diseases — simple diarrhea, for instance — against which new medicines would be of limited help if any. Why should not efforts to reduce such diseases by securing access to off-patent medicines, to clean drinking water or to sanitation be funded insofar as they are no less cost-effective than the Health Impact Fund? I have no objection to such an extension of the reward scheme I have sketched. We can think of this scheme as the central module of a larger health reform project. Once this central module is specified and implemented, it can certainly be extended to other social factors essential to human health. It makes sense, nonetheless, to begin with the central module which will provide a useful paradigm for possible extensions and an impetus for further reform.

But why start with *this* module, centering around new medicines? Would the money not do more to protect the health of poor populations if it were spent on a global program of universal access to clean water or healthy nutrition? Perhaps it would. But let us not disregard the political realities. Bitter experience over many decades has shown that the world's governments are not prepared to spend tens of billions of dollars on clean water or nutritious food supplements. The provision of such basic goods is thought to deserve a few millions here and there, but certainly not tens of billions. The idea of spending such sums on supporting domestic corporations, by contrast, is entirely familiar and commonplace — in fact, the affluent countries are spending *hundreds* of billions *each year* on export credits and subsidies, which aggravate severe poverty abroad, in the agricultural sector alone. A politically realistic way forward might then tie together the two objectives of protecting the poor and providing business opportunities to large corporations. The HIF I have sketched is meant to fit this description. There may be more cost-effective schemes for protecting the poor. But such alternative schemes are useless nonetheless if they cannot attract the funds they plan to spend. Aligning with the powerful interests of the pharmaceutical and biotechnology industries, the HIF has better prospects for success.

I am aware that I have not had the space to discuss fully how the proposed HIF should best be designed. This is evidently a highly complex question. Addressing it adequately would require specification of the reward mechanism: definition of an appropriate metric for the GBD, rules for allocating the GBD among the various diseases, ways of collecting sufficient data to assess ex post the global burden each disease imposes and to make plausible baseline projections some years into the future, rules for allocating specific disease burden reductions among contributing registered innovators, specific rules for determining a monetary reward for a given set of GBD reductions, adequate mechanisms for curbing corruption and gaming, and special rules for incremental innovations and for the phase-in period. Another aspect of the design concerns the agency administering the reward mechanism and the arbitration procedures for settling conflicts about the interpretation and application of the rules. A third design aspect concerns the treaty rules for funding the scheme along with the penalties for free-riding by countries that seek to take advantage of HIF-supported innovation without sharing its cost. We have an interdisciplinary and international team — supported by the Australian Research Council, the BUPA Foundation and the European Commission — hard at work on detailing workable solutions to these challenges. Our work is documented, with some time lag, at [www.IncentivesForGlobalHealth.org](http://www.IncentivesForGlobalHealth.org).

Let me close with two more general lessons this essay supports. One

concerns the tragicomical disputes over globalization. The friends of WTO globalization spend billions to have the media reiterate the benefits of free markets and free enterprise. The opponents of WTO globalization mobilize millions of people to demonstrate against the damage free markets threaten to do to human values and well-being. In this unequal dispute, the reality of WTO globalization is overlooked by both sides — intentionally by the proponents, most often, and inadvertently by the opponents. The reality is that WTO globalization is opening markets where this serves important corporate interests in powerful countries, is preserving barriers to free exchange where this serves important corporate interests in powerful countries, and is shutting down free and open markets where this serves important corporate interests in powerful countries. The third type is exemplified by the case we have discussed, as large pharmaceutical corporations have won the right to use monopoly patents to block free trade in vital medicines worldwide. The second case is exemplified by the uneven fortunes of protectionism: while poor WTO members are forced to open their markets, wealthier members maintain their tariffs and anti-dumping duties as well as their huge export credits and subsidies to domestic producers. To be sure, these protectionist measures are often theoretically illegal under WTO rules. But less developed countries usually lack the resources to bring and win cases against the US or EU. Moreover, such a country has little to gain from winning as affluent members typically continue their Treaty contraventions even in the face of clear-cut WTO rulings, confident that the weaker member will prudently refrain from imposing the retaliatory measures such rulings may entitle them to and that these retaliatory measures would, in any case, not seriously hurt them.

The other more general lesson is about political change. There is much lament about how evil corporations are putting profits above people, above health, above animal welfare, above the environment. These laments are true, but usually misdirected. The *root* of the evil lies not in how corporations do business, but in how *we* regulate and incentivize them. If we structure markets so that corporations can earn billions by getting people to smoke, then corporations will work hard to get people to smoke. If we structure markets so that corporations can earn billions by getting people to stop smoking, then corporations will work hard to get people to stop smoking. Highlighting the moral responsibilities of corporations and their leaders is appropriate even if it makes little difference to what they do. But it may also detract from *our* responsibility as citizens to structure markets so as to encourage good corporate behavior. Having failed to do so, it is now *our* responsibility to devise politically realistic reforms, that is, reforms that the more powerful corporations and governments may well support or at least accept. This responsibility motivates

the reform effort I have described. We must restructure the existing global patent regime so that pharmaceutical innovators lose the financial stake in the proliferation of their target diseases and gain a financial stake in the elimination of these diseases. If we can thus redirect present incentives, then the immense powers of free enterprise will be marshaled *against* the devastating diseases that are now allowed to proliferate. If we manage to reorient pharmaceutical and biotechnology companies by aligning their profits with GBD reduction, these companies will be much more effective than the current assortment of ad hoc initiatives at defeating these diseases which bring so much misery and premature death to poor people everywhere. Working for this goal is politically realistic insofar as the envisioned structural reform is in the interest not only of the poor worldwide but also of the global pharmaceutical industry whose profitability it would enhance and whose tarnished image it would help to restore. These benefits come at very little cost because of the huge inefficiencies the reform reduces and because the benefits of intellectual property can be extended without cost.

## NOTES

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1. POGGE, T. Eradicating systemic poverty: brief for a global resources dividend. *Sur – International Journal on Human Rights*, São Paulo, v. 6, p. 136-158, 2007.
2. Ibid., note 27 and RONEY, M. The global millionaire boom. *Business Week*, 17 Oct. 2007. Available online at: <[www.businessweek.com/bwdaily/dnflash/content/oct2007/db20071017\\_916634.htm](http://www.businessweek.com/bwdaily/dnflash/content/oct2007/db20071017_916634.htm)>. Accessed on: 18 April 2008.
3. DAVIES, J.; SANDSTROM, S.; SHORROCKS, A. and WOLFF, E. *The world distribution of household wealth*. Helsinki: UNU-WIDER, 2006, Appendix 1, Table 10a; and KROLL, L. and FASS, A. The world's billionaires. *Forbes*, New York, 3 Aug. 2007. Available online at: <[www.forbes.com/2007/03/07/billionaires-worlds-richest\\_07billionaires\\_cz\\_lk\\_af\\_0308billie\\_land.html](http://www.forbes.com/2007/03/07/billionaires-worlds-richest_07billionaires_cz_lk_af_0308billie_land.html)>. Accessed on: 18 April 2008.
4. Over the 1984-2004 globalization period, household final consumption expenditure per capita (in constant dollars) rose 56.3% in the high-income OECD countries. During the same period, real (inflation and purchasing-power adjusted) consumption expenditure reportedly rose 48.62% at the median, 33.72% at the 15<sup>th</sup> percentile, 31.92% at the 7<sup>th</sup> percentile, 22.87% at the 2<sup>nd</sup> percentile, and 9.64% at the 1<sup>st</sup> percentile. See Table 6 in POGGE, T. Growth and inequality: understanding recent trends and political choices. *Dissent*, New York, v. 55, Issue 1, 2008, p. 82-93. Available online at: <[www.dissentmagazine.org/article/?article=990](http://www.dissentmagazine.org/article/?article=990)>. Accessed on: 18 April 2008. See also MILANOVIC, B. *Worlds apart: measuring international and global inequality*. Princeton: Princeton University Press, 240 p., 2005, p. 108-111.
5. The 1979 data are from <<http://62.237.131.23/wiid/wiid.htm>>, line 4664. Accessed on: 18 April 2008. And from LEONHARDT, D. Larry Summers's evolution. *New York Times Magazine*, 10 June



2007. Available online at: <[www.nytimes.com/2007/06/10/magazine/10wwIn-summers-t.html?ref=magazine](http://www.nytimes.com/2007/06/10/magazine/10wwIn-summers-t.html?ref=magazine)>. Accessed on: 18 April 2008. The 2005 data are from RONEY, M. The global millionaire boom, op. cit..

6. The 1990 data are from Table 1 of REDDY, S. and MINOIU, C. *Chinese poverty: assessing the impact of alternative assumptions*. New York: Institute for Social, Economical Research and Policy/ Columbia University, p. 1-35, 2007. Available online at: <[www.socialanalysis.org](http://www.socialanalysis.org)>. Accessed on: 18 April 2008. The 2004 data are from the World Bank's World Development Indicators dataset, which is available to subscribers only. Accessed on: 18 April 2008.

7. See <<http://62.237.131.23/wiid/wiid.htm>>, line 476 (2004). Accessed on: 18 April 2008.

8. POGGE, T. *World poverty and human rights: cosmopolitan responsibilities and reforms*. Cambridge: Polity Press, second edition, 2008, chs. 6-8.

9. This calculation assumes constant nominal profit each year. In reality, annual profit may rise (e.g. through population growth) or fall (through reduced incidence of the disease or through competition from "me-too" drugs developed by competing firms).

10. Announced in 2003, this joint WHO/UNAIDS program was meant to provide, by 2005, anti-retroviral treatment to 3 million (out of what were then estimated to be 40.3 million) AIDS patients in the less developed countries. In fact, the number of patients receiving such treatment increased by only 0.9 million to reach 1.3 million by the end of 2005. See WHO, *Evaluation of WHO's contribution to "3 by 5"*. Geneva: WHO, 2006. Available online at: <[www.who.int/hiv/topics/me/3by5%20Evaluation.pdf](http://www.who.int/hiv/topics/me/3by5%20Evaluation.pdf)>. Accessed on: 18 April 2008.

11. A prize is a specific reward offered for the development of a new medicine that meets certain specifications. It can be in the form of a cash payment or in some other form, for instance the extension of a patent on another medicine that is in high demand by affluent patients. An advance purchase commitment (APC) is a promise to buy, at a pre-set and lucrative price, a certain large number of doses of a new medicine that meets certain specifications. An advance market commitment (AMC) is a promise to subsidize the sale of a certain large number of doses of a new medicine that meets certain specifications. The only AMC issued thus far — funded by Italy, the UK, Canada, Russia, Norway, and the Gates Foundation — is for vaccines against pneumococcal disease, a major cause of pneumonia and meningitis among the poor. News reports suggest that it is designed to serve pharmaceutical industry interests first and foremost. See, for example, MILLER, J. Vaccines for Africa 'face 700% mark-up'. *The Independent*, 18 Nov. 2007. Available online at: <[news.independent.co.uk/health/article3172164.ece](http://news.independent.co.uk/health/article3172164.ece)>. Accessed on: 18 April 2008.

12. In Thailand, Sanofi-Aventis sold its cardiovascular disease medicine Plavix for 70 baht (\$2.20) per pill, over 60 times the price at which the Indian generic firm Emcure agreed to deliver the same medicine (clopidogrel). See OXFAM. *Investing for life*. Oxfam Briefing Paper, Nov. 2007, p. 20. Available online at: <[www.oxfam.org/en/files/bp109\\_investing\\_for\\_life\\_0711.pdf/download](http://www.oxfam.org/en/files/bp109_investing_for_life_0711.pdf/download)>. Accessed on: 18 April 2008.

13. See SELGELID, M. Ethics and drug resistance. *Bioethics*, Johannesburg, v. 21, n. 4, p. 218-29, May 2007.

14. Personal communication from Aidan Hollis, based on his rough calculation. See also HOLLIS, A. *An efficient reward system for pharmaceutical innovation* (working paper). Calgary: University



of Calgary, 2005, p. 8. Available online at: <[www.patent2.org/elibrary.html](http://www.patent2.org/elibrary.html)>. Accessed on: 18 April 2008. Hollis there quantifies the deadweight loss in the region “of \$5 billion – \$20 billion annually for the US. Globally the deadweight loss is certain to be many times this figure, because in many markets drug insurance is unavailable and so consumers are more price-sensitive”.

15. See the Special issue on disease mongering. MOYNIHAN, R. and HENRY, D. (ed.). *PLoS Medicine*, Cambridge, United Kingdom, v. 3, issue 4, p. 425-465, 2006. Available online at: <[collections.plos.org/plosmedicine/diseasemongering-2006.php](http://collections.plos.org/plosmedicine/diseasemongering-2006.php)>. Accessed on: 18 April 2008.

16. The TRIPS Agreement is Annex 1C of the Marrakesh Agreement Establishing the World Trade Organization, signed in Marrakesh, Morocco on 15 Apr. 1994. Its full text is available online at: <[www.wto.org/english/tratop\\_e/trips\\_e/t\\_agm0\\_e.htm](http://www.wto.org/english/tratop_e/trips_e/t_agm0_e.htm)>. Accessed on: 18 April 2008. Relevant are Articles 8(1) and 27(2). The full text of the Doha Declaration is available online at: <[www.who.int/medicines/areas/policy/tripshealth.pdf](http://www.who.int/medicines/areas/policy/tripshealth.pdf)>. Accessed on: 18 April 2008. Most relevant are Articles 4-6.

17. To be sure, to benefit many, the intellectual achievement must typically be physically encoded in multiple copies: in books, CDs, seeds, DNA molecule tokens, pills, or vaccines. Such physical instantiations of intellectual creations and discoveries do have a cost that rises — typically at a decreasing rate — as additional copies are made. But such physical reproduction is separable from, and adds nothing to the cost of, the creative intellectual labors. The creative intellectual ingredient into physical reproduction is entirely cost-free at the margin.

18. NOZICK, R. *Anarchy, state and utopia*. New York: Basic Books, 384 p., 1974, p. 181.

19. The most pertinent passages are LOCKE, J. An essay concerning the true original, extent, and end of civil government [1689]. In: LASLETT, P. (org.). *Two treatises of government*. Cambridge: Cambridge University Press, 1960, §27 and §33; and NOZICK, R. *Anarchy, state, and utopia*, op. cit., p. 181-182. Nozick approves of patents but, as I show in the text, this endorsement is inconsistent with the basis Nozick offers for it.

20. In this essay, I am not separately addressing utilitarian arguments for a global monopoly-patent regime. But it is obvious how they are bound to fail: even if funding pharmaceutical innovation in a way that includes the poor is less convenient for the affluent than the existing globalized monopoly-patent regime, this inconvenience is vastly outweighed by all the sickness and premature deaths that the present regime is adding to the burdens of poverty.

21. This injustice is independent of, and additional to, the great national and international injustices that keep half of humankind trapped in severe and avoidable poverty.

22. Before 2005, Indian law allowed only patents on processes, none on products. As a result, India’s thriving generic pharmaceuticals industry, inventing new processes for manufacturing known medicines patented elsewhere, cheaply supplied such medicines for poor patients in India and throughout the world’s poor regions. “But when India signed the World Trade Organization’s agreement on intellectual property in 1994, it was required to institute patents on products by Jan. 1, 2005. These rules have little to do with free trade and more to do with the lobbying power of the American and European pharmaceutical industries. India’s government has issued rules that will effectively end the copycat industry for newer drugs. For the world’s poor, this will be a double hit — cutting off the supply of affordable medicines and removing the generic competition that drives down the cost of brand-name drugs.” EDITORIAL. India’s choice. *The New York Times*, 18 Jan. 2005. Available online at:

<[select.nytimes.com/gst/abstract.html?res=F10610F8395C0C7B8DDDA80894DD404482](http://select.nytimes.com/gst/abstract.html?res=F10610F8395C0C7B8DDDA80894DD404482)>.  
Accessed on: 18 April 2008.

23. A push program might assign the same task to two or three innovators. But this would double or triple the cost and thereby dramatically erode the cost advantage over its pull-program alternative.

24. See especially KREMER, M. and GLENNERSTER, R. *Strong medicine: creating incentives for pharmaceutical research on neglected diseases*. Princeton NJ: Princeton University Press, 2004.

25. This informational deficit — though not the other problems with prizes — can be overcome through a tender system: The planners would publish the specifics of the medicine they wish to have invented and then invite companies and other capable agencies to enter competing “bids”, specifying the prize each would expect for producing a qualifying medicine as well as a deadline and a penalty for delays. The planners could then select the organization whose bid seems most attractive overall.

26. For an excellent discussion, see HOLLIS, A. *Incentive mechanisms for innovation*. Calgary: IAPR Technical Paper-University of Calgary, 43 p., 2007, p. 15-16. Available online at: <[www.iapr.ca/iapr/files/iapr/iapr-tp-07005\\_0.pdf](http://www.iapr.ca/iapr/files/iapr/iapr-tp-07005_0.pdf)>. Accessed on: 18 april 2008.

27. HOLLIS, A. *A comprehensive advance market commitment: a useful supplement to the patent system?* (working paper). Calgary: University of Calgary, 2007. Available online at: <[www.patent2.org/elibrary.html](http://www.patent2.org/elibrary.html)>. Accessed on: 18 April 2008.

28. In the case of medicines targeting communicable diseases, this benefit will increase super-proportionally: Each user of such a medicine benefits from others using it as well, because wide use can decimate or even eradicate the target disease and thereby reduce the probability that this disease will adapt and rebound with a drug-resistant strain (see note 13).

29. This corresponds roughly to the effective patent life of 20-year pharmaceutical patents, which are filed many years before market clearance.

30. See POGGE, T. *World poverty*, op. cit., ch. 9.

31. The QALY or quality-adjusted life year is a common measure of gains against the mortality and morbidity that constitute the GBD. It can be refined in various ways which I lack the space to discuss here. Basically, one QALY is an additional year of healthy life or a longer additional period of impaired life (e.g., 1.25 additional years with a 20% impairment of age-specific functioning).

## RESUMO

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Ao estabelecer altos preços para medicamentos avançados que se encontram fora do alcance de pacientes pobres e estimular a negligência de doenças concentradas nas populações mais pobres, o acordo TRIPS produz em escala maciça doenças e mortes evitáveis. Tal injustiça pode ser evitada através de um Fundo de Impacto sobre a Saúde Global (Health Impact Fund) que oferece àqueles que detêm a patente dos medicamentos a opção de oferecer os medicamentos a preço de custo em troca de uma recompensa monetária anual baseada no impacto deste medicamento na saúde global.

### PALAVRAS-CHAVE

Compromisso antecipado de mercado – Doença – Fundo de Impacto sobre a Saúde – Incentivos – Justiça – Medicamentos – Monopólio – Patentes – Pobreza – Bem público – Pesquisa – Direitos – TRIPS

## RESUMEN

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El Acuerdo ADPIC/TRIPS, al imponer unos precios sobre los medicamentos avanzados más allá del alcance de los pobres y al fomentar la ignorancia de las enfermedades que más les afectan, produce muertes y enfermedades evitables a una escala descomunal. Esta injusticia puede ser remediada a través de un Fondo de Impacto sobre la Salud que otorga a los propietarios de patentes la opción de establecer los precios de cualquier nuevo medicamento a nivel del costo a cambio de una recompensa monetaria anual en función del impacto de este medicamento sobre la salud global.

### PALABRAS CLAVES

Compromiso Anticipado de Comercialización– Enfermedad – Fondo de Impacto sobre la Salud – Incentivos – Justicia – Medicina – Monopolio – Patente – Pobreza – Bien público – Investigación – Derechos – ADPIC/TRIPS



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#### ABSTRACT

This paper presents some ideas about the impact that court rulings can have on the political system. Unlike what is usually written about the role of the Judiciary on the subject of human rights, when the emphasis is placed on the patterns and methods the courts devise to respond to claims for the justiciability of these rights, the authors – who focus on the Chilean case – illustrate how strategic litigation can, even with adverse judicial outcomes, have a positive impact on the satisfaction of social rights. The paper will also show how this impact depends more on the sensibility of the political system to respond to the desperate situation in which many of its citizens find themselves, and on the fear of political pressure, than on the possibilities opened up by major court rulings.

Original in Spanish. Translated by Barney Whiteoak.

#### KEYWORDS

Courts – Social rights – Right to health – HIV/AIDS – Public interest litigation – Chile



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# ACCESS TO MEDICAL TREATMENT FOR PEOPLE LIVING WITH HIV/AIDS: SUCCESS WITHOUT VICTORY IN CHILE

Jorge Contesse and Domingo Lovera Parmo

## 1. Introduction

Access to health and courts of law have been frequent bedfellows. Experiences from around the world, of which those from South Africa and India are best known, illustrate how courts of law have been instrumental in enforcing the legal protection of social rights. Civil society organizations have learned to use the Judiciary to secure the satisfaction of their rights, something that the political system simply neglected to do, in spite of what had been established in the international treaties that their governments had signed up to.<sup>1</sup> Generally speaking, it has been minority groups from a political point of view – that is, groups that encounter formidable obstacles for the satisfaction of their claims to be satisfied through the “political process” – that have opted to turn their backs on this process and apply instead to the courts. But there are also cases of groups of people who, while not necessarily being minorities (many of these groups are, in fact, highly organized), have not had their social rights satisfied. This is the focus of our paper.

Among these groups are people living with HIV/AIDS and their claims for access to and coverage by adequate medical treatment. A significant part of these claims has been pursued through public interest litigation strategies, perhaps emboldened by the case in the United States brought by the NAACP.<sup>2</sup> In *Brown v. Board of Education*, of 1954, for example, the United States Supreme Court declared school segregation to be unconstitutional. These strategies are obviously designed to defend in court the claims that the political

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*Notes to this text start on page 156.*

process simply (and often intentionally) ignores; or otherwise claims that the political process has never before addressed.

This strategy is not free of criticism. As has been observed repeatedly, turning to the courts, brandishing the Constitution over all other legal provisions, to secure satisfaction for the claims of marginalized sectors or claims that are not considered justiciable, and which are normally related to the allocation and reallocation of financial resources, poses an enormous challenge for our forms of government. The discussion of these litigation strategies has focused on the correspondence that should exist between courts and democracy. Therefore, countries where the courts have been more actively engaged in satisfying social rights have provided a fertile ground for discussion on the role of the courts in this type of conflict. The question that most frequently crops up is: what role should the courts play in resolving these claims? And if they do indeed have a role to play – as we have assumed in this paper – to what extent should they exercise their jurisdiction? Is it enough for them to declare welfare laws and programs unconstitutional when they violate the Constitution, or should they force lawmakers to pass welfare plans (with the subsequent rearrangement of fiscal resources)? And should the latter be the case, should the courts interfere in the development of these plans, for instance by monitoring the work of ministries and parliaments? These are questions that receive a lot of attention in the comparative literature and that, it must be noted, are also a major digression from the purpose of this paper. Our intention in these pages is more precise: we are interested in showing how it is possible to achieve success even when losing the cases judicially. Through litigation, it is possible to “incentivate” the political process to accept and respond to the claims of marginalized groups, and to respond and discuss how to satisfy the demands that, analyzed in a specific legal context, cannot always simply be claimed in court.

Such is the context of the Chilean case: with a Constitution rewritten by specialists appointed by the government’s Military Junta and reviewed, ultimately, by Pinochet himself, Chile – a model student on the subject of free trade – delegates the satisfaction of social rights, such as health and education, to a system in which the private sector plays the primary role, while the State is assigned a merely subsidiary role, just as Pinochet and his associates wanted.<sup>3</sup> The HIV/AIDS cases illustrate how a political system that is resistant to attending to certain demands can be forced by judicial decisions that do not even recognize the existence of rights, to address these claims, collaborating, even without knowing it, to strengthening the regime of rights and, in doing so, making the democracy more robust and inclusive.

This article is structured as follows. In the first section, we shall make a brief analysis of the treatment of social rights by the Chilean legal and

constitutional system (2). Although these rights are recognized in the Constitution, their satisfaction hinges on the so-called *constitutional protection action* (equivalent to *amparo* in other Latin American countries). We shall then report the cases brought before Chilean courts by people living with HIV/AIDS, the judicial rulings on these cases, and the political impact that years of litigation have finally produced (3). This includes a detailed account of the litigation strategies used, and the judicial response to them – as we have said, rejecting these cases. Together with the judicial response, we shall also analyze the political impact of these cases and how they eventually prompted the Chilean government to petition the United Nations Global Fund, together with the very same organizations that, on a local level, had held the State accountable for its omissions. Finally, we shall present some conclusions (4).

## **2. Social rights in Chile: privatizing social protection**

Chapter III of the Chilean Constitution, entitled “Constitutional Rights and Obligations”, embraces civil and political rights and also economic, social and cultural rights.<sup>4</sup> While the former are protected by a specific judicial action called in Chilean constitutional jargon a “writ of protection”,<sup>5</sup> social rights are not included.<sup>6</sup> The “writ of protection” enables people who suffer “deprivation, disturbance or threat” in the legitimate exercise of their rights (civil and political), regardless of the source (from the State or from other individuals) and regardless of whether it involves an action or an omission that caused the abuse, to turn to the courts to seek judicial remedy.<sup>7</sup>

There are many reasons explaining why social rights, in spite of their recognition by the Constitution, find themselves excluded from this emergency protection remedy.<sup>8</sup> First, the commission entrusted with rewriting the draft of the Constitution of 1980 – known as the Commission for the Study of the New Constitution (CENC) – interpreted social rights according to their most traditional sense, that is, as positive rights. It subscribed to the idea that this was a category of rights contrasting with so-called negative rights – civil and political – and whose implementation required exclusively government intervention through the allocation of resources.<sup>9</sup> And this was precisely what it wanted to erase from the Chilean constitutional map: a State provider of social services. In this vein, a renowned Chilean constitutionalist and member of the CENC, while discussing the scope and range of the “writ of protection” noted that for a right to deserve protection “it should be a guarantee to which one has access



in virtue of the simple fact of living in this territory and that does not depend on provisions that the State must furnish”.<sup>10</sup>

As many authors have asserted, there is a false dichotomy between negative rights – civil and political – and positive rights – social. In practically all rights it is possible to find the need for social provisions, regardless of whether they are for a so-called civil or political right or for a social right. For example, the right to property, which is usually presented as a model of civil and political rights, necessarily requires positive action by the State, as it is guaranteed through the establishment of property registration; the same can be said about the right to due legal process, which, were it not for a legal structure consisting of certain characteristics, could not be considered properly satisfied.<sup>11</sup> Nevertheless, in Chilean constitutional doctrine and, as we shall see further ahead, also in its jurisprudence, the idea that social rights are entirely different from “genuine” rights still persists, consequently they cannot be the subject of judicial protection.

The second reason explaining the lack of recognition for social rights is the moment in history in which the CENC was working on the preliminary version of the Constitution. At the time, its members, especially the final reviewers of the draft – the Military Junta, with Pinochet at the helm – mistrusted citizenship and politics. As far as they were concerned, “excessive democracy” in the early 1970s had been responsible for the failure of the grassroots program of Salvador Allende. In this context, a citizenry that is too active and too aware of how public policy is planned and implemented constituted a threat.<sup>12</sup> Pinochet saw Congress, which he had closed after taking power, as a body that was open to demagoguery and populism,<sup>13</sup> a reason why he would later set up his own particular version of “checks and balances”: a “protected” democracy, which would include appointed senators, lifelong senators, a Security Council with broad participation of the Armed Forces and – no doubt the hardest legacy to undo – an electoral system that undermines the will of the people, forcing the formation of two political coalitions and leaving minority voices without representation.<sup>14</sup> It is no surprise, then, that social rights have been and continue to be interpreted, demonstrating the endurance of the constitutional conceptions of the dictatorship, as aspirations instead of rights.

If, in the view of the founders of Chile’s “protected democracy”, social rights were manifestations of State policy, any involvement by the citizenry in their discussion and implementation would clearly be best avoided. And this was achieved, in part, by preventing these rights from being endowed with justiciability through the *constitutional protection act*.

The constitutional practice, once democracy had been restored, did little to improve the situation. The return of democracy has prompted a

“technocratic” vision of social rights, whose satisfaction is assigned to programs run centrally by the State Administration, which, while in some cases it has embraced the notion of rights to explain these initiatives, in practice it has not managed to “empower” the people these programs were designed to help.<sup>15</sup> As a result, social rights have remained relegated to a secondary position in the constitutional spectrum, with a dominant role played by the private sector, which handles health and social welfare provisions, and a state that, as the United Nations Committee on Economic, Social and Cultural Rights has observed, does not appear to have fully understood what the realization of social rights means.<sup>16</sup> Nevertheless, there have been some examples in this context that contradict the underlying norm that public policies are planned and implemented “from above”, without any dialogue with institutional and social actors. Litigation and the subsequent alliance between civil society and the State to provide universal coverage for people living with HIV/AIDS is perhaps the most notable of these examples, one that illustrates that you often need to do more than just knock on the door to generate this kind of dialogue.

### **3. The Chilean case: success without victory?**

During the 1980s, Chilean civil society put its individual claims aside and rallied behind the common and urgent goal of overthrowing the Pinochet dictatorship. When this objective was finally achieved, the specific demands of civil society groups began to appear in the public arena.<sup>17</sup> By the mid-1990s, various civil society organizations had begun to draw up their own thematic agendas for discriminated minorities. One of the more organized sectors that participated in this process was the group of people living with HIV/AIDS, which claimed (and still claims) greater attention from the State. The ignorance of the population, caused among other reasons by the lack of educational campaigns and information about the disease, transformed people living with the human immunodeficiency virus into a group of disadvantaged citizens that were calling for more visibility. Part of the strategy developed by this minority group to force the State to concede to its demands, and that helped the State formulate public policies for HIV/AIDS, were the legal cases brought before the courts that challenged the prevailing constitutional conceptions.

What follows is an account of these cases. In the first section, we shall review the legal and constitutional arguments for their claims, namely that by not providing medical treatment for all individuals, the Chilean government was violating their constitutional rights.<sup>18</sup> In the second section, we shall illustrate the impact that these cases have had on the political process.

### *A. The HIV/AIDS cases in the courts*

Between 1999 and 2001, there were several cases of low-income citizens claiming free drugs from the State to treat the disease.<sup>19</sup> Given the silence of the political powers – Legislative and Executive – these citizens decided to try their luck with the Judiciary. At the time, treatment cost approximately US\$1,000 per month and added to this unaffordability was the social cost that often came with no longer being an anonymous carrier of the virus, through exposure to the stigma and to the discrimination that exists against people living with HIV/AIDS.

Over three years of legal battles, all the cases brought before the Judiciary were “writs of protection”. In 1999, three cases were filed requesting the courts to find the State guilty of maladministration by not providing medication.<sup>20</sup> In addition to this, they also claimed a violation of the right to life that the Constitution guarantees all people in Chile.<sup>21</sup> According to the way the “writ of protection” is configured, and as we have already seen, the right to health is not protected by the Constitution. The Court of Appeals, the tribunal that first hears these cases, through a *sui generis* procedure of admissibility created by the Supreme Court in the 1990s, judged the case to be groundless.<sup>22</sup> Without examining the issue in depth, the court declared the writ inadmissible since it dealt with a subject “that exceeds the bounds of the protection procedure”.<sup>23</sup> As a result, unable to overturn this ruling of inadmissibility, the claimants saw their chances of staying alive go up in smoke. In fact, it was necessary for the Inter-American Commission on Human Rights to intervene, by applying precautionary measures,<sup>24</sup> for the Chilean State to agree to provide anti-retroviral drugs to the claimants. But in spite of this, the drugs did not arrive with the necessary urgency and one of the claimants died, while another, in despair, committed suicide. Only one of them was able to control the progression of the disease and relieve the acute situation he was in.

A year later, 24 people sought legal recognition for their right to receive free and full treatment for HIV/AIDS. This second group of cases was filed drawing on the “jurisprudence” of Chilean courts.<sup>25</sup> By ruling on a series of cases involving the right to life, the courts had signaled that this right was “absolute”.<sup>26</sup> Within this context, the claimants argued that, just as the courts themselves had recognized, the right to life was absolute and, consequently, generates responsibilities for the State that are not only negative, but also positive. Furthermore, they included an argument based on a little known supreme decree, passed by the military government of General Pinochet in 1984, which explicitly compelled all health services to provide full and free treatment to patients with sexually transmitted diseases, including HIV/

AIDS.<sup>27</sup> In a highly formalistic culture, it was believed that now, faced with a clear and precise rule, the courts would accept the petition. Added to this was the wide press coverage given the cases in 1999, which led more people to take their cases to court and, subsequently, raised social awareness of the problem.

Nevertheless, the courts once again rejected the cause of the claimants. According to the court that first examined the case, what was involved was not the protection of human life, but instead the protection of health; and since the right to health it not covered by the writ of protection, the petition should be refused. Since it had interpreted the case as involving the right to health, the court invoked a context of limited economic resources – as the State had argued – which, in its opinion, justified denying the admissibility of the case to avoid interfering in the decisions of the government’s technical agencies (when to invest, what to invest in and how to go about it). But together with this argument that, while debatable, does not refute the rationality that is expected from the Judiciary, the court also remarked that the threat to the lives of the claimants did not originate from the State or from the limited access to medical treatment, but “from the disease that, lamentably, afflicts [the claimants] [...] not being able to deem as [arbitrary and illegal] the omissions they attribute to the Health Services and the respective Ministry”.<sup>28</sup> In this ruling, the court stated the obvious: the threat to life is posed by the disease that afflicts the claimants, but when called upon to set the institutional wheels in motion to protect these people, it preferred to look the other way. It was the job of the Executive, not of the Judiciary, to decide on the best way to allocate funds for this problem that, as the ruling appeared to imply, the claimants had brought on themselves. Moreover, and placing a limitation on the validity of these cases to defend groups of people, the court ruled that writs of protection could not be filed as class actions, on behalf of an indeterminate number of people for the protection of common interests.<sup>29</sup> The Supreme Court confirmed this decision and, once more, the claimants had to turn to the Inter-American Commission on Human Rights. One year after appealing to this international body, five of the 24 claimants had already died.

In 2001, a new writ of protection was filed on behalf of three people in advanced stages of the disease. It argued, once again, that the lack of provision of medication by the health services posed a risk of death to the claimants and that it was the constitutional and legal duty of the State to provide them due protection. The role played by the media in these campaigns was also extremely important: they gave coverage to the facts, enabling Chilean society to grow acquainted with the human drama of people living with HIV/AIDS and, in consequence, with the social duty owed them by the State and the

community. This was the context behind the first (and only) judicial victory. The Court of Appeals of Santiago, the same court that had rejected two such cases in as many years, although on this occasion the ruling came from a different panel, interpreted the case as dealing with the right to life, not to health, and that the allegations of the State, that the allocation of tax resources cannot be made by courts of law, were groundless, since the human right to life, just as other courts had established beforehand, “is an absolute right that may not be subject to any economic considerations”.<sup>30</sup> For the first time, the courts stood behind people for whom all institutional doors had been shut, paving the way for groups of disadvantaged citizens who are marginalized from the political process to aspire to have their neglected claims submitted for recognition and protection.

The high spirits, however, did not last long. The Supreme Court, sitting as a court of appeals, overturned the decision, claiming that the case dealt with the right to health, not the right to life, and therefore did not qualify for the protection remedy. In spite of the imminent risk of death to the claimants, confirmed by medical certificates, the Court stuck to the position that these cases were “outside the bounds of the writ of protection”. This being the case, the Court went on to say, it dealt with a subject that “corresponds to the health authorities [assigned with] putting into practice the health policies planned and implemented by the State Administration, in accordance with the means at their disposal, and with other criteria that it is not our role to elaborate on”.<sup>31</sup> The Supreme Court, therefore, in the central doctrine of the ruling, declared, first, that there was a clear dichotomy (and even a tension) between the right to life and the right to health, and, second, that it was not in its jurisdiction to examine how the Executive plans and implements its policies – in this case, referring to the prevention and protection of HIV/AIDS. And so, the judicial channel for the claimants was once again extinguished: public policy and the law, said the Supreme Court, run on two different tracks.

This was an elegant way of dismissing the case. However, it also prompted a growing suspicion of the true reasons governing the decisions of the Supreme Court when it comes to ruling on cases that clearly involve the public interest.

### ***B. The cases in politics***

The case transcended the courts and, in spite of this legal defeat, the cause of people living with HIV/AIDS became ingrained in the public debate and made it impossible for the government to keep on refusing their claims. Civil society organizations kept up their pressure and, with the help of the media and the academic community, which were closely following the

conduct of various institutional actors, they succeeded to persuade the government to adopt policies to redress the shortfalls in the public health system. An agenda on HIV/AIDS was agreed on between the social and institutional actors, enabling Chile to gather the momentum to adopt a more aggressive approach to combat this pandemic. The state, together with non-governmental organizations,<sup>32</sup> applied for funding from the United Nations to finance universal access to anti-retroviral drugs, as the law, the Constitution and, so it appeared, social morality dictated. This was when, “[in] the third quarter of 2001, there began a new process of improvement [and increase of coverage] that permitted the incorporation of new people to the triple therapy policy”.<sup>33</sup>

This increase [in anti-retroviral drugs coverage] was obtained through a process of negotiations with pharmaceutical companies that secured an average discount of 50% in the price of drugs and an increase in the national budget for [people living with HIV/AIDS] of 33% for the year 2002.<sup>34</sup> However, this is only part of the story. Because, in addition to this, the number of claims brought before the courts, the media exposure given the human situations behind the cases that in court received nothing more than a docket or cause number, and the negotiations that occurred between interest groups and the state authorities would not permit the public policies for the area to take any other course.

Vivo Positivo, for example, an NGO sponsored by the Human Rights Clinic of the Diego Portales University, in the writs of protection that were filed, assumed an important role in the planning and implementation of the (new) state policies for people living with HIV/AIDS. The legal cases created a whole new set of circumstances in which “we [a group of people living with HIV/AIDS] were placed at the table with our [then] most immediate counterparts associated with the Ministry of Health, that is to say, CONASIDA, directors of hospitals, officials in charge of HIV programs. [...] Beforehand, we were not sitting at the same table, in fact we were not even sitting”.<sup>35</sup>

This NGO, therefore, was in charge of one of the sections of the Chilean project submitted to the Global Fund: the section on capacity building and development of the necessary conditions for the social integration of groups of people living with HIV/AIDS.<sup>36</sup> Moreover, it is interesting to note that Vivo Positivo played a key role in the “social control” of the execution of the Chilean Global Fund project. Through technical consultations, Vivo Positivo installed itself in hospitals for the purpose of promoting the participation of women and, during a drug supply shortage, it got together with “all the relevant actors involved in the acquisition, distribution and monitoring of treatment”<sup>37</sup> to work on the public policy project.



It was not only the Administration that felt the blow. Parliament also acted, approving late in 2001 a law on HIV/AIDS<sup>38</sup> that established as the duty of the Ministry of Health “the direction and technical orientation of public policies on the subject”, that is, “to develop, execute and evaluate” these policies, with special emphasis on preventing discrimination and controlling the “spread of this pandemic”.<sup>39</sup> Article 6 of the law assigns to the state the responsibility of “ensuring treatment for people infected or sick with the virus” and creating adequate public policies.

The origin of this regulation is open to at least two interpretations. First, it is possible to claim that the law’s excessive emphasis on the Executive (through the Ministry of Health) as “the” promoter and programmer of public policies will prevent the courts, in the future, from once again trying to dictate how the state spends its limited tax revenues. This implies an interest in restricting the scope of action of the courts in favor of the political decisions of Congress and the technical decisions of the Administration. The second possible interpretation is that the law originated from the impact that the legal cases had on the political system, and that lawmakers genuinely decided to resolve an issue that they had previously preferred (at the very least) to overlook.<sup>40</sup> Although some lawmakers had for years been trying to push legislation for the prevention and protection of HIV/AIDS, the opportunity presented by these new circumstances – of broad social awareness – was what finally prompted Parliament to pass a specific law on the subject.<sup>41</sup>

Perhaps there is a little of both these interpretations. Nonetheless, a more careful examination may tip the balance (slightly) towards the second explanation. That is to say, there is good reason to believe that the approval of the HIV/AIDS law did indeed represent a genuine willingness to tackle a “problem” that Congress had previously, as a passive bystander, left in the hands of the courts and of the Executive. For example, the law establishes, for public health institutions, the obligation to provide beneficiaries of the system “the healthcare they require”,<sup>42</sup> adding, in its transitory provisions, that people living with HIV/AIDS will benefit from a tax credit equivalent to the amount they have paid in taxes and duties on the import of expensive medicines.<sup>43</sup> Although it does not establish the free provision of drugs (which is covered by the Chilean petition to the Global Fund), it is without doubt a step forward that – and we would like to emphasize this – would perhaps never have happened were it not for the years of litigation.

In this section, it was our intention to demonstrate the impact of litigation by people living with HIV/AIDS both on the State Administration and on Parliament. This had a dual purpose. On the one hand, in descriptive terms, the idea was to illustrate that it is possible for a public interest litigation strategy to have an impact on the political process. On the other, we also



wanted to draw attention to the fact that the political regimes and governments of Latin America, characterized by what Carlos Nino has called “hyperpresidentialism”, tend to make it more complicated to defend the claims that have been cast to the sidelines of public debate. The “blow” that litigation has dealt, or has attempted to deal, should convince two more actors (Congress and the Judicial branch) – actors that are very often unwilling to engage in institutional dialogue.<sup>44</sup>

#### **4. Conclusions: three lessons on the political impact of litigation**

There are many lessons that can be drawn from litigation and the subsequent political negotiation concerning cases of access to medication for people living with HIV/AIDS. In these final pages, and in conclusion, we shall reconstruct some of the history of these cases: what interests us most is to emphasize the importance of the strategy of submitting cases that equate *prima facie* the protection of the right to health with protection of the right to life; the decisive influence that organized civil society can exert on the political and social process; and how these organized efforts can rouse the political system out of its lethargy.

First, it is worth noting the persistent strategy of litigators to present their cases in different ways: while the claimants have insisted that cases involving access to anti-retroviral drugs were cases in which the (right to) life of the plaintiffs was at stake, the government and the courts have always alleged that they are cases that concern the right to health. The reason for choosing one right or the other, as we have explained, has to do with the potential for judicial success inferred by one or other interpretation of the cases. By presenting cases as involving the right to life, they qualify for constitutional protection and, moreover, can draw on other earlier rulings by courts that have promptly afforded full protection for this right. However, when presented as dealing with the right to health, courts could quickly dismiss the cases based on a justification that has accompanied Chile’s recent constitutional history, that is, when dealing with a right whose satisfaction requires the allocation of tax revenues, it is the responsibility of the Administration, not the Judiciary, to decide on how these (scarce) resources shall be redistributed.

For sure, these approaches that appear conflicting represent litigation strategies far more than they do any correct interpretation of what fundamental rights require. We have already said that the sharp division between civil and political rights and economic, social and cultural rights is considered to have been surmounted in human rights theory. And this is not only the result of

academic exercises: it seems like common sense to conclude that if the state is negligent in protecting the health of its citizens, sooner or later the situation is going to arise when their lives are at risk. As we have seen, the response of the Chilean courts (and also the actions of the litigators) has been extremely formalist: what the Constitution, the law and in particular that little-known supreme decree had to say about the obligations of the state mattered far more than the underlying arguments, which involved the desperate claim of a group of people with HIV/AIDS who were fighting for their lives. In retrospect, it does seem rather nonsensical to argue inadmissibilities, or the absence of legal resources to protect common interests, for the purpose of closing the door on the complaints lodged against the state by its organized citizenry.

The best evidence that the Judiciary can do something, when it wants to, is the sentence pronounced months earlier to ban the morning-after birth-control pill: the arguments used in this case were entirely admissible in the HIV/AIDS cases, but this latter situation, for reasons beyond the speculations of this paper, but which are not difficult to imagine, seem less deserving attention. The same common sense, only this time amplified owing to the attention that the cases received in the Chilean press, was more than sufficient for the state to conclude that it was not a real option to be satisfied with the rulings that had been handed down. It had to do more. In this sense, although the judges have no reason to go against what is provided for in the law or in the Constitution, these cases illustrate how reality far supersedes the law, making the division between the right to life and the right to health an obsolete classification. Instead of helping to understand things better, this division only complicates them, and, in doing so, makes the lives of the claimants worse than they already were. In some cases, this distinction only served to end the lives of the people that saw in the Judiciary a possibility of recovering their neglected and distressful existence.

The second lesson to be drawn from Chile's HIV/AIDS cases is related to the potential that civil society can have when it organizes and, more importantly, when it partners with institutional actors. To begin with, the non-governmental organization that filed the cases took a position "against" the state, eventually denouncing it before the Inter-American Commission on Human Rights for omitting to address the situation faced by its citizens who, in spite of being protected by constitutional rights and administrative regulations, were dying as a result of the state's negligence. The three years that followed the litigation saw dialogue, albeit with limited results, between the various powers of the state and civil society, from which arose a variety of political, legal and constitutional proposals. All this resulted in something unprecedented: the Chilean State, in conjunction with a civil society organization, petitioning the United Nations for funds to tackle the problem of the lack of access to medicines.

What is most notable is that the shift in strategy, from confrontation to direct collaboration, suggests, in principle, that it may be better to attempt to build bridges with the state. However, we do not deem it possible to draw this conclusion without looking more closely at the context of the case and its particular characteristics. In other words, it is difficult to say with any certainty what the result would have been had the Chilean State not consistently adopted the attitude of delivering unfavourable rulings, clearly not recognizing the violation of the claimant's fundamental rights. This would certainly have weakened the negotiating position of the plaintiffs.

Finally, it is interesting to recall that one of the main points raised when criticizing courts that "take rights seriously" is that they should not interfere in matters concerning the authorities that have representation and legitimacy which, it is argued, the courts lack.<sup>45</sup> Ultimately, the administration of medicine for people living with HIV/AIDS involves considerable amounts of financial resources that, we assume, should only be spent after intense and often lengthy political discussion. First, Parliament and the Administration are in the best technical position to plan these policies and, second, it is in them, and nowhere else, that the authority has been vested to discuss how and when the (always scarce) resources should be spent. Although the scope of this paper precludes a detailed consideration of these criticisms,<sup>46</sup> it seems necessary to emphasize how organized public interest litigation can impact the "political process" that years earlier either paid no attention to the claims or preferred to deem them simply "not justiciable".

This impact, both desirable and morally justified for those whose claims are ignored, such as in the case of the claims of people living with HIV/AIDS, requires more than just an organized civil society. It also needs a political system that is sensible and sensitive enough to realize that it has a problem to resolve, which, in this case, is the fact that members of its community are dying as a result of an inappropriate state action.<sup>47</sup>

Years of litigation in Chile's national courts prompted the Administration to petition the United Nations Global Fund and the Parliament to pass a special law for people living with HIV/AIDS, causing the state to rouse from its lethargy and, eventually, provide a response, although in many cases one that came too late for the people it was constitutionally bound to protect but whose claims it consistently blocked. The struggle to secure access to medication for people with a terminal illness, which began in the judicial sphere, would attempt several other approaches until finally emerging gracefully through the action, very often not deliberate, of institutional and social actors that, while playing to their own agendas, ended up pursuing a common objective that was impossible to ignore: providing social protection for people who are marginalized from the political and legal debate.

## NOTES

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1. Such as, for example, the International Covenant on Economic, Social and Cultural Rights, which stipulates in its article 2.1 that " Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."
2. National Association for the Advancement of Colored People.
3. This is the interpretation that Chilean constitutional doctrine makes of article 4, item 3, of the Constitution, which stipulates that: " the state recognizes and protects the intermediate groups through which society organizes and structures itself and guarantees them the adequate autonomy to fulfill their own specific purposes" .
4. CHILE. *Political Constitution of the Republic of Chile*, Santiago, 1980, Chapter III.
5. The writ of protection, or *recurso de protección*, is equivalent to *amparo* in Argentina, Mexico and Peru, to *tutela* in Colombia and to *mandato de segurança* in Brazil.
6. CHILE. *Political Constitution of the Republic of Chile*, Santiago, 1980, article 20 (establishing which rights are protected and which are not). Although social rights fall outside the scope of the writ of protection, this judicial action does permit certain aspects of these rights to be claimable in the judicial sphere, namely, the freedom to send one's children to the educational establishments of one's choice, the freedom to work in the area of one's choice and equal access to services for the promotion, protection and recovery of health of the individual: but, it is understood, only to the extent that these services are available.
7. There is another constitutional motion called " writ of inapplicability due to unconstitutionality" . Through this motion, the Constitutional Court may declare that a law is inapplicable for the specific case it is ruling on. Once the inapplicability has been declared, the same court, ex officio or at the request of any person, will declare the unconstitutionality of the law, excluding it from the legal system.
8. Some of these ideas were presented in LOVERA PARMO, D. *El Informe de Chile ante el Comité de Derechos Económicos, Sociales y Culturales: el Papel del Derecho*. Anuario de Derechos Humanos, Universidad de Chile, Santiago, no. 1, 2005, p. 168-69.
9. On the discussion about social rights in constitutions, see HARE, I. Social rights as fundamental rights. In: HEPPLER, B. (ed.). *Social and labour rights in a global context*. Cambridge: Cambridge University Press, 2002, p. 153; DAVIS, D. M. The case against the inclusion of socio-economic demands in a Bill of Rights except as directive principles. *South African Journal of Human Rights*, Johannesburg, v. 8, 1992, p. 475- 490.
10. CHILE. Actas de Sesiones Comisión Constituyente, reprinted in SOTO, E. *El Recurso de Protección*. Santiago: Editorial Jurídica de Chile, 1982, p. 508.
11. HOLMES, S. & SUNSTEIN, C. R. *The Cost of Rights: Why Liberty Depends on Taxes*. New York: W. W. Norton & Co., 255 p., 1999, p.15.

12. Pinochet had “recommended” to the commission drafting the constitution that they diminish the role of political parties. MOULIAN, T. *Chile: Anatomía de un Mito*. Santiago: Lom Ediciones, 386 p., 1997, p. 242.

13. Ibid, p. 243.

14. On this subject, see CONTESSE SINGH, J. *Dos Reflexiones sobre 17 Años de Democracia*. Buenos Aires: Nueva Doctrina Penal, n. 2, 2007, p. 615-631

15. See CONTESSE, J. & DELAMAZA, G. *Pobreza y Derechos Humanos: análisis de dos programas sociales*. Documento de Trabajo, Programa Ciudadanía y Gestión Pública, no. 15, Univ. de Los Lagos, Santiago, 2005.

16. UNITED NATIONS. *Economic and Social Council, Concluding Observations of the Committee on Economic, Social and Cultural Rights*. Chile, 26 Nov. 2004, E/C.12/1/Add.105, par. 12, 19, 25, 26 and 28.

17. CONTESSE, op. cit.

18. The cases claim the violation of their right to equality (there was no clear procedure on how people would have access to treatment. In some hospitals, the procedure was simply “first come first serve when a place is available”) and their right to life (the right to life implies both negative obligations – not to kill – and positive duties – to provide the health conditions that enable people to enjoy life).

19. The cases presented here were sponsored by the Public Interest and Human Rights Clinic of the Diego Portales University and represented by the organization Vivo Positivo. What the claimants were requesting was for the public health service to provide *tritherapy*. This is a combination of three drugs that blocks the progression of HIV, mainly through protease inhibition. As one report from Chile’s AIDS Advisory Committee points out, “the simultaneous and sustained action of tritherapy prevents the development of resistance, increases the organism’s defenses and stops the virus from reproducing until it become almost undetectable, which means that patients can stay healthy for longer and lead a practically normal life, without the risk of imminent death”. AIDS ADVISORY COMMITTEE. *Revista Chilena de Infectología*, 1998, p. 183, cited in ZÚÑIGA, A. El interés público del derecho a la vida. In: GONZÁLEZ, F. (ed.). *Litigio y Políticas Públicas en Derechos Humanos*. Santiago: Universidad Diego Portales, 2002.

20. In some cases, the health services had run out of the medication and for this reason the claimants alleged that the state had not acted diligently, properly organizing the delivery of the drugs.

21. According to article 19, no. 1, item 1 of the Political Constitution of the Republic of Chile: “The Constitution guarantees all people: 1. The right to life and to the physical and psychic well-being of the individual”.

22. The “writ of protection” was originally conceived as an informal action. Its purpose was to permit any person to have access to the courts to demand protection for their fundamental rights. The Supreme Court, however, without there having been a constitutional delegation in this respect, under pressure from the quantity of writs being filed, decided to establish an admissibility procedure; a prior declaration by means of which the appeals courts could, without making any kind of substantive ruling, determine whether the petition had any plausible justification. CHILE. *Auto Acordado sobre Tramitación del Recurso de Protección de Garantías Constitucionales*. Supreme Court, 24 June 1992.

23. ZÚÑIGA, op. cit., p. 108.

24. In cases of "extreme gravity and urgency", a person may appear before the Inter-American Commission on Human Rights and request that it adopt measures to protect their fundamental rights when the state of which they are a national does not offer such protection. As this case clearly shows, the risk was life threatening. ORGANIZATION OF AMERICAN STATES (OAE). *American Convention on Human Rights*. Pact of San José, Costa Rica, 7-22 Nov. 1969, article 48.2.

25. The term "jurisprudence" has been placed between inverted commas because there is no system of precedents (*stare decisis*) in Chile. The arguments contained in judicial decisions, either from the same court or from higher courts, have only force of rhetoric, which is why, to be used, they depend on the court's receptiveness to what was presented in these previous rulings. In cases specifically related to the right to life, as we have said, it has been possible to detect an underlying rationality in previous rulings handed down by Chilean courts that shared similar characteristics (these cases are addressed in the following footnote).

26. CHILE. *Court of Appeals of Santiago*, Docket No 167-84 (" [...] it is natural law that the right to life is what we have for nobody to commit an offense against ours, but under no circumstances does it give us dominion over our own lives, so as we could destroy it if we wanted to, but instead the faculty to demand from others its inviability."); CHILE. *Court of Appeals of Santiago*, 30 Oct. 1991, Docket No. 17.956 (" it is the imperative duty of the public authorities to safeguard the health and life of the people that form its society. This does not only imply that the state should abstain from disturbing the life of the members of its community; it also implies the duty to adopt positive protection measures. These principles have been embodied in legislation that is lower in hierarchy than constitutional legislation and, therefore, it is sufficient to cite the Criminal Code whose article 494 no. 14 sanctions as an offense the situation of not relieving or assisting a person who is hurt, wounded or in danger of dying, and in circumstances when this occurs in a deserted place."); CHILE. *Court of Appeals of Copiapó*, 24 Mar. 1992, Docket No. 3.569 and *Supreme Court*, 27 May 1992, Docket No. 18.640 (" [...] life is guaranteed by the Constitution to the extent that the individual could be deprived of it by agents unknown to them, by an offense by third parties, being clear that the defendant's attitude was a serious threat to the patient, concerning their right to life and physical and psychic well-being, given that persisting with their attitude could result in the progressive deterioration of the patient's health and a possible fatal outcome if the treatment advised by their doctor was not provided, unnecessarily putting the life of the patient at risk"); CHILE. *Court of Appeals of Santiago*, 20 Oct. 1999, Docket No. 3.618 (" [...] the parental denial to replace the blood that was lost puts the life [of the child] in grave danger and is illegal because it deprives a person of their physical well-being and their life, which is guaranteed in article 19, no. 1 of the Constitution", and going on to order " that the doctors in whose care in minor has been placed and who conducted the necessary surgical procedure to restore the child's health may perform the transfusion of blood and/or hemoderivatives that they deem necessary"). For an analysis of these rulings, see GÓMEZ, G. *Derechos Fundamentales y Recurso de Protección*. Santiago: Ediciones Universidad Diego Portales, 2005.

27. CHILE. Supreme Decree No. 362. *Regulation on sexually transmitted diseases*. Ministry of Health, 7 May 1984.

28. CHILE. *Court of Appeals of Santiago*, 6 Nov. 2000, Docket No. 1.705, 1.825 and 1.905.

29. Although the lawsuit had a potential to embrace more people, it did not represent an indeterminate number of people, but was instead filed on behalf of 24 fully individualized people. Again, the Court, to deny the case, responded to arguments not expressed by the parties.

30. The court added that “establishing an order of priority for human immunodeficiency [virus] (HIV) carriers to have access to pharmacological treatment that will enable them to live, based on technical reasons, but determined ultimately by economic reasons, is legally and morally unacceptable, since it necessarily establishes an arbitrary discrimination between people who find themselves in an identical situation”. CHILE, *Court of Appeals of Santiago*, 28 Aug. 2001, Docket No. 3.025.

31. CHILE. *Supreme Court*, 9 Oct. 2001, Docket No. 2.186.

32. The project presented by Chile was developed “by the *Comité País*, comprised of representatives of Vivo Positivo, Conasida, the Pan American Health Organization and the University of Chile, which oversees the Global Fund-Chile project”. Proyecto Fondo Global, componente for talecimiento Sociedad Civil. *Revista Vivopositivo*, Santiago, year 3, no. 9, 2003, p. 16.

33. CHILE. National AIDS Commission/Ministry of Health. *Estrategia de Atención Integral a Personas que Viven con VIH/SIDA*. Santiago, p.6. Available at: <<http://www.conasida.cl/docs/conasida/adinteg.pdf>>. Last access on 1 Dec. 2007.

34. Ibid.

35. Haciendo Historia. *Revista Vivopositivo*, Santiago, no. 13, 2005, p. 17. For an account of the legal cases undertaken by the NGO, see La Historia Juzgada (Movimiento de Personas Viviendo con VIH/SIDA). *Revista Vivopositivo*, Santiago, no. 13, 2005, p. 19.

36. El Proyecto Chileno. *Revista Vivopositivo*, Santiago, year 3, no. 8, 2003, p. 20.

37. “Haciendo Historia”, op. cit.

38. CHILE. *Law 19.779*, that sets rules in relation to the human immunodeficiency virus and establishes a tax credit for terminal illnesses, 14 Dec. 2001.

39. *Law 19.779*, op. cit., articles 1 & 2.

40. This kind of impact, we would like to stress, is not so uncommon. The same occurred with the case of the families of people who were detained or who disappeared under the Pinochet dictatorship. After years of campaigning and battling in court, the families managed to “impact” the politicians, who decided to revisit this issue that had for many years been relegated. As a result, for example, government lawmakers – with the backing of those from the opposition – declared that the sentences, one in particular pronounced in early 2007, constituted “a stimulus for the Executive and the Legislative to resolve the issue of amnesty in Chile once and for all [...] we cannot fall back on the criteria of the judges on the matter of amnesty and *prescripción* (statute of limitations) for crimes against humanity. Now it is up to us and to the government”. Fallo que rechazó la amnistía insta a parlamentarios a zanjar discusión. *La Nación*, Santiago, 15 Mar. 2007, p. 5.

41. Vivo Positivo also participated in the process to formulate and promulgate this law. La historia Juzgada, op. cit.

42. *Law 19.779*, op. cit., article 6, item 2. CHILE. *Law 18.469*, which regulates the exercise of



the constitutional right to the protection of health and creates a regime of healthcare services, 23 Nov. 1985.

43. Transitory articles 1 & 3 (the latter establishing the tax revenues to be used to pay these benefits).

44. Some idea of this on the topic of social rights was suggested by ABRAMOVICH, V. Courses of action in economic, social and cultural rights: instruments and allies. *Sur – International Journal on Human Rights*, São Paulo, year 2, no. 2, p. 180-216, 2005, p. 197 (“When, in public policy planning, the constitutional or legal precepts determine agendas on which the validity of economic, social and cultural rights depend, and the appropriate authorities have not adopted the necessary measures, it is the job of the Judiciary to chasten this omission and send the matter back to the authorities so that appropriate measures are taken. This aspect of judicial action can be regarded as participation in a “dialogue” between the various branches of the state to observe the legal and political program established by the Constitution or by human rights conventions”). For an analysis of this “dialogue” in Chile’s case, and on the subject of litigation on the so-called “morning-after pill”, see CONTESSE SINGH, J. ‘Las instituciones funcionan’: sobre la ausencia de diálogo constitucional en Chile. *Revista Derechos y Humanidades*, Santiago, v. 12, 2007 (in press).

45. DAVIS, D. M., *supra* footnote 9 and PEREIRA-MENAUT, A. Against Positive Rights. *Valparaíso University Law Review*, Valparaíso, no. 22, p. 359-383, 1987-1988, p. 368. José Cea explains, in the Chilean case, the reasons the CENC had to not configure a democracy “centered in the state”. CEA, J. L. *Derecho Constitucional Chileno*. Santiago: Ediciones Pontificia Universidad Católica de Chile, tomo 2, 2003, p. 55.

46. On this subject, see LOVERA PARMO, D. Implosive Courts, Law and Social Transformation: the Chilean Case. *Cambridge Student Law Review*. Cambridge, no. 3, 2007, p. 30-43.

47. As Jeremy Waldron suggests, in what he calls the core of the case against judicial review – and, therefore, assuming that institutions *ought* to function like this – a community should be able to display “democratic institutions”, basically a large deliberative body of representatives accustomed to dealing with difficult issues, and where the main constitutional and legal topics are decided through a process that connects “both formally (through public hearings and consultation procedures) and informally with wider debates in society”. Only a community displaying these types of institutions is in a position to start to remove the courts from the decision-making that *ought* to be resolved by the “political process”. WALDRON, J. The Core of the Case against Judicial Review. *Yale Law Journal*, New Haven, no. 115, Apr. 2006, p. 1346-1406, p. 1361.

## RESUMO

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Este trabalho apresenta algumas idéias relativas ao impacto que as decisões judiciais causam no sistema político. Diferentemente do que se costuma destacar do trabalho dos tribunais em matéria de direitos sociais, quando se põem em relevo os padrões e formas em que os tribunais os concebem para satisfazer as demandas de justiciabilidade desses direitos, os autores – que se centram no caso chileno – mostram como o litígio estratégico pode causar, apesar de resultados judiciais adversos, um impacto positivo na satisfação dos direitos sociais. Esse impacto depende mais da sensatez do sistema político para levar em conta a situação desesperada em que se encontram muitos de seus cidadãos, ou o temor da pressão política, do que das possibilidades que oferecem as grandes declarações provenientes dos tribunais.

### PALAVRAS-CHAVE

Tribunais – Direitos sociais – Direito à saúde – HIV/AIDS –  
Litígio de interesse público – Chile

## RESUMEN

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El presente trabajo avanza algunas ideas relativas al impacto que las decisiones judiciales tienen en el sistema político. A diferencia de lo que suele destacarse del trabajo de las cortes en materia de derechos sociales, donde se pone de relieve los estándares y formas en que las cortes se las ingenian para satisfacer las demandas de justiciabilidad de estos derechos, los autores— que se centran en el caso chileno—muestran cómo el litigio estratégico puede causar de todas formas, y a pesar de resultados judiciales adversos, un positivo impacto en la satisfacción de los derechos sociales. Ese impacto depende más de la sensatez del sistema político para caer en cuenta de la situación desesperada en que se encuentran muchos de sus ciudadanos o del temor a la presión política, antes que en las posibilidades que ofrecen las grandes declaraciones provenientes de las cortes.

### PALABRAS CLAVES

Cortes – Derechos sociales – Derecho a la salud – VIH/SIDA –  
Litigio de interés público – Chile



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#### ABSTRACT

This article addresses the system of intellectual property law in Brazil and its relation to the country's policy of universal access to AIDS medicines. It also presents the key working strategies of a Brazilian civil society group – GTPI/REBRIP – to tackle the main problems and challenges that are identified.

Original in Portuguese. Translated by Barney Whiteoak.

#### KEYWORDS

Intellectual property – Essential medicines – HIV/AIDS – Civil society – TRIPS



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# ACCESS TO MEDICINES AND INTELLECTUAL PROPERTY IN BRAZIL: REFLECTIONS AND STRATEGIES OF CIVIL SOCIETY

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## 1. The HIV/AIDS epidemic in Brazil

The policy of universal access to antiretroviral (ARV) treatment in Brazil has produced some important results. From 1997 to 2004, the country saw a 40% reduction in mortality and a 70% reduction in morbidity; from 1993 to 2003, the average age at death from AIDS increased by nearly five years, reflecting a significant increase in life expectancy.<sup>1</sup> Furthermore, there was a reduction of 80% in hospitalizations, generating a cost saving to the tune of US\$2.3 billion.<sup>2</sup>

These figures demonstrate that access to proper ARV treatment over the past 10 years has substantially transformed the lives of patients and the methods of controlling HIV infection, improving quality of life for people living with AIDS, increasing their life expectancy, reducing the transmissibility of the virus and causing a significant decline in mortality rates. The Brazilian program establishes the importance of assuring universal access to treatment for all who need it.

According to estimates from the World Health Organization (WHO), nearly 6.5 million people in low- and middle-income countries are in urgent need of ARV treatment. However, due primarily to patent protection and high prices charged by drug companies, only 1.3 million people actually receive treatment. Nearly 80% of the 3 million people who die each year from AIDS have no access to the available medicines.<sup>3</sup>

Brazil is one of the few countries in the world that has a policy of universal free access to AIDS treatment. The National STD/AIDS Program estimates

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that some 546,000 people are infected with the HIV virus in Brazil. Of these, 180,000 take ARV drugs to treat the disease.<sup>4</sup> The Ministry of Health's budget for purchasing antiretroviral drugs in 2007 was R\$984 million.<sup>5</sup> Authoritative estimates demonstrate that 80% of this money is used to acquire 11 patented medicines and 20% is spent on 7 drugs that are manufactured domestically by Brazilian companies.<sup>6</sup>

The fact that such a huge portion of the budget is being spent on patented medicines has put the sustainability and universality of this healthcare policy in jeopardy.<sup>7</sup>

Access to proper treatment is essential for thousands of people infected with AIDS in Brazil to live more dignified lives. The Brazilian government has both a legal and moral obligation to provide full treatment to all those who need it. The initial success of the STD/AIDS Program was largely attributed to the local manufacture of drugs that did not enjoy patent protection in Brazil. Today, a growing portion of ARV drugs are either patented or have patents pending in Brazil. These patents could make the country's policy of universal free access to AIDS treatment unsustainable.

## *2. The policy of universal free access to ARVs in Brazil*

The adoption of the universal treatment policy occurred within a favorable historical timeframe in virtue of Brazil's democratization process, which intensified after 1985. This movement resulted in an overhaul of the country's constitutional structure with the promulgation of the new Constitution of the Federative Republic of Brazil in 1988.<sup>8</sup>

The "Public Health Movement" dated back to the 1970s and was comprised of medical professionals and students. This movement played a key role in securing the constitutional recognition that "healthcare is the right of all citizens and the duty of the State" (Article 196, Brazilian Constitution).<sup>9</sup> This new constitutional provision spurred the development of a public health system. The challenge then emerged to establish a public healthcare system that obeyed the fundamental principles of universality, integrality and equality in access to healthcare services for all forms of treatment – without prejudice or privilege of any kind. In this environment, Brazil's current public health system came into being, now known as the Unified Health System (SUS) and regulated by Laws 8080/90 and 8142/90. Of particular importance is that SUS coverage allows for "full therapeutic treatment", including pharmaceuticals, which implies the obligation of the State to provide medicines for all who need them.

When it came to tackling the HIV/AIDS epidemic in Brazil, the first official program was set up in São Paulo in 1983 after consultations between

the organized gay community and State Health Department officials. As a nationwide response, the Brazilian national government created the National AIDS Program in 1986.<sup>10</sup>

In 1985 and 1986, the first two non-governmental organizations (NGOs) were created to combat the epidemic: the AIDS Prevention Support Group (GAPA) in São Paulo and the Brazilian Interdisciplinary AIDS Association (ABIA) in Rio de Janeiro. This resulted in a string of prevention campaigns and initiatives to combat discrimination and prejudice, and also to build solidarity amongst affected populations.<sup>11</sup> Meanwhile, the number of people seeking treatment was also on the rise.

The first AIDS medicine on the market was zidovudine (AZT), which the United States Food and Drug Administration (FDA) approved for use against HIV/AIDS in 1987. The Brazilian Ministry of Health made the drug available in 1991. But just as AZT use in Brazil was growing more widespread, transnational pharmaceutical companies were launching new medicines to control AIDS. Monotherapy with AZT alone was deemed ineffective, and so combined therapy (known colloquially as a “cocktail”) became the recommended treatment internationally.<sup>12</sup>

As AIDS treatment advanced, many doctors began to prescribe medications that were not yet officially recommended by the Brazilian healthcare system. The uneven pace between the emergence of new products, their incorporation by the public health system and the acute need for new treatment regimens for some individuals who were already resistant to existing drugs led many to take legal action in the courts to secure access to the medications they needed.

The first lawsuits claiming individual entitlement to the latest medicines began to be filed in 1996, with courts ruling in favor of the patients. The main arguments they employed drew on the principles embodied in the Federal Constitution, the Organic Health Law 8080/90 and the various State Constitutions, emphasizing the right to healthcare and the right to life.<sup>13</sup>

Also in 1996, amid widespread social mobilization and pressure from the National AIDS Coordination Authority, Law 9313 was approved. It is also known as the Sarney Law after the senator who proposed it. This law strengthens the existing legal framework guaranteeing free access to ARVs. The approval of this law decisively improved the National AIDS Program’s structure for purchasing medicines.

While it would be an exaggeration to claim that the lawsuits over entitlement to medicines were a decisive factor behind the approval of Law 9313/96, it is fair to say that the legal battles waged by AIDS NGOs helped to shape a favorable environment for the approval of the law. That is to say, the exercise of a right by the citizenry contributed to a more structured and better organized response from their government. An important driving force behind

the ongoing process of constructing and implementing a policy of free access to ARVs in Brazil was the legal mobilization of civil society.

Another factor of considerable importance in the implementation of Brazil's universal access policy was the ability to produce ARV medicines locally. Domestic public enterprises and private drug companies were able to produce these drugs at much lower costs than those charged by transnational companies. Production of these drugs began in the early 1990s, since the intellectual property law in force at the time (Law 5772/71) did not include recognition of patents for pharmaceutical products and processes.

However, in addition to the Sarney Law, 1996 also saw the approval of a new Intellectual Property Law (Law 9279/96), completely overhauling the existing legal regime that permitted medicines to be produced locally at affordable prices. The obligation to grant patents to the pharmaceutical sector was imposed by an international agreement, the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPs). This agreement radically changed this situation and seriously undermined the universal access policy in force in Brazil.

Brazil's new intellectual property law sought to adjust to the rules of international law established within the framework of the World Trade Organization (WTO), which had been created less than two years earlier in December 1994. Member States signed a series of multilateral agreements, among them the TRIPS Agreement, which established the obligation to recognize intellectual property for all fields of technology, including the pharmaceutical sector.

Accordingly, countries had to modify their domestic legislations to bring them in line with TRIPS, which for many meant they had to recognize patents in fields of technology that were poorly developed internally, while transnational companies based in developed countries enjoyed greater market protection. In the case of medicines, an essential component in guaranteeing the right to health, TRIPS established that they be treated like any other merchandise, dealing a blow and raising obstacles to the implementation of health policies, as we shall see later in this paper.

## **II. Access to medicines and the system of intellectual property in Brazil: principal characteristics and problems**

As we have seen, the creation of the WTO in 1994 and the signing of the TRIPS Agreement obliged all the organization's member states to alter their domestic legislations and recognize a minimum standard of protection for intellectual property in all fields of technology, including pharmaceuticals. However, the TRIPS Agreement granted delayed phase-in periods for developing and least-developed countries that did not previously recognize patents in some fields of



technology – such as pharmaceutical products and processes. Developing countries would have until 2005 to incorporate the minimum protection standards into their domestic legislations. Least-developed countries were granted a further extension until 2016, in accordance with the provisions of the Doha Declaration on the TRIPS Agreement and Public Health, signed in 2001.

The objective of the patent protection system introduced by the TRIPS Agreement was to contribute to the promotion of technological innovation and to the transfer and dissemination of technology in a manner conducive to social and economic social welfare (Article 7) and to permit members to adopt measures necessary to protect public health and to promote the public interest in sectors of vital importance to their economic and technological development (Article 8).

The TRIPS Agreement, then, permits member countries to include in their legislations some flexibilities and public health safeguards. The main flexibilities built into the TRIPS Agreement are: compulsory licensing (Article 31), parallel imports (Article 6), experimental use (Article 30), Bolar exceptions (Article 30) and health sector participation in analyzing pharmaceutical patent claims (implicit in Article 8), each of which will be analyzed later in this article.

However, Brazil did not make use of the 10-year transition period granted by the WTO to recognize patents in the field of medicines. This period, offered to developing countries that did not previously recognize pharmaceutical patents, could have allowed domestic pharmaceutical companies to garner the strength to compete with transnational drug companies specializing in Research and Development (R&D). Brazil used less than two years of the transition period, altering its law in 1996, although it only came into effect in May 1997.<sup>14</sup> Furthermore, Brazilian legislation failed to adopt some of the flexibilities permitted by TRIPS and, in some areas, went much further than what was required by the Agreement.

Since then, other challenges have emerged that threaten the country's policy of universal access to AIDS medicines. The greatest such challenge has been the increase in the cost of treatment with new patented drugs that are not manufactured domestically. Medical guidelines increasingly require these drugs to substitute or complement previous treatments. In addition to this, there has also been an increase in the number of patients receiving treatment.

### ***1. TRIPS flexibilities in Brazilian legislation and the use of compulsory licensing***

The Brazilian Intellectual Property Law (LPI) included some of the flexibilities of the TRIPS Agreement that are in the interest of public health (Table 1). These flexibilities are mechanisms intended to mitigate the adverse effects of the rights conferred on patent holders, with a view to restoring the balance between intellectual property rights and the right of access to knowledge.

**Table 1: Flexibilities built into the TRIPS Agreement in the interests of health<sup>15</sup>**

FLEXIBILITIES	DEFINITION
Compulsory Licensing	<p><b>Provided for in Article 31 of the TRIPS Agreement</b> When a government licenses companies or individuals that are not the patent owners to manufacture, use, sell or import a product under patent protection without the consent of the patent holder. The TRIPS Agreement allows compulsory licensing as part of the Agreement's overall attempt to strike a balance between promoting access to existing drugs and promoting research and development into new drugs. Nevertheless, the term "compulsory licensing" does not actually appear in the TRIPS Agreement. Instead, it uses the phrase "other uses without the authorization of the right holder".</p>
Parallel Imports	<p><b>Provided for in Article 6 of the TRIPS Agreement</b> When a product manufactured legally overseas is imported by another country without the consent of the owner of the intellectual property rights. The legal principle is "exhaustion", the idea that once a patent holder has sold a batch of its product on the market, its patent rights are exhausted as to those specific goods and it cannot prevent their resale to other countries. This trade is sometimes called the "grey market."The TRIPS Agreement confirms that none of its provisions, with the exception of those dealing with non-discrimination, can be used to address the issue of exhaustion of intellectual property rights. The decision is left to domestic law.</p>
Bolar Exception	<p><b>Provided for in Article 30 of the TRIPS Agreement</b> This allows manufacturers of generic drugs to use a patented invention to obtain marketing approval prior to patent expiration, without the permission of the patent owner.</p>
Experimental Use	<p><b>Provided for in Article 30 of the TRIPS Agreement</b> Allows researchers to use patented inventions in their research, in order to understand the invention more fully. Reverse engineering depends upon experimental use.</p>
Health sector participation in analyzing pharmaceutical patent claims <sup>16</sup>	<p><b>Implicit in Article 8 of the TRIPS Agreement</b> Refers to the participation of Ministry of Health officials in the processes to analyze pharmaceutical patent claims.</p>

In the case of health, these flexibilities have two different types of goals, one that is more immediate and another for the medium- and long-term. Compulsory licensing, parallel imports and the Bolar exception are flexibilities whose goal is immediate, that is, obtaining medicines at more reasonable prices either by making generic drugs or by importing products that are sold internationally at lower prices.

Compulsory licensing has been incorporated by Brazilian legislation and can be brought into play for a number of reasons. Article 68 of Brazil's intellectual property law stipulates that a patent shall be subject to compulsory licensing if its owner exercises the rights therein in an abusive manner or abuses economic power. The same article also establishes that a compulsory license may be granted when the patented product is not exploited inside Brazil or

when the sale of the protected product fails to satisfy the needs of the market (the “local working” requirement). Compulsory licenses may also be issued in cases of dependent patents, under the terms provided for in Article 70 of the LPI law. Finally, Article 71 states that a compulsory license may be issued in cases of national emergency or public interest declared by the Federal Executive Authorities.

The Bolar exception, meanwhile, was incorporated through an amendment to the LPI, with Law 10196/2001 adding item VII to Article 43. The use of this flexibility has a twofold advantage for the country: in addition to promoting quicker entry of generic drugs into the market, it also enables information on the invention to be used for research.

Parallel imports have also been incorporated into Brazilian law, albeit only in a limited way, since its use is restricted to situations in which a compulsory license has been issued in virtue of abuse of economic power (Art. 68, paras. 3 & 4, LPI). There is currently a bill of law (PL 139/99) working its way through the National Congress to incorporate this flexibility in full. This is an extremely important mechanism for drug access policies, since multinational pharmaceutical companies usually set different prices for the same drug in different countries. If domestic legislation permitted parallel imports, Brazil would be able to import medicines from wherever it is sold at the lowest price.<sup>17</sup>

Experimental use and health sector participation in analyzing pharmaceutical patent claims are flexibilities with medium- and long-term goals, since they are designed to encourage domestic technological development either by using the information disclosed about the patent or by blocking the concession of exclusive rights for claims that do not meet the legal patentability requirements.

Experimental use is permitted in Brazil by Article 43, II of the LPI law. It represents one of the ways of striking a balance between the interests of the patent holder and the national interests of a country, as it allows patented information to be used to promote domestic scientific and technological development. This scientific experimentation can be conducted by any research laboratory, either public or private.<sup>18</sup>

Health sector participation in analyzing pharmaceutical patent claims was incorporated by Law 10196/2001, which added Article 229c to Brazil’s intellectual property legislation. This mechanism determines that pharmaceutical patents may only be awarded with the prior consent of the Brazilian National Sanitary Supervision Agency (ANVISA), the government watchdog responsible for the safety and quality of medicines in Brazil.

Given the importance of the topic and the essential nature of pharmaceutical products, Brazilian lawmakers considered patent-granting important enough for each case to warrant the most rigorous and technical

examination possible by the State. Prior consent by ANVISA is not, therefore, simple interference in the patent-granting procedure. It is a measure to protect patients, by preventing drug patents from being awarded when they are undeserved.<sup>19</sup>

Prior consent is in full compliance with the TRIPS Agreement, which in Article 8 permits members, when formulating domestic laws, to adopt the measures necessary to protect public health and promote the public interest in sectors of vital importance to their socio-economic and technological development. The pharmaceutical sector should qualify under this provision.

Although these TRIPS flexibilities have all been incorporated into Brazilian legislation and are compatible with international rules governing the matter, it is another matter as to whether the country will actually exercise these powers to obtain medicines at more affordable prices. Actual exercise of TRIPS flexibilities has been limited, not only in Brazil but also in almost all developing nations. More recently, some developing countries have made use of them, particularly compulsory licensing, as a means of widening their access to treatment. Prominent examples include Thailand<sup>20,21</sup> and also Brazil in 2007.<sup>22</sup>

In fact, compulsory licensing has already been used on several occasions by a number of countries, including some in the developed world.<sup>23</sup> It is important to note that despite publicly taking a stance against the issue of compulsory licenses for the treatment of diseases such as AIDS, developed countries, such as the United States of America for example, have made use of these licenses when their own interests are at stake.

In Brazil, the threat of compulsory licenses has been the main strategy employed to pressure drug companies in price negotiations for ARV medications. The Oswaldo Cruz Foundation's official pharmaceutical laboratory, called the Drugs Technology Institute, or Farmanguinhos for short, was able to provide the Ministry of Health with a credible threat of local production should stalled negotiations necessitate a compulsory license. Drug companies have preferred to lower the price of their products rather than have them produced by Brazil's domestic industry.<sup>24</sup>

However, since the Brazilian government had never actually issued a compulsory license for the domestic production of medicines, this negotiating strategy grew increasingly less effective and the prices agreed in later rounds were unsatisfactory. In 2004 and 2005, for example, the price of nelfinavir and efavirenz remained unchanged, while the price of lopinavir/ritonavir was cut by just 1%. The discounts secured for the new drugs tenofovir and atazanavir were respectively 5.2% and 7.7%. Indeed, the average annual expenditure per patient in 2005 rose to R\$6,124, on a par with the figure in 1998.<sup>25</sup> This increase in costs has undermined the sustainability of the National STD/AIDS Program.

In 2005, during a round of negotiations with the drug company Abbott to lower the price of lopinavir/ritonavir (Kaletra®), used at the time by some 17,000 people, the Brazilian government set the stage for a compulsory license by declaring, in an official decree, that the medicine was of public interest and that the company would have to offer a lower price. After months of talks, the Ministry of Health struck a deal with Abbott, accepting a fixed price of US\$1,380 per patient per year until 2011, regardless of the increase in demand or variations in international prices. Furthermore, the deal also came with a guarantee that no compulsory licenses would be issued for this drug in Brazil. Many civil society groups considered it a bad deal and clearly TRIPS-plus, since it included clauses that are more restrictive than those adopted by TRIPS.<sup>26</sup>

The failure to issue a compulsory license in this case prompted member organizations of the Working Group on Intellectual Property of the Brazilian Network for the Integration of Peoples (GTPI/REBRIP) to file a “civil public action” (or a class action) to compel the federal government to issue a compulsory license for lopinavir/ritonavir Kaletra®. The strategy employed by GTPI/REBRIP will be examined in detail later in this article.

The use of compulsory licensing has been widely supported by Brazilian civil society in recent years as a means of countering the threat posed to the sustainability of the universal access policy by the high costs of medicines. Nevertheless, the mechanism was used for the first time in Brazil in 2007, for the drug efavirenz. The cost per patient per year in Brazil had stood at US\$580 since 2003, while on the international market prices could be found that were twice as low. After lengthy negotiations with Merck, the only offer the company made was to reduce prices by 2%, which was unacceptable. To put it in perspective, this price was twice as high as the one Merck offered Thailand after that country issued a compulsory license for the same medicine.

Brazil declared efavirenz to be of public interest in April and the compulsory license was issued in May 2007.<sup>27</sup> While preparations for local production are underway at two public laboratories (Farmanguinhos and Lafepe), the generic version of the drug has been imported from India since July of 2007 at a cost of R\$365 (or approx. US\$ 190) per patient per year,<sup>28</sup> a third of the price offered by Merck.

This compulsory license has illustrated the government’s commitment to the sustainability of its policy of free access to HIV/AIDS treatment in a context where patented drugs are sold at exorbitant prices that are unaffordable for the vast majority of developing countries. Furthermore, the possibility that the government could, as it has indicated, make further use of compulsory licensing for other medicines<sup>29</sup> is extremely positive, since it is a move to assure the sustainability of not only the National STD/AIDS Program, but also the entire public health system.

## ***2. Limitations of the Brazilian system of intellectual property protection***

Although Brazil has adopted nearly all the flexibilities of interest for public health provided for in TRIPS, there are some internal problems both in its patent legislation and in the way it is implemented that can be detrimental to public health. Of these, the following stand out:

- a) pipeline mechanism;
- b) guidelines for examining patents adopted by the National Industrial Property Institute (INPI)
- c) difficulty implementing the role of the Ministry of Health in the process of analyzing pharmaceutical patents (prior consent);
- d) TRIPS-plus provisions being voted in the National Congress.

### **a) Pipeline mechanism**

Until it was altered in 1996, intellectual property legislation in Brazil banned the concession of patents for some fields of technology, such as food and pharmaceutical products and processes. This ban was lifted by the country's new Industrial Property Law (Law 9279/96), which, in view of the conditions laid out in the TRIPS Agreement, recognizes patent protection for all areas of technology. The agreement requires all WTO members to provide patent protection for inventions in all technological sectors.

However, when it altered its legislation to comply with TRIPS, Brazil went beyond the obligations that had been taken on internationally and included in the new law a provision to validate patents that had never been filed in Brazil, but had been filed and granted overseas. This is known as the pipeline mechanism.

The pipeline mechanism is a temporary provision whereby applications were accepted for existing patents in fields of technology that Brazil did not previously recognize, enabling patent protection for, among other things, food and pharmaceutical products. Pipeline patent applications would only be subject to a formal analysis and would follow the terms of the patent granted overseas, not being submitted to the Brazilian patent office, the National Industrial Property Institute (INPI), for a technical analysis of the patentability requirements – novelty, inventiveness and industrial application. The pipeline mechanism was not required under the TRIPS Agreement.

Worse still, pipeline patents have granted protection to inventions that were already in the public domain. Brazil applies the principle of absolute novelty for patents, meaning that if the technology filed for patent protection is already part of the state of art,<sup>30</sup> anywhere or at any time, it cannot be protected.<sup>31</sup> The



inventions protected by the pipeline mechanism were already known in the state of art, since they had already been published abroad. And because the patent requests were filed in Brazil after the period of priority<sup>32</sup> had expired, the inventions were already in the public domain and no longer qualified for protection.

The concession of pipeline patents is, therefore, a frontal violation of the principle of non-withdrawal from the public domain, whereby knowledge, once in the public domain, can never again be removed. Passage into the public domain means the asset is shared by everyone and the people collectively acquire the right to keep it available and prevent its individual appropriation.<sup>33</sup>

Although they are often confused, Brazil's pipeline mechanism is neither the same nor the equivalent of the mailbox rule provided for in the TRIPS Agreement that exists in other countries, such as India. The mailbox rule establishes that from "day one" of TRIPS (1995), national patent offices can receive patent requests in areas not previously recognized and hold them in a "mailbox" for review after the domestic patent law comes into effect. In the case of pipeline patents, retroactive protection was possible for items filed or already patented in other countries, even after the period of priority. Therefore, it permitted the concession of patents for knowledge that was already patented abroad even before "day one" of TRIPS. Furthermore, pipeline patents are not subject to any technical analysis by the Brazilian patent office.

Pipeline patents have had a significant impact on sensitive areas of social interest and also on the country's technological and economic development. According to data released by the INPI, within the legal timeframe of one year from the publication of Law 9.279/96, no less than 1,182 **pipeline requests were filed,**<sup>34</sup> **of which more than half have already been granted and the rest is under review.**<sup>35</sup>

Efavirenz, a drug for which Brazil recently issued a compulsory license, is protected by a patent obtained through the pipeline mechanism. That is to say, when the drug's patent claim was filed in Brazil, it did not fulfill the patentability requirement of "novelty" (since the information on the invention had been published abroad five years previously).<sup>36</sup> In other words, this active ingredient could have been produced generically in Brazil, like it was in India.

Other medicines that are crucial to tackle the HIV/AIDS epidemic, such as lopinavir/ritonavir, abacavir, nelfinavir and amprenavir, also acquired their protection through the pipeline mechanism, as did the cancer drug imatinib (known commercially as Glivec or Gleevec).

Given the huge impact of pipeline patents in Brazil, the GTPI decided to legally dispute this mechanism for granting patents. This case will be examined later in this article in the section that addresses the main working strategies of the GTPI.



## **b) Guidelines for examining patents adopted by the INPI**

The job of the INPI, an independent federal agency linked to the Ministry of Development, Industry and Foreign Trade, is to enforce the rules governing intellectual property in Brazil, taking into consideration its social, economic, legal and technical function, in accordance with intellectual property legislation and the Brazilian Constitution. One of its responsibilities, therefore, is to analyze patent applications in various areas of knowledge, including medicines.

To analyze requests for drug patents, the INPI drafted the “guidelines for examining patent applications in the areas of biotechnology and pharmacy filed after 31/12/1994”.<sup>37</sup> This document is designed to help examiners interpret the Brazilian patent law and so determine what does and what does not qualify for patent protection. However, these guidelines are much broader than the rules contained in Brazil’s intellectual property legislation and they are also inconsistent with the objectives of the Brazilian Constitution for protecting intellectual property (art. 5, item XXIX of the Constitution), causing countless patents to be granted in breach of the prevailing rules in the country.

The following examples are worth mentioning to illustrate the problem: the LPI does not permit protection for mere discoveries (article 10) or for applications that do not fulfill the novelty requirement (article 11). However, the INPI guidelines do allow for the possibility of protecting new uses for known products, facilitating the practice known as evergreening to the detriment of protection for real pharmaceutical innovations. Another clear example of the guidelines conflicting with the law is their permission to patent DNA sequences, under the justification that they are merely chemical compounds and not a part of living beings.

## **c) Prior consent from ANVISA**

According to Brazilian legislation on intellectual property, applications for pharmaceutical patents must obtain the prior consent of ANVISA. Prior approval is required in virtue of the importance of public health,

The main problem implementing this flexibility lies in the fact that the INPI does not publish the decisions in which ANVISA does not grant prior consent, which prevents the failed patent application process from being completed. This means that the patent claim remains pending and the would-be owner enjoys a *de facto* monopoly.

## **d) TRIPS-plus legislation**

In addition the problems highlighted above, there is another complication that needs to be addressed on the subject of intellectual property in Brazil. A number

of bills are currently making their way through the National Congress that, if approved, would represent the inclusion of TRIPS-plus measures in Brazilian legislation.

TRIPS-plus measures are forms of protection for intellectual property that are more restrictive than those mandated by TRIPS.<sup>38</sup> They generally benefit the interests of patent holders to the detriment of the public interest and are, as a rule, included in bilateral trade agreements negotiated between developed and developing countries. Even though Brazil is not currently negotiating any bilateral deals involving intellectual property protection, bills introducing these measures are still being voted in the Brazilian Legislature, and we need to be on the alert so they are not approved. This is very plain evidence of how TRIPS-plus measures can be implemented by developing countries separately from bilateral or regional free trade agreements.

An example of this is Bill of Law 29/2006, which aims to include a TRIPS-plus measure by establishing a linkage between drug registration and patent protection. If approved, it will, in practice, annul the Bolar exception flexibility provided for in Brazilian law. This case will be examined in more detail further ahead, when we address the working strategies of the GTPI.

### **III. The GTPI/REBRIP and its role: main working strategies to tackle the existing problems and challenges**

Given the importance of continuing public policies such as universal access to antiretroviral treatment and the challenges and obstacles imposed by the new rules on intellectual property protection, Brazilian civil society groups, with the support of international organizations, decided to join forces to address this pressing and complex issue. In 2001, they formed the Working Group on Intellectual Property of the Brazilian Network for the Integration of Peoples (GTPI/REBRIP).

REBRIP is a network of NGOs, social movements, unions and independent professional associations that are engaged in the processes of regional integration and trade, and are committed to the construction of a democratic society grounded in economic, social, cultural, ethical and environmentally sustainable development. These organizations pursue alternative forms of integration that contrast with the logic of trade and financial liberalization prevailing in the economic agreements currently being negotiated.<sup>39</sup>

Due to the ongoing debate on intellectual property on the international stage and the impact caused by international trade agreements on a local level, it grew necessary to set up a group specifically to address topics concerning intellectual property and its repercussions on Brazilian society's access to knowledge. This was the context behind the creation of the GTPI, which has

been coordinated by the Brazilian Interdisciplinary AIDS Association (ABIA) since its creation in 2001 (having been reappointed coordinator in the last two meetings of REBRIP). The GTPI is comprised of several Brazilian civil society groups and two international organizations, in addition a number of activists and researchers.<sup>40</sup>

The GTPI works primarily on the following fronts in an attempt to minimize the negative impact of the patent system in Brazil:

- 1) Identifying alternatives that can widen access to medicines;
- 2) Strengthening cooperation among countries from the Global South to promote information sharing and possible joint efforts by civil society;
- 3) Shaping and mobilizing public opinion on the social impact of intellectual property trade agreements;
- 4) Monitoring international forums that discuss the topic of intellectual property and access to medicines.

Hemispheric cooperation is key to tackling the issue of intellectual property and access to medicines, since the changes to the legal framework in the field of intellectual property have had a far more profound impact on countries from the southern hemisphere. In fact, there always was and still is an imbalance between developed and developing nations in terms of technological development, in terms of their capacity to handle the intricate technical workings of the latest pharmaceutical patents in their national patent offices and, primarily, in terms of the purchasing power of their populations to afford patented medicines. This is what makes cooperation among countries from the southern hemisphere, both by organized civil society and by governments, so vital to the success of the efforts of Brazilian civil society.

This cooperation is aimed at establishing new partnerships for the purpose of broadening dialogue and sharing information, methodologies and working technologies, in addition to promoting the active engagement of domestic and international civil society in working out agreements between the governments of their countries. The sharing of information will help each country achieve tangible results, while respecting the particularities of each nation. A good example of this liaison between organizations from the Global South is their input for examining patents, which will be addressed later in this paper. Since the same patent applications are filed in different countries, the same arguments questioning whether to grant a specific patent can also be used by organizations from other countries.

Another important working strategy of the GTPI is the education of individuals, social movements and organizations that work in areas affected by the system of intellectual property. The subject of intellectual property, most

notably the issue of pharmaceutical patents, is normally viewed as a topic for specialists that is little understood by these organized groups. The GTPI has developed specific methodologies to address the topic, publishing information booklets (on domestic and international legislation and on key issues such as compulsory licensing in Brazil<sup>41</sup>) and organizing thematic workshops and activities for all audiences to demonstrate how intellectual property affects their lives and their work.

The GTPI has also sought exposure in the domestic and international media as a way of shaping public opinion on the topic. We believe that the concepts and theories about the link between patents and innovation are up for dispute and that the engagement and visibility of civil society is extremely important.

Furthermore, the GTPI also considers it important to participate in initiatives that, besides discussing the impacts caused by the current system of protection for intellectual property, aim to actually come up with new models and alternatives. The debate on other ways of stimulating invention has been intensifying between leading international players and we believe that more emphasis should be given to the collaboration of southern hemisphere countries, since these nations are the main victims of the current system. This is why we consider it so important to monitor the discussions and negotiations playing out in the Intergovernmental Working Group on Public Health, Innovation and Intellectual Property (IGWG) of the World Health Organization.

On a national level, the GTPI's advocacy agenda has taken shape and its inclusion on the list of influential players on the subject in Brazil is justified by the concrete actions that it has taken in recent years. We would like to highlight four such actions taken by the GTPI that are designed to assure and widen access to medicines in Brazil, primarily for the treatment of HIV/AIDS. These are: (a) a civil public action to issue a compulsory license, (b) input for patent examination in the INPI and a patent annulment case, (c) legal opinions on bills and (d) petitioning the Brazilian Attorney General on the constitutionality of pipeline patents. We shall now briefly address each of these actions and their main outcomes:

#### **a) Civil public action to issue a compulsory license**

The cost of purchasing the drug Kaletra® (a combination of the active ingredients lopinavir and ritonavir), produced by Abbott Laboratories, represented approximately 30% of the National STD/AIDS Program's expenditure on medicines in 2005. This exorbitant amount led the Brazilian government to enter into negotiations with Abbott to reduce the price of the drug.

After failed attempts at negotiation, Brazil's then Minister of Health in June 2005 declared Kaletra® to be of public interest. This declaration was the first step towards issuing a compulsory license for reasons of public interest, since it would enable domestic production of the drug at a lower cost and a transfer of technology. At the time, Brazil was paying US\$1.17 per tablet of Kaletra®. But estimates were putting the production price by local firm Farmanguinhos, in the event of the compulsory license being issued, at US\$0.41.<sup>42</sup>

However, at the same time that it declared Kaletra® of public interest, the Brazilian government also gave Abbott a timeframe in which to offer a lower price for the drug and so avert the compulsory license from being issued. And so, in October 2005, a contract was signed between the Brazilian government and Abbott to supply the drug.<sup>43</sup> The deal, which did indeed lower the price, also came with clauses that conflicted with the national public interest, such as an obligation not to issue a compulsory license, no technology transfer or foreign direct investment to manufacture the drug locally, and fixing the stipulated price until the end of 2011, when the drug patent would be close to expiring.

Once the agreement was signed, civil society organizations from the GTPI, in conjunction with the Public Prosecution Service, filed a civil public action – the first of its kind in Brazil – against the government and Abbott demanding that a compulsory license be issued for lopinavir/ritonavir. A favorable judicial decision would enable local production of a generic version of the drug.<sup>44</sup>

The case received a negative preliminary decision, on the grounds that issuing a compulsory license would trigger retaliation by the developed world and possible shortages of the drug, while the very capacity of domestic industry to produce the medicine in Brazil was also called into question. Preliminary decisions, however, are decisions based on a preliminary analysis of the strength of the case and by no means represent the final judicial decision.

In order to counter the arguments used in the preliminary decision, the GTPI, with the support of the international organization Doctors Without Borders/Médecins Sans Frontières (MSF), enlisted domestic and international specialists in 2006 to assess the technical capacity of four Brazilian pharmaceutical firms (two public and two private) to produce antiretroviral medicines. The specialists determined that the Brazilian firms do indeed have the capacity to produce both first-line and second-line antiretroviral drugs.<sup>45</sup> These results were corroborated by two additional studies conducted simultaneously in Brazil by the Clinton Foundation and the United Nations Development Program (UNDP). Local firms could, therefore, fully supply domestic demand for the drug and until production got up to speed, the medicine could be imported from other countries where the patent holder sells it.

These arguments were employed in the civil public action to influence the

ruling of the judge, since the unfavorable preliminary decision is, as the expression already suggests, only preliminary and does not shut the door on the case. The civil public action is still in the discovery stage and is awaiting judgment.

### **b) Inputs for patent examination in the INPI and patent annulment case**

In 2006, GTPI member organizations also attempted to exploit administrative channels to prevent the Brazilian patent office (INPI) from granting undue patents for essential medicines. The group submitted inputs for the examination of two patents: the first referred to an application by Abbott for a second patent for the lopinavir-ritonavir combination (Kaletra®) and the second was for a patent application made by Gilead for its tenofovir disoproxil fumarate medication (Viread®).

Inputs for patent examination are a provision contained in Brazilian intellectual property law that permits any interested parties to submit documents and information to assist in the examination of patent applications being analyzed by the INPI (article 31, LPI).

The purpose of the two submissions to the INPI was to present the technical grounds for not granting patents for these two antiretroviral drugs. The inputs called into question the patent claims of each medicine using different arguments. In the case of tenofovir disoproxil fumarate, each of the substances described were known in the state of art before the application's filing date. The active ingredient that combats AIDS is tenofovir, which has been known since 1989, and the other compounds developed have no new technical effect for a specialist in the subject, since they are standard practices used in organic synthesis. This application for an invention patent, therefore, does not present any inventiveness.<sup>46</sup>

In the case of lopinavir/ritonavir, the company filed a second patent application ("divisional patent application") for the product. To complicate matters, the first patent was conceded through the pipeline mechanism – a provision of Brazilian law considered by many jurists to be unconstitutional, permitting patents to be granted without an evaluation of the patentability requirements prescribed by law. The problem is that there are no legal provisions for divisional applications when the parent application is a pipeline patent. These types of patent applications, therefore, cannot be approved by the INPI because they do not meet the patentability requirements imposed by Brazilian law.

Still on the subject of the GTPI's involvement in the granting of patents, in mid-2007 its members filed a patent annulment case that questioned the validity of a patent awarded for a diagnostic kit. Not only are patents not permitted for diagnostic kits in Brazil, in accordance with the permission



contained in TRIPS, but the patent in question was also granted through the pipeline mechanism.

This case is still in its early stages in the courts and doubts have been raised about the legitimacy of civil society organizations filing this kind of legal action. But if the legitimacy is accepted, the GTPI has plans to file other such cases questioning the legality of patents granted unduly for essential supplies in Brazil.

### **c) Legal opinions on bills**

Another form of involvement by the GTPI consists of accompanying congressional bills on the subject of intellectual property. The purpose of this is to prevent the approval of laws that conflict with the public interest and escape huge subsequent expenditures. It is, therefore, a preventative action strategy.

On this topic, we highlight two cases in which the GTPI has intervened:

- inclusion of antiretroviral drugs on the list of unpatentable subject matter;
- linkage between drug registration and expiry of intellectual property rights.

The first case refers to Bill of Law 22/2003, which plans to include ARV medicines on the list of subject matter not entitled to patent protection in Brazil. In 2005, GTPI member organizations sent representatives involved in the analysis of the bill a legal opinion advocating its approval. The bill is in full compliance with the underlying principles of the Brazilian Constitution, which gives the right to health and the right to life precedence over the commercial rights and economic interests of pharmaceutical companies. Furthermore, it also conforms to international regulations on the subject, which, while recognizing industrial property rights, also admits that developing countries like Brazil can and should adopt measures to protect public health and assure access to medicine for everyone in extreme cases of epidemics, such as AIDS. The analysis of the bill was favorable, but it still needs to be voted in the House of Representatives.

The second legal opinion<sup>47</sup> opposes the approval of Bill of Law 29/2006, which intends to link the registration of a drug to the expiry of its patent. The opinion was submitted to senators and representatives involved with health concerns. In practice, linkage between patents and drug registration raises an additional barrier to the entrance of generic drug on the market, since it links the start of the registration process for generic versions of a drug to the expiry of the patent. In other words, it delays the onset of competition and amounts to a *de facto* extension of patent terms, which is completely at odds with public



health interests. If this bill is approved, it will effectively remove the Bolar exception from Brazilian law. An opinion has already been filed to shelve the bill, but this needs to be analyzed by the Senate standing committees.

#### **d) Petitioning the Brazilian Attorney General**

Towards the end of 2007, the GTPI presented the Brazilian Attorney General with a petition<sup>48</sup> demonstrating the unconstitutionality of the two articles of Brazil's intellectual property legislation that created the pipeline mechanism for granting patents. The petition calls on the Attorney General to bring a Direct Case of Unconstitutionality (ADIN) against the pipeline mechanism before the Supreme Court, since civil society organizations do not have the standing to file this kind of legal case.<sup>49</sup>

The ADIN process permits a thorough examination, on a federal level, of the constitutionality of Brazilian laws or normative acts. In other words, it can be used to call into question whether any given piece of federal or state legislation is consistent with the country's Constitution. The issue is judged directly by the Supreme Federal Court – the highest court of law in Brazil – and a declaration of unconstitutionality results in the law in question being removed from the legal system and prevented from having any legal effect.

Pipeline patents were granted during the *vacatio legis* period of Brazil's current intellectual property law, which was altered in 1996. They are in breach of the Constitution because they have conferred patent protection on knowledge that was already in the public domain, violating the vested right of the people. They are also in breach of the purposes established by the Constitution for protecting intellectual property, since they do not serve the economic or technological interests of the country. There is, therefore, nothing to justify these patents. A report commissioned by the authors of the petition estimates that these pipeline patents have cost Brazil in the billions of dollars.

This type of mechanism to revalidate patents was adopted in very few nations other than Brazil and some of these countries, for example Ecuador, have already declared it to be inconsistent with the intellectual property protection system adopted internationally.<sup>50</sup>

The purpose of the petition is to open an ADIN case, in other words to demonstrate that pipeline patents are unconstitutional. Nevertheless, it was also considered important for the case to demonstrate that pipeline patents are not part of the international intellectual property protection system and, in some respects, are inconsistent with it. This strategy was designed to prevent the rules of the international intellectual property protection system from being used adversely when questioning these patents before the Brazilian Judiciary,

which, as we have already seen, occurred with the preliminary decision on the civil public action to force a compulsory license for Kaletra.

Therefore, the petition demonstrated that the pipeline mechanism was not adopted as a requirement of any international trade deal sealed by Brazil and also that it is inconsistent with the TRIPS Agreement and both the Paris Convention for the Protection of Industrial Property (PCPIP) and the Patent Cooperation Treaty (PCT) of the World Intellectual Property Organization (WIPO).

A number of letters have been received from international civil society organizations that specialize in the field expressing their support for the GTPI's initiative and corroborating the arguments on the inconsistency of pipeline patents with the international system.<sup>51</sup> These letters of support also highlight the importance of the initiative on an international level, primarily because of the leadership role Brazil plays on the international stage on issues related to intellectual property and public health.

Indeed, Brazil has taken the lead in recent years to ensure that the intellectual property protection rules adopted on an international level do not pose a risk to the public health systems of developing nations. However, on a domestic level, the country has adopted an approach that consistently gives preference to intellectual property rights before public health, in stark contrast to the attitude it displays in international forums. But calling into question the legality of pipeline patents, which are so blatantly at odds with public health interests, is another step towards making the discourse already adopted on the international stage start to prevail inside Brazil.

Finally, we should emphasize that pipeline patents are far from being a problem of the past. As we have already mentioned, hundreds of patent application filings are still pending a decision by the INPI. And countless other cases, for which patents have already been granted and are nearing their expiry date, are working their way through the Brazilian Judiciary with a view to having their protection terms extended.<sup>52</sup>

The petition was registered in late December 2007 and the GTPI is awaiting an audience with the Brazilian Attorney General to address the case.

#### **IV. Final remarks: a brief evaluation of the strategies adopted, the results obtained and the main challenges ahead**

Civil society faces a host of challenges in its attempt to keep policies for universal access to medicines out of reach of intellectual property rules. These challenges include finding alternatives inside the current patent system, by forcing the use of the TRIPS flexibilities, and also monitoring international discussion on the subject, especially on “innovation and access”, which implies the discussion of new models of protecting industrial property.

The complexity of the topic and the amount of time needed to accompany the discussions are major hurdles in the way of civil society's involvement in matters of intellectual property protection. Consequently, the production of informative material in accessible language and demonstrations of the impact this system has on people's daily lives are crucial for society to fully grasp the issue. Training courses for activists and civil society organizations with a direct interest in the issue have also proven to be invaluable.

The strategies proposed by Brazilian civil society reveal the importance of the challenges both today and also for the future of developing countries, and they can be grouped into three approaches: (a) a product-by-product perspective; (b) the domestic patent system; and (c) the need to reform the international patent system. The first involves the constant monitoring of newly approved drugs and the barriers to their access. We feel it is very important to strengthen cooperation between developing countries, since they will probably all confront the same problems with the same medicines. The second is related to the overall domestic patent system and its impact on the country's health policies. This broader perspective poses structural challenges for the ongoing implementation of health policies. Finally, the most challenging of these approaches is to consider alternative means of stimulating new drug development that do not necessarily involve intellectual appropriation, notably the system of patents, which puts prices out of reach of the most vulnerable populations.

We believe, therefore, in the importance of strengthening civil society and reinforcing its networks to improve information sharing, support for domestic problems and the search for joint alternatives to counter the negative impacts that patents have on access to health.

Finally, we believe that the courts can and should be used as a potential channel for defending collective rights, principally because: (a) it is a means of finding alternatives inside the current patent system in force in Brazil; (b) it is a means of raising public awareness about the negative impacts that intellectual property rights have on access to health; (c) it is a means of promoting participation and involving the Judiciary in the adoption of measures to pressure the Executive to use TRIPS flexibilities for the protection of public health.

Concerning the use of existing flexibilities, particularly compulsory licensing, the recent case of efavirenz provided a window into how society at large views the issue. While there was heavy pressure in the mainstream media against the compulsory license issued by the Brazilian government, many groups supported the public interest and the importance of the measure. These groups have been pressuring the government to use the flexibilities for the protection of public health as part of an HIV/AIDS and healthcare agenda. Furthermore, there was significant international support for the adoption of the compulsory license.<sup>53</sup>

This case also demonstrated that the Brazilian government is committed to its policy of universal access to treatment and healthcare. Nevertheless, there were some key conditions in place that enabled the government to take this step: the important precedent opened by Thailand when it issued a compulsory license and the ability of the international pharmaceutical market to supply the licensed drug. This supply reduced the possibility of there being a shortage of the drug.

However, the battle is by no means over and there are many other barriers to be crossed. It is well known that the price of new antiretrovirals is rising and that a larger slice of the Ministry of Health's budget goes on buying these drugs. A growing number of patients are taking second-line AIDS drugs that are patented in Brazil. Furthermore, the very latest medicines are also patented in other developing countries that produce generic drugs, such as India. In other words, should a compulsory license be issued for these new drugs, the market will not be able to supply them and the only alternative will be domestic production.

There are numerous developments and numerous contexts to monitor if we are to properly accompany what happens not only on a national level, but also on the international stage, since the decisions taken in this arena have a direct impact on the domestic system. Furthermore, it is also important to monitor what goes on in the domestic systems of other developing countries, since it is highly likely that the same will also happen in your country.

This is why it is vital for groups working in the field to share information and experiences, so they can develop joint strategies to tackle the problems they have in common and adapt successful experiences to their own specific contexts. This is the primary objective of this article.

## NOTES

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48. Petition available in full on the website of Conectas Human Rights: <[http://www.conectas.org/noticia.php?not\\_id=192](http://www.conectas.org/noticia.php?not_id=192)>. Last access on 22 January 2008.
49. Parties that may legitimately file a Direct Action of Unconstitutionality (ADIN) are listed in Article 103 of the Brazilian Constitution. They are: the President of the Republic; the Directing Board of the Federal Senate; the Directing Board of the Lower House; the Directing Board of a State Legislative Assembly or of the Legislative Chamber of the Federal District; a State Governor or the Governor of the Federal District; the Brazilian Attorney General; the Federal Council of the Brazilian Bar Association; a political party represented in the National Congress; a confederation of labor unions or a professional association on a nationwide scale.
50. Decision available at <<http://intranet.comunidadandina.org/Documentos/Procesos/1-AI-96.doc>>. Last access on 15 December 2007.
51. At the time this article was completed in January 2008, the groups and researchers who had sent letters of support were: Fundación IFARMA - Colombia; Oxfam International; Thai Network of People Living with HIV/AIDS; (TNP+); AIDS ACCESS Foundation; Thai Foundation for Consumers; Thai Rural Doctors Society; Thai Chronic Renal Failure Network; Thai Alternative Agriculture Network; Thai Parents Network; Thai Rural Pharmacist Society; Thai NGOs Coalition on AIDS; FTA Watch; Drug Study Group; Prof. Kevin Outterson (Boston University School of Law); Prof. Brook K. Baker (Northeastern University School of Law); Knowledge Ecology International (KEI); Third World Network; Lawyers Collective HIV/AIDS Unit; Indian Network for People Living with HIV/AIDS; Delhi Network of Positive People; Alternative Law Forum; Cancer Patients Aid Association and ActionAID India.
52. According to consultations made with the Regional Federal Tribunals in November 2007.
53. Petition in support of the Compulsory License for the Drug Efavirenz in Brazil. Available at <[http://www.agenciaaids.com.br/arquivos/lista\\_abia.doc](http://www.agenciaaids.com.br/arquivos/lista_abia.doc)>. Last access on 21 January 2008.

## RESUMO

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O presente artigo aborda o sistema de proteção à propriedade industrial vigente no Brasil e sua relação com a política de acesso universal a medicamentos para tratamento da AIDS. Ainda, apresenta as principais estratégias de atuação de um grupo da sociedade civil brasileira - GTPI/REBRIP - em relação aos principais problemas e desafios identificados.

### PALAVRAS-CHAVE

Propriedade industrial – Medicamentos essenciais – HIV/AIDS – Sociedade civil – TRIPs

## RESUMEN

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El presente artículo aborda el sistema de protección a la propiedad industrial vigente en Brasil y su relación con la política de acceso universal a medicamentos para el tratamiento del SIDA. También presenta las principales estrategias de actuación de un grupo de la sociedad civil brasileña –GTPI/REBRIP– en relación con los principales problemas y desafíos identificados.

### PALABRAS CLAVES

Propiedad industrial – Medicamentos esenciales – VIH/SIDA – Sociedad civil – TRIPS

## ANNEX

### HUMAN RIGHTS CENTERS

HUMAN RIGHTS AND PEACE CENTRE (HURIPEC)  
FACULTY OF LAW, MAKERERE UNIVERSITY, UGANDA

**Contact information:**

Site: [www.huripec.ac.ug](http://www.huripec.ac.ug)

Email: [info@huripec.ac.ug](mailto:info@huripec.ac.ug) or [webmaster@huripec.ac.ug](mailto:webmaster@huripec.ac.ug)

Address: HURIPEC, Faculty of Law, Makerere University, P.O. Box 7062, Kampala, Uganda

Tel: +256-414-532-954, Fax: +256-414-543-110

**Teaching:** Several undergraduate and masters courses; Diploma in Forced Migration & Refugee Studies; Annual school on International Criminal Law (2008+); student academy on Economic, Social and Cultural Rights

**Research:** Decentralization, Governance and Economic, Social and Cultural Rights

**Publications:** East African Journal of Peace & Human Rights

The Human Rights and Peace Centre at the Faculty of Law, Makerere University is devoted to both teaching and research in human rights, democratic governance and the protection of vulnerable groups, in Uganda specifically, and the wider African continent generally. HURIPEC has pioneered the interdisciplinary teaching of human rights and ethics, leading to the adoption of new curricula in several faculties at Makerere where such subjects were not traditionally taught. It has also implemented projects on child survival, public legal education, minority rights and the specific situation of Northern Uganda.

Since 2006, HURIPEC has organized a number of research projects, specifically on: Decentralization and Human Rights; Rights and Democratic Governance, and on Economic, Social and Cultural Rights, leading to the publication of several working papers that are available at [www.huripec.ac.ug](http://www.huripec.ac.ug). Recent books include: *University Human Rights Teachers' Guide*, 2005 (by E. Wamala & G.W. Kasozi) and *Africa's New Governance Models: Debating Form and Substance*, 2007 (by J. Oloka-Onyango & Nansozi Muwanga).

THE GRADUATE PROGRAM IN HUMAN RIGHTS AT THE FEDERAL  
UNIVERSITY OF PARÁ – BRAZIL

Contact information:

Site: <http://www.ufpa.br/ppgd>

Email: [pgdireito@ufpa.br](mailto:pgdireito@ufpa.br)

Address: Rua Augusto Corrêa, n.1 – Campus Universitário – Profissional,  
CEP: 66075-900 Belém – PA, Brasil

Tel.: (91) 3201-7723

Teaching: Graduate Degrees: Master's and Doctorate in Human Rights,  
Coordinator: Prof. Dr. Paulo Sérgio Weyl Albuquerque Costa  
Non-Degree Graduate Work: Course of studies for Specialization  
in Election Law and Specialization in Criminology

Research: Constitutionalism, Democracy and Human Rights; Human Rights  
and Social Inclusion; Human Rights and the Environment

Publications: Books published/organized and articles: COSTA, Paulo Sérgio  
Weyla. *Direitos Humanos em Concreto*, Curitiba, Juruá, 2008;  
BELTRÃO, J. F. et al. (Org.), *Antropologia e Patrimônio Cultural  
- Diálogos e Desafios Contemporâneos*. Florianópolis - SC: Nova  
Letra/ABA, 2007. v. 1. 353 p.; BRITO Filho, J. C. M., *Direito  
Sindical*, 2. ed. São Paulo: Editora LTr, 2007. v. 1. 374; SCAFF,  
Fernando Facury (Org.), *Constitucionalismo, tributação e direitos  
humanos*, São Paulo: Renovar, 2007. v. 1. 327 p.

The program of Graduate Studies in Human Rights at the Federal University of Pará is structured around the following elements:

a) *Interdisciplinary Study*: Expertise in human rights requires a familiarity with different areas of knowledge. The teaching faculty brings together professors with degrees in law, sociology, anthropology, economics, and philosophy, which gives an interdisciplinary character to projects, areas of research, and curriculum structure.

b) *Focus on vulnerable groups*: The economic globalization that produced work conditions of a precarious nature and growth in unemployment increased the rate of exclusion in societies, affecting the capacity for public policy implementation by the United Nations. Within the program, the activities of teaching, research, and expansion of human rights have a focus on socially and economically vulnerable groups, specifically addressing the social inclusion of indigenous populations of the Amazon. With regard to human rights education, instruction focuses on the study of the living conditions of these groups, with the aim of offering the empirical expertise necessary for the promotion of their rights, as well as the carrying out of research that seeks alternatives to the current situation;

c) *Protection of human rights and the environment*: The set of problems faced in the Amazon Region requires a consideration of environmental factors. The ecological equilibrium of the environment is understood as a human right. In this sense, public policies that are developed for their protection are related in an intrinsic way to the sustainable use of the natural resources of the region. With this in mind, research in the area looks at the relationship between human rights protection and environmental protection in the sense of coordinating

sociocultural systems and the biophysical environment, and even examining the way in which nature is appropriated for use and the resulting transformation of Amazonian space;

d) *Collaboration with organizations for the protection of human rights*: Master's students in human rights will have to complete an internship with a governmental or non-governmental organization for the protection of human rights whose operations and activities will strengthen the empirical material for master's-level research. With regard to this, two goals are sought: the guidance of master's research toward the concrete problems of human rights violations in the region and the application of the experience obtained by the students with an aim to strengthen the actions of these institutions.

**CENTRE FOR COMPARATIVE AND PUBLIC LAW  
FACULTY OF LAW, THE UNIVERSITY OF HONG KONG, CHINA**

**Contact information:**

Site: [www.hku.hk/ccpl](http://www.hku.hk/ccpl)

Email: [fkleung@hku.hk](mailto:fkleung@hku.hk)

Address: 304 KK Leung Building, The University of Hong Kong, Pokfulam Road, Hong Kong, China or KK Leung and Public Law, Faculty of Law, the University of Hong Kong

**Teaching:** The Centre for Comparative and Public Law ('CCPL') provides institutional support to the LL.M in Human Rights, through which core teaching in international human rights law is conducted. This programme offers places for one year full-time, or two years part-time study (more information below).

**Research:** Extensive, focusing on public law, international human rights law and comparative law. Visit [http://www.hku.hk/ccpl/research\\_projects\\_issues/index.html](http://www.hku.hk/ccpl/research_projects_issues/index.html)

**Publications:** Extensive. Some examples include:

A. Books: *Interpreting Hong Kong's Basic Law—the Struggle for Coherence* (2008), edited by Hualing Fu, Lison Harris, and Simon NM Young; *Human Rights in Asia: A Comparative Legal Study of Twelve Asian Jurisdictions, France and the US*, (2006), edited by Carole Petersen, Albert Chen, and Randall Peerenboom; *Hong Kong's Constitutional Debates* (2005), edited by Johannes Chan and Lison Harris; *National Security and Fundamental Freedoms: Hong Kong's Article 23 under Scrutiny*, (2005), edited by Fu Hualing, Carole J Petersen, and Simon NM Young; *Enforcing Equal Opportunities: Investigation and Conciliation of Discrimination Complaints in Hong Kong* (2003), Carole J. Petersen, Janice Fong, and Gabrielle Rush

B. Occasional Papers: Please visit <http://www.hku.hk/ccpl/pub/occasionalpapers/index.html>

C. Submissions to Government: Please visit <http://www.hku.hk/ccpl/pub/submissions/index.html> [ccpl/pub/occasionalpapers/index.html](http://www.hku.hk/ccpl/pub/occasionalpapers/index.html)

CCPL was established within the Faculty of Law of the University of Hong Kong in mid-1995 with the aim of promoting research in the fields of public and comparative law, including human rights law, and to disseminate the results of that research through publications and making materials available on-line. CCPL's research projects include the international law implications of the resumption of Chinese sovereignty in 1997, including the Hong Kong treaty project, immigration law and practice, equality and the law in Hong Kong, the Hong Kong Bill of Rights, human rights protection under the Basic Law and international human rights law.

As noted above, CCPL supports the LL.M in Human Rights. This programme was established at the Faculty of Law in 1999 to meet the increasing demand for practical and theoretical knowledge about human rights throughout the Asia-Pacific region. It remains the only such programme in all of Asia. Professors teaching on the LL.M in Human Rights are experts in their field. The programme is the most internationally diverse in the university. Its students have come from many Asian countries, including the People's Republic of China, Bangladesh, Cambodia, India, Indonesia, Japan, Mongolia, Nepal, Pakistan, the Philippines, South Korea, Sri Lanka, Taiwan, Thailand and Vietnam. The programme has also attracted students from Europe (Czech Republic, United Kingdom, Romania, Turkey, France, the Netherlands), the Pacific (Australia, New Zealand and Fiji) and the Americas (Canada, United States, and Puerto Rico). Students have included high ranking state officials, judges, prosecutors, practicing lawyers, academics, journalists, civil society activists and staff of national human rights institutions.

In addition to the compulsory courses (Public International Law if not already taken; International and Regional Protection of Human Rights; History Theory and Politics of Human Rights; National Protection of Human Rights), the LL.M has offered the following optional courses in recent years: Comparative Constitutional Law, Current Issues in Human Rights, Dealing with Legacies of Human Rights Violations, Economic, Social and Cultural Rights, Equality and Non-discrimination, Ethnicity, Human Rights and Democracy, Human Rights in China, Human Rights in Hong Kong, International Environmental Law, International Criminal Law, International Humanitarian Law, The Rights of the Child in International and Domestic Law. For more details of the LL.M in Human Rights, please see [http://www.hku.hk/ccpl/human\\_rights/index.html](http://www.hku.hk/ccpl/human_rights/index.html)

For more about CCPL's work, find the Centre's annual reports at [http://www.hku.hk/ccpl/about\\_centre/about\\_centre.html](http://www.hku.hk/ccpl/about_centre/about_centre.html).

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