Alicia Ely Yamin, JD, MPH, is the Joseph H. Flom Global Health and Human Rights Fellow at Harvard Law School. She also teaches at the Harvard School of Public Health and is Special Advisor to Amnesty International's global campaign on poverty, Demand Dignity. Please address correspondence to the author at ayamin@law. harvard.edu.

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SUFFERING AND POWERLESSNESS: THE SIGNIFICANCE OF PROMOTING PARTICIPATION IN RIGHTS-BASED APPROACHES TO HEALTH

Alicia Ely Yamin

Being included in the society in which one lives is vital to the material, psychosocial, and political empowerment that underpins social well-being and equitable health... Any serious effort to reduce health inequities will involve changing the distribution of power within society and global regions, empowering individuals and groups to represent strongly and effectively their needs and interests and, in so doing, to challenge and change the unfair and steeply graded distribution of social resources (the conditions for health) to which all, as citizens, have claims and rights.

— Closing the gap in a generation: Health equity through action on the social determinants of health, WHO Commission on Social Determinants of Health

ABSTRACT

In a rights framework, participation is inextricably related to power. Through effective participation, we can challenge political and other forms of exclusion that prevent people from having power over the decisions and processes that affect their lives and health. Yet concepts of power are as contested as notions of participation. Thus, I argue here that, far from there being a formula for what participation means in a rights-based approach to health, the way in which we conceptualize the role of participation is closely linked to how we understand power and, in turn, the purpose and meaning of human rights themselves. I outline three ways of thinking about domination and participation-as-empowerment. In a liberal understanding of how power operates, there is an overarching concern for ensuring processes of participation that enable competing groups to express their voices on the proverbial level playing field, so that no one group may impose its will on the others. Critics of this approach assert that it ignores the power relations in which participatory processes are embedded, which determine which of the issues that affect health get decided — and which issues are never brought to the table because they are systematically blocked. If a second dimension of power entails deciding what gets decided, participatory approaches need to challenge the definition of what is "up for contention," or they risk merely legitimating social control. A third dimension of power entails securing compliance from oppressed groups by shaping their perceptions of their own interests. A human rights-based approach concerned with the effects of this form of domination on people's health calls for developing critical consciousness before there can be any truly "empowering" participation. I conclude by arguing that much is at stake in defining participation in a human rights framework to health, because in defining what we are calling for, we will determine how relevant human rights are to the daily struggles of people around the world for well-being.

INTRODUCTION

We should all be alarmed, not only by the fact that millions of people are slipping into poverty due to the current global economic crisis, but also by the tendency of governments to slash social programs and dictate aid without meaningful input from those who are most affected.¹ A fundamental distinction of a human rights approach to development and policy-making that affects health is that it aims to enable those who are most impacted by poverty, patriarchy, and disease to be active participants in constructing the solutions to their problems. If health is a matter of rights, it cannot be considered a handout, and the people who receive services are not objects of charity from their own governments or from the G–20; they are agents who have a role to play in the definition of programs and policies that structure the possibilities for their own well-being.

As the Critical Concepts articles in this issue point out, "participation" has long been promoted in public health and development. During the 1970s, "people-centered development" and "community development" models emerged as alternatives to the top-down, state-led development models of the 1950s and 1960s, which had focused almost exclusively on economic growth. In public health, the 1978 Alma-Ata Declaration called for a paradigm shift from curative health care to a primary health care model that recognized the "social roots of illness" and emphasized community participation.2 Today, participation is stressed in the discourses of a wide array of actors, from grass-roots social movements to the World Bank. Yet, as authors in this issue note, the common rhetoric masks deep divisions about the concept and practice of participation, which can range from tokenistic consultation or the opportunistic use of community resources to a genuine means for people to claim fully their human rights, including their health rights.

Under international human rights law, the central importance of participation has been emphasized in relation to the right to health per se, as well as to women's reproductive and sexual health, children's health, and indigenous health, and with respect to disabilities.³ However, participation goes beyond questions of health in a human rights framework; participation is, as Sam Foster Halabi cites in his article in this issue, "the right of rights" because it allows us to claim our other rights. Indeed, participation goes to our most fundamental understanding of being human and to the purpose of rights.⁴ As former

United Nations (UN) High Commissioner for Human Rights Mary Robinson has stated, "Participation and active involvement in the determination of one's own destiny is the essence of human dignity."⁵

That is, in a rights framework, we are not merely the sum of our subjective desires. Rather, we have some objective interest in developing our "life plans" or "capabilities," and rights are conceived of as tools that enable us to do so. Rights preserve our freedom and our capacity for meaningful choice; they allow us to have self-determination and power over our lives, as embedded as those selves and lives are in communities and social contexts. Moreover, rights are held in relation to duty-bearers. In a rights paradigm, rather than view powerlessness as simply bad luck or misfortune, we think of it as injustice because we implicitly believe that it is related to domination, and we also implicitly believe that the state has a role to play in securing a remedy.

In a rights framework, active participation in domains ranging from the cultural to the political is both expressive of human agency and instrumental to self-determination. Through effective participation, we can challenge political and other forms of exclusion that prevent us from having power over the decisions and processes that affect our lives and our health. Thus, if patterns of suffering and ill health must be understood as reflections of power relations as much as biological factors in a rights framework, the goal of a rights-based approach to participation should be to subvert the subordination and marginalization — the "pathologies of power" in Paul Farmer's terminology — that prevent certain groups and individuals from realizing their rights, including their health rights.8

Other articles in this issue note the intimate and inextricable relationship between participation and power in a rights framework. Pol De Vos et al. explicitly prefer the term "empowerment" to participation. Yet, as these authors also acknowledge, concepts of power, including the vocabulary we use to discuss it and the ways in which we think about it — where it lies, how far it extends, how it works — are as contested as notions of participation, and these disagreements are inescapably political.

Thus, I argue here that, far from there being a formula for what participation means in a rights-based approach to health, the way in which we conceptualize the role of participation is closely linked to how we understand power and, in turn, the purpose and meaning of human rights themselves. For example, participatory approaches that focus on promoting opportunities for voice in health policy-making, programming, and budgeting implicitly adopt one paradigm of power. Other approaches, such as that espoused by De Vos et al., who call for an explicit class analysis to transform landless peasants and urban proletarians into collective agents of social change, reflect a very different view of how power operates and what it means.

Drawing on the work of a variety of scholars and, in particular, British sociologist Steven Lukes, I outline three ways of thinking about domination and participation-as-empowerment. None of these sociological models is pure when applied to rights-based approaches to health in practice, and authors cited often draw on multiple understandings of power. Nor do I mean in any way to suggest that achieving "authentic" participation guarantees empowerment in practice, which obviously depends upon other substantive conditions as well. My goal here is simply to make explicit certain assumptions of differing understandings of how domination constrains our ability to "determine our own destiny" and to distinguish some implications for designing and evaluating channels for participation in the context of rights-based approaches to health.

In a liberal understanding of how power operates, there is an overarching concern for ensuring processes of participation that enable competing groups to express their voices on the proverbial level playing field, so that no one group may impose its will on the others. Critics of this approach assert that it ignores the power relations in which participatory processes are embedded that determine which issues that affect health get decided — and which issues are never brought to the table because they are systematically blocked. If a second dimension of power entails deciding what gets decided, participatory approaches need to challenge the definition of what is "up for contention," or they risk merely legitimating social control. Lukes points to a third dimension of power,

which entails securing compliance from oppressed groups by shaping their perceptions of their own interests. A human rights-based approach concerned with the effects of this form of domination on people's health calls for developing critical consciousness before there can be any truly "empowering participation." I conclude by arguing that much is at stake in defining participation in a human rights framework to health because, in defining what we are calling for, we will determine how relevant human rights are to the daily struggles of people around the world for well-being.

PARTICIPATION IN PROCESSES THAT PROMOTE PLURALISTIC VOICE

The understanding of participation as involving the "right and responsibility of people to make choices and therefore, to have power over decisions which affect their lives" can be traced back to early efforts to promote participatory approaches in health and development. However, in recent years, a number of authors, including former United Nations (UN) Special Rapporteur Paul Hunt, have explicitly emphasized the nature of participation as a human right, one which states have a legal obligation to ensure. Thus, the concept of participation is linked not just to the "community" or to development projects but also to rights of citizenship and democratic governance.

We have long understood that authoritarian regimes that disregard people's voices with impunity can have especially disastrous consequences for health, as illustrated in studies by Amartya Sen and Jean Drèze comparing famine in China and India. However, corruption, lack of responsiveness, and an absence of connection to and participation from the people who are ostensibly served plague health systems in societies that are formally democratic as well.

Thus, democratizing health systems, and health policy-making more broadly, is part of any rights-based approach to health. For example, in a recent monograph on participation in the context of the right to the highest attainable standard of health, Helen Potts defines a health system that allows for "active and informed participation" as essentially one that follows the pluralistic model of liberal democracies: opportunities for the revelation of people's preferences and policy choices based on expressed preferences.

ences, and for the implementation of elected policies followed by monitoring and assessment.¹⁶

Although the World Bank (the Bank) eschews an explicit rights framework, the four preconditions that the Bank sees for participation to be "empowering" are not substantially different from criteria that Potts sets out for "active and informed participation" in a rights-based approach to policy making: people's access to information on public health issues, their inclusion in decision making, local organizational capacity to make demands on institutions, and accountability of those institutions to the public.¹⁷ Indeed, the Bank also stresses the link between voice and governance, as do other development banks and agencies.¹⁸ De Vos et al. criticize the Bank for removing an analysis of power relations from the concept of empowerment, but, arguably, the Bank has adopted a particular analysis of power (and governance): a liberal framework that focuses narrowly on the process of participation.

Liberal conception of power: Connections to other rights

In his early essay, "The Concept of Power," Robert Dahl, a leading exponent of the liberal, or pluralist, view of power, wrote that "A has power over B to the extent that he can get B to do something that B would otherwise not do."19 In discussions of participation, power, and health, decision-making arenas need not be confined to policy-making fora. For example, the domination Dahl describes can occur in any context of asymmetrical power, including landowner-tenant and employer-worker relations, as well as in authoritarian families and the doctor-patient setting.²⁰ Any human rights framework is concerned with curbing imposition of will through coercion, force, manipulation, and the like at both the microlevel and macrolevel.21 Nevertheless, for purposes of understanding what dynamics underpin social and political action (and inaction) in the face of the brutal inequalities in health that exist across the world today, we really want to examine participation — and power — at the level of community or society decision making. Dahl's views have evolved but remain consistent in his assertion that liberal democracy is the means to equalize political power and in his understanding of effective participation: "before a policy is adopted . . . all members of the demos must have equal and effective opportunities for making known to other members their views about what the policy should be."22 Similarly, Potts argues that, for there to be effective

participation in health policy-making,

all affected parties should have an equal opportunity to be part of the process. The process is also to be transparent; the participants need to understand the information that is related to the issue at hand, in order to make the best possible decisions.²³

In addition to political participation, other civil rights, such as freedoms of association and information, are essential to allowing people effective participation in health, understood as an exercise in citizenship. For example, there is substantial evidence that when small farmers have information that allows them to compare prices, rules, and policies, their participation in decisions affecting their lives rises significantly. As Peter Uvin notes, the right to information has been a cornerstone of a rights-based approach to development in India, which has had dramatic effects on health.24 Similarly, the elimination of discrimination, which prevents certain groups, such as women or minorities, from having an equal opportunity to voice opinions about a given issue that could affect their health, is also key to enabling rights-based participation.

Halabi challenges the intrinsic connection between political participation and the right to health in the context of Indonesia, arguing that greater political and civil rights accompanied a diminished commitment to health as a public good. Yet, as he notes, this need not be the case. Further, the gotong royong established by Suharto involved "community participation" in the form of resource provision, such as labor and time.25 Thus, Halabi is absolutely right to problematize overly simplistic assertions regarding the interdependence and indivisibility of all human rights by pointing out that participation without achievement of actual health benefits is hollow. However, it is equally important not to conflate utilitarian modes of participation with rights-based approaches that seek to change who makes decisions regarding health.

An emerging role for courts

As a rights framework requires there to be opportunities for review and accountability for participation, it is of particular note that certain judiciaries are increasingly catalyzing citizen participation in policymaking relating to important health issues, ranging

from environmental standards to food and agriculture policy, to priority-setting in health systems. For example, in July 2008, the Colombian Constitutional Court, which has long been a staunch protector of economic and social as well as civil rights within a highly neoliberal state, ordered a dramatic restructuring of the country's health system. Referencing goals the legislature had itself declared when enacting the country's sweeping health care reform in 1993 and amending it in 2007, Judgment T 760/08 called for, among other things, the updating and unification of the two-tiered benefits packages between the contributory and subsidized insurance regimes. Notably, the Court deliberately did not itself attempt to define the content of a new benefits package, nor even the criteria in accordance with which benefits were to be determined.²⁶ Rather, the Court, conscious of its limitations as a non-representative body, called for a process that included relevant epidemiological information as well as "direct and effective participation of the medical community and the users of the health system."27

In 1993, when Colombia adopted a health reform based on US managed care, and again in 2007, when the health system underwent minor reforms, there was virtually no opportunity for vigorous debate or deliberation. Indeed, Colombia has been cited as an example of health care reform achieved through closed processes led by teams of technocrats. ²⁸ Today, various "implementation commissions" have been formed by different interest groups and recognized by the Court. The aim of the Court in involving these commissions in follow-up hearings is to foster pluralistic participation with respect to the content of the new benefits package and, in turn, the priorities of Colombia's health system, given a highly diverse society and finite resources.

Decentralization

As both Halabi and Walter Flores et al. discuss, support for decentralization of health sectors has been based historically on this logic of opening spaces for democratic participation. For example, in an early document setting out indicators to monitor progress toward the initiative "Health for All by the Year 2000," the WHO stated that community involvement could be assessed by "the level of involvement in and the degree of decentralization in decision making as well as the development of effective mechanisms for the expression of people's needs and demands."²⁹

In the 1980s and 1990s, at the behest of the Bank, decentralization became a key pillar of neoliberal reform agendas in health sectors, along with privatization and targeting. Decentralization has occurred in myriad ways with more and less budgetary and programming control being shifted from central governments to state or provincial governments and has also, in some cases, implied transfer of responsibility to indigenous communities for managing their own health care.³⁰

Halabi is not alone in his critique of decentralization; evidence regarding the effects of decentralization on the health of the poor is mixed. It is unquestionably true that, in many instances, decentralization has not led to authentic democratic space or participation but rather to enhanced local capture by elites and the reproduction of national inequities at the regional level.31 In their account of what has happened in Guatemala, Flores et al. laud the significance of the Urban and Rural Development Councils Law, "which creates mechanisms for participation in the allocation of public budgets from community to central government levels," yet conclude that, although spaces are necessary, they are insufficient to adequately address the economic and social rights needs of the poor in Guatemala.

Indeed, as all of the Critical Concepts pieces in this issue illustrate in one way or another, many forms of domination that jeopardize people's well-being are left untouched by their ability to choose among competing policies in the context of health. Let me be clear: placing limits on the capacity of elites and autocratic governments to impose their will on individuals and groups, and democratizing health policymaking through broader participation, are critical in any human rights framework. Further, participation in any rights paradigm relates to providing individuals with information and tools to make informed choices about their well-being and not merely to the use of their labor or resources. Nevertheless, by exploring the ways in which power relations structure (in)action, we can better understand the less visible ways of securing compliance from disadvantaged groups and individuals, which have enormous impacts on both dignity and well-being.32

CHALLENGING AGENDAS AND BOUNDARIES OF PARTICIPATION

The value of participation in health and development

has often been challenged, not just from conservative quarters, but from progressive academics and practitioners as well, who assert that these participatory approaches fail to genuinely empower the people that they ostensibly serve.³³ Underlying many of these critiques of participatory approaches are critiques of the liberal understanding of what power means and how it is exercised to control and exclude disadvantaged groups. For example, a leading critic of participatory development, Bill Cooke, has argued that, "because participatory processes prioritize what happens within the participatory group, [they] foster the assumption that they represent a natural, uncontestable way of things. . . . Simultaneously, important and malign structural forces outside the cognizance and/or influence of participants are ignored and sustained."34 Further, labeling an approach a "rightsbased approach" does not avoid the central fact that, as Frances Cleaver has written, rights, including the right to participate, "do not exist in a vacuum but rather are embedded in social relations; these very social relations may either enable or constrain the exercise of" agency.35

To avoid devolving into the same kinds of "managerialist participation" that have plagued health and development practice, we require a rights framework that acknowledges that the power to decide what gets decided can be a greater constraint on the choices of others than the ability to overcome opposition. Therefore, it is important to consider not just who gets their way within policy debates or participatory forums, but how the agenda and the boundaries of participation are set. We can acknowledge that preliminary agendas "need to come from somewhere" while still recognizing that "somewhere" is a political space.³⁶ Further, we need to confront the factors that prevent many issues of inequalities from ever arising in decision-making arenas in the first place.³⁷ Understanding domination in this second way leads us to re-think our demands for participation in a number of ways.

Mobilization of bias: Looking beyond "political" actors

First, meaningful participation requires more than having access to information and opportunities to express one's preferences. For example, the unfolding saga of health care reform in the United States speaks to how some interests, such as providers and insurers, are organized, while others, such as patients,

are not.³⁸ All organization, including political organization, involves "a mobilization of bias . . . in favor of the exploitation of certain kinds of conflict and the suppression of others . . . some issues are organized into politics and others are organized out."39 The agenda is now being set for the US health care reform debate. As of this writing, several legislative proposals have been made for single-payer plans, yet, at best, there will be one or two subcommittee hearings on the single-payer option, and it will never come up for a vote. Indeed, the universe of possibilities for health care reform has likely already been established.⁴⁰ The outstanding question seems to be only whether organized pharmaceutical companies, the insurance industry, and such provider associations as the American Medical Association will succeed in defeating even the possibility of a robust public option to be offered alongside the private insurance option.41

Similarly, in the very different context of Colombia, some social movements that are critical of the privatized model of health care adopted by the 1993 reforms are dubious of the participation channels opened by the Constitutional Court's decision, discussed above. In their view, participation in that process can only divert attention away from the real struggle to change the model of the health care system — a discussion that has been successfully organized out of the realm of possibility by the well-organized managed care and insurance companies in that country.

Further, even in the unlikely event that patients were somehow able to participate in this deliberative dialogue on an equal footing with organized insurance companies — that is, the goal of liberal participation — that does not change the fact that the rules of the game may have already been set. That is, what is covered by the new social insurance scheme will be decided primarily by the criteria for determining health care priority setting and not simply by whether different interests — for example, stakeholders with cancer vs. those with HIV/AIDS - have an equal opportunity to express themselves. The ethicists Norman Daniels and James Sabin have pointed out that determining basic principles for priority setting requires a fair process.42 Potts also stresses the importance of fairness in the rule-making process and not just the decision-making process.⁴³ Insofar as the Colombian Ministry of Social Protection preselects these criteria behind closed doors, citizen participation in approving the final agenda may turn out to be substantially less meaningful than the Court intended.

Certainly, pluralistic participation strategies in health and development can "open up political spaces that otherwise would not have been available." However, from this perspective on domination, certain kinds of participation can actually disempower the poor further. As Uma Kothari has argued, initiatives "designed to bring the excluded in often result in forms of social control that are more difficult to challenge, as they reduce the spaces of conflict and are relatively benign and liberal."

In the case of the US, despite polls that indicate strong public support for a universal single-payer plan, the active lobbying of pharmaceutical and insurance companies and managed care and provider organizations, together with a mainstream media controlled by corporate interests, has mobilized a bias against a universal single-payer plan so effectively as to suppress even the possibility of an overt conflict on the issue.⁴⁶ However, it is often the case that defining political discourses requires only inaction — not active lobbying — on the part of actors beyond the range of observable political behavior. In his classic study, The unpolitics of air pollution: A study of non-decision making in the cities, Matthew Crenson documents how US Steel for a long time effectively prevented the issue of air pollution from even being raised in Gary, Indiana, where the corporation had been responsible for the town's prosperity and then "decisively influenced the content of the anti-pollution ordinance finally enacted."47 Moreover, Crenson writes, "US Steel influenced the content of the pollution ordinance without taking any action on it, and thus defied the pluralist dictum that political power belongs to political actors." 48 In a 2006 study of participation in a community in rural Peru, Mario Rios and Henry Armas come to similar conclusions with respect to the mining company that has historically dominated economic activity there.49

In its virtually exclusive focus on the state, human rights scholarship and advocacy has long neglected the power of non-state actors. Yet, as we will explore in greater depth in a forthcoming issue of this journal, in an increasingly globalized and market-driven world, the power of actors outside the political process to construct agendas — from domestic and multi-national corporations to the World Trade Organization and international financial institutions — clearly needs to be included in our power mapping analysis and advocacy if we are concerned with agendas that are constructed largely in secret, beyond the reach of democratic political space and bear deeply on people's capabilities for well-being.⁵⁰ Similarly, authors from very distinct political perspectives have argued that foreign aid for health and other development issues — from both donor states and private sources — often thwarts democratic accountability and participation mechanisms in those countries by encouraging responsiveness only to donors, rather than civil society.51

Social and historical context in determining power relations

Second, as noted above, participation does not occur in a vacuum. Rather, it is always embedded in specific power relations.⁵² As a result, formulaic designs or indicators of participation in health are likely to ignore the complex realities of and constraints upon people's lives.⁵³

In contrast, when we situate participation in a specific historical context, it is possible to identify the accumulation of agenda-setting power over time. In such settings, elites need not actively exercise control over agendas in order to exclude the marginalized and poor. For example, Flores et al. describe how Guatemala's internal conflict generated a "climate of generalized terror that gripped the population," leading to such fear and intense insecurity that people stopped seeking spaces for social participation even though they could not explain exactly why they did so. Flores et al. emphasize the need for regenerating the social fabric and building trust between the government and its citizens as "essential and basic elements that cannot be separated from the processes of social participation." But trust does not mean naïve faith in the beneficence of the state; rather, I take Flores et al. to be calling for a trust in confrontational politics and a social fabric that is strong enough to encourage and sustain open conflict over health as a deeply and inexorably political issue, without resort to violent suppression.

"Invited" vs. "claimed/demanded" spaces

Third, we must recognize that power shapes the boundaries of the participatory spaces themselves. Therefore, it is important to distinguish between participation that occurs in "invited" and "claimed" spaces.⁵⁴ Invited spaces are those created and substantively controlled by health planners and policy makers, for example, while claimed or demanded spaces (along the lines of what De Vos et al. describe) are those demanded, created, claimed, or chosen by communities or social movements themselves.⁵⁵ In the former, the spaces and definition of at least the preliminary agenda are effectively controlled by the government or some other "authority." Such spaces can open greater opportunities for authentic participation, such as in Brazil's constitutionally-created health councils, which have allowed for a genuine transfer of control over priority-setting and budgeting to affected populations.⁵⁶ However, they can also close possibilities, reinforce existing privileges, and preclude alternative perspectives.⁵⁷ Even when individual and community inputs beyond those of mainstream nongovernmental organizations (NGOs) are officially invited, those efforts often amount to nothing more than co-optation.⁵⁸

Similarly, as Flores et al. note with respect to Guatemala, the spaces can come to be "merely administrative entities" — "without a political dimension" that would allow real challenges to agenda-setting power and the political ideologies that underlie that power. The de-politicization of participation — as a neutral process occurring in a neutral space — is deeply problematic from a rights perspective concerned with challenging the power to define what can be decided in relation to people's health. Thus, although within a pluralist, or liberal, framework, legislating the creation of participatory spaces in health policy-making is a positive indicator, the creation of officially sanctioned processes for participation does not guarantee empowerment from this perspective.⁵⁹ Indeed, at times it can be construed as merely a means to legitimate political and social control.60

Participation across spheres of decision making: Beyond health care

Fourth, as the UN Committee on Economic, Social and Cultural Rights has made clear, participation should not just be at the project or program level but "in all health-related decision making at the com-

munity, national and international levels."⁶¹ However, it is by seeing power through this second lens that we understand better *why* it is critical to go beyond participation in a single sphere or level and consider broader "social participation" in health, as Flores et al. advocate. It is precisely the restriction of spheres of participation that allows those with power to decide which issues shall be open for discussion.

All too often, even so-called "rights-based approaches" to health and development emphasize "local contexts," while ignoring wider power structures.62 But if participation in health is largely limited to the local community level or to delivery of health programs, key decisions that take place at a district or central level relating to resource allocation, health care workforce, structuring of health systems, and the like which drive the possibilities for people to realize their rights to health — are never "up for contention."63 As a result, participation in development and health practice has too often meant incorporating marginalized people into agendas that they are unable to question in really fundamental ways and "producing grassroots knowledge ignorant of its own partiality."64 Also, as De Vos et al. note, efforts to democratize decision making on health issues at the national level are misplaced if they ignore or cause complacency with regard to the international level, where the real agenda setting for trade, economic, and development policy occurs.65

Perhaps it is worth making explicit that, similarly, devising strategies for participation cannot be confined to the health sector when we have abundant evidence that social determinants of health, including workplace and neighborhood characteristics, education, and income inequalities, have a far greater impact on population health than "downstream" questions relating to health care.66 In no human rights framework is participation confined to the health sector, but in this model there is an explicit focus on the need to work across sectors in order to open up the scope of issues that can be contested, which, in turn, can promote better health outcomes. For instance, De Vos et al. cite examples of empowering participation in the Philippines, where there is an explicit recognition that "health is tied to subsistence and livelihood, which directly relate to issues of land and income," so that "communities that are able to take control of their own land are able to take control of their lives. The rise in family income . . . that occurred when

formerly landless peasants came to own the land they farmed resulted in better nutrition and improved access to health care."

Suppressed conflict and "the community"

Fifth, the very concept of "community participation" becomes more problematic when we look beyond observable conflict to covert, or suppressed, conflicts. As feminists have long pointed out, the notion of "community" masks power imbalances within communities. Participatory approaches that emphasize "consensus" ignore the ways in which group dynamics, just as participatory spaces, are always embedded in power structures and how subordinate perspectives are often never articulated as a result.

Thus, if we are interested in participation as a mechanism to make visible those issues that may have been excluded from decision making altogether, we would require indicators of the frequency and extent to which community participation in broader policy processes in a given context have raised and furthered issues that are routinely marginalized, such as sexual and mental health. Moreover, in instances of specific policy discussions, we would want to know which issues are raised and which are not.70 Perhaps in sexual and reproductive health, saving mothers' lives rises to the level of discussion, but empowering women to have safe abortions does not. Perhaps in mental health discussions, the needs of persons with intellectual disabilities or psychosocial problems are considered, while the needs of those with psychiatric disabilities are not.

Examining non-issues and silent spaces, where conflict has been suppressed, can be more telling in terms of assessing how empowering participation really is than looking just at how specific decisions come out. Moreover, when group identities and dynamics exclude or actively harm certain people's health interests, a rights perspective that is truly concerned with dignity and empowerment will place limits on "participation."

CRITICAL CONSCIOUSNESS AND PROMOTING PARTICIPATION IN HEALTH TO DEEPEN DEMOCRACY

The greatest power of colonialism, as Frantz Fanon recognized, went far beyond global exploitation to its capacity to colonize the interior worlds of its sub-

jects.⁷¹ Lukes suggests that truly the greatest form of domination is:

the power to prevent people, to whatever degree, from having grievances by shaping their perceptions in such a way that they accept their role in the existing order of things, either because they can see no alternative to it or because they see it as natural and unchangeable, or because they value it as divinely ordained and beneficial.⁷²

Thus, there is no conflict, either overt or suppressed. Demands do not become political issues; they are not even felt. Yet, perhaps more than any other, this cultural and ideological domination — which produces willing compliance in the face of stark inequalities — prevents people from controlling their own destinies and furthering their health interests.

Internalized domination and living a life of dignity

Citing studies of Indian widows who have internalized society's disparaging perception of them, Lukes notes that "this can be understood as domination because the people or society around them mirror back to them a confining or contemptible picture of themselves, thereby imprisoning them in a 'false, distorted and reduced mode of being." Similarly, Flores et al. allude to a long history that preceded the conflict of the late 20th century of a dominant class and ethnic group not only exercising repression but also controlling both the means of communication and education to project their own experience and culture as the norm, simultaneously creating "bipolar categories of ethnicity" and rendering invisible the perspective of the indigenous groups that they dominated.74 In such a setting, as they claim, it is naïve to think that the "[i]nclusion of traditionally excluded groups in decision-making processes" will or could create meaningful agency.

Asserting the existence of such internalized cultural and ideological domination is profoundly controversial in that it inevitably appears to be passing paternalistic judgment about those who suffer from the inequities that they themselves participate in maintaining. We need not resort to the Marxist language of "false consciousness," with its exclusionary focus on class, to assert that everyone is not the best judge of his or her own interests, as the utilitarian Jeremy

Bentham claimed. Domination is never complete; social actors do not have unitary or even dual, but myriad and conflicting interests and even identities.⁷⁵

Yet, I would argue that a truly empowering rightsbased approach to health seems to require 1) some notion of objective interests in fully realizing one's life plan or capabilities, and 2) an account of how domination often works against individuals' interests, including their health interests, by "stunting, diminishing and undermining their powers of judgment and by falsifying and reducing their self-perceptions."⁷⁶ A participatory process that permits the revelation of preferences may be meaningless in such a context.⁷⁷ As Martha Nussbaum has written, "[when] someone who has no property rights under law, who has no formal education, who has no legal right of divorce, who will very likely be beaten if she seeks employment outside of the house . . . says that she endorses traditions of modesty, purity and self-abnegation, it is not clear that we should consider this the last word on the matter."78 Similarly, studies in societies as diverse as Peru and Swaziland have found that women often believe that their husbands or partners are entitled to be violent with them if the women fail to please them in one way or another.⁷⁹ We need a conception of power and powerlessness that allows us to take such suffering seriously.

Further, internalized domination affects not just whether a person perceives herself to be suffering but how much. In his writing about widows reporting less ill-health than widowers in the context of the great Bengal famine, Sen concludes, "quiet acceptance of deprivation and bad fate affects the scale of dissatisfaction generated and the utilitarian calculus gives sanctity to that distortion."80 That is, people's subjective assessments of their own suffering are mediated by unjust power relations, and if we accept those assessments at face value — as utilitarian health utility measures based upon subjective preferences would have us do — we are in effect affirming those injustices. The philosopher Will Kymlicka similarly notes that if people adapt their preferences to what they can realistically hope to achieve, it raises serious problems for evaluating the justness of political and institutional arrangements on the basis of their ability to satisfy people's preferences.81

Critical consciousness

Understanding this dimension of domination as

hegemony, to use Antonio Gramsci's term, calls for distinct approaches to participation, which centrally include fostering critical consciousness as a precondition to effective participation. As Sen has written:

The most blatant forms of inequalities and exploitation survive in the world through making allies out of the deprived and exploited [as the] underdog learns to bear the burden so well that she overlooks the burden itself. Discontent is replaced by acceptance, hopeless rebellion by conformist quiet, and anger... by cheerful endurance."82

Meaningful, that is, "empowering," participation, therefore, requires challenging hegemonic forms of thought that create a sense of "false necessity" about the way in which social reality is viewed as being divinely ordained, natural, or unchangeable.⁸³

Focusing on internalized domination calls our attention to the socialization that precedes and perpetuates the systemic inequalities in societies and in patterns of health. For example, Alex Scott-Samuel has written of the links between patriarchal masculinity, neoliberalism, and health inequalities and the fact

that worldwide acceptance of child-hood socialisation into the . . . negative features of [a] hegemonic masculinity is what subsequently results in power inequalities between individuals, between social/racial/gender groups and between institutions — and in turn — in the individual and the structural violence through which power inequalities are expressed.⁸⁴

As De Vos et al. mention, leading thinkers in "empowerment approaches" to participation in health, such as Susan Rifkin, have come to advance the work of Brazilian Paolo Freire, who spent much of his life developing forms of popular education to promote critical thinking to confront structures of oppression.⁸⁵ Freire's pedagogy rejects what he termed a "banking notion of education," whereby reality is treated as static and unchangeable and knowledge is deposited into students by the teacher. Rather, he calls for a constant humanizing praxis — conscientização — of progressively engaging students in dialogical practice to transform their own worlds and the

injustice, exploitation, and oppression that dehumanize not only them but also their oppressors.⁸⁶

Dialogue, in a Freirian model, is not merely a tactic of participatory approaches - a way to engage community members in a particular task, for example.87 Nor does it simply imply a shift from teaching to listening, as so many participatory approaches have tended to emphasize. As Ute Buhler has written, "the assumption that whatever 'local people' say is valid is as patronizing as its opposite. Both stand in the way of serious engagement."88 Buhler cites Enrique Dussel, the Argentine philosopher of liberation: "denying the possibility of arguing is denying the Other as someone who argues."89 Rather, dialogue for Freire is an acknowledgement of the "social and not merely individualistic character of knowing."90 Such a pedagogical approach to participation in health challenges the contrived restriction of the outsider's role to "facilitator," just as it does that of the professional health expert who takes over. As Buhler argues, "both can stand in the way of genuine dialogue and exchange."91

"Emancipatory participation" that calls for awakening critical consciousness about models of economic development, political rule, state formation, and the like transcends issues of levels of engagement — that is, community, national, international — and even questions of health per se. Rather, it is centrally concerned with the ways in which people come to feel themselves to be — and therefore can participate as — fully human Subjects within historical processes and social contexts. ⁹²

Deepening democracy through participation

If, in a pluralistic framework of power, participation in health is linked with liberal democracy, another Brazilian thinker, Roberto Unger, links challenging "false necessity" — that is, understanding that society is made and imagined rather than given as a natural fact — with what he refers to as "empowered democracy." Empowered democracy, for Unger, rejects the notion that "our basic social arrangements must either be taken as a given, or humanized through compensatory redistribution and welfare assistance." Rather, by challenging the idea that current social set-ups are fated or inevitable, empowered — and empowering — democracy can free people's life chances from the "degrading logic of social hierarchies and division."

Unger's empowered democracy is more radical than, but broadly consistent with, calls for new and deeper forms of engagement between citizens and the state, which go beyond conventional liberal democracy and imply a "reconceptualization of the meanings of participation and citizenship in relationship to democratic governance." John Gaventa writes that

citizenship has traditionally been cast in liberal terms, as individual legal equality accompanied by a set of rights and responsibilities and bestowed by the state on its citizens. Newer approaches aim to bridge the gap between citizen and state by recasting citizenship as practiced rather than as a given.⁹⁶

Citizenship is thus not meant to exclude non-citizens; it is a social concept as much as a legal one, intended to change the kinds of claims that people can make upon the governments where they live.

Gaventa argues that such notions "suggest a more active notion of citizenship — one that recognizes the agency of citizens as 'makers and shapers' rather than as 'users and choosers" of policies, programs, or interventions.⁹⁷ Returning to the example of restructuring the social insurance scheme in Colombia, for instance, such a notion of citizenship would require inclusive forms of deliberation about health care rationing and delivery that connect to a broader democratic process by contributing to enhancing public awareness of the health system as a core social institution, as well as the need to set limits and the types of evidence, grounds, and conditions which may appropriately play a role in that process based on discussions about what people owe each other in a democratic society. It is not merely a matter of providing individuals and groups with an opportunity to choose the policies that advance their particular interests, but rather providing an opportunity to shape the structures and practices in which those choices occur.

We have examples — such as the participatory budgeting and health councils in Brazil — that are often cited as providing both greater voice from ordinary people to set agendas and greater accountability from the state in responding to the demands of citizens. However, in general, such a view of citizenship, and participation, calls for constructing radically new relationships between ordinary people

and the institutions, including health institutions, that affect their lives.⁹⁸

Further, building such new relationships does not just mean improving "voice" and "responsiveness" within existing institutions; it often means subverting the institutional arrangements that underlie the reproduction of class, race, patriarchal, and other social relations. Giles Mohan and Samuel Hickey argue that, in this framework, participation is not merely a means by which given citizenship roles are reproduced and state obligations fulfilled, but rather, it offers the prospect that citizenship "can be claimed from below" by women and other marginalized groups "through their own efforts in organized struggles, rather than waiting for it to be conferred from above."

In short, participation is obviously not the answer to all forms of oppression that affect health. However, participatory spaces can and should open new possibilities for deliberative engagement that are "multiscaled and span political arenas; that employ dialogical political methodologies . . . and involve political agents engaged with both structural conditions and popular agency." For Unger, in an empowered democracy, the role of rights — and I would argue rights-based participation — is to strengthen "our experimental capacities" and empower us to see and think more than our institutional and discursive systems can allow. 102

CONCLUSIONS

We live in a world of brutal inequalities where the relationships between ordinary citizens and even democratic states are increasingly in crisis, marked by marginalization and alienation of large segments of the population. The significance of defining how we understand and apply participation in rights-based approaches to health relates to how we interpret and respond to that reality.

Not all aspects of rights-based approaches to participation are open for debate. All rights-based approaches draw attention to the accountability and responsiveness of institutions and governance. Further, in any rights framework, participation is conceived of as a right of citizenship and as a means of challenging forms of domination that exclude people from decision making and restrict their self-determination. Further, human rights is an unapologetically modern-

ist project for social emancipation, in which suffering is related to powerlessness and freedom to living in dignity.¹⁰³

Yet, I have argued that applying the label of "rights-based approach" does not resolve the most fundamental questions we face in designing and evaluating participation. Contested conceptions of participatory approaches in health and development inexorably draw us back to providing an account of power, and power as domination, that explains social and political action (and inaction) in the face of staggering injustices in health.

In a liberal democracy, if the participation process is fair and transparent, no one elite group or actor should be able to impose their will indefinitely or be able to veto democratically supported policies that affect people's health. In other words, the winner can't take it all — or, at least, not all of the time. On the other hand, understanding domination as including other dimensions of power, including the power to define the boundaries and agendas for participation, calls for a different approach to evaluating the "realness" of participation. De Vos et al. assert that the participation process is important, but the outcomes — that is, "the redistribution of resources and power in the political process, and the increased ability of marginalized communities to control key processes that influence their lives" — are the key to evaluating whether participation is really empowering. Finally, acknowledging the existence of a third dimension of power — internalized domination — means, as Lukes notes, that judging the extent or exercise of power "is not a straightforward factual question." 104 In turn, nor is judging the empowering potential of participation. Rather, these require "taking a view about how to interpret the meaning of acquiescence" in specific settings — whether by women or minorities or lower classes and castes — and how to determine when it signifies compliance to power as domination. 105

Further, our conceptualization of what power means and how it operates to exclude and subjugate people has profound implications not just for participation, but also for how we understand human freedom and human rights in general. That is, our notion of agency reflects our notion of agents. In a narrow, conventional liberalism, Lukes notes that people are taken to be "autonomous and rational actors faced with a feasible set of choices, more or less aware of the external constraints they face, sometimes

cooperating and even collaborating with those who dominate them, and resisting, even rebelling when the opportunity arises"; in turn, domination is construed merely as "subjecting people to external coercion and constraints" that restrict their options to live as they choose. 106 However, a view of domination and freedom that only requires non-interference with preferences precludes critically examining, in Nussbaum's words, "the many ways in which habit, fear, low expectations, and unjust background conditions deform people's choices and even their wishes for their own lives." 107

Historically, this narrow liberal view of power and freedom has led to an extremely limited conception of human rights as merely shields from government interference. 108 Even as mainstream human rights analysis and practice have been extended to include positive obligations and increasing attention to economic and social rights, including health, human rights has largely maintained an understanding of human beings as autonomous individuals, without fully appreciating how "social relations constitute structures of choices within which people perceive, evaluate and act."109 I have argued here that a truly empowering human rights framework, by contrast, needs to take into account to what extent a person or group is in control of their choices and what has influenced their preferences. 110 In this view, freedom is not a given but rather a problem that requires political imagination.

Ultimately, underlying different understandings of what is required for truly empowering participation in rights-based approaches to health are different accounts of the political and social circumstances necessary for people to have "equal dignity and an equal entitlement to shape their own lives, making their own choices and developing their gifts in reciprocal relations with others." At a recent international meeting relating to human rights-based approaches to safe motherhood, one participant noted that some donors are wary that rights-based approaches are really about "radicalizing the poor and re-making the world." Some would argue that they are — or they should be.

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- 5. Cited in H. Potts, *Participation and the right to the highest attainable standard of health* (Essex: University of Essex Human Rights Centre, 2008), p. 8.
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- 8. See A. E. Yamin, "Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care," *Health and Human Rights: An International Journal* 10/1 (2008), pp. 45–63. Available at http://www.hhrjournal.org/index.php/hhr/article/view/27/105. See also, P. Farmer, *Pathologies of power: Health, human rights, and the new war on the poor* (Berkeley, CA: University of California Press, 2003).
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- 70. Murthy and Klugman (see note 68).
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- 73. M. Nussbaum and J. Glover (eds), Women, culture and development: A study of human capabilities (Oxford: Clarendon Press, 1995), cited in Lukes (see note 7), p. 119.
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- 79. See, for example, Physicians for Human Rights, "Epidemic of inequality: Women's rights and HIV/AIDS in Botswana & Swaziland" (2007). Available at http://physiciansforhumanrights.org/library/report-2007-05-25.html; and the National Institute of Statistics and Informatics (INEI), Peru: Encuesta Demografica y de Salud Familiar (Population and Family Health) (ENDES Continua 2004) (November 2005), paras. 158–171 cited in Physicians for Human Rights, "Deadly Delays: Maternal Mortality in Peru" (see note 15).
- 80. A. Sen, Resources, values and development (Oxford: Blackwell, 1984), p. 309.
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- 82. Sen (see note 80), pp. 308-309.

- 83. See R. M. Unger, False necessity: Anti-necessitarian social theory in the service of radical democracy (New York: Verso, 2004).
- 84. A. Scott-Samuel, "Patriarchy, masculinities and health inequalities," *Gaceta Sanitaria* 23/2 (2009), pp. 159–160.
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- 91. Buhler (see note 88), p. 3.
- 92. See Freire (see note 85), p. 36.
- 93. Unger (see note 83), p. xliii.
- 94. Ibid., p. lxxii.
- 95. Gaventa (see note 13), pp. 25-41, at 28.
- 96. Ibid., p. 29.
- 97. Ibid.
- 98. Ibid., p. 25.
- 99. It also means questioning the conventional narratives of the causes for underdevelopment. Compare this view with V. Gauri, "Social rights and economics: Claims to health care and education in developing countries," *World Development* 32/3 (2004), pp. 465–477.
- 100. G. Mohan and S. Hickey, "Relocating participation within a radical politics of development: Critical modernism and development," in Hickey and Mohan (eds) (see note 13), p. 67. See also, Gaventa (see note 13), p. 31; and N. Kabeer (ed), *Inclusive citizenship: Meanings and expressions*, Claiming citizenship:

- Rights, participation and accountability 1 (London: Zed Books, 2005).
- 101. Mohan and Hickey (ibid.), p. 69.
- 102. Unger (see note 83), p. lxxii.
- 103. This challenges the work of Michel Foucault, for example, for whom power is divorced from both freedom and truth. Foucault's pioneering work "defaced power," focusing on the ways in which power relations are organized and the techniques on which they depend, rather than on the groups and individuals who dominate and are dominated as a result. For Foucault, power operates through individuals, not against them. Human rights is one discourse of truth among many. Thus, for Foucault, there are no truly emancipatory projects for society, whether through human rights or otherwise; it simply does not make sense to speak of people being free to live their own lives. M. Foucault, Power/Knowledge: Selected interviews and other writings 1972-1977 (Brighton [UK]: Harvester, 1980), p. 142; compare Lukes (see note 7) pp. 89-92.
- 104. Lukes (see note 7), p. 113.
- 105. Ibid., p. 113.
- 106. Ibid., p. 114.
- 107. Nussbaum (see note 78), p. 114.
- 108.See Yamin (see note 8).
- 109. A. Przeworski, *Capitalism and social democracy* (Cambridge, UK: Cambridge University Press, 1985), p. 136, cited in Lukes (see note 7), p. 9.
- 110. See Lukes (see note 7), pp. 114-115.
- 111. Ibid., p. 117.