



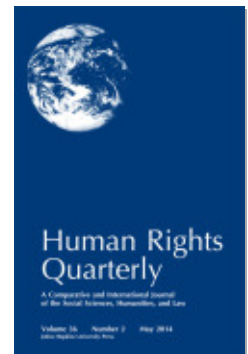
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Taking Equality Seriously: Applying Human Rights Frameworks to Priority Setting in Health

*Alicia Ely Yamin** & *Ole Frithjof Norheim***

ABSTRACT

Health systems communicate and enforce norms relating to equality in many ways, including the ways in which priorities are set at micro and macro levels of decision making. This article examines three common forms of priority setting and how rights-based conceptions of equality may influence them. The relevance of human rights to these processes has grown especially urgent due to the increasing attention that the World Health Organization is placing upon achieving universal health coverage and due to discussion of the post 2015 development agenda.

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I. INTRODUCTION

The foundational principle of human rights is that all human beings are equal in rights, dignity, and worth.¹ Health is a human right in and of itself, and, at the same time, the condition of health reflects the enjoyment of many other human rights. Thus, a human rights framework cannot merely be concerned with inequalities in health care. Rather, a human rights-based approach needs to confront the fact that more than sixty-five years after the Universal Declaration of Human Rights (UDHR) was adopted without dissent, the world is still ravaged by inequalities in power, money, and resources both within and between countries, which have profound implications for the distribution of population health.² As Michael Marmot, Chair of the World Health Organization (WHO) Commission on Social Determinants of Health has stated, “The fact that holders of such power may relinquish it with reluctance must not deter us from pursuing what is just. The fact that . . . social injustice is a matter of life and death needs continuously to be brought to the fore.”³

In public health, there is increasing evidence that social inequality, not just absolute deprivation, is bad for health.⁴ Among rich countries, there is considerable evidence that the more unequal countries produce worse health and quality of life outcomes, and the steeper the gradient of the social ladder, the worse the outcomes are in terms of life expectancy, infant mortality, crime rates, and a host of other indicators.⁵ Thus, the WHO Commission on Social Determinants of Health has suggested that addressing health inequalities requires a two-pronged approach: first, reducing exposures and vulnerabilities linked to position on the social ladder, and second, reducing the social gradient itself.⁶

Historically, human rights law has been most concerned with identifying those who are consistently kept low on the proverbial ladder and with the social relations such as gender, race, and caste that keep them in place. In so doing, the human rights field has highlighted that poverty is not only about

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1. Universal Declaration of Human Rights, *adopted* 10 Dec. 1948, G.A. Res. 217A (III), U.N. GAOR, 3d Sess, at pmb1, U.N. Doc. A/RES/3/217A (1948).
 2. WORLD HEALTH ORGANIZATION (WHO) COMMISSION ON SOCIAL DETERMINANTS OF HEALTH, *CLOSING THE GAP IN A GENERATION: HEALTH EQUITY THROUGH ACTION ON THE SOCIAL DETERMINANTS OF HEALTH* (2008) [hereinafter *CLOSING THE GAP*]; see also MADISON POWERS & RUTH FADEN, *SOCIAL JUSTICE: THE MORAL FOUNDATIONS OF PUBLIC HEALTH AND HEALTH POLICY* (2006); PUBLIC HEALTH, ETHICS, AND EQUITY (Sudhir Anand, Fabienne Peter & Amartya Sen eds., 2004).
 3. Editors, *An Interview with Sir Michael Marmot*, 4 *SOC. MED.* 109, 110 (2009).
 4. See, e.g., *CLOSING THE GAP*, *supra* note 2; ICHIRO KAWACHI & BRUCE P. KENNEDY, *THE HEALTH OF NATIONS: WHY INEQUALITY IS HARMFUL TO YOUR HEALTH* (2002).
 5. See, e.g., RICHARD WILKINSON & KATE PICKETT, *THE SPIRIT LEVEL: WHY MORE EQUAL SOCIETIES ALMOST ALWAYS DO BETTER* (2009).
 6. See Editors, *supra* note 3; *CLOSING THE GAP*, *supra* note 2.

lack of money; it is also about discrimination and disempowerment.⁷ It is invariably women, racial and ethnic minorities, disabled persons, and other marginalized populations who are not only disproportionately represented among the most economically disadvantaged but also, consequently, those whose effective enjoyment of rights is most impaired.⁸ Further, in a human rights framework, the ways in which certain people and populations persistently face deprivations across different spheres of life represent not just inherent vulnerability but active processes of exclusion and marginalization, for which there should be accountability and redress.⁹ In short, there is no question that equality concerns relating to health go far beyond the health system in a human rights framework.

Moreover, social inequalities cannot be the only inequalities with which a rights framework is concerned when applied to health. Kenneth Arrow and others famously criticized the work of John Rawls for not providing a way to determine who is worse off between a very poor person and a slightly less poor person who suffers from ill health.¹⁰ Indeed, Amartya Sen's assertion that income is the wrong space in which to judge inequality seems particularly applicable when considering the demands of a rights-based approach to health. Sen argues instead for evaluating differences in capabilities—"our ability to achieve various combinations of functionings that we can compare and judge against each other."¹¹ Thus, for example, a disabled person with the same income as a non-disabled person does not enjoy the same capabilities because he or she suffers from a "conversion handicap," a differential ability to convert resources into actual opportunities to enjoy good living and to effectively enjoy rights.¹² As Sen's argument implies, relative differences in income can translate into absolute differences in capabilities, or effective enjoyment of rights, including the right to health. What a person has matters less than what a person can do with what he or she has. Capabilities are influenced by individual states of ill health and disability, but they are also heavily influenced by the nature of society and legal frameworks. For example, in countries where access to schools, workplaces, health facilities, and transportation does not accommodate the needs of physically disabled people, their ability to participate on equal terms in society becomes deeply impaired, and so ineluctably, does their health status. Thus, pro-poor policies

7. See, e.g., WILKINSON & PICKETT, *supra* note 5, at 160–62.

8. Effective enjoyment of rights is closely related to Amartya Sen's notion of capabilities. See, e.g., AMARTYA SEN, *INEQUALITY REEXAMINED* (1992); AMARTYA SEN, *COMMODITIES AND CAPABILITIES* (1999).

9. See, e.g., UNITED NATIONS OFFICE OF THE HIGH COMMISSION FOR HUMAN RIGHTS (OHCHR) & WORLD HEALTH ORGANIZATION (WHO), *HUMAN RIGHTS, HEALTH AND POVERTY REDUCTION STRATEGIES* (2008).

10. Kenneth Arrow, *Some Ordinalist-Utilitarian Notes on Rawls's Theory of Justice*, 70 J. PHIL. 245 (1973).

11. AMARTYA SEN, *THE IDEA OF JUSTICE* 233 (2009).

12. *Id.* at 258.

are not enough to address human rights concerns regarding inequalities; policy makers also must consider the factors that underlie the incidence and distribution of diseases and disabilities, as well as the penalty that social choices and institutional arrangements impose.¹³

Even though the realization of a human rights approach to health equality calls for the transformation of society along an array of social determinants of health, it is also true that health systems lie at the center of the right to health.¹⁴ Legitimate claims of entitlements to services and medications, as well as other foundational conditions necessary to promote health must be understood as fundamental rights, and in turn assets of citizenship in a democratic society. In a human rights framework, health systems are far more than delivery apparatus for goods and services. Rather, they are core social institutions, akin to a fair justice system or a democratic political system.¹⁵ As one of the leaders of the Millennium Project Task Force on Child and Maternal Health, Lynn Freedman, writes, “Health systems are part of the very fabric of social and civic life. A new respect for the role of health systems in creating or reinforcing poverty and, conversely, in building a democratic society should be the foundation for policies.”¹⁶ Health systems communicate and enforce values and norms relating to equality in many ways, including: the provision of differentiated or universal entitlements, how both patients and providers are treated within the system, the manner in which services are financed, the extent of social solidarity in resource allocation for health, the degree of transparency and accessibility of pertinent information, and—critically—the ways in which priorities are set at both macro and micro levels of decision making. Indeed, the Director-General of the WHO has asserted that: “Universal health coverage is the single most powerful concept that public health has to offer.”¹⁷

Therefore, this article focuses on priority setting principles and processes as critical ways of implementing equality concerns in health systems. In Part 2, we examine three common forms of priority setting and how rights-based conceptions of equality might play a role in them. In so doing, we look not just at social inequalities, which are themselves complex, but also at other ethical considerations in assigning care, including the severity of a patient’s

13. *Id.* at 259.

14. Paul Hunt & Gunilla Backman, *Health Systems and the Right to the Highest Attainable Standard of Health*, 10 HEALTH & HUM. RTS. 81 (2008).

15. Lynn P. Freedman, *Achieving the MDGs: Health Systems as Core Social Institutions*, 48 DEVELOPMENT 19, 20 (2005); Hunt & Backman, *supra* note 14; Alicia Ely Yamin, *Toward Transformative Accountability: A Proposal for Rights-Based Approaches to Fulfilling Maternal Health Obligations*, 7 SUR INT’L J. HUM. RTS. 95 (2010).

16. Freedman, *supra* note 15, at 20.

17. See Press Release, WHO, 65th World Health Assembly Closes with new Global Health Measures (26 May 2012), available at http://www.who.int/mediacentre/news/releases/2012/wha65_closes_20120526/en/.

condition and the capacity of a patient to benefit from treatment. It is increasingly recognized that priority setting within a health system must include an understanding of the effectiveness of investments across health behaviors, social, economic, and cultural factors, characteristics of the physical and built environment, genetics, and not merely “within the health care domain alone.”¹⁸ However, within the space constraints of this article, the focus is primarily on priority setting with respect to health care. Part 3 discusses why rights-based frameworks call for procedural approaches to priority setting in health, what the minimum requirements of those procedural approaches would entail, and some of the limits to relying on procedural approaches to achieve substantive equality. The aim of this article is not to attempt to outline a monolithic human rights approach to priority setting in health. On the contrary, it seeks to map out some of the questions and challenges we need to confront together from our different disciplinary perspectives if human rights principles and concepts are to be meaningfully incorporated into health priority setting processes. The relevance of human rights to these processes has grown especially urgent due to the increasing attention that is being placed upon achieving universal health coverage by the WHO and in the context of post 2015 development agenda discussions.¹⁹

II. APPLYING HUMAN RIGHTS CRITERIA TO THREE COMMON FORMS OF PRIORITY SETTING

All health care systems engage in some form of priority setting, even in the wealthiest of countries. As the assignment of relative priorities to activities, programs, services, or types of patients necessarily involves the allocation of resources, priority setting is closely linked to rationing, whether explicit or implicit.²⁰ Explicit rationing is achieved through limiting benefits packages. Countries with very different resource capacities, which have defined—if not always implemented—essential health service packages include Uganda, Ethiopia, Tanzania, Nigeria, Mexico, Chile, Israel, Afghanistan, Colombia, and Bangladesh.²¹ Implicit rationing is often done through ability to pay for services, waiting lists, and providers’ prescribing behaviors. Implicit ration-

18. David Kindig & John Mullahy, *Comparative Effectiveness – of What?: Evaluating Strategies to Improve Population Health*, 304 J. AM. MED. ASS’N. 901, 901 (2010).

19. See Editors, *supra* note 3; David B. Evans, Robert Marten & Carissa Etienne, *Universal Health Coverage is a Development Issue*, 380 LANCET 864, 864-65 (2012); see also CLOSING THE GAP, *supra* note 2.

20. KEITH SYRETT, LAW, LEGITIMACY AND THE RATIONING OF HEALTHCARE: A CONTEXTUAL AND COMPARATIVE PERSPECTIVE (2007).

21. WHO, *Essential Health Packages: What Are They For? What Are They For? What Do They Change?*, WHO Service Delivery Seminar Series, Technical Brief No. 2 (3 July 2008).

ing, while often less controversial politically, inherently lacks transparency, and as a result is in practice often discriminatory.²² The issue of how to combine or choose between implicit and explicit rationing is one of several issues that arise as priority setting takes place across very different health care systems with different models for service delivery and financing. Here we distinguish three forms of health care priority setting and evaluate some of their implications from a rights perspective.

A. Priority Setting by Market Mechanisms

Under international law, health, including but not limited to health care, is a right.²³ Health care is recognized as being of special moral importance across numerous philosophical traditions because it is critical to enabling people to enjoy important capabilities, to preserve a range of normal functions and choices, and ultimately to live lives of dignity.²⁴ Consequently, even where we may tolerate many other inequalities, inequalities in health care are of special concern because such care is not merely another commodity to be allocated by the market.²⁵ In General Comment 14, the UN Committee on Economic, Social and Cultural Rights (UNCESCR) stated with respect to states parties' obligations under the International Covenant on Economic, Social and Cultural Rights (ICESCR):

Health facilities, goods, and services must be affordable for all. Payment for health care services, as well as services related to the underlying determinants of health, must be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.²⁶

Thus, uniform fees that pose unduly high burdens on the poor violate equity principles. Arguably, they also substantively discriminate against poor people on the basis of their economic and social situation. The WHO has recognized the need to reduce out-of-pocket payments for health as a critical

22. See SYRETT, *supra* note 20.

23. U.N. Econ. & Soc. Council [ECOSOC], CESCR Committee on Economic, Social and Cultural Rights, *Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights: The Right to the Highest Attainable Standard of Health*, ¶¶ 1, 2, U.N. Doc. E/C.12/2000/4 (11 Aug. 2000) [hereinafter *UN Standard of Health Report*].

24. NORMAN DANIELS, *JUST HEALTH CARE* 103 (1985); Amartya Sen, *Elements of a Theory of Human Rights*, 32 *PHIL. & PUB. AFF.* 315, 329 (2004).

25. See Sen, *Elements of a Theory*, *supra* note 24.

26. See UN Standard of Health Report, *supra* note 23, ¶ 12(b).

priority in improving coverage and in turn, productivity and overall levels of well-being.²⁷

A rights perspective goes further. If health is a right, access to care should be based on need and not ability to pay. Therefore, the financial barriers that are posed by treating health care as merely another commodity make market-based priority setting for essential services simply incompatible with a rights framework. Out-of-pocket payments for services can not only create barriers to accessibility of services, but can also severely affect a patient's entire family.⁸ Indeed, protection from financial risk should surely be a function of the health system. In practice, unfortunately, lack of availability, as well as accessibility, both physical and economic—interrelated elements of a right to health under CESCR General Comment 14—contribute to large inequalities in health, even in middle and high income countries that rely heavily on prices set by the market. As evidence of this, in the United States in 2007, health care costs accounted for over sixty percent of all bankruptcies.²⁸

In a number of countries courts have struck down barriers to care derived from market-based and financial considerations. In India, for example, the Delhi High Court has held that private health care facilities must provide care to the indigent as a matter of right.²⁹ In Colombia, the Constitutional Court has not only struck down financial barriers to accessing care based on the right to health, but has also made clear that health policies and programs must be aligned with Article 13 of the Constitution regarding the adoption of measures in favor of marginalized groups.³⁰

On the other hand, in the Chaoulli case, the Canadian Supreme Court upheld a challenge to legislation in Quebec that prohibited private insurance for medically necessary hospital and physician services.³¹ The Court agreed with the appellants, who claimed that the prohibition deprived them of access to health services that are not subject to the long waiting times of the public Canadian Medicare system and that such deprivation violated their rights under both the Canadian and Quebec Charters.³²

Aeyal Gross, Professor of Law at Tel Aviv University who has studied the case in depth, has cited fears that the decision would “result in the possible creation of a two-tier Charter rights structure [that] rather than guaranteeing a right to publicly funded health care guarantees a right to buy, if one is

27. See CLOSING THE GAP, *supra* note 2.

28. David U. Himmelstein, Deborah Thorne, Elizabeth Warren & Steffie Woolhandler, *Medical Bankruptcy in the United States, 2007: Results of a National Study*, 122 AM. J. MED. 741, 741-42 (2009).

29. All India Lawyers Union (Delhi Unit) v. Govt. of Nct of Delhi and Others, Delhi H.C., WP(C) No. 5410/1997 (2009).

30. Constitutional Court of Colombia. Judgment SU 225/98 (1998), Magistrado Ponente: Eduardo Cifuentes Muñoz.

31. Chaoulli v. Quebec (Attorney General) [2005] 1 S.C.R. 791 (Can.).

32. *Id.* (The case was decided on the basis of the right to life and security, not a right to health per se).

able, private insurance covering ‘medically necessary’ services.”³³ However, nine years after the case it appears not to have substantially undermined the Canadian Medicare system or the fundamental principle that there should be equal access to essential care based on need. Unlike in some jurisdictions, the government reacted to the judgment by investing increased funds in the public system in order to attempt to curtail waiting times for everyone. Further, there is evidence from the judgment of Judge Marie Deschamps that fostering this kind of dialogue between the legislature and judiciary in order to redress some of the inadequacies of democratic politics was indeed what the Court sought.³⁴

It is impossible to consider a health system’s commitment to equal availability, accessibility, acceptability, and quality by examining service delivery alone; the financing of health systems is central to equality and the right to health.³⁵ Four principal forms of funding exist for health systems: taxation, including social insurance schemes, private insurance, out-of-pocket user charges, and voluntary donations.³⁶ There are no pure systems. Even in countries with robust, publicly financed health care systems, such as Japan, the United Kingdom, Canada, and the Scandinavian countries, some services are implicitly rationed by the price mechanism.³⁷ Systems heavily based on general progressive income taxation tend to be the most egalitarian, with government percentage of expenditure on health, rather than total expenditure, demonstrating government commitment.³⁸

Nevertheless, social health insurance tends to work only for those employed in the formal economy, while leaving out those not in the formal sector. In Colombia in 2008, the Constitutional Court adjudged the differentiated insurance schemes for those in the formal economy and those in the informal economy, or earning less than twice the minimum wage, as constituting unconstitutional discrimination.³⁹ By 2013, Colombia had

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33. Aeyal M. Gross, *The Right to Health in an Era of Privatization and Globalization: National and International Perspectives*, in IMPLEMENTING SOCIAL RIGHTS 289, 312 (Daphne Barak-Erez & Aeyal Gross eds., 2007); see dissent in *Chaoulli v. Quebec*, *supra* note 31, ¶ 164.
 34. See SYRETT, *supra* note 20, at 204 (citing Sujit Choudhry, *Worse Than Lochner?*, in ACCESS TO CARE, ACCESS TO JUSTICE: THE LEGAL DEBATE OVER PRIVATE HEALTH INSURANCE IN CANADA 95 (Colleen Flood, Kent Roach & Lorne Sossin eds., 2005)).
 35. See UN Standard of Health Report, *supra* note 23, ¶ 12(a)-(d).
 36. See CLOSING THE GAP, *supra* note 2.
 37. Examples vary, but low-priority services such as removal of tattoos, some forms of plastic surgery, in-vitro fertilization, dental care for adults, medications for non-chronic diseases (such as allergic rhinitis or flu) are generally financed by copayment or fully out of pocket. RUDOLF KLEIN, PATRICIA DAY & SHARON REDMAYNE, *MANAGING SCARCITY: PRIORITY SETTING AND RATIONING IN THE NATIONAL HEALTH SERVICE 8* (1996) *Poverty, Social Exclusion and Health Systems in the WHO European Region*; ANGELA COULTER & CHRIS HAM, *THE GLOBAL CHALLENGE OF HEALTH CARE RATIONING* 42 (2000).
 38. JAN ABEL OLSEN, *PRINCIPLES IN HEALTH ECONOMICS AND POLICY* 124 (2009).
 39. WHO, *How Does Litigation Affect Health Financing?*, The World Health Report, Technical Brief No. 15 (2010) (citing Constitutional Court of Colombia. *Sentencia T-760/08* (2008) Magistrado ponente: Manuel José Cepeda Espinosa [hereinafter *Litigation and Health Financing*]).

devised new health laws, as well as adopted other reforms to its system, which among other things, created a unified benefits package.

However, the extent to which a rights framework prohibits intrusion of the price mechanism into allocation of care remains contested. As noted above, all systems include some use of the market for implicitly rationing non-essential services. Yet drawing the line between essential and non-essential care is not a straightforward exercise in many cases. Under different circumstances, the same procedures could be classified as necessary for a dignified life or deemed superfluous. Take, for example, breast or facial reconstruction versus cosmetic enhancement. Dental care, which is often excluded from explicit health plans, can in fact result in issues of life or death, as gum infections can spread to the heart and loss of teeth can affect nutrition. Viagra can be used to treat pulmonary hypertension as well as impotence.⁴⁰ Further, what is essential to enable a person to maintain a normal range of opportunities is deeply informed by his or her occupation and geographical context.

A human rights framework does not provide clear lines as to where those boundaries are to be drawn. Courts assessing such questions have responded in widely varying ways. For example, South Africa's Constitutional Court has chosen to assess the "reasonableness" of governmental decisions to include or exclude care and Colombia's Constitutional Court has followed a "minimum core" approach mandating immediate inclusion of services in the obligatory insurance plan as well as certain additional services, and consigning other services to progressive realization in accordance with "maximum available resources."⁴¹

Rather, they are invariably the product of social negotiations that are deeply contextualized, based both on social values and norms in a given society as well as on clinical and economic considerations. However, as discussed below, taking seriously the equality demands underlying a rights framework does require justification for decisions regarding the aspects of care deemed permissibly market-allocated, together with opportunities for meaningful public deliberation about those choices.

B. Priority Setting in National Health Plans

The adoption and implementation of a national plan of action constitutes a core obligation of states parties to the ICESCR, according to the UNCESCR,

40. Christopher F. Barnett & Roberto F. Machado, *Sildenafil in the Treatment of Pulmonary Hypertension*, 2 VASC. HEALTH RISK MGMT. 411 (2006).

41. *Soobramoney v. Minister of Health (KwaZulu-Natal)* 1998 (1) SA 765 (CC)(S. Afr.); *Minister of Health v. Treatment Action Campaign (TAC)* 2002 (5) SA 721 (CC)(S. Afr.); see KLEIN, DAY & REDMAYNE, *supra* note 37.

which asserts that such a plan of action and concomitant strategy must be “based on epidemiological evidence and address the health concerns of the whole population, and shall be devised, and periodically reviewed, on the basis of a participatory and transparent process [and] they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored.”⁴² The Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Morbidity and Mortality, a 2012 resolution from the UN Human Rights Council, also calls for a national plan of action and details what should be included in the plan from a human rights perspective, including essential medicines and services in accordance with international guidelines.⁴³ Further “the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.”⁴⁴

Virtually all countries regularly develop national health plans in which they identify broad priority strategies and areas such as preventive health programs, including immunizations, screening, and blood pressure control, HIV care and treatment programs, women’s health programs, children’s health programs, mental health programs, health programs for minority populations, and other related programs.⁴⁵ The evaluation of what is contained in—and omitted from—national plans of action reveals much about a health system’s values relating to equality, as well as the adequacy of public policies. Subjecting plans of action to public scrutiny and requirements of justification, although frequently not done, is essential from a rights perspective.⁴⁶ It is often the case that the effective enjoyment of the right to health requires not one action, such as the dispensing of a medication, but rather an entirely different chain of decision making, beginning with the plan of action. For example, in many countries plans of action relating to maternal health omit strategies for cultural adaptation of birthing facilities or translation into indigenous languages.⁴⁷ Plans may rely upon mobile units to reach dispersed and remote communities in the event of obstetric emergencies,

42. See UN Standard of Health Report, *supra* note 23.

43. UN Human Rights Council, *Technical Guidance on the Application of a Human-Rights Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Morbidity and Mortality*, U.N. Doc. A/HRC/21/22 (2 July 2012) [hereinafter *Technical Guidance*].

44. See UN Standard of Health Report, *supra* note 23, ¶ 43(f); *Technical Guidance*, *supra* note 43.

45. US DEPT. OF HEALTH & HUMAN SERVICES, NATIONAL HEALTHCARE QUALITY AND DISPARITIES REPORT 2012 (2012).

46. See *Technical Guidance*, *supra* note 43.

47. Sabine Gabrysch, et al., WHO, *Cultural Adaptation of Birthing Services in Rural Aya-cucho*, Peru, 87 BULL. WHO 724 (2009), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2739914/>.

but may fail to consider the absence of reliable communication networks or the non-feasibility of road travel at night in zones of armed conflict. Similarly, HIV plans may make no provisions to address stigma faced by sex workers, injection drug users, or men who have sex with men (MSM), or may fail to provide condoms or lubricants through accessible means to these populations. In effect, such plans of action are discriminatory and fail to meet human rights standards.

Similarly, measuring progress on national plans of action must take into account disparities from a human rights perspective.⁴⁸ UNCESCR and the Committee on the Rights of the Child have both noted that human rights law requires that routinely collected health data be disaggregated along lines of gender, race, ethnicity, and even income quintile.⁴⁹ Moreover, a variety of human rights documents call for special consideration for marginalized and disadvantaged groups.⁵⁰

Therefore, from a human rights perspective, we must determine whether socially disadvantaged groups are faring better or worse.⁵¹ However, despite the fact that equality is, as a general rule, better for population health, and that more social equality appears to facilitate economic growth in the long run, there can be deep tensions between health maximization strategies and those focused on equality and distributive effects.

Take for example a middle-income country, such as Peru, Brazil or Colombia, where the majority of maternal deaths are concentrated in urban and peri-urban areas among the working poor, but in which inhabitants of remote rural areas have far higher maternal mortality rates.⁵² These poor campesina women, who are often of indigenous or Afro descent, face multiple dimensions of exclusion—based on gender, ethnicity, race, class, and in some cases, language. In addition to poor access to health care, they often also lack access to education, adequate water and sanitation, employment, and land rights.⁵³

Meaningful concern for health equality would seem to demand that even if social determinants cannot be equalized quickly, the campesina women at

48. Paula Braveman and Sofia Gruskin have stated, for example, that: "Routine assessment of potential health implications for different social groups should become standard practice in the design, implementation and evaluation of all development policies;" Paula Braveman & Sofia Gruskin, *Poverty, Equity, Human Rights and Health*, 81 BULL. WHO 539 (2003).

49. *General Comment No. 15 (2013) on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24)*, Comm. Rts. Child, U.N. Doc. CRC/C/GC/15 (2013) ¶ 22.

50. See OHCHR & WHO, *supra* note 9; see Technical Guidance, *supra* note 43.

51. See Technical Guidance, *supra* note 43.

52. AMNESTY INT'L, *FATAL FLAWS: BARRIERS TO MATERNAL HEALTH IN PERU* (2009), available at <http://www.amnesty.org/en/library/asset/AMR46/008/2009/en/442a4678-9f6d-4f91-9045-3c47198144d7/amr460082009eng.pdf>.

53. *Id.*

least should have equal access to family planning, skilled birth attendance, emergency obstetric care, and referral networks, which have been shown to be the pillars of an effective strategy to reduce maternal mortality.⁵⁴ Indeed, in a landmark decision, *Alyne da Silva Pimentel v. Brazil*, the UN Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) found precisely that these intersecting forms of discrimination—on the basis of class, race, and gender—faced by a woman of Afro descent called for reallocation of resources and planning by the government of Brazil.⁵⁵ However, redressing this equity gap implies more than merely formal equality regarding resources; providing women in remote or marginalized areas with anywhere near an equal claim to care as urban women will require not the same but far greater resources per person, simply because factors such as infrastructure, transportation, and communications staffing need to be ramped up. And, if budgets remain fixed—which of course they need not—the result will almost certainly be that progress on achieving the aggregate goal will not be accomplished as fast. That is, more women will likely die, at least in the short and medium term.

It is worth noting that these dilemmas are not unique to health or social rights generally; we need only substitute access to justice for access to care to see that achieving substantive equality with respect to civil and political rights is equally complex. A government strategy that seeks to increase access to justice for the greatest number of people by building courthouses and funding public defenders' and judges' positions in urban areas—where more absolute numbers require such access—would never pass muster from a human rights perspective. The provision of meaningfully equal access to justice for people in poor, remote communities also requires infrastructure, translation services, and so forth. In practice, it requires more than formal, or one-to-one, equality with respect to investment.⁵⁶ Moreover, we readily tolerate certain inefficiencies in civil and political rights, and in the institutional systems we use to provide them, to preserve people's dignity. For example, the notion that underlies many of the evidentiary rules in the US criminal justice system—that it is better to let a hundred guilty persons go free than to imprison one innocent person—is based on the fundamental

54. Lynn P. Freedman, Wendy J. Graham, Ellen Brazier, et al., *Practical Lessons from Global Safe Motherhood Initiatives: Time for a New Focus on Implementation*, 370 *LANCET* 1383 (2007).

55. Comm. Elim. Disc. Women, (CEDAW), 49th Sess., 11-29 July 2011, Views of the Committee on the Elimination of Discrimination against Women under article 7, paragraph 3, of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women Concerning Communication No.20/2008, U.N. Doc CEDAW/C/49/D/17/2008 (2011).

56. Kenneth Roth, *Defending Economic, Social and Cultural Rights: Practical Issues Faced by an International Human Rights Organization*, 26 *HUM. RTS. Q.* 63 (2004).

offense to human dignity that arbitrary loss of personal freedom entails.⁵⁷ If the human rights community has generally avoided delving into the programmatic and budgetary implications of demands to ensure equal access to civil and political rights, however, it cannot do so with respect to economic and social rights, such as health.

UNCESCR's General Comment 14 does not make a direct claim for equality in access to care. Rather, it imports the concept of equity from the health and development domains, setting out a basic obligation to ensure an "equitable distribution of health facilities, goods, and services."⁵⁸ However, equity is not a uniformly defined concept in the health and development domains.⁵⁹ Clearly, not all health inequalities constitute health inequities. For example, greater investment should not be placed in men's as opposed to women's health in developed countries merely because women have longer life expectancies. To determine which inequalities constitute inequities from a human rights perspective, we need to examine how they are produced and, in turn, whether governments and other actors can be held accountable for redress.

Goren Dahlgren and Margaret Whitehead's famous argument that "health inequalities count as inequities when they are avoidable, unnecessary and unfair" does not get us terribly far, because there is no consensus as to what is avoidable, unnecessary, and unfair.⁶⁰ For example, an equitable distribution of health facilities, goods, and services that could address maternal mortality, among other things, surely calls for more than merely establishing a threshold minimum in light of available resources under human rights law.⁶¹ But how much more?

Some have suggested that, at a minimum, equity requires a Rawlsian maxi-min approach to equality—ensuring that the worst off benefit as much as possible from any allocation of social institutions and resources.⁶² For example, an equitable distribution might be one which provides greatest access to a certain package of "health facilities, goods and services" in rural provinces with high indigenous or other minority populations, even if

57. RONALD DWORKIN, *JUSTICE FOR HEDGEHOGS* (2011).

58. See UN Standard of Health Report, *supra* note 23, ¶ 43(e).

59. *Id.*

60. GÖRAN DAHLGREN & MARGARET WHITEHEAD, *POLICIES AND STRATEGIES TO PROMOTE SOCIAL EQUITY IN HEALTH. BACKGROUND DOCUMENT TO WHO—STRATEGY PAPER FOR EUROPE* (1991); Ole Frithjof Norheim & Yukiko Asada, *The Ideal of Equal Health Revisited: Definitions and Measures of Inequity in Health Should be Better Integrated with Theories of Distributive Justice*, 8 *INT'L J. EQUITY IN HEALTH* 40 (2009).

61. The concept of equity is supplemented by the concept of a minimum level under human rights law. That is, there should be at least a minimum level of obstetric services. UN process indicators provide content to this idea. See Alicia Ely Yamin & Deborah P. Maine, *Maternal Mortality as a Human Rights Issue Under International Law*, 21 *HUM. RTS. Q.* 563, 576 (1999).

62. JOHN RAWLS, *A THEORY OF JUSTICE* (1971). See also, LARRY S. TEMKIN, *INEQUALITY* (1993).

the better-off segments of the population in the capital city receive a more extensive package of goods and services. In many countries, this would be a huge advance for the well-being and mortality rates of poor and marginalized women, but it is far from substantive equality. Indeed, relative inequality could increase under such a scheme.

These are complex challenges and human rights law does not provide simple formulas for how to address the competing concerns that countries face in practice. However, if human rights frameworks are to be meaningfully integrated into national health plans and evaluation, they must go beyond the announcement of abstract principles and begin to grapple with tensions between equality claims and aggregate advances. In turn, human rights advocates will need to articulate the varied dimensions of equality that are important from a human rights perspective and how they relate to concepts of equity in priority setting.

C. Evidence-Based Priority Setting

As critical as they are, national plans of action are only a starting point for ensuring that both equality and equity are adequately considered in priority setting. They are necessarily broad and must be accompanied by other priority setting mechanisms to enable decisions regarding different clinical interventions. The need for evidence-based priority setting stems from the fact that many forms of old and new technologies—defined broadly to include all types of preventive, curative, and rehabilitative services—are widely used despite lack of good quality evidence about their effectiveness. In response, many high and middle income countries monitor and evaluate the introduction of new service modalities, such as costly new cancer drugs or technical procedures, through health technology assessments, which are aimed at ensuring that new technologies have been proven effective.⁶³ Countries including Mexico, the United States, the United Kingdom, The Netherlands, Germany, Sweden, Denmark, Norway, Finland, Australia, and New Zealand have all institutionalized health technology assessments.⁶⁴

The standards of documented effectiveness vary among countries and systems.⁶⁵ Evidence from randomized clinical trials, or other types of studies where evidence of this standard is lacking, provides the main basis for

63. Steven D. Pearson & Michael D. Rawlins, *Quality, Innovation, and Value for Money: NICE and the British National Health Service*, 294 J. AM. MED. ASSOC. 2618-19 (2005).

64. ALISON WEIGHTMAN, SIMON ELLIS, ADRIENNE CULLUM, LESLEY SANDER, & RUTH TURLEY, *GRADING EVIDENCE AND RECOMMENDATIONS FOR PUBLIC HEALTH INTERVENTIONS: DEVELOPING AND PILOTING A FRAMEWORK* (2005); see Pearson & Rawlins, *supra* note 63.

65. CHRISTOPHER HAM & GLENN ROBERT, *REASONABLE RATIONING: INTERNATIONAL EXPERIENCE OF PRIORITY SETTING IN HEALTH CARE* (2003).

priority setting decisions regarding clinical interventions.⁶⁶ Systematic reviews, including meta-analyses, which synthesize evidence from multiple, separate studies that address related hypotheses, are also used in a number of countries.⁶⁷ A meta-analysis theoretically provides a more powerful estimate of the true effect size than the effect size derived in a single study.⁶⁸

Almost all countries that conduct such health technology assessments include or add evidence on cost effectiveness in their assessment. The United States is an exception. In the United States, Medicare, even after the Patient Protection and Affordable Care Act, does not: such evidence was explicitly precluded in the legislation.⁶⁹ The National Institute of Health and Clinical Excellence in the United Kingdom (NICE) is probably the institution that most explicitly uses cost effectiveness analysis as evidence for service recommendations. NICE applies an informal threshold for cost per Quality Adjusted Life Years (QALY) gained of approximately £ 20,000–30,000.⁷⁰ A QALY is a year of life adjusted for its quality or its value, where a year in perfect health is considered equal to 1.0 QALY and the value of a year in ill health would be discounted. The quality adjustment is typically based on patients' and laypersons' stated preferences about the health state in question, based upon surveys. Stated preferences clearly can vary substantially among different countries and social contexts, but often the information on which QALYs are calculated is not available for every country. Therefore, international calculations typically stand as a proxy for the preferences within a given country, which can be problematic.⁷¹

Indeed, the degree to which the assumptions built into QALYs are transparent and readily accessible to the public affect whether they are acceptable priority setting tools from a rights perspective. In practice, almost all countries that engage in evidence-based priority setting do accept evidence on QALYs and other forms of cost effectiveness as relevant. However, they also generally add other types of information. It is also important to understand that QALYs are used to determine allocations of resources among services, such as treatment for one cancer versus another, or the comparative effectiveness

66. David L Sackett, William M. C. Rosenberg, J. A. Muir Gray, R. Brian Haynes & W. Scott Richardson, *Evidence Based Medicine: What it is and What it Isn't*, 312 BRIT. MED. J. 71 (1996).

67. Elliott M. Antman, Joseph Lau, Bruce Kupelnick, Frederick Mosteller & Thomas C. Chalmers, *A Comparison of Results of Meta-Analyses of Randomized Control Trials and Recommendations of Clinical Experts: Treatments for Myocardial Infarction*, 268 J. AM. MED. ASSN. 240 (1992); C.D. Mulrow, *Rationale for Systematic Reviews*, 309 BRIT. MED. J. 597 (1994); J.C. Bailar, 3rd, *The Promise and Problems of Meta-Analysis*, 337 N. ENGL. J. MED. 559 (1997).

68. Mulrow, *supra* note 67.

69. Peter J. Neumann, Allison Rosen & Milton C. Weinstein, *Medicare and Cost-Effectiveness Analysis*, 355 NEW ENG. J. MED. 1516 (2005).

70. *Id.*

71. *Id.*

of interventions for a particular disease—they are not used to set priorities among individual patients.⁷²

Some argue that a single quantitative scale for comparing health status, and in turn, inequalities in that status, is incompatible with non-utilitarian theories of justice. For example, from the perspective of Sen's capability theory, Jennifer Prah Ruger argues,

one cannot quantifiably compare one individual's inability to hear or see with another's inability to bear children or to walk. These reductions in individuals' capabilities for functioning are qualitatively different and different people will have widely diverging views on which functional capability reduction is better or worse than the other.⁷³

Even if the utility of QALYs in priority setting is accepted, concern for equality in a rights framework raises important questions with respect to how QALYs are applied in practice within health systems. That is, when blindly applied, cost effectiveness analysis provides no special priority to patients with the most severe illnesses and does not consider effects on marginalized and vulnerable populations. Therefore, cost effectiveness should never be the sole criterion for priority setting in a rights framework.

Despite the pitfalls of over-reliance on cost effectiveness, we also believe that failure to take into account cost effectiveness at all can also lead to unjust results and exacerbate inequalities. Ethicists have identified the problem of the bottomless pit or voracious need, whereby a few people with very severe and costly conditions, who may in fact receive minimal clinical benefits, disproportionately absorb resources, depriving many others of needed care. The percentage spent on the last two years of life, and in particular the last six months of life, in the US health care system is often cited as an example of how failure to integrate cost effectiveness analysis into system-wide health care priority setting can produce such a perverse effect.⁷⁴ In light of the disproportionate unmet health needs of younger members of racial and ethnic minority groups who are reliant upon the much more austere and variable provisions of Medicaid, for example, this distortion of health spending priorities arguably undermines health justice in the United States.

But these are not easy questions. Indeed, dementia care poses particular challenges. Dementia care costs are projected to rise dramatically in the next decades in the United States, as well as elsewhere. In a 2013 study led by Michael D. Hurd, the projected costs associated with dementia care are

72. See SYRETT, *supra* note 20, at 89.

73. Jennifer Prah Ruger, *Health and Social Justice*, 364 LANCET 1075, 1079 (2004).

74. Donald R. Hoover, Stephen Crystal, Rizie Kumar, Usha Sambamoorthi & Joel C. Cantor, *Medical Expenditure During the Last Year of Life: Findings from the 1992-1996 Medicare Current Beneficiary Survey*, 37 HEALTH SERV. RES. 1625 (2002).

expected to more than double from \$159 billion in 2010 to \$379 billion in 2040.⁷⁵ Such care cannot be deemed to be cost effective as long as there is no way to prevent, cure, or effectively treat dementia-related conditions. Nevertheless, the elderly are not disposable and the need for care in old age is universal. In societies where paid care is not available for dementia and other long-term conditions, there is often a disproportionate burden placed upon women for unpaid care, which produces another cascade of discriminatory effects. All societies need to find better ways to pool resources, as well as to structure their work forces, to insure against and fund such care.⁷⁶

In practice, most countries combine cost effectiveness analysis with other considerations, such as severity of untreated disease and magnitude of the clinical health benefit. That is first, who has the worst lifetime health in the absence of treatment, and second, who has the greatest health benefit if provided with treatment? These two types of information can provide the decision maker with important information as to what the distributional impact will be for the affected population. Giving some priority to those who will lose the most health without the intervention will reduce a certain kind of inequity in distribution. If the clinical benefit is significant, a human rights framework requires that everyone in society should have a fair chance to receive it even if it is more expensive to provide access to certain people than others. For example, based on a right to health analysis, the jurisprudence of the Colombian Constitutional Court has held that life-saving surgery or treatment, such as chemotherapy, should be available to everyone, even if making that available to people who live in some areas of the country requires undertaking substantial costs relating to transportation of patients to adequate facilities and infrastructure development in the remote areas.⁷⁷

In short, health equality in a rights framework is a more multi-dimensional concept than equality with respect to many other rights. An analysis of equality in health must consider social inequalities, but also other factors such as severity of illness. Cost effectiveness cannot be the primary driver of health resource allocations in a rights framework. Nevertheless, nor can a rights framework be blind to empirical questions of clinical effectiveness and cost effectiveness. To do so leads to clearly inappropriate allocations of resources that potentially deprive large populations of their health rights

75. Michael D. Hurd, Paco Martorell, Adeline Delavande, Kathleen J. Mullen & Kenneth M. Langa, *Monetary Costs of Dementia in the United States* 368 *NEW ENG. J. MED.* 1326, 1332 (2013).

76. Special Rapporteur on Extreme Poverty and Human Rights, *Report of the Special Rapporteur on Extreme Poverty and Human Rights*, *HUM. RTS. COUNCIL*, U.N. DOC A/HRC/23/36 (2013) (by Magdalena Sepúlveda Carmona); *Montevideo Consensus on Population and Development*, U.N. Economic Commission for Latin America and the Caribbean (ECLAC), ¶¶ 18-32 (2013).

77. See *Litigation and Health Financing*, *supra* note 40.

and produce or exacerbate certain inequalities. We need not accept cynical mantras of scarcity that are so often proffered with respect to resources for health, as well as other social spending. Nonetheless, it is unethical as well as ill advised to ignore the reality of rationing in all health systems. Indeed, as so much of health is due to social determinants, calling for further spending on medical care may be counterproductive in achieving greater social justice, and enjoyment of economic and social rights generally, in a society.

III. PROCEDURAL APPROACHES TO PRIORITY SETTING: THE NEED FOR PUBLIC DELIBERATION AND INSTITUTIONALIZATION

As is evident from the discussion above, priority setting always has ethical, normative, and technical dimensions. There is no single answer as to how much priority to give the worst off in terms of lifetime health deprivation or how much weight to assign to the magnitude of a health benefit from a given treatment. Therefore, while acknowledging the importance of evidence for better priority setting, many countries and institutions also rely on procedural approaches to achieve equitable outcomes. In the United Kingdom, for example, NICE has established a “citizen’s council” that provides input on issues relating to ethical values.⁷⁸ Michael Rawlins, the director of NICE, has argued that the public’s perception of NICE’s decision making as legitimate and fair is critical to its success in setting priorities.⁷⁹

Interest in democratic procedural approaches may be growing today primarily because purely evidence-based approaches only partially respond to the pressure from a combination of rising health care costs, diffusion of new technology, stakeholder pressure, and intense media coverage of individual cases.⁸⁰ However, from a rights perspective, they also embed important democratic processes and values into health systems. In fact, some courts have recognized that a process for fair deliberation is required to ensure that the priority setting decisions are legitimate in rights terms.⁸¹ We therefore consider the underlying need for procedural approaches, together with one very prominent framework for establishing a fair procedural priority setting process, “Accountability for Reasonableness,” which we see as consistent with rights-based approaches.

78. Paul Dolan, Aki Tsuchiya, & Allan Wailoo, *NICE’s Citizen’s Council: What do We Ask Them, and How?* 362 *LANCET* 918, 919 (2003).

79. Editorial, “*Cobertura de Salud en Colombia es una de las mas Altas del Mundo en este Momento*”: *Mincomercio*, PORTAFOLIO (Colombia) (21 Apr. 2010), available at http://www.portafolio.co/detalle_archivo/CMS-7640652.

80. PETER SINGER, *HOW ARE WE TO LIVE? ETHICS IN AN AGE OF SELF-INTEREST* (1997).

81. See Litigation and Health Financing, *supra* note 39.

A. Principles and Criteria for Priority Setting

Substantial principles for fair priority setting are derived from two key objectives: efficiency and equity in the distribution of health and health care.⁸² Often, these objectives are entirely compatible: services that both improve equity and maximize health should clearly have high priority. There is increasing evidence, for example, that focusing child health investments on the worst off in society produces the largest health benefits at the population level.⁸³

Sometimes, however, just as in the discussion of national health plans above, the two objectives may point in different directions with respect to priority setting within the context of clinical care and may need to be balanced against each other. Although people disagree about how much weight the different concerns should have when they conflict, there are criteria that all theories of resource allocation in health care recognize.⁸⁴ This set of accepted criteria states that at the level of a health program the priority of a given condition and its intervention should be assessed in terms of: the severity of disease, if untreated or given standard care, the clinical effectiveness of the intervention, the cost effectiveness of a specified intervention, and the strength of evidence on all of these factors.⁸⁵ This information can, in concrete cases, be formulated in terms of characteristics of the patient, the condition of the patient, and the health intervention in question. It is important to note that normatively irrelevant criteria for priority setting include prohibited grounds of discrimination under international law, such as race, ethnicity, religion, sex, social status, sexual orientation, and physical or mental disability.⁸⁶

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82. Alan Williams, *Intergenerational Equity: An Exploration of the "Fair Innings" Argument*, 6 J. HEALTH ECON. 117, 117–18 (1997); Alan Williams, *QALYs and Ethics: A Health Economist's Perspective*, 43 SOC. SCI. & MED. 1795 (1996); ERIC NORD, *COST-VALUE ANALYSIS IN HEALTH CARE: MAKING SENSE OUT OF QALYs* 23–24 (1999); Erik Nord, Jose Luis Pinto, Jeff Richardson, Paul Menzel, & Paul Ubel, *Incorporating Societal Concerns for Fairness in Numerical Valuations of Health Programmes*, 8 HEALTH ECON. 25, 38 (1999); Norman Daniels, *Four Unsolved Rationing Problems: A Challenge*, 24 HASTINGS CENT. REP. 27, 27–29 (1994); Norman Daniels & James Sabin, *Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers*, 26 PHIL. & PUB. AFF. 303, 323–25 (1997); THE GLOBAL BURDEN OF DISEASE AND INJURY SERIES, VOL. 1: A COMPREHENSIVE ASSESSMENT OF MORTALITY AND DISABILITY FROM DISEASES, INJURIES, AND RISK FACTORS IN 1990 AND PROJECTED TO 2020 61–62 (Christopher J.L. Murray & Alan D. Lopez eds., 1996); Alan Williams, *Ethics and Efficiency in the Provision of Health Care*, in PHILOSOPHY & MEDICAL WARFARE (J.M. Bell & Susan Mendus eds., 1988).
83. Mickey Chopra et al., *Strategies to Improve Health Coverage and Narrow the Equity Gap in Child Survival, Health, and Nutrition*, 380 LANCET 1331, 1338 (2012).
84. Chris Ham, *Health Care Rationing*, 310 BRIT. MED. J. 1483 (1995); CHRISTOPHER HAM & LOUISE LOCOCK, *INTERNATIONAL APPROACHES TO PRIORITY SETTING IN HEALTH CARE: AN ANNOTATED LISTING OF OFFICIAL AND SEMI-OFFICIAL PUBLICATIONS, WITH A SELECTION OF KEY ACADEMIC REFERENCES* (1998); see Coulter & Ham, *supra* note 37.
85. See Coulter & Ham, *supra* note 37.
86. General Comment No. 20, *Non-Discrimination in Economic, Social and Cultural Rights*, adopted 2 July 2009, U.N. ESCOR, Comm. on Econ., Soc. & Cult. Rts., 42nd Sess., ¶ 15, ¶ 15, U.N. Doc. E/C.12/GC/20 (2009).

However, differentiation based on prohibited grounds is not always unreasonable. For example, UNCESCR's General Comment 20 states that age falls under "other" prohibited grounds of discrimination in several contexts, referring both to old age and to young age.⁸⁷ Yet, advanced age is used as a criterion for greatly increasing insurance premiums in some health systems that are based upon private insurance.⁸⁸ Age also factors into priority setting in allocating scarce interventions.⁸⁹

In a rights framework, the latter is probably permissible, while the former is not. That is, if health and health care are accepted as matters of special moral importance—as they must be if they are asserted as rights—then by definition the market cannot solely set access to care.⁹⁰ Just as women of reproductive years have greater health needs than men, so too do elderly people. And actuarial fairness—determining payment according to the level of risk faced—is not the equivalent of fairness based on an equal right to care. Moreover, age-related discrimination in insurance premiums probably undermines the aim of pooling risk to insure against catastrophic costs such as dementia care, as mentioned above.

On the other hand, as also suggested above, when allocating scarce interventions or services—whether a transplant or a vaccine in limited supply—a plausible "fair innings" argument can be made that younger people have a greater claim because they are worse off if they die young than older people who are closer to or have surpassed a normal life span.⁹¹ Thus, age is not a sufficient basis upon which to allocate such resources or interventions, but it does seem one that is ethically relevant to consider under certain circumstances.⁹² An adequate rights framework, therefore, can neither consign certain groups to being expendable nor ignore intergenerational equity, including the equal opportunity of younger cohorts of people to live as long as older people already have.⁹³

87. *Id.*

88. The Senate Bill passed on 19 Oct. 2009 allows older people to be charged as much as twice the premiums of younger people. 111 S. 1796, 111th Cong. (2009).

89. See UN Standard of Health Report, *supra* note 23, ¶ 25.

90. See Sen, *Elements of a Theory*, *supra* note 24.

91. Williams, *Intergenerational Equity*, *supra* note 82.

92. See Govind Persad, Alan Wertheimer & Ezekiel Emmanuel, *Principles for Allocation of Scarce Medical Interventions*, 373 LANCET 423, 425-26 (2009).

93. Broadening from specific interventions to resources, Norman Daniels suggests the "prudential lifespan account," which assumes we all age and that resources should be allocated as if we all go through different life stages. See NORMAN DANIELS, *JUST HEALTH: MEETING HEALTH NEEDS FAIRLY* 178 (2008). See also Ole Frithjof Norheim, *Priority to the Young or to Those with Least Lifetime Health?* 10 AM. J. BIOETHICS 60, 61 (2010).

B. Unresolved Problems in Priority Setting

Despite some agreement on a theoretical level about the importance of efficiency and equity, there remains substantial disagreement on what characterizes acceptable priority strategies. Norman Daniels, a Rawlsian ethicist, has identified what he calls four “unsolved rationing problems” in health care, which are deeply related to equality concerns.⁹⁴ The first challenge is the priorities problem: how much priority should a society give to the most severely ill patients compared to patients who are less ill but who can be helped more for lower costs?⁹⁵ In medical practice it is a well-established norm that the worst off in terms of overall health in the absence of interventions should have the highest priority. However, as noted above, there are limits to this norm. For severe conditions, such as terminal cancer, there are sometimes technological limits to further health improvement, such as prolonged life. If the costs are high, and the outcome only few days or weeks, such outcomes may not be important enough to warrant priority over interventions that could benefit many others who are not as badly off. All agree that the worst off should have some priority, but there is legitimate disagreement over how much priority.

Sadly, all health care priority setting involves life and death choices. The needs of an identified patient in a particular instance must be considered in light of the needs of other patients in the system. While the right to dignity always requires addressing suffering, continual investment in biomedical treatment as opposed to palliative care may not always be justified and may undermine dignity interests in some cases. However, there are no fine-grained philosophical arguments or technical criteria that force the use of reason to determine exactly how large the differential magnitude of benefits for the less badly off has to be in order to trump providing the benefits for the worse off.

The second problem is the best outcomes or fair chances problem: how to balance the aim of maximizing health and securing equal chances for all?⁹⁶ Health maximization through cost effectiveness analysis may be in conflict with the goal of securing for everyone fair chances to a health benefit, which, as discussed above, is a core principle underlying a universal right to health. Fairness therefore requires that severity of disease and magnitude of health benefits be considered in an all-inclusive judgment about what is a fair share of health benefits.

A third challenge is the aggregation problem: when should society allow an aggregation of modest benefits to a large number of people to outweigh more significant benefits to a small number people?⁹⁷ Here again, blind cost

94. DANIELS, *supra* note 93, at 298.

95. *Id.*

96. *Id.*

97. *Id.*

effectiveness analysis assumes that all aggregation of benefits is acceptable. However, trivial goods should not be able to break ties that could result in the loss of fundamental rights for some. One example is whether to provide treatment for allergic rhinitis to many for the same costs as saving the life of one person. Even if the aggregated sum of health benefits may be far greater in the former option, a rights framework would lean toward the unacceptability of withholding a life saving intervention for the individual. On the other hand, many health goods that provide broad benefits are not trivial at all, and life-saving interventions may provide very low quality of life for minimal time.

The fourth unresolved challenge is the democracy problem: when must a society rely on a fair democratic process to determine what constitutes a fair rationing outcome?⁹⁸ In the case of priority setting for health care, market accountability does not function, nor does simple voting because majority rule does not provide reasons for decisions. As there is disagreement on ethical principles for priority setting, a fair choice situation must rely on some fair deliberative processes.

C. Accountability for Reasonableness and the Importance of Participation and Deliberation to Rights-Based Approaches to Priority Setting

In order to address these problems, Daniels developed a framework called Accountability for Reasonableness together with James Sabin, in keeping with Rawls' ideas regarding the use of public reason. This framework and the general conditions for fair process have been embraced by NICE in the United Kingdom.⁹⁹ They have been applied to evaluate coverage exclusions by managed care organizations in United States,¹⁰⁰ as well as public agencies in Canada.¹⁰¹ The framework is also influential in the priority processes

98. *Id.* at 137-38.

99. See Weightman, et al., *supra* note 64.

100. See Daniels & Sabin, *supra* note 82, at 303-04.

101. Peter A. Singer, Douglas K. Martin, Mita Giacomini & Laura Purdy, *Priority Setting for New Technologies in Medicine: Qualitative Case Study*, 32 *BRIT. MED. J.* 1316, 1316-18 (2000).

evolving in Mexico,¹⁰² Chile,¹⁰³ Canada,¹⁰⁴ Sweden,¹⁰⁵ and Norway.¹⁰⁶

Daniels and Sabin have proposed four conditions that must be met to ensure Accountability for Reasonableness.¹⁰⁷

1. *Publicity Condition*: Decisions regarding both direct and indirect limits to meeting health needs and their rationales must be publicly accessible. The mere listing of criteria, without an explanation of their rationale or their application, is insufficient to meet this requirement.

2. *Relevance Condition*: The rationales for limit setting decisions should aim to provide a reasonable explanation of how they will help to meet the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be reasonable if it appeals to evidence, reasons, and principles that are accepted as relevant by fair-minded people who are disposed to finding mutually justifiable terms of cooperation. Where possible, the relevance of reasons should be vetted by stakeholders in these decisions, a constraint easier to implement in public than in private institutions.

3. *Revision and Appeals Condition*: There must be mechanisms for challenge and dispute resolution regarding limit-setting decisions in atypical cases. More broadly, there should be opportunities for revision and improvement of policies in the light of new evidence or arguments.

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102. Jaime Sepulveda, Flavia Bustreo, Roberto Tapia, Juan Rivera, Rafael Lozano, Gustavo Olaiz, Virgilio Partida, Lourdes Garcia-Garcia, & Jose Luis Valdespino, *Improvement of Child Survival in Mexico: The Diagonal Approach*, 368 LANCET 2017, 2020 (2006); Felicia Marie Knaul, Hector Arreola-Ornelas, Oscar Mendez-Carniado, Chloe Bryson-Cahn, Jeremy Barofsky, Rachel Maguire, Martha Miranda & Sergio Sesma, *Evidence is Good for Your Health System: Policy Reform to Remedy Catastrophic and Impoverishing Health Spending in Mexico*, 368 LANCET 1828 (2008); Emmanuela Gakidou et al., *Assessing the Effect of the 2001-06 Mexican Health Reform: An Interim Report Card*, 368 LANCET 1920 (2006); Eduardo Gonzalez-Pier, Cristina Gutierrez-Delgado, Gretchen Stevens, Mariana Barraza-Llorens, Raul Porra-Condey, Natalie Carvalho, Kristen Loncich, Rodrigo H Dias, Sandeep Kulkarni, et al., *Priority Setting for Health Interventions in Mexico's System of Social Protection in Health*, 368 LANCET 1608 (2006); Julio Frenk, Eduardo Gonzalez-Pier, Octavio Gomez-Dantes, Miguel A. Lezana & Felicia Marie Knaul, *Comprehensive Reform to Improve Health System Performance in Mexico*, 368 LANCET 1524 (2006); Rafael Lozano, Patricia Soliz, Emmanuela Gakidou, Jesse Abbott-Klaffer, Dennis M. Feehan, Cecilia Vidal, Juan Pablo Ortiz & Christopher J.L. Murray, *Benchmarking of Performance of Mexican States with Effective Coverage*, 368 LANCET 1729 (2006).
103. Veronica Vargas & Sergio Poblete, *Health Prioritization: The Case of Chile*, 27 HEALTH AFF. 782, 782-92 (2008).
104. Lydia Kapiriri, Ole Frithjof Norheim & Douglas K. Martin, *Priority Setting at the Micro-, Meso- and Macro-Levels in Canada, Norway and Uganda*, 82 HEALTH POL'Y 78, 78-94 (2007).
105. FRANK HONINGSBAUM ET AL, PRIORITY SETTING PROCESSES FOR HEALTHCARE IN OREGON, USA; NEW ZEALAND; THE NETHERLANDS; SWEDEN, AND THE UNITED KINGDOM (1995).
106. Ole Frithjof Norheim, *Rights to Specialized Health Care in Norway: A Normative Perspective*, 33 J. L. MED. ETHICS 641 (2005).
107. See Daniels & Sabin, *supra* note 82, at 323; Martin F. McKneally, Bernard M. Dickens, Eric M. Meslin & Peter A. Singer, *Bioethics for Clinicians: 13. Resource Allocation*, 157 CAN. MED. ASSOC. J. 163 (1997); Singer et al., *supra* note 101.

4. *Enforcement/Regulatory Condition*: There is either voluntary or public regulation of the process to ensure that conditions one, two, and three are met.

Processes where these conditions are met ostensibly make it possible to involve the public in assessing health plans and health authority decisions. The framework is developed from the theory of deliberative democracy—the idea that legitimate democracy emerges from the public deliberation of citizens.¹⁰⁸ As argued by Daniels, “the four conditions connect decisions at any institutional level to a broader educative and deliberative democratic process” and as such we believe they are broadly consistent with a human rights approach to priority setting.¹⁰⁹

Some constitutions, as well as legislation across a wide array of countries, mandates emergency medical care, regardless of the resources of the patient.¹¹⁰ Further, the legal enforceability of the right to life, and the doctrinal connections that many courts have drawn between the right to health and the right to life, have resulted in a tendency to focus on care that is immediately necessary to prevent death. Nevertheless, the courts serve health rights more broadly when their decisions foster a deliberative dialogue among the public, as well as institutions of government regarding the society’s values with respect to these dilemmas in health care priority setting. As Keith Syrett writes, courts can play an important role in priority setting by enhancing

deliberation upon rationing questions not only in respect of a specific limit-setting decision, but it may also act as a stimulus for broader debate within political institutions and civil society. . . . [I]t can facilitate attainment of legitimacy, especially by engendering openness in decision-making which will enable ‘social learning’ on issues of resource allocation to take place, leading to a more informed process of deliberation from which legitimacy may be said ultimately to derive.¹¹¹

108. Bill New, *The Rationing Agenda in the NHS*, 312 *BRIT. MED. J.* 1593 (1996); Rudolf Klein, *Dimensions of Rationing: Who Should do What?* 307 *BRIT. MED. J.* 309, 310-11 (1993); see Daniels & Sabin, *supra* note 82, at 323; AMY GUTMAN & DENNIS THOMPSON, *DEMOCRACY AND DISAGREEMENT* 361 (1996); David M. Eddy, *Anatomy of a Decision*, 263 *J. AM. MED. ASSOC.* 441 (1990); JON ELSTER, *DELIBERATIVE DEMOCRACY* (1998); Ezekiel J. Emanuel & Jeffrey Emanuel, *What is Accountability in Health Care?*, 124 *ANN. INTERN. MED.* 226 (1996).

109. See DANIELS, *supra* note 93, at 119.

110. S. AFR. CONST., 1996; Examination and Treatment for Emergency Medical Conditions and Women in Labor, 42 U.S.C. § 1395DD (1986); Imron Subhan & Anunaya Jain, *Emergency Care in India: The Building Blocks* 3 *INT’L J. EMERG. MED.* 207, 209 (2010).

111. See Alicia Ely Yamin, O Parra-Vera & Camila Gianella, *Judicial Protection of the Right to Health in Colombia: An Elusive Promise?*, in *LITIGATING HEALTH RIGHTS: CAN COURTS BRING MORE JUSTICE TO HEALTH?* 103 (Alicia Ely Yamin & Siri Gloppen eds., 2011); see SYRETT, *supra* note 20, at 146.

However, a word of caution about expecting too much from public participation and deliberation in priority setting, even when there is judicial involvement aimed at promoting a rights-based approach to health. The same factors that Kenneth Arrow famously showed cause market failure in the health sector—moral hazard, decisions under conditions of uncertainty, and asymmetrical information—are also likely to cause partial democratic failure.¹¹²

Providers often determine not just supply but also the demand for health services. Provider-induced demand may distort perceptions of the true need for health services and these distortions are likely to affect different areas of health and populations differentially. Moreover, since third-party payers often finance health care goods and services, unrealistic expectations from the public may be formed. For example, the relatively high rates of expensive diagnostic tests using MRIs, CT scanners, and similar technologies in the United States, may be attributed to a combination of an overreliance on specialist care, fee-for-service payment incentives, and public expectations of state of the art care.

Also, there is often scientific uncertainty about the effects of a given intervention. For example, contrary to what most people believe, the magnitude of benefit is small or the quality of evidence is weak for interventions such as HPV vaccine use to prevent cervical cancer, integrated management of childhood illness, and the use of pay-for-performance in health service reforms.¹¹³ This scientific uncertainty is compounded by asymmetric information between providers and patients, which leads to mistaken public perceptions. These mistaken beliefs sometimes lead to demands for unproven therapies or very costly therapies with marginal benefits, as is poignantly the case with some treatments for terminal cancer patients. Taken together, these three factors make democratic decision making difficult with respect to priority setting in health care.

Moreover, effective democratic mechanisms require strong civil societies, an educated population trained in critical discussion and reflection, accountable governments, and strong institutions that can facilitate adequate processes. A genuinely fair process is impossible in countries with weak civil societies, hierarchically organized health systems, gender inequality, and steep asymmetries in power structures.¹¹⁴ As South African feminist scholar Nancy Fraser has noted, effective participation requires “the sort of

112. Kenneth Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 961 (1963).

113. Jacqueline Ruttimann, *Halt Called on Single-Drug Antimalarial Prescriptions: Irresponsible Treatments Could Render Artemisinin Ineffective*, NATURE (20 Jan. 2006), available at <http://www.nature.com/news/2006/060116/full/news060116-13.html>.

114. Alicia Ely Yamin, *Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health*, 11 HEALTH & HUM. RTS. 5 (2009).

rough equality that is inconsistent with systemically-generated relations of dominance and subordination.”¹¹⁵ In “stratified societies”—societies whose basic institutional framework generates unequal social groups in structural relations of dominance and subordination—“full parity of participation in public debate and deliberation is not within the reach of possibility.”¹¹⁶

Thus, in addition to the complexities of fostering democratic decision-making with respect to health care, we should be cautious about expectations for health care equity emerging from priority setting processes that occur against the backdrop of gross social inequality. It is sometimes the case, for example that the insurance and pharmaceutical industries are so well-financed and well-organized that they are able to influence the very issues placed into public discussion, while patients groups are left with little real voice. As Fraser has argued, “any consensus that purports to represent the common good in this social context should be regarded with suspicion, since this consensus will have been reached through deliberative processes tainted by the effects of dominance and subordination.”¹¹⁷

In order to argue for how much priority should go to the worst off in society—as well as to how to discern who is worst off regarding health conditions—we require deliberative, participatory processes and cannot rely solely on standardized quantitative measures in a rights framework. Nevertheless, in order for those processes to be meaningful, we require some degree of background equality. Thus, we find ourselves in either a vicious or virtuous cycle. The empirical public health evidence illustrates that there are detrimental effects of social inequalities. To that, we can add the normative argument from human rights that steep social inequalities undermine the possibility of establishing just institutional arrangements and priority setting that would protect universal enjoyment of the right to health.

D. Institutionalization of Priority Setting: Similar Treatment for Similar Cases

Many governments and health care organizations in principle support such ideals as transparency and accountability, while in fact their decisions fail to meet these conditions, including the regulatory condition set out by Daniels and Sabin.¹¹⁸ In our view, the framework of procedural priority setting is only satisfied if decisions are properly institutionalized and integrated with other priority setting approaches.

115. Nancy Fraser, *Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy*, 25 *SOC. TEXT* 56, 76 (1990).

116. *Id.*

117. *Id.* at 73.

118. DANIELS, *supra* note 93, at 118-19.

In general, institutionalization would include the development of national health strategies and plans of action based upon robust situational analyses, evidence-based priority setting, a regularly updated essential drugs list, clinical practice guidelines, and oversight or redress mechanisms that address atypical or ambiguous cases. As noted above, there should be ongoing, meaningful opportunities for democratic participation in all of these various dimensions of priority setting processes, which enable affected people to participate in the resolution of their own problems and more broadly in the deliberation of what is owed to one another among citizens.¹¹⁹ Such institutionalization, if done correctly, can over time contribute to raising awareness of the public and ameliorating some of the background factors of social inequality, which inhibit meaningful democratic participation in priority setting processes.

In addition to a commitment to a coherent use of resources that is publicly justified, a respect for formal equality requires that institutionalized priority setting aim to ensure the similar treatment of similar cases.¹²⁰ Formal equality implies that the right to health, like all rights, is only meaningful if its content can be universally provided. The linkages between formal equality and universality have direct implications for the growing enforcement of health claims—and de facto influence on priority setting—by courts in many countries around the globe. That is, when a court enforces a right to a given treatment or service, it should be something that at a minimum can be provided to everyone who is similarly situated. This was indeed the rationale of the South African Constitutional Court in determining that the KwaZulu-Natal provincial government's decision to deny extremely expensive dialysis care to a patient was reasonable, in light of its inability to provide such care for all.¹²¹

Part of the argument Octavio Ferraz and other scholars make with regard to the way that courts function in Brazil relates to the failure to consider the ability to universalize care. This failure, he argues, yields perverse decisions.¹²² He suggests that this approach in Brazil, where the courts take thousands of cases every year regarding health claims, results in increased inequity because the medical care decisions are allocated on a first-come first-served basis.¹²³ Ferraz asserts that “first-come first-served” favors people who are relatively better off financially, who are better informed, and who know their rights and are prepared to claim them—morally irrelevant criteria for determining who gets health benefits.¹²⁴

119. See Yamin, *supra* note 15.

120. General Comment No. 20, *supra* note 86, ¶ 15.

121. See Soobramoney v. Minister of Health, *supra* note 41.

122. Alicia Ely Yamin, *Shades of Dignity: Exploring the Demands of Equality in Applying Human Rights Frameworks to Health*, 15 HEALTH & HUM. RTS 1 (2009).

123. *Id.*

124. *Id.*

Similarly in Colombia, before the Constitutional Court issued a structural judgment in 2008 regarding the health system, the Court was criticized for granting extremely expensive medical care, irrespective of the possibility of making the given treatment or service universally accessible.¹²⁵ In an influential concurrence in a 2004 case (T 654/04), Justice Rodrigo Uprimny suggested that

[t]he Court has not asked itself whether a given treatment is universalizable, whether it can be conceded to everyone in similar circumstances. By not posing that question, the jurisprudence of the Court runs the risk that, in the name of equality and the realization of social rights, it can provoke profound inequalities, as the treatment can be so costly as not to be provided to all who need it. Thus the judicial decision would be sanctioning [not a right, but] a privilege, which runs counter to the principle of equal treatment.¹²⁶

However, judicial decisions have led to policy changes that have expanded access to a number of treatments in both Brazil and Colombia, as well as elsewhere.¹²⁷

In short, there are contested understandings of what justice requires in terms of priority setting and the emphasis human rights law places on equality does not by itself resolve all of those disputes. Applying a rights framework to priority setting does however demand a process that is fair and that entails meaningful public deliberation, which is broadly consistent with notions of Accountability for Reasonableness. A rights-based approach also requires institutionalization of priority setting processes, which enables both the effective accountability of decision makers and individual challenges. In contexts of sharp social inequality, establishing such conditions with respect to the health system is perpetually challenging.

IV. CONCLUSION

As the world focuses increasingly on the post 2015, post Millennium Development Goals era, achievement of universal health coverage has loomed large in global discussions as both a goal and a means of development.¹²⁸ Whether equality concerns will be adequately reflected in national governments' approaches to arriving at universal health coverage remains to be seen. Human rights frameworks are relevant to these discussions, not only in specifying elements of a universal right to health, including health care, but also in ensuring that human rights understandings of equality and fairness

125. *Id.*

126. *Id.* at concurrence.

127. *Id.*

128. See Evans, Marten & Etienne, *supra* note 19.

are prominent in the difficult tradeoff decisions that national policy makers will need to make on the path to universal coverage.

The equal worth of all human beings is central to human rights and inequalities in health are a sensitive marker of inequalities in other domains. However, adjudging the demands of equality is nowhere more complex than in the realm of health, where the institutional arrangements of society interact with different biological conditions. This article has argued that applying a human rights framework to priority setting does provide important guidance with respect to different forms of priority setting. For example, treating health care as a product to be allocated by the market is simply inconsistent with a rights framework and produces substantial inequalities in health outcomes as well as access to care. Moreover, a health system that depends upon mobilization of cash for access to care signals a cultural acceptance of the exclusion of the poor.¹²⁹ Similarly, a human rights framework concerned with redressing inequalities insists that attention be paid to poor and marginalized groups in national plans of action and that aggregate outcomes be weighed against “fair chances” for all, even if it results in certain “inefficiencies.”¹³⁰

However, specific priority setting decisions cannot all be derived from transcendent principles of human rights and often careful and contested balancing is required. For example, there is no way to discern from human rights standards exactly how much priority should be given to the most severely ill patients in a particular society or how much emphasis should be placed upon capacity to benefit from a clinical intervention. On the contrary, what human rights requires is a process of meaningful democratic deliberation, which includes those who are or will be affected by the decisions taken, with all of the challenges that such deliberation entails in practice. As we seek to operationalize rights-based approaches to health in priority setting and health policymaking that take equality seriously, a society will surely need to grapple with the need to address failures of participation and deliberation in the health system, just as it has struggled to set standards with respect to democratic political systems. There are undoubtedly challenges in promoting a rights-based approach to priority setting, which emphasizes not only equality, but also meaningful participation and accountability. However, the promise of establishing health, and health care, as assets of citizenship that people can claim, and a health system which reflects a society's commitment to equal dignity, for all merits the effort.

129. See Freedman, *supra* note 15, at 21; Dianne McCormack & J. MacIntosh, *Research with Homeless People Uncovers a Model of Health*, 23 WEST J. NURS RES. 679 (2001); WHO, POVERTY, SOCIAL EXCLUSION AND HEALTH SYSTEMS IN THE WHO EUROPEAN REGION.

130. *Id.*