Bioethics & Human Rights: Access to Health-Related Goods

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BIOETHICS & *Human Rights*

ACCESS TO HEALTH-RELATED GOODS

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There are many good reasons for a merger between bioethics and human rights. First, though, significant philosophical groundwork must be done to clarify what a human right to health would be and—if we accept that it exists—exactly how it might influence the practical decisions we face about who gets what in very different contexts.

Bioethics has gone global. No longer primarily limited to the hospital or doctor's office, bioethics has expanded its purview to accommodate issues of global significance: pandemics, international drug trials, physician brain-drain, human genetic engineering, population control, and access to pharmaceuticals, to name but a few. In response to this shift, commentators have called for human rights—a ready-made, legally sanctioned, universal moral framework—to serve as the lingua franca of the new global bioethics. Claiming that traditional bioethical principles are excessively focused on the individual and lack universal traction, proponents of this movement argue that human rights can provide much-needed guidance on difficult health-related issues that affect whole nations, populations, and even humanity itself.

But before human rights is imported wholesale into bioethics (or bioethics into human rights), significant philosophical groundwork must be done to clarify exactly how human rights claims should be understood. In this paper, we attempt some of this philosophical spadework as a prelude to examining the potential usefulness of the human rights framework for discussions bearing on one global issue in which human rights are increasingly, but not always successfully, deployed: namely, access to health care and the allocation of health-related goods, such as the

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social determinants of health.[1] More broadly, we ask what exactly it means to assert that human rights can or should constitute the lingua franca of a globalized bioethics, and what we can reasonably expect from such a framework as we grapple with these important and difficult questions.[2]

Why Bioethics *and* Human Rights?

There are many good reasons for a merger between bioethics and human rights. Bioethicists with strong commitments to social justice should find it natural to embrace the language and political agenda of the human rights movement—precisely the prescription urged upon bioethics by such distinguished advocates of human rights as the late Jonathan Mann, Paul Farmer, and George Annas.[3] Although there might be some doctrinal nipping and tucking required in the transition from the philosophical languages of human capabilities, utility, or opportunity to the lingua franca of human rights, there are many advantages to be gained by making this move.

In the first place, as Henry Shue points out, the human rights paradigm focuses attention on the legitimate claims of individuals in their dealings with oppressive or negligent states, thus underscoring the individual's status not as a mere supplicant for favors from duty-bearing bureaucrats, but as a person who can stand up and speak in her own name.[4] Moreover, the human rights movement has both political and legal dimensions that mere moral appeals manifestly lack. In contrast to ivy-covered bioethics scholars scribbling away in their ivy-covered studies,[5] advocates for human rights enjoy the political support of a worldwide network of influential international organizations such as UNESCO and the World Health Organization and nongovernmental organizations such as Amnesty International, Partners in Health, Global Lawyers and Physicians, and Doctors without Borders, for whom human rights has become a kind of moral-political Esperanto. In addition, because the moral claims of the human rights movement are embedded in legally binding covenants that have been ratified by many state governments, they often pack a more effective punch than arguments from bioethics or individual state-based regulatory institutions that lack global influence.[6]

But there are also good reasons for theorists and activists allied with the human rights movement to welcome an alliance with bioethics. First, bioethics draws deeply from moral and political philosophy and from the great religious ethical traditions, and it thus devotes a great deal of attention to moral foundations and philosophical critique. Although we hold that human rights are above all *moral* rights that should be enshrined in national and international law, the human rights movement tends at times to ossify into a highly legalistic and bureaucratic practice, guided not by critical reason but rather by majority vote at highly politicized conclaves. Instead of clear and rigorous argument about the existence conditions of various contested rights, there is sometimes little more than appeals to past practice or, even worse, highly bureaucratized verbal sludge that occludes, rather than fosters, clear thinking.[7] This can lead in turn to the proliferation of many ill-considered and highly controversial rights, such as a right to vacations with pay or to the "highest attainable standard of health," fuelling suspicion in some quarters that human rights, and especially so-called positive rights of assistance, are not real rights at all.

In addition, notwithstanding its excessively narrow focus on rights to *health care*, the field of bioethics (along with political philosophy) has produced an abundance of careful reflection on the strengths and inherent limitations of rights language, especially with regard to the allocation of scarce, potentially lifesaving goods.[8] One familiar way of thinking about such rights claims is to view them as rights to particular medical treatments, such as antiretrovirals for HIV or drugs to treat various forms of tuberculosis; indeed, the human rights advocacy literature is littered with such claims.[9] But as we shall demonstrate below, the best thinking in bioethics and political philosophy has shown that a focus on unmediated rights to particular medical interventions is misplaced. This is not to conclude that such notions as a right to health care or a right to health do no work at all; on the contrary, they get us beyond libertarianism and found claims based in justice for access to health and its social determinants, including health care—important work indeed. As we shall see, however, they are of very limited use in determining exactly who should get exactly what in very different contexts circumscribed by varying degrees of resource scarcity, and reliance on the human rights framework may even *preclude* consideration of better methods for making difficult allocative decisions.[10]

Why Worry about Foundations?

Those familiar with the literature on human rights may have been scratching their heads at our mention of the need for greater clarity about the foundations of human rights. "Don't these philosopher-bioethicists realize," they might be asking, "that the success of human rights as a truly global movement depends precisely on everyone's willingness simply to bracket such foundational questions?" As Jacques Maritain, a member of the original UNESCO committee that penned the Universal Declaration of Human Rights, once famously reported, "we agree about the rights *but on condition that no one asks us why*."[11]

Although an insouciant dismissal of foundational issues often passes for common wisdom in contemporary human rights advocacy circles, we believe that it is fundamentally misguided and manifestly false even with regard to the UDHR itself, where rights are clearly grounded in a universally recognizable, although still somewhat

inchoate, concept of human dignity. This is not the place for a comprehensive treatment of these issues, which would require a book-length treatise, but we want to at least briefly motivate here a more serious look at foundational issues and then suggest a particular conception of human rights that should put the human rights movement on a more secure theoretical footing.[12] Our analysis owes much to the insights of many contemporary scholars on human rights.

Any plausible understanding of human rights should have to measure up to three important criteria. First, it must give us reliable practical guidance in distinguishing genuine human rights from a mere wish list of good things to have, or from rights that we might expect within every self-respecting *liberal* polity. Such an understanding should help us to get a handle on what we will call the *genuineness problem*; that is, it should help us sort through the troubling multiplication of highly questionable right claims. Our theory should help us sift the wheat of human rights from the chaff of controversial or wrongheaded rights claims.

Second, it should ascribe rights based on universally shared human characteristics, not on norms or values that are characteristically European or liberal. This criterion addresses what we will call the *problem of universal reach*—that is, the worry, expressed both by many non-Western commentators and by many Anglo-Americans, that the whole apparatus of human rights (including the UDHR and the covenants) might represent a decidedly liberal or Western imposition of values on people born and raised within cultures shaped by Islam, Confucianism, and a host of other world religions, for whom individual autonomy is not the paramount concern.[13]

Finally, an adequate account of human rights should reflect, if not wholly then at least to a great extent, the contemporary practice of human rights. It must distinguish itself from the venerable tradition of Lockean "natural rights," which embraced a decidedly minimalist vision of the content of universal morality, a vision that had room only for so-called negative rights—that is, rights to security in one's person and property, against egregious violations of liberty, murder, genocide, and so on. In other words, any plausible theory must take into account the historicity of the practice of human rights, a practice made possible by the social and economic conditions of modernity. We shall call this the *practice problem*.

Although most commentators implicitly seem to accept all three of the above elements for a credible theory of human rights, when considered together within the same package, these criteria exhibit internal tensions and pose vexing challenges. Such an account must be critical—allowing for arms-length philosophical critique of the deliverances of human rights practice—while at the same time respecting that practice as a source of norms to be explained and honored, not just criticized. A successful account must strive for universality without either imposing liberal or sectarian views on other peoples or simply culling the list of human rights from a careful inventory of norms *already actually embraced* by the people of each and every nation on earth. If the former takes us toward a "maximalist" account of human rights, the latter takes us in the opposite direction, toward a minimalist list of rights, perhaps one restricted to so-called negative rights against murder, genocide, and the like.[14] This would conflict with our practice criterion above, which is rightly concerned with much more than mere protection from external threats such as murder and genocide. And if we cannot find evidence of actual agreement among all the nations and peoples of the earth on what we would call our list of genuine human rights, how then can we legitimately cast these as universal rights? Are universal rights just those to which everyone could or should consent, or could not reasonably reject, were they to think seriously about the matter? Are they rights that might be found in every major cultural or religious tradition *suitably reinterpreted* so as to make room for human rights?[15]

One predictable response to this welter of confusing and difficult questions is to simply bury our heads in the sand, trusting the contemporary practice of human rights to distin-

The notion of a right to health care may be crucially important but also limited. At most, such a right removes the issue of access to basic health care from free-market vagaries, allowing us to say that some failures to obtain access are not simply unfortunate but actually unjust. But it cannot tell us which failures are unjust, given limited resources and an expanding list of expensive, marginally effective treatments for diseases.

guish what's genuine and what isn't. The problem with this move is that it assumes the contemporary practice of human rights to be in perfectly good working order in every respect.[16] What if it isn't? What if large numbers of people and states in the Muslim world, for example, vigorously take issue with the promulgation of a right that passed all the tests posed by UNESCO, the WHO, and the United Nations? And what of the not insignificant number of Western critics who view so-called positive or welfare rights as not really genuine rights?[17] Would a mere appeal to practice appease such doubters and critics? We doubt it. We cannot simply rely on the contemporary legal practice of human rights to satisfy our three criteria for a credible theory of such rights. We need to reach for an account of what's at stake in debates over human rights that will satisfy our criteria of genuineness, universal reach, and practice.

An Interest-Based Conception of Human Rights

As the UDHR clearly states, the moral foundation of international human rights is the concept of human dignity. The problem, of course, is that this overarching concept harbors a vast array of competing particular conceptions of dignity over which people disagree. A full treatment of this massive subject being impossible here, we shall simply assume, without argument, our favored interpretation of what human dignity means within a theory of human rights.

Following Joseph Raz, we hold that rights occupy a middle ground in the moral landscape between fundamental interests, on the one hand, and the assignment of responsibilities and duties, on the other.[18] So the first order of business in constructing a credible theory of human rights is to identify a set of basic or fundamental human interests whose fulfillment is a necessary condition for living a decent or dignified human life. Such interests will no doubt include items traditionally lumped under the heading of civil and political rights (such as the right to religious liberty, to personal security, and to freedom from arbitrary arrest) and items usually placed under the rubric of cultural and economic rights (such as the right to subsistence, to an education, to health care).

Great care must be taken at this stage to enumerate only the most important interests—those that would be immediately recognized by most people everywhere as prerequisites to a decent human life. Our favored theorists write, therefore, of "basic rights," "fundamental human capacities," and the necessary conditions for agency or human flourishing.[19] In so doing, they point us in the direction of a useful criterion of genuineness—only those rights that protect fundamental or basic human interests are real human rights—which can in turn help stem the rising tide of rights proliferation. (A right to some leisure time, yes; a right to paid vacations, probably not.)

A credible theory of human rights must also include a robust account of the various duties and responsibilities to respect, protect, and fulfill those rights. We reject the Hobbesian view that in order to count as real, human rights must be legally enforceable,[20] and we also reject the related claim that, in order to be real, rights must in fact be "claimable" here and now against specific persons or organizations,[21] but we do agree that rights must be at least theoretically claimable to count as real—that is, some persons or organizations responsible for making good on the right must at least be potentially identifiable. If there is no way a responsible party could be identified, then we are talking about a mere "manifesto right," not a real right. But even though we reject the enforceability and (immediate) claimability theses as plausible existence conditions for human rights, we maintain that if such rights are going to be at all *effective*, they must be both claimable and enforceable here and now.

Sometimes the responsibilities correlated with rights will exhibit a familiar one-to-one, individualistic structure: If somebody borrows five dollars from you, then you have a right to have that debt paid, and the borrower is responsible for paying it. More often, however, we will encounter what Henry Shue has aptly called "waves of duty." Supposing that we have a right to be free from poverty or hunger, the responsibility for making good on these rights will rest in the first instance on us or our parents, who should be working for our living; if local conditions (drought, Janjawid militia, political corruption) make it impossible for us to provide for our own needs, then it might be the responsibility of our local, state, or national government. If all of those fall through, then the responsibility might shift to regional networks of states, to the WHO or the UN, and so on. It might be extremely difficult to locate appropriate duty-bearers in many situations, especially if so-called positive rights to assistance are at stake, but airy talk of human rights without any concern for correlative duties, or an exclusive focus on the demand side of rights without any concern for the supply side, is what Wittgenstein would have called "just gassing."

Three Conceptions of Human Rights

With the preliminaries now in place, we turn finally to the point and purpose of this paper, which is to provide an account of the human right to health-related goods en route to assessing the ultimate claim that human rights should provide the lingua franca for a globalized bioethics. Toward this end, we will review three different but commonly encountered ways of conceiving human rights to health-related goods.

The Demand-Side Conception. According to an all-too-frequently voiced "demand-side conception" of

human rights, if some people in a given circumstance need a good in order to live (or to have an opportunity for a decent life), then they have a human right to that good. As directed by our interest-based theory of rights, this conception focuses on basic interests or fundamental human capacities, but it ignores the supply side—the responsibilities, duties, or costs that must correlate with rights, especially (though not exclusively) with welfare rights. In order for human rights to engender remedial responsibilities recognized by other parties—that is, in order for them to be genuine rights—the burdens they impose on others must not be viewed as unreasonable or excessively burdensome.

A good example of the demand-side conception can be found in the International Covenant on Economic, Social and Cultural Rights, according to which each person on earth has a human right to "the highest attainable standard of physical and mental health" (Art. 12, 1). This is one of the foremost examples of hyperbolic drafting nonsense in the history of the human rights movement. Suppose that the government of a relatively resource-poor country has managed, after herculean efforts, to achieve what it considers a sufficient level of health care for all its citizens. Beginning with a dismal average life expectancy of, say, fifty years, this government has succeeded, by dint of vigorous public health interventions, in extending that figure to sixty. It now wants to turn its attention to other sectors of the welfare state—to enhanced education, say, or perhaps even to support of the arts. But according to a rigorous reading of this human right, the government must continue to spend more on health until it reaches not just a sufficient level, but the highest level attainable. Does this mean that it cannot spend public monies on other things until its morbidity and mortality figures match those of the Japanese, who are currently the healthiest people on earth? Or does it just mean that it is obligated to achieve the highest attainable standard of health with the resources available to it? Even if we adopt the latter, more relaxed interpretation, it strains credulity to think that health needs should be thought of in this maximalist fashion. As James Griffin observes, such an objective is not even a reasonable social aim, let alone a right.[22]

Notwithstanding the important corrective gloss on this right provided by the 2000 General Comment on the Covenant, which we discuss below, the right to the highest attainable standard of health encourages an unhelpful and possibly dangerous focus on demand as opposed to supply. The demand-side conception of human rights should thus be set aside in favor of a more balanced conception.

An Ideal Conception of Human Rights. Once we join a realistic concern for the supply side of human rights with a reasonably short list of genuinely fundamental human interests required by a conception of human dignity, we have what we shall call an "ideal" conception of human rights. Cost and burdens to others will be a factor, as will some sense of claimability. That is, it must be possible, at least in theory, to assign responsibilities to other individuals or organizations to make good on the right claims. This structure of human rights will tell us what is required in order for every human being to lead a life of dignity in which all their basic needs would be met. It will also offer the citizens and public officials of every state a target for political action and legal reform, as well as a basis for criticizing the actions or inactions of governments. As we noted above, such a conception would be fairly capacious, encompassing both traditional civil and political rights and a robust set of welfare entitlements to services such as education and health care, but it would have to pass the criterion of universal reach in order to keep things basic and avoid the problem of endlessly proliferating rights.

The ideal conception faces two challenges posed by the fact of extreme scarcity in the world we actually inhabit. First, some might question whether it makes sense to talk about a right to health-related goods in a world in which roughly half of all human beings are living in severe poverty (defined as living on two dollars or less a day). The human rights activists, politicians, and international

Concrete rights to health-related goods will thus depend on particular institutions within particular socioeconomic contexts, and will have to respond to varying degrees of scarcity and different priorities in different states. Thus, human rights to health-related goods will function less as action-guiding premises in political argument than as the conclusions we reach through deliberation in contexts thick with particular cultural and economic values.

lawyers can talk about rights to health and health care all they want, this objection might go, but there's just no way this right claim will ever be realistically honored for the vast majority of these people in our lifetime. And if that is the case, then to claim such a right is not only unrealistic but is also a cruel hoax on the world's poor, who are led to believe that their rescue will come from human rights treaties and bureaucrats at the WHO.[23] A supposed human right to health-related goods, on this view, constitutes a hollow "manifesto right" in the worst sense of that term—an empty promise with no possibility of realization in sight. The most we can responsibly claim on this view is that access to a sufficient amount of health-related goods is a laudable goal of every state, but not an actual right.

In our view, this charge makes the mistake of treating actual claimability as an existence condition for human rights. As we noted above, so long as a rights claim invokes fundamental human interests or capabilities and does so in a way that would not place excessive or unfair burdens on others, we can speak of it as a legitimate rights claim—even though it is not presently enforceable and even though those responsible for making good on it cannot presently be identified. The crucial question is whether sound moral arguments exist to elicit a sense of responsibility in others to respect, protect, and fulfill the claimed right. We think such arguments are indeed available in abundance,[24] and we therefore conclude that a right to health-related goods is compatible with the unfortunate likelihood that it will not be honored for the majority of the world's poor for many years to come.[25]

It thus makes perfectly good sense, we believe, to assert that the satisfaction of basic health needs can and should function politically and legally both as a crucially important social goal and as a human right. Consequently, when human rights documents acknowledge, as they must, the problems of scarcity and underdevelopment through such phrases as "reasonable accommodation" and "progressive realization," this is not, as some critics argue, a thinly veiled shell game demonstrating the hollowness and nonexistence of rights to health-related resources. If such documents were in fact to demand the immediate fulfillment of such a right even in the most destitute and resource-poor states, such a demand would indeed amount precisely to an excessive burden on those states and their citizens, which are charged, at least in the first instance, with meeting a raft of fundamental needs other than health.[26]

Still, as most contemporary human rights documents properly insist, "progressive realization" is not an empty or idle demand. It calls on states to draw up and implement plans for meeting health-related needs as soon as they are capable of doing so, and if they fail to enact such plans, then their inhabitants have a valid moral claim and cause of legal action against those states that have signed the relevant human rights covenants. This will involve setting targets and assigning responsibilities to various parties and ministries.

The second scarcity-related challenge to the ideal conception of human rights poses more of a problem regarding the usefulness of human rights for contemporary bioethical debates bearing on the allocation of resources in a global context. The key question here is how far this ideal conception of human rights can take us in debates over who should receive which resources here and now in resource-poor settings. In other words, how helpful is the ideal conception in our efforts to specify the actual content of a right to health-related goods, given the hand that we have been dealt? We shall argue that it does not get us very far at all, and that the lingua franca of human rights, while important and helpful in many ways, is not a sufficient methodological tool for a globalized bioethics.

How might we determine the content of the human right to health? One initially attractive and quite popular answer to this question is to claim that the concept of an ideal right to health care provides practical guidance on what such a right might cover. Inspecting the nature of the right and its philosophical grounds, according to this view, should help us answer questions about quite specific access problems, like those raised in recent South African cases, where human rights were invoked to determine access to HIV/AIDS drugs: (1) Did the research subjects in the initial trials of AZT for the control of perinatal transmission of HIV have a human right to receive AZT rather than placebo?[27] (2) Does everyone on earth have a human right to highly active antiretroviral therapy (HAART)? And, (3) did the government of South Africa violate the human rights of HIV-infected pregnant women by not making the drug Nevirapine widely available to them?[28]

These are precisely the questions that commentators like George Annas have tried to answer solely from within the human rights framework. While their answers may sometimes conform to what we believe to be the just outcome, we argue that this move from a proper (or ideal) conception of human rights directly to claims bearing on access to particular treatments is a false start, and that any concept of a right to health or health care, developed within either a national or a global setting, is incapable of solving complex allocation problems within a context of scarcity—that is, within the context of the real world.[29] As bioethicists have gradually learned over the past three decades, the notion of a right to health care may be crucially important, but it is also quite limited in what it can tell us. At most, such a right removes the issue of access to a basic level of health care from the vagaries of the free market. It allows us to say that some failures to obtain access to needed health care are not simply unfortunate, as the libertarians would tell us, but are actually unjust. It cannot tell us which failures of access are unjust, given limited

resources and a ceaselessly expanding list of highly expensive, marginally effective treatments for diseases.[30]

As Baruch Brody put it a long time ago, the concept of a right to health care is useless when it comes to the most important and persistent question facing physicians, health care administrators, legislators, and citizens today: namely, exactly who should get exactly what—and how much—medical care?[31] To answer this complex question, we need to get very specific: How much benefit will treatment X for disease Y yield, for how long, and for how many people? Are there other, competing treatments for Y (or for other diseases affecting other groups) that might yield a greater "bang for the buck"? Are those who suffer from Y especially deserving in some way—for example, are they children, the victims of past discrimination, the medically or socially "worst off"? Are they too old or too sick to benefit much from whatever treatment we give them? Are there other, perhaps better ways to indirectly advance health through social determinants rather than directly with health care? Whatever the answers to such questions might be, they cannot simply be read off the notion of a right to health or health care.

To make matters even worse, no matter what approach we take to these allocation questions—whether we adopt utilitarian cost-effectiveness analysis, Rawlsian justice, hypothetical consent theories,[32] or some other philosophically freighted method—we are still unlikely to reach a single, univocally right answer. On the contrary, given the plurality of values in contemporary societies, we will often be faced with many possible ways of allocating our resources, several of which will often be deemed sufficiently (if not univocally) just.[33] So even if we grant, as we should, that all poor pregnant women in a poor country have a right to a sufficient level of health-related goods, it will remain an open question exactly how a government wielding a woefully inadequate public health budget should attempt to meet their fundamental health needs.

As Norman Daniels points out in an extended discussion of just such a case, different people will bring different sets of priorities to such situations, which will, in turn, suggest very different social policies, all of which might reasonably be said to advance the progressive realization of a right to health-related goods. Daniels posits a hypothetical but all-too-plausible case. Imagine a religiously conservative, highly patriarchal developing country that wishes to improve its efforts in the area of maternal and child health. The policy options suggested by various parties within the government and citizenry might include the following:

- an outreach program designed to deliver education and services to married women;
- increased investment in expensive emergency obstetric facilities and personnel, especially in urban or semiurban areas where they can reach the most people;
- a program to provide trained birthing attendants at all peripheral centers, concentrating on the underserved rural population;
- changing the country's marriage law to forbid communities and families from forcing young women to marry at a very early age; and
- a program to increase the enrollment of girls in secondary schools, in hopes of increasing their literacy and autonomy and allowing them to defer having children until they have physically matured and become better educated.[34]

Institutional human rights are best understood as an attempt to spell out the demands of a universal conception of morality in particular social contexts. Different people deliberating under different conditions will come to different conclusions as to how best to realize these demands, but they should all be working toward the same ultimate goal of providing for basic human interests.

The interesting thing about this case is that while an ideal human right to health-related goods could justify each of the above strategies for improving maternal and child health, it is also so abstract as to leave the choice among these very different strategies completely underdetermined. Should we opt for a direct health intervention via urban clinics or an indirect approach via legal reform or education? Should we give priority to serving the greater number through urban clinics or to serving those in the medically worse off rural population? Should we strive to achieve the greatest overall net benefit or focus instead on achieving equity between groups? Daniels contends—correctly, we think—that an unmodi-

fied human rights framework is simply mute on these crucial questions. He would agree with Brody that rights language alone, including the lingua franca of human rights, is practically useless in helping us to rank and choose among the various priorities that animate these very disparate policy options, all of which are aimed at improving maternal and child health.

Given this theoretical impasse, the regnant consensus in bioethical justice theory is that a just, deliberative, political process must be put into place, through which various proposals can be fairly debated and a definitive distributive policy eventually chosen. In short, when substantive theories of justice run out of gas, leaving us with a plurality of "just enough" distributive options, we must have recourse to a fair political process.[35] The notion of a right to health and health care may well demand the removal of financial barriers to "basic" or "adequate" health care, but the most it can usually do toward this end is direct us to create public institutions within which problems of allocation amid scarcity can be fairly debated and resolved. It cannot be expected to yield a comprehensive laundry list of specific treatments, especially at the ragged edge of contemporary health care where mounting expectations fuel exploding costs. As Michael Ignatieff concludes, "At best, rights create a common framework, a common set of reference points that can assist parties in conflict to deliberate together."[36]

An "Institutional Conception" of Human Rights

If human rights claims cannot be truly effective action guides for individual conduct and policy unless they come to grips with both the scarcity and the priorities problem, then our ideal conception of human rights, not to mention mere manifesto rights, is insufficient for the establishment of public policy. It is all well and good for advocates to condemn this instance of individual conduct or that social policy as human rights violations, but unless we can specify actual duty-bearers responsible for protecting or fulfilling these putative rights, they will remain ineffective. So it is not nearly sufficient merely to articulate, invoke, or demand that certain freedoms be respected or that various goods be made available. If we are serious about human rights, then we must also ask broader strategic questions about how our social world must be structured in order for the multiplicity of rights to be respected, protected, and fulfilled.

In some instances, what will be necessary is that various private parties, state governments, or multistate institutions simply get out of people's way (or stop oppressing them) so that they can provide for themselves.[37] (Overly restrictive global trade and intellectual property agreements come to mind.) But in the vast majority of cases, we need to design and maintain institutions—like educational systems, police, land reforms, and the empowerment of women—that will help minimize the frequency of human rights violations. When these preventive institutions fail and human rights are violated—for example, when villagers in Darfur are raped, pillaged, cut off from access to food and medicines, and eventually shot—we then need backup institutions, like national or regional courts, international and NGO service providers, charitable organizations, and, as a last resort, military force.

Once we have figured out what means must be secured to advance which ends, and once we have established institutions responsible for linking means and ends, we may then be in a position to assign explicit duties to various parties that will transform ideal or mere manifesto rights into genuine human rights actually enjoyable by real people. As Shue observes, this transformation involves more than mere assertion or conceptual analysis. Knowledge of *what* a right means does not tell us *how* to guarantee it—which is a complex and difficult task involving deep historical understanding of a particular region and sophisticated, interdisciplinary empirical understanding of how to bring about desirable results.[38] Here we want to stress that these institutions are not only crucial vehicles for securing and guaranteeing respect for human rights; they are also the appropriate venue for deliberative, democratic discussions bearing on the *content* of those rights as well—that is, discussions about who owes exactly what to whom. Following Shue, we call this growing appreciation of matching duties with institutions the "institutional turn" in human rights theory.[39]

Covenants, Comments, and Declarations on the Right to Health. "General Comment No. 14" on the International Covenant on Economic, Social and Cultural Rights (1966), drafted at the United Nations in May 2000, acknowledges the reality of limited economic resources and the limits of human powers to actually ensure *health*, rather than *access* to the goods, services, and environmental conditions necessary for health.[40] So the dubious standard of the "highest attainable" level of health may legitimately be qualified by the limited resources states have at their disposal. The General Comment thus retains the maximalist language of the covenant while attempting to soften its demands on struggling economies that cannot realistically provide everyone with decent, basic health care.[41] Still, the General Comment resists the conclusion that this recognition of limits allows state governments carte blanche in interpreting the right or in discharging their obligations under it. They are still obligated to work toward the "progressive realization" of the full right to health by undertaking to provide a minimum of essential primary care (section 43), to adopt a national health policy with a detailed plan for realizing the right to health, and to provide public health infrastructures targeted at maternal health (section 36).

The General Comment clearly takes the institutional turn in its practical understanding of the right to health. It acknowledges the ubiquitous fact of scarcity and its implications for health policy, and it wisely eschews a focus on particular controversial treatments. The crux of its approach to the duty to fulfill the right to health-related goods is to insist that states establish both infrastructures for the protection of the public's health and institutions for the delivery of affordable basic health services.[42] The closest the General Comment comes to specifying access to particular drugs occurs in its endorsement of the Alma-Ata Declaration on the availability of primary health care, which mandates the provision of so-called essential drugs as defined by the WHO.[43]

Let us now take stock. We have argued in this section that, in the abstract, a human right to health-related goods entails only a right to institutions that will provide procedures for determining who should get what in a context of scarcity and pluralism regarding values and priorities, but that the decisions made within these institutions should reflect the values of the ideal conception of human rights. Concrete or "effective" rights to health-related goods will thus depend on particular institutions within particular sociocultural contexts, and will have to be responsive to varying degrees of scarcity and different health-related priorities in different states. They will emphasize process over abstract, substantive claims to specific treatments or to manifesto rights. The results of this process of deliberation will give us our list of effective, institutionally articulated human rights. Thus, at the end of the day, human rights to health-related goods will function less as powerful, specific, action-guiding premises in political argument than as the conclusions we reach through deliberation in contexts thick with particular cultural and economic values. They are the ribbon, colored in United Nations blue, that we wrap around conclusions we have already reached within an institutional process shaped by our ideal conception of human rights.

Are Institutional Human Rights Really *Human* Rights?

When we call a small subset of exceptionally important claims *human* rights, we point to their universal reach. We imply that everyone has a right to have such claims respected, protected, and fulfilled solely on the basis of being human. Human rights are thus distinguished from civil, political, or liberal rights insofar as they do not depend on any particular social, cultural, or institutional context for their existence.[44]

But now a final problem immediately looms: If the ideal conception of human rights must be embedded in an institutional conception in order for human rights to become truly effective and action guiding, and if the institutional conception will yield conclusions relative to degrees of scarcity and particular health-related priorities of particular cultures and states, then such institutional human rights cannot be ascribed to us simply on the basis of our humanity, and we must conclude, contrary to our usual way of speaking, that they do not have universal reach. In other words, institutional human rights are not, strictly speaking, unmodified *human* rights. They will, rather, bear much more resemblance to *political* rights, which are recognized by particular states on the basis of their own particular political culture and value priorities.

Does this mean that a human right to health-related goods is somehow incoherent? Not at all. Institutional human rights are best understood as an attempt to spell out the demands of a universal conception of morality in particular social contexts. Even though the specific rights determined through institutional processes will differ from place to place, depending on the vagaries of economic circumstance and priority rankings, they are all nested within a common value framework that does have universal reach—namely, our ideal conception of human rights. This ideal conception, let us recall, is founded on a conception of fundamental human interests or capacities necessary for a decent human life. These interests or capacities do have universal reach—we have them simply by virtue of being human—and they thereby provide us with a criterion of genuineness that allows us to separate real from pseudo rights claims.

It is this same ideal conception of human rights that mandates the creation of specific institutions in order to realize its universal demands in particular contexts. Different people deliberating under different socioeconomic conditions will come to different conclusions as to how best to realize these demands, but they should all be working toward the same ultimate

In order to get to specific conclusions on global health policy, we need to engage in much more fine-grained reasoning concerning costs and benefits, sustainability, and the priorities that animate our decisions. Abstract appeals to human rights cannot substitute for this kind of normative slogging.

goal of providing for basic human interests. Thus, although specific human rights claims emanating from differing institutional contexts will not, strictly speaking, be grounded solely on appeals to our common humanity and enjoy universal reach, they will be tethered to institutions that are, in turn, charged with the task of making ideal human rights real and effective in concrete circumstances.

Do Institutional Human Rights Function as Real *Rights*?

To pursue this somewhat deflationary line of thought further, institutional rights can also be distinguished from ideal human rights in another sense. Beyond being relative to time, place, economic circumstances, and differing priorities, institutional rights may not actually be rights with corresponding entitlements. Let's go back to Norman Daniels' hypothetical case study involving a poor country's efforts to improve maternal/child health.[45] We saw that there were several possible policy routes to this shared end. The government could focus, for example, on education regarding the importance of midwives for married women, on the provision of relatively high-cost care for the urban population, on broader coverage for the rural population, on legal reform discouraging early marriage, or on secondary education for girls. Supposing that all of these options represent different policy choices stemming from the common value of promoting health for women and children, and supposing further that this common value is supported in turn by the ideal right to health-related goods, the question arises whether the women or children targeted by any one of these very different approaches to fostering the right to health-related goods have any greater entitlement to resources than the possible claimants targeted by any of the alternative policies. All can claim an entitlement to equal consideration by institutions charged with making good on the right to health-related goods, but the potential beneficiaries of the urban-centered plan do not appear to have a stronger claim of entitlement than, say, the potential beneficiaries of legal reform of the status of women or those who might benefit from more secondary education. And if this is true for most institutional rights, then it would appear that such rights are not entitlements at all when viewed alongside other claims on the same resources for the same ideal purpose. Of course, all potential claimants with regard to all live policy options can and should claim an ideal right to health-related goods to address their unmet basic needs, but at the institutional level, where the claims of this ideal human right are manifestly underdetermined, it is hard to see how any potential recipient of any one policy might have a stronger claim, based in human rights, than any other claimant. With regard to these other claimants, no one has a decisive entitlement to the resources in question, and this fact makes the question of which policy to pursue look like a straightforward policy question—albeit one nested within an ideal human right—rather than a question of rights properly so called.

More Philosophy, More Practical Argument

The practice of human rights has a lot to offer bioethics scholars and activists concerned with global justice and with achieving health for all people. Perhaps most importantly, it offers a practical institutional and legal framework within which we can pursue answers to the question of what we owe to one another with regard to health-related goods. What we have called the ideal conception of human rights provides us with a highly credible moral and legal standard against which all efforts in public health and development can be judged; and what we have called the institutional conception provides concrete measures by which the abstract and universal standard can be effectively realized in different political and cultural contexts.

On the other hand, a distinctly philosophical approach to human rights demonstrates the need for greater clarity about the foundations of human rights, and the need for greater modesty and self-awareness concerning what any framework of rights is capable of yielding with regard to our specific duties of justice in the area of health and development. A lot depends on exactly how we conceive of human rights. Much more thought also needs to be brought to the difficult problem of reconciling our various criteria for a plausible theory of human rights—that is, the genuineness criterion, universal reach, and fidelity to human rights practice.

Answers to specific questions in health policy—for example, do all the world's poor have a human right to antiretroviral drugs?—cannot be simply read off the demand-side or ideal conceptions of a human right to health-related goods. In order to get to specific conclusions on global health policy, we need to engage in much more fine-grained reasoning concerning costs and benefits, sustainability, and the priorities that animate our decisions. Abstract appeals to human rights cannot substitute for this kind of normative slogging. And since we often lack canonical answers to precisely these kinds of questions, we will need to fall back on a process of deliberation with just ground rules. As Daniels has pointed out, human rights advocates often contend that their framework offers the total package for seeking global justice in health, but they often fail to notice or acknowledge the nettlesome priorities problem, let alone resolve it.

Greater attentiveness to philosophical questions might also, we contend, lead to greater modesty with regard to the deliverances of institutionally defined human rights. Many people seem to believe that because "human rights" are involved, both ideal and institutional conceptions of human rights must have universal

reach. While this is true with regard to the ideal conception, it is not true with regard to rights defined within particular institutional settings. Such rights do remain tethered to an ideal conception, but they will always be economically and culturally relative, and thus lack universal reach in their particularity. They therefore bear more resemblance to political rights than genuinely *human* rights. Insofar as institutional rights do not bestow actual, exclusive entitlements vis-à-vis other potential claimants to resources under the ideal conception of a human right to health-related goods, they bear even more resemblance to policy judgments than to standard rights claims.

In short, the fields of both bioethics and human rights have a lot to gain from contact with one another. Since neither side currently offers the total package for seeking justice in health at the global level, both should work together toward this end.

Acknowledgments

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References

1. Since the notion of a "right to health" obviously assumes the impossible in many cases involving people who cannot possibly be cured, and since the notion of a right to *health care* is excessively narrow, omitting the social determinants of health, we prefer the language of a "right to health-related goods."

2. We explore another facet of this larger agenda in a forthcoming companion paper: "Bioethics and Human Rights: Curb Your Enthusiasm," *Cambridge Quarterly of Healthcare Ethics* 19, no. 1 (2010).

3. J. Mann, "Medicine and Public Health, Ethics and Human Rights," *Hastings Center Report* 27, no. 2 (1997): 6-13, at 6; P. Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (Berkeley: University of California Press, 2003), 213-46. See also P. Farmer, *Never Again? Reflections on Human Values and Human Rights*, Tanner Lectures on Human Values (Salt Lake City: University of Utah, 2006); G.J. Annas, *American Bioethics* (New York: Oxford University Press, 2005).

4. H. Shue, *Basic Rights*, second ed. (Princeton, N.J.: Princeton University Press, 1996), 15.

5. With an appreciative nod to Tom Lehrer, "Bright College Days," available at http://www.youtube.com/watch?v=dl3mRjydcPw.

6. The United Nations' International Covenant on Economic, Social, and Cultural Rights (1966), and the corresponding Covenant on Civil and Political Rights (1966) are two such binding covenants.

7. An instructive case in point is UNESCO's Universal Declaration on the Human Genome and Human Rights, which tends to substitute a motley collection of "recallings," "solemnly recallings," "bearings in mind," "bearings in mind also," and "recognizings" for rigorously stated premises, and then confidently "proclaims" and "adopts" a number of propositions that may or may not have any direct relationship to all the above; http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html.

8. Current work in bioethics is well on its way to expanding the narrow focus on health care. See N. Daniels, *Just Health* (Cambridge, U.K.: Cambridge University Press, 2008).

9. See Farmer, *Pathologies of Power*, and Annas, *American Bioethics*.

10. We are grateful to April Harding for emphasizing this last point to us. One specific worry in this connection is that a simplistic insistence on a human right of access to health-related goods might lead some to conclude that any rationing of life-sustaining health care is morally or constitutionally illicit, which it most certainly is not. See, for example, the human rights-inspired claim to virtually unlimited renal dialysis in the South African constitutional case, *CCT 32/97, Thiagraj Soobramoney vs. Minister of Health (Kwazulu-Natal)*, available at: http://graduateinstitute.ch/faculty/clapham/hrdoc/docs/soobramoney.pdf.

11. J. Maritain, introduction to *Human Rights: Comments and Interpretations* (New York: Columbia University Press, 1949), 9; italics in original.

12. For an extended treatment, see J. Griffin, *On Human Rights* (Oxford, U.K.: Oxford University Press, 2008), and E.M. Fenton, "Overlapping Consensus and Human Rights" (PhD dissertation, University of Virginia, 2008).

13. A. Sachedina, *Islam and Human Rights* (Oxford, U.K.: Oxford University Press, 2009); The wording of this criterion is due to D. Miller, *National Responsibility and Global Justice* (Oxford, U.K.: Oxford University Press, 2007), 164. See also J. Rawls, *The Law of Peoples* (Cambridge, Mass.: Harvard University Press, 2001), and M. Ignatieff, *Human Rights as Politics and Idolatry* (Princeton, N.J.: Princeton University Press, 2001).

14. See Ignatieff, *Human Rights as Politics and Idolatry.*

15. For two good examples of this attempt to reconstruct various religious traditions in order to render them compatible with human rights, see J. Cohen, "Minimalism about Human Rights: The Most We Can Hope For?" *Journal of Political Philosophy* 12 (2004): 190-213, and Sachedina, *Islam and Human Rights.*

16. For a more complete and devastating criticism of the reliance on current practice, see Griffin, *On Human Rights*, 202-6. See also J. Tasioulas, "Human Rights, Universality, and the Values of Personhood: Retracing Griffin's Steps," *European Journal of Philosophy* 10 (2002): 79-100.

17. See M. Cranston, *What Are Human Rights?* second ed. (London, U.K.: Bodley Head, 1973), and Ignatieff, *Human Rights as Politics and Idolatry*.

18. J. Raz, "On the Nature of Rights," *Mind* 93 (1984): 194-214.

19. See Shue, *Basic Rights*; M.C. Nussbaum, *Women and Human Development: The Capabilities Approach* (Cambridge, U.K.: Cambridge University Press, 2000), and "Capabilities and Human Rights," *Fordham Law Review* 66 (1997): 273-300; for discussion of agency, see Griffin, *On Human Rights*, and J. Griffin, "First Steps in an Account of Human Rights," *European Journal of Philosophy* 9, no. 3 (2001): 306-327; on human flourishing, see A. Buchanan, *Justice, Legitimacy, and Self-Determination: Moral Foundations of International Law* (Oxford, U.K.: Oxford University Press, 2004). See also J. Nickel, "Poverty and Rights," *Philosophical Quarterly* 5, no. 220 (2005): 385-402.

20. R. Geuss, *History and Illusion in Politics* (Cambridge, U.K.: Cambridge University Press, 2001), 143.

21. O. O'Neill, *Bounds of Justice* (Cambridge, U.K.: Cambridge University Press, 2000), 105, and *Towards Justice and Virtue* (Cambridge, U.K.: Cambridge University Press, 1996), 131-34. John Tasioulas provides a sound argument against both Geuss and O'Neill in "The Moral Reality of Human Rights," in *Freedom from Poverty as a Human Right*, ed. T. Pogge (Oxford, U.K.: Oxford University Press, 2008).

22. See Griffin, *On Human Rights*, 99.

23. See Geuss, *History and Illusion in Politics*. See also O'Neill, *Towards Justice and Virtue*, 133.

24. See Daniels, *Just Health*, and A.K. Sen, "Elements of a Theory of Human Rights," *Philosophy and Public Affairs* 32, no. 4 (2004): 315-56, among many others.

25. We could say the same thing for the existence of much less controversial, so-called negative rights bearing on the security of persons and property in places like Somalia and Darfur, where the existence of the rule of law has completely broken down.

26. Office of the High Commissioner for Human Rights, opening address at the signing of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, "From Vision to Action: The Road to Implementation of the Convention," at http://www2.ohchr.org/english/issues/disability/docs/speakingnotesfinal.doc.

27. See G.J. Annas and M.A. Grodin, "Human Rights and Maternal-Fetal HIV Transmission Prevention Trials in Africa," *American Journal of Public Health* 88, no. 4 (1998): 560-63.

28. Annas, *American Bioethics*, 59-67.

29. While we agree with Annas's conclusions regarding the South African Nevirapine controversy, we reject his (and Michael Grodin's) application of a human rights analytical framework to the initial AZT studies on the vertical transmission of HIV. The Nevirapine controversy was an ethical and legal no-brainer. The hapless Mbeki government of South Africa flunked a rudimentary "rationality test" at the South African Supreme Court, which found that the government's policy was medically, legally, and morally bankrupt. Indeed, the Supreme Court's decision in this case provides an excellent example of what we call the "institutional approach" to human rights. Though sensitive to costs and the legitimate role of the country's health ministry in setting health care priorities, the court found that the government had failed to frame, let alone implement, a plan to advance the health rights of women and children in South Africa in the midst of a catastrophic AIDS epidemic. In so doing, it had failed to implement the "progressive realization" of the right to health-related goods. As for the application of a human rights framework to the placebo-controlled AZT trials of HIV perinatal transmission, Annas and Grodin invoke human rights as a corrective foil for what they perceive as a noxious moral relativism in permitting a placebo-controlled trial of AZT in Africa or Asia but not in the United States or Europe. Suffice it to say here that one important purpose of the studies was to conclusively determine whether AZT constituted a medically acceptable, cost-worthy, and sustainable treatment modality within developing countries. To invoke a human right to AZT in this context thus constitutes a massive begging of the question. See J.D. Arras and R. Crouch, "AZT Trials and Tribulations," *Hastings Center Report* 28, no. 6 (1998): 26-34. For a convincing demonstration that one can morally approve of such placebo-controlled studies without resorting to moral relativism, see A.J. London, "The Ambiguity and the Exigency: Clarifying 'Standard of Care' Arguments in International Research," *Journal of Medicine and Philosophy* 25, no. 4 (2000): 379-97.

30. D. Callahan, *What Kind of Life?* reprinted ed. (Washington, D.C.: Georgetown University Press, 1995).

31. B. Brody, "Why the Right to Health Care Is Not a Useful Concept for Policy Debates," in *Rights to Health Care*, ed. T.B. Bole and W.B. Bondeson (Dordrecht, the Netherlands: Kluwer Academic Publishers, 1991), 113-31.

32. For cost-effectiveness analysis, see A.F. Gibbard, "Health Care and the Prospective Pareto Principle," *Ethics* 94, no. 2 (1984): 261-82; D.M. Eddy, *Clinical Decision-Making: From Theory to Practice* (Boston, Mass.: Jones and Bartlett, 1996). On the Rawlsian approach, see J. Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard University Press, 1971/1999), and Daniels, *Just Health.* For hypothetical consent, see R. Dworkin, "Justice and the High Cost of Health," in *Sovereign Virtue* (Cambridge, Mass.: Harvard University Press, 2000), 307-19; and P. Menzel, *Strong Medicine: The Ethical Rationing of Health Care* (New York: Oxford University Press, 1990).

33. N. Daniels and J. Sabin, *Setting Limits Fairly: Can We Learn to Share Medical Resources?* (New York: Oxford University Press, 2002); L.M. Fleck, *Just Caring: Health Care Rationing and Democratic Deliberation* (Oxford, U.K.: Oxford University Press, 2006).

34. See Daniels, *Just Health,* 321-23.

35. A. Gutmann and D. Thompson, *Democracy and Disagreement* (Cambridge, Mass.: Harvard University Press, 1998). See also S. Gruskin and N. Daniels, "Justice and Human Rights: Priority Setting and Fair Deliberative Process," *American Journal of Public Health* 98, no. 9 (2008): 1573-77.

36. See Ignatieff, *Human Rights as Politics and Idolatry,* 20.

37. See Shue, *Basic Rights,* 40. This would also, naturally, be the libertarian's sole response to global injustice. See L. Lomasky, "Liberalism beyond Borders," *Social Philosophy and Policy* 24 (2007): 206-233.

38. See Shue, *Basic Rights,* 160-61.

39. Ibid., 153-80. For another powerful articulation of the institutional turn in human rights, see T. Pogge, *World Poverty and Human Rights: Cosmopolitan Responsibilities and Reforms* (Cambridge, Mass.: Polity Press, 2002).

40. Committee on Economic, Social and Cultural Rights, "Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights—General Comment No. 14," (2000), at http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument.

41. As Jonathan Quick et al. observe, a third of the world's population—roughly two billion people—lack regular access to essential medicines. In the poorer areas of Africa and Southeast Asia, 50 percent of the population lacks access to these drugs. J. Quick et al., "Twenty-Five Years of Essential Medicines," *Bulletin of the World Health Organization* 80, no. 11 (2002): 913-14; and the "Montreal Statement on the Human Right to Essential Medicines," at http://www.accessmeds.org/Statement.html.

42. The emphasis on states may be problematic, however, since states may not always be best placed to create the necessary infrastructure.

43. General Comment No. 14, sec. 44(d). The WHO's "essential medicines" project can be accessed at http://www.who.int/medicines/en/. See also Quick et al., "Twenty-Five Years of Essential Medicines," and the "Montreal Statement on the Human Right to Essential Medicines."

44. This claim must be qualified immediately, however, because our conception of human rights is firmly rooted in the conditions of modernity and thus differs from traditional conceptions of natural rights, which do not owe their existence in any way to social conditions or institutional sources. Through this qualification we satisfy the "practice criterion" for human rights.

45. See Daniels, *Just Health,* 321-23.