

From Conception to Realization: *A Human Right to Health*

To the Editor: John Arras and Elizabeth Fenton are, it seems, trying to write a provocative piece (“Bioethics and Human Rights: Access to Health-Related Goods,” Sept-Oct 2009). Sharp digs at the United Nations generally and the World Health Organization specifically, quick observations about commentators that lend support to their positions with inadequate attention to more nuanced writings, and sweeping generalizations about the nature of human rights and about those academics and practitioners working in the area all make for lively reading. Reaching beyond the rhetoric, however, one is left to conclude, after many pages of reflection and at times inchoate attack, that human rights may offer something important to bioethics, as long as it does not take away from what bioethics has to offer. But is this really a contentious position?

To build on what is proposed in this article, a few points about human rights would seem to require attention. While certainly the authors’ emphasis on the right to health is well placed, determining the value of rights for bioethical discourse requires explicit attention to the indivisibility and interdependence of rights as concerns both the underlying determinants of health and the delivery of health services. We must try to assess the value of such rights as privacy, education, information, participation, and freedom from discrimination as they interact with the right to health and with one another. To consider the right to health in isolation is to miss a key contribution of rights to health and well-being and an important area for reflection and debate.

With respect to the authors’ specific focus on the right to health—or, more accurately, on the component of

the right to health concerned with access to health care and the allocation of health-related goods—several points are worth emphasizing. As I have noted in earlier writings, a rights-based approach sets out a process, contributes legal accountability and established criteria to be debated within the process itself, but was never intended to determine “who should receive which resources here and now in resource-poor settings.” Its distinct contribution is requiring analysis of which rights and which populations would be impacted by each intervention, with specific attention to the availability, accessibility, acceptability, and

fact that human rights treaties and the procedural mechanisms to implement them are institutionalized challenges the credibility of this notion. These mechanisms do not determine what the “right answer” should be in attempting to answer health—or other—policy questions, but the fact that this approach has been agreed to by the governments of the world and not simply picked up haphazardly by individual governments supports not only its philosophical underpinnings, but its universal credibility under international human rights law.

Sofia Gruskin

Harvard School of Public Health

One is left to conclude, after many pages of reflection and at times inchoate attack, that human rights may offer something important to bioethics, as long as it does not take away from what bioethics has to offer. But is this really a contentious position?

quality of the proposed intervention and the establishment of accountability mechanisms in relation to meeting goals. While it seems the authors would be willing to engage with these points given their attention to so-called institutional conceptions of human rights, explicit attention to these criteria and their implications for health would do much to clarify the specifics of the right to health and move away from the “ideal conception” of human rights that they find so disconcerting.

We would all likely agree that philosophically, human rights are intended to be generally applicable to every human being everywhere around the world and can be understood to be ascribed to us on the basis of our humanity. It appears, however, that the authors think that the

To the Editor: While we are encouraged by Arras and Fenton’s efforts to consider the philosophical traditions of the right to health and how bioethicists can contribute to the human rights endeavor, we disagree with their vacillating and at times contradictory concerns for the health and human rights enterprise. Where the authors resurrect criticisms of the very existence of a human right to health, these criticisms neglect the ethical development of the right to health, the evolving efforts to define its normative content, and the successful efforts to achieve rights-based accountability.

It is true that human rights tend “to ossify into a highly legalistic and bureaucratic practice,” but this construction of human rights through the United Nations does not deny rights any moral

foundation; rather, the development of human rights exemplifies how bioethics has made influential policy gains through the right to health. As a result of World War II atrocities, states developed human rights pursuant to international law, seeking to realize “freedom from want” and secure “the highest attainable standard of health.” Through the authors’ criticism of the codification of a right to health as “hyperbolic drafting nonsense,” it becomes clear that they have considered neither the interpretive gains nor the dynamic nature of interdependent human rights, with this evolving legal discourse benefiting from ethical clarifications of state obligations.

To the extent that any “practice problem” exists in the definition of the right to health, the UN’s human rights institutions ameliorate problems of “endlessly proliferating rights” through the formal evolution of normative frameworks. Combining the stability necessary in a universal rights-based tradition with the dynamism necessary to account for changing global conditions, the UN’s 2000 General Comment on the right to health has provided a blueprint for its progressive realization in a globalizing world, specifying the ethical ends of health policy. Rather than looking only to the allocation of “health-related goods”—a reductionist interpretation that reverts back to bioethics’ traditional fixation on medicine—the General Comment specifies obligations to respect, protect, and fulfill the various human rights that underlie the public’s health.

Although the authors view the right to health as “a cruel hoax on the world’s poor,” numerous legislative and jurisprudential examples illustrate how human rights obligations can provide accountability for health policy. The authors’ argument that the right to health “is incapable of solving complex allocation problems within a context of scarcity” misinterprets the achievement of rights-based accountability for the

allocation of antiretroviral therapies. In the South African case, the authors fail to acknowledge how litigation over Nevirapine broke a political deadlock, assuring access to a key medical intervention unjustly denied to the poor and marginalized. Indeed, with civil society groups advancing the right to health to claim health care services globally, human rights organizations increasingly act in concert with social movements to prioritize health needs.

In a world of “imperfect obligations,” there is great enthusiasm for a revitalized synergy between bioethics and human rights, with ethical frameworks structuring competing considerations of utility, equity, and capability to create just health policy. As these ties strengthen, linking legal obligations with moral accountability, bioethics and human rights can complement each other to create the institutions necessary to realize the highest attainable standard of health.

Benjamin Mason Meier

University of North Carolina
at Chapel Hill

Lisa Forman

University of Toronto

Arras and Fenton reply:

Unfortunately, both of our correspondents have, at least in part, misunderstood our aim and argument in this paper. First, both suggest that our focus on access to health-related goods is too narrow and, according to Meier and Forman, “reductionist.” We agree with Meier and Forman that bioethics has often had far too narrow a focus on medical care, but the term “health-related goods” was chosen explicitly to signal that we included under it not only health care but also the complex interplay of social, political, and cultural factors now well-recognized as having an important influence on health. We agree that, to the extent that human rights or social policy protect and foster health at all, they do so by focusing on these social determinants

ON THE WEB

■ Bioethics Forum

www.bioethicsforum.org

President Obama’s Groundbreaking Order on Hospital Visitation and Decision-Making

By CAROL LEVINE

The changes President Obama calls for in his April 15 memorandum are groundbreaking, but anyone who might be vulnerable to being excluded as a hospital visitor or substitute decision-maker should be prepared to be a forceful advocate. Culture change takes a long time.

Overturning Health Reform:

A Cautionary Tale

By WENDY E. PARMET

A judicial defeat of health care reform, especially by the Supreme Court, would require reversing or at least questioning much of the settled precedent on which our post-New Deal jurisprudence stands.

Also: **Susan Hawthorne** analyzes the newly proposed options for changing ADHD’s diagnostic criteria for DSM-V; **Dhruv Khullar** explains why you can’t trust Vitaminwater; **Ann E. Mills** and **Patti M. Tereskerz** look at the uncertain future of gene patents; and **Ross White** wonders why so many Republicans are all of a sudden opposed to individual mandates.

■ The Health Care Cost Monitor

www.healthcarecostmonitor.org

Small Steps Toward Cost Control

By RICHARD B. SALTER

It is hard to overstate how fiscally irresponsible health care reform is. One finds many admirable goals that come with unaffordable price tags. No reasonable person would consider the act’s small, tentative, and horizon-focused steps toward reining in medical spending to balance its massive new entitlements. This gap between rhetoric and reality makes Obama, Pelosi, and Reid sound like demented Peronists every time they open their mouths.

of health and not simply on the delivery of health care, important though that is.

Gruskin argues—rightly, in our view—that many different human rights (like education, privacy, and freedom from discrimination) must be interpreted and weighed in terms of their contribution to health. But this important point only reinforces our argument that the institutions required to protect and deliver on the right to health—the institutions that can tell us who gets what as their entitlement under the right—must be designed relative to the circumstances in different places and at different times. However, contrary to Gruskin’s interpretation, we do not view this institutionalization as a threat to the universality of the ideal conception of human rights. Rather, we take the ideal conception as an important starting point in telling us which fundamental human interests must be protected and, therefore, which human rights everyone shares. But that conception does *not* tell us what people in vastly different circumstances are actually entitled to as a function of those rights. For that we need institutions. Far from threatening the credibility of the ideal conception of universal human rights, institutionalization is the meat on the bones of that conception.

Meier and Forman have simply misread us on several points. First, we clearly note that the General Comment of 2000 significantly improves on the hyperbole of the framing of the right to health in the Universal Declaration on Human Rights and argue that this is in fact a good example of what we have called the institutional turn in bioethics and human rights. Second, we did not say—nor would we ever say—that the right to health is a cruel hoax on the world’s poor. Our criticism of the ideal conception of human rights is that it is unable to meet the challenge of scarcity. *Without* institutionalization, we argue, *without* an account of how the right will be protected and fulfilled when resources are scarce—an account like that

offered by the General Comment—the right to health is such a hoax. The third misreading charges that we ignore a key case in which human rights were invoked to ensure access to the HIV drug Nevirapine in South Africa. On the contrary, we state unambiguously in a footnote that this case was “an ethical and legal no-brainer.” Perhaps in line with our agreement with the authors on this point, we wholeheartedly endorse the agenda they lay out in their final paragraph, which seems to us to be a succinct summary of our argument.

Fine-Tuning the Future

To the Editor: In “Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation” (Nov-Dec 2009), Nancy Dubler and colleagues aptly and accurately indict clinical ethics consultants, or CECs, for failing to develop standards of practice, standards for education, and standards for accrediting clinical ethics educational programs. Acting to fill this void, in eleven substance-packed pages they spell out standards for clinical ethics consultation, propose institutional and peer oversight of consultations, suggest criteria for ensuring CECs’ qualifications and competency, detail standards for evaluating CEC education, and outline a plan for credentialing and privileging CECs.

Their report—a product of the Clinical Ethics Credentialing Project—is good on many points and so likely to improve the level of clinical ethics consultation that it almost seems impolitic to criticize the details. As with most policy recommendations, however, there is always room for improvement. One item that appears to have been overlooked is the role that the clinical ethicists’ professional society, the American Society for Bioethics and Humanities, might play in developing fieldwide standards. Dubler and colleagues cite the achievements of hospital

chaplains and palliative care specialists in achieving training standards for their fields, yet these fields set standards by working with their professional societies. It seems odd and potentially self-defeating to offer a proposal for developing fieldwide standards and credentialing procedures without involving the field’s professional society.

My primary concern, though, is the narrowness of CEC education envisioned in the report. While noting that “CEC services may do other things to promote an institutional environment that supports ethical discourse on many levels,” the CEC report “focus[es] on CEC activities involving individual patient cases.” Setting aside the point that “supporting ethical discourse” is an odd and somewhat disparaging characterization of CECs’ important role as ethics educators, policy advisors, and researchers, CECs are also involved in “the clarification of institutional ethics policies” and other issues beyond disagreements over patient care, as Dubler and colleagues themselves remark. A 2006 survey of ASBH members shows that most have multiple tasks: six in ten are engaged in clinical ethics consultation, and almost all are involved in education and research or scholarship. Yet the section of the report addressing the competencies to be taught in clinical ethics education programs ignores these other things that CECs do. Since we know that institutions expect CECs to serve as ethics educators, policy analysts on ethics issues, and researchers, it seems shortsighted to develop standards for education that fail to evaluate programs on their ability to educate CECs to perform these tasks competently.

Moreover, as the report properly notes, successful clinical ethics consultation often involves discussion of the “history of bioethics.” Yet the criteria proposed for evaluating CEC education programs omits standards for teaching the history of bioethics and—perhaps more to the point—for teaching the history of clinical ethics. Modern