Theological Studies
69 (2008)

HEALTH AND HUMAN RIGHTS

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The AIDS pandemic has focused renewed attention on the relationship between the promotion of health and the protection of human rights. Recent work by Paul Farmer and others challenges bioethics to address urgent questions of global health equity not only on the level of method but in the form of strategic partnerships with the most vulnerable populations. This article highlights both the promise and the limits of a human rights framework for bioethics.

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We thus find ourselves at a crossroads: health care can be considered a commodity to be sold, or it can be considered a basic social right. It cannot comfortably be considered both of these at the same time. This, I believe, is the great drama of medicine at the start of this century. And this is the choice before all people of faith and good will in these dangerous times.[1]

IT HAS BEEN SAID that there is “no more vibrant, hope-filled or complex idea alive in the world today than human rights and dignity for all.”[2] From the difficulty of overcoming Western emphases on the individual that underlie international human rights documents to the persistent gap between rhetoric and action, human rights are indeed a complex (even fractious) foundation for ethics in a globally conscious age. The recent call by Cardinal Renato Martino, head of the Pontifical Council for Justice and

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The author acknowledges the generous support of the Association of Theological Schools and the Henry Luce III Fellows in Theology Program in the preparation of this essay.

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[1] Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* (2003; Berkeley: University of California, 2005) 175.

[2] International Federation of Red Cross and Red Crescent Societies and François-Xavier Bagnoud Center for Health and Human Rights, “Human Rights: An Introduction,” in *Health and Human Rights: A Reader*, ed. Jonathan M. Mann et al. (New York: Routledge, 1999) 21–24, at 21.

Peace, for Roman Catholics to break ties with Amnesty International because of Amnesty's stance on the "right to a safe abortion" illustrates well how difficult it is to maintain strategic alliances even between groups that share fundamental and passionate commitments to the importance of promoting human dignity.[3] Yet, in the wake of the AIDS pandemic, the relationship between promoting health and protecting human rights has never seemed more obvious. Although the spread of HIV/AIDS has taken various paths, it has become apparent everywhere that the most important factor in vulnerability to infection and death is not biological but societal, that is, membership in a group already discriminated against, marginalized, or stigmatized. As Jonathan Mann put it, "we have learned that the HIV pandemic flourishes where individual capacity to learn and to respond is constrained"; discrimination is not only "a tragic result of the pandemic but a root societal cause."[4] And as rapidly developing technologies reveal great promise for improving human health and well-being and equally great risk of merely deepening existing inequalities within and between nations, it has never seemed more important to find "languages of advocacy" capable of transcending political and cultural borders and powerful enough to raise up human dignity against the overwhelming influence of market values.

A right to health has long been recognized in international human rights agreements, at least implicitly.[5] Article 25 of the Universal Declaration of Human Rights holds that "everyone has the right to a standard of living adequate for . . . health and well-being of himself and his family, including food, clothing, housing, medical care and the right to security in the event of . . . sickness and disability. . . . Motherhood and childhood are entitled to special care and assistance."[6] But it is only in the last decade that the link between systemic human rights abuses and vulnerability to disease has come to be widely recognized. The outcry over access to antiretroviral drugs in poor, AIDS-ravished areas brought attention and urgency to the meaning of a "human right to health"; the Declaration of Commitment by the United Nations General Assembly in 2001 and the launching of the

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[3] The editor, "Amnesty and Abortion," *America* 197.13 (October 29, 2007) 5.

[4] Jonathan Mann and Jean-Marie Andrieu, "Health and Human Rights," *UNESCO Courier* 48.6 (June 1995) 26–31.

[5] A "right to health" is generally understood as having two components: a right to adequate medical care and a right to the conditions necessary for the protection or promotion of health. It is not understood as a "right to be healthy." Often the term "right to health" is used as a shorthand for the World Health Organization's articulation in the preamble to its 1948 Constitution of a fundamental right to "the enjoyment of the highest attainable standard of health." See Judith Asher, *The Right to Health: A Resource Manual for NGOs* (London: The Commonwealth Medical Trust, 2004) 17.

[6] See http://www.pdhre.org/rights/health.html (accessed November 7, 2007).

World Health Organization's "3 by 5 Initiative" are often heralded as important symbolic milestones in a growing willingness to view access to lifesaving care as a universal human rights issue and thus to bring HIV/AIDS under the umbrella of international law.[7]

But the HIV/AIDS pandemic not only galvanized human rights advocacy in new directions; it also led to an important shift in understanding how human rights violations affect health. As AIDS progressed, it showed that the impact of human rights on health is not limited to the cases such as torture, imprisonment under inhumane conditions, or summary execution and "disappearances" that have traditionally linked health and human rights. Rather, the epidemiology of AIDS exposes the health consequences of gross disparities in social and economic power:

> In the United States the brunt of the epidemic today is among racial and ethnic minority populations, inner city poor, injection drug users, and, especially, women in these communities. In Brazil, an epidemic that started among the jet set of Rio and Sao Paulo with time has become a major epidemic among the slum-dwellers in the favelas of Brazil's cities. The French, with characteristic linguistic precision, identify the major burden of HIV/AIDS to exist among "les exclus," those living at the margins of society.[8]

Recognizing that HIV/AIDS, like some other infectious diseases, "makes a preferential option for the poor and marginalized" highlights both the indivisibility of social/ economic and civil/political rights, and the organic connection between marginalization and victimization: "Just as the poor are more likely to fall sick and then be denied access to care, so too are they more likely to be the victims of human rights abuses, no matter how these are defined."[9] The newly emerging field of Health and Human Rights builds on natural synergies between public health and human rights while at the same time focusing attention on underlying structural factors contributing to vulnerability to disease and determining options for addressing health care crises. As we will see below, a human rights paradigm not only

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[7] Sofia Gruskin and Daniel Tarantola, "Health and Human Rights," in *Perspectives on Health and Human Rights,* ed. Sofia Gruskin et al. (New York: Routledge, 2005) 3–57, at 4. The United Nations General Assembly's Declaration of Commitment (2001) recognized HIV/AIDS as a "global emergency" and a "formidable challenge to the effective enjoyment of human rights." It expressly linked protection for human rights with reductions in infection rates. The "3 by 5 Initiative" was launched by the World Health Organization in 2003. It set a target of providing antiretroviral drugs to 3 million people in low resource areas by 2005; this target was seen as part of a strategy to achieve universal access.

[8] Jonathan Mann, "Medicine and Public Health, Ethics and Human Rights," *Hastings Center Report* 27.3 (1997) 6–13, at 10.

[9] Farmer, *Pathologies of Power* 138. The use of "preferential option" to describe the progression of the HIV/AIDS pandemic is Farmer's.

challenges conventional assumptions and methodologies in public health but also has important implications for contemporary bioethics.

CHANGING THE SUBJECT

One way to think about the impact of HIV/AIDS, as a global public health emergency, is that it gave unparalleled currency to the central question for public health: What is necessary to ensure the conditions in which people can be healthy?[10] Although public health analysis has long recognized the impact of social factors on health, particularly poverty, first-stage approaches to the pandemic reflected longstanding tendencies in public health policy to focus on altering individual behaviors. Despite evidence that a constellation of social or contextual factors play an important role in determining who will get sick or disabled and who will die from preventable diseases—for example, social status and integration, gender, employment, childhood education and nutrition, and exposure to "dignity-denying situations"—prevention and education programs have overwhelmingly operated on the assumption that individuals possess, if not complete control over their choices, at least equal control.[11]

A human rights paradigm challenges both the focus on individual behavior and the contextual blindness often seen in public health policy by recognizing ill health as the result "not only of the behavior of certain disease organisms or particular individuals but of institutional arrangements and prevailing structures of cultural attitudes and social power which in turn result in differential vulnerabilities to disease and unequal access to resources."[12] A human rights lens is acutely sensitive to conditions that diminish agency, and to the impact on health of abusive and discriminatory practices, such as domestic violence and the multiple forms of discrimination against girls and women in male-dominated societies.[13] Public health and human rights discourses share a commitment to health as a "common good" to which all people are entitled; at the same time, a human rights focus links the right to health with a full range of related human rights, for example, the right to: bodily privacy, information, assembly, and association;[14] fair wages and decent and safe housing; and clean water and ad-

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[10] Mann, "Medicine and Public Health" 7.

[11] Ibid. 8.

[12] Daniel Callahan and Bruce Jennings, "Ethics and Public Health: Forging a Strong Relationship," *American Journal of Public Health* 92 (2002) 169–76, at 172.

[13] Anne Donchin, "Converging Concerns: Feminist Bioethics, Development Theory, and Human Rights," *Signs: Journal of Women in Culture and Society* 29 (2003) 299–324, at 300.

[14] Mann makes the point that the impetus for needle exchange programs in HIV/AIDS prevention came from a union of drug users in Amsterdam; the ability

equate nutrition. Such a focus therefore challenges common wisdoms under which public health goals are necessarily incompatible with respect for human rights.

As academic disciplines and as professional practices, both public health and human rights are motivated by a fundamental concern for human dignity and have a stake in advocating for the dispossessed; however, bringing a human rights framework to bear takes questions of public health beyond a broad passion for social justice, a "subjective sense of outrage at the suffering of the poor," by invoking "a set of agreed upon standards that limit what governments can do that would contribute to social injustice and defines what they must do to redress such injustice."[15] Although not uncontested, the language of human rights lends a normative structure to generalized moral ideals. More important, it translates perceptions of injustice into a demand for programs of social change; thus, it explicitly recognizes that "new understandings of the connection between socioeconomic conditions and poor health will only generate change when they are reframed into political claims and pressed by social movements."[16] Finally, and particularly salient in light of the increasingly global scale of public health threats as well as opportunities, human rights thinking and activism exposes overlapping power hierarchies (local, national, international) that control development and distribution of health care goods and services. Thus, a human rights perspective challenges narrow or one-dimensional analyses of problems such as access to life-saving drugs; these are not just local delivery and compliance problems, but are deeply embedded in competing and controlling global market interests and transpolitical market relationships.

One conclusion to be drawn is that invoking a human rights framework *socializes* or *contextualizes* public health issues by shifting the strategic question from, What is the best way to influence individual health-related behaviors to avert a crisis or realize a goal? to, What are the interrelated social, political, economic, and cultural factors and relationships that encourage or constrain the possibilities for being healthy, especially for those who are already marginalized? In a different way, a human rights framework also socializes or contextualizes bioethics—and, if Paul Farmer is correct, it has the potential to help bioethics find its prophetic voice.

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of drug users to form a union and to meet publicly without restrictions was critical to generating a strategy.

[15] Stephen P. Marks, "Human Rights in Development: The Significance for Health," in *Perspectives on Health and Human Rights* 95–116, at 97.

[16] Lynn P. Freedman, "Human Rights and the Politics of Risk and Blame: Lessons from the International Reproductive Health Movement," in *Perspectives on Health and Human Rights* 527–36, at 527.

TOWARD PRAGMATIC SOLIDARITY

It is difficult to imagine a more passionate or articulate advocate for health (and health care) as a human right than Farmer. A physician and medical anthropologist, who splits his time between Harvard and Haiti, he has been openly critical of the blindness of Western medicine (and medical ethics) to the health needs of the destitute poor, and of the failure of international human rights campaigns to incorporate social and economic rights. His 2003 book *Pathologies of Power* is remarkable in many ways, not the least of which is that it is an analysis of trends in global health, addressed to a broad audience, based on the principles of liberation theology.[17] In the manner of liberation theology's "observe, judge, and act," Farmer moves back and forth between personal testimonies of patients in Haiti, Peru, Mexico, and Russia he has treated or interviewed through his work with Partners in Health (hereafter, PIH), critical social analysis of local and global factors affecting health and access to care, and a call for political, economic, and social action.[18] If the result is not exactly a blueprint for health policy reform, it is at least an "interrogation" of the central assumptions and concerns of anyone who professes to care about health care and the ethical issues that surround it today.

Farmer's main argument is that we live in a time when we have the scientific and economic resources to deal effectively with many of the diseases, such as malaria, tuberculosis, and AIDS, that affect and kill vast numbers of people in the world, and yet "the reach of science and of globalization has stopped short of bringing reasonable opportunity for survival within the grasp of the [most deprived]."[19] This is not accidental, but rather the result of deeply entrenched "structures of violence." Linking unnecessary (or "stupid") deaths (due to lack of access to treatments readily available to the affluent) to acts of violence perpetrated on innocent victims by unjust regimes, Farmer argues for analysis that takes into account the "historically given and, often enough, economically driven conditions [that] guarantee that violent acts will ensue." Following Gustavo

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[17] See n. 1 above. See also the following works by Paul Farmer: *Infections and Inequalities: The Modern Plagues* (Berkeley: University of California, 1999); *AIDS and Accusation: Haiti and the Geography of Blame* (Berkeley: University of California, 1992); *The Uses of Haiti* (Monroe, Me.: Common Courage, 1994); and Farmer, Margaret Connors, and Janie Simmons, ed., *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence* (Monroe, Me.: Common Courage, 1996).

[18] Partners in Health is a Nongovernmental Organization (hereafter, NGO) founded in 1987 in Haiti's Central Plateau. Now 20 years old, PIH operates in eight other sites in Haiti and five additional countries. See http://www.pih.org/who/history.html (accessed November 7, 2007).

[19] Amartya Sen, foreword to *Pathologies of Power* xvii.

Guttierez and Jon Sobrino, Farmer uses the term “structural violence” broadly to include a range of offenses against human dignity: “extreme and relative poverty, social inequalities ranging from racism to gender inequality, and the more spectacular forms of violence that are uncontestedly human rights abuses, some of them punishment for efforts to escape structural violence. . . .” To understand human rights violations, when and where (and to whom) they occur, he argues, we need to understand violence structurally, as a matter of “power and connections,” and this is as important when those violations take the form of a lack of access to life-saving medical resources as when citizens are gunned down for speaking out against a repressive government.[20]

Farmer offers a three-part caution for analyzing the relationship between structural violence and suffering in a global context. Analysis must be: (1) geographically broad so that the connections between the suffering of the powerless and the actions of the powerful are exposed; (2) historically deep to take account of embedded relationships of oppression such as colonialism, the effects of which reach far out of the past; and (3) take simultaneous consideration of various social axes such as gender, race and ethnicity, sexual preference, and immigrant status as they relate to poverty. No “honest assessment of the current state of human rights” can neglect attention to multilevel and interconnected inequalities and the way in which those inequalities (whether of race, gender, creed, or class) drive human rights violations.[21]

Farmer’s dependence on central principles of liberation theology builds on a seminal article by Brazilian theologian Márcio Fabri dos Anjos who argues that contemporary medical ethics is in need of “socializing”:

> Liberation Theology draws essential ethical conclusions from [the] “social locus” of the medical encounter. When this “locus” focuses on individualism and personal interests, the link between medical ethics and social reality is lost. Similarly, when this ”locus” is restricted to that group (or social class) of persons who have access to medical resources and basic health conditions, then medical ethics loses its force as a critical mechanism for social criticism and is reduced to a mere casuistry for the economically privileged. The “locus” of Liberation Theology is precisely the world of the poor and the disenfranchised; it is from here that it seeks a fundamental ethical vision, and identifies the most urgent issues of life and health.[22]

When medical ethics ignores gross discrimination in the distribution of care or fails to contribute to closing the gap of “socio-medical disparities,” it

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[20] Farmer, *Pathologies of Power* 8–9, 11.

[21] Ibid. 42–48, 50, 219.

[22] Márcio Fabri dos Anjos, “Medical Ethics in the Developing World: A Liberation Theology Perspective,” *Journal of Medicine and Philosophy* 21 (1996) 629–37, at 634.

cannot, from this perspective, be either credible or effective.[23] Liberation theology brings to medical ethics not only the "world of the poor and disenfranchised" but also a social commitment, a call to solidarity that recognizes a "human existential condition in which issues of economic advantage and disadvantage affect all people."[24]

Farmer carries dos Anjos's insight further, arguing that liberation theology provides a moral compass for advocacy on behalf of health as a human right. To begin with, it grounds a human rights agenda in a "preferential option for the poor"; therefore it focuses attention on the real physical and material needs of the poor and calls for both personal conversion and work for structural change.[25] It presumes, in addition, that genuine change will result from social and political movements rooted in small communities of poor people. Born in the struggle for economic and social rights, a liberation theology perspective takes a critical approach to laissez-faire, liberal doctrine, calling into question its assumption of a level playing field and therefore its confidence in the power of civil and political rights to guarantee conditions for the poor to change their circumstances: "When children living in poverty die of measles, gastroenteritis, and malnutrition, and yet no party is judged guilty of a human rights violation, liberation theology finds fault with the entire notion of human rights as defined within liberal democracies."[26] Finally, liberation theology takes its direction from the voices of the poor and links observation and judgment with what Farmer calls "pragmatic solidarity."[27] Following Sobrino, liberation theology insists that "the only correct way to love the poor will be to struggle for their liberation. This liberation will consist, first and foremost, in their liberation at the most elementary level—that of their simple, physical life, which is at stake in the present situation."[28]

Although *Pathologies of Power* addresses several contemporary health issues embedded in poverty—for example, AIDS and malaria—the incidence of tuberculosis provides the clearest illustration of what Farmer means by "pragmatic solidarity." The best epidemiological and biomedical research shows that deaths from tuberculosis today (numbering in the millions each year, despite the development of effective therapy in the mid-20th century) "occur almost exclusively among the poor, whether they reside in the inner cities of the United States or in the poor countries of the

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[23] Ibid. 631.

[24] Ibid. 635.

[25] See Farmer, *Pathologies of Power* 141.

[26] Ibid. 142.

[27] Ibid. 138.

[28] Jon Sobrino, *Spirituality of Liberation: Toward Political Holiness* (Maryknoll, N.Y.: Orbis, 1988) 32, as quoted in Farmer, *Pathologies of Power* 145.

Southern hemisphere."[29] Working with a sister organization, Zanmi Lasanti, in the rural Central Plateau region of Haiti, Partners in Health sought to understand why many patients did not complete tuberculosis therapy and therefore had poor outcomes. In February 1989, a new, aggressive, community-based program was instituted that offered a continuum of services including diagnosis, adequate drug therapy, and closely monitored follow-up care. Those diagnosed with tuberculosis received daily visits from a village health worker as well as regular reminders of clinic appointments. Relying on the insights of health workers from the community, however, the program also provided nutritional and financial assistance, including a travel stipend. By June 1991, 46 of the 50 patients enrolled in the "enhanced" treatment program showed no symptoms of tuberculosis. The case underscores two important points: (1) taking seriously the lived experience of the poor can challenge both therapeutic and research-based assumptions, for example, about the nature of "noncompliance" with a therapy regime; and (2) solidarity implies being willing not only to question research priorities in light of the concerns of the poor, but also to design programs to remedy inequalities of access to the basic services people need in order to make and realize healthy choices for their lives.[30]

Farmer argues, correctly, that growing interest in the link between health and human rights needs to reach beyond HIV/AIDS to focus on other pressing issues along the "epidemiological divide."[31] At the same time, HIV/AIDS remains a powerful context for examining the role of poverty, gender, and culture (including religion) in the spread of disease and for thinking about the meaning of "pragmatic solidarity" as it applies to the greater vulnerability of poor women to infection and death from HIV/AIDS.

At the end of 2006, women accounted for 48 percent of all adults living with HIV worldwide, and for 59 percent in sub-Saharan Africa. Over the past two years, the number of women and girls infected with HIV has increased in every region of the world. In the United States, women of color comprise the fastest-growing population with HIV infections.[32] Gen-

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[29] Farmer, *Pathologies of Power* 147.

[30] See ibid. 150, 239.

[31] Farmer uses the term "the great epi divide" to indicate the two worlds of health risk, one comprised of those who die of diseases typically associated with old age, and the other comprised of those who die from violence, hunger, and preventable communicable diseases. Most of those on the "wrong side" of the "epi divide" have brown or black skin; many are female; all are poor. See Tracy Kidder, *Mountains beyond Mountains: Paul Farmer and the Quest to Save the World* (New York: Random House, 2003) 125.

[32] See "HIV/AIDS and Women," International Women's Health Coalition, http://www.iwhc.org/issues/hivaids/overview.cfm (accessed November 7, 2007).

der inequality, combined with severe poverty, is increasingly recognized as a significant factor in the spread of HIV and a determinant of who will live with and who will die from AIDS. Experts identify seven factors that explain how gender and poverty intersect to create situations of disproportionate risk for poor women:

(1) *Lack of or poor access to comprehensive reproductive health services and information for women and girls.* Despite international commitments to improve quality and access to health care for women, for example, following UN conferences in Cairo (1994) and Beijing (1995)—overall funding for women's health remains inadequate and often mired in debates over the meaning of "women's health" and the place of reproductive services in primary health care.[33] Moreover, movements to privatize health care, for example, in health care policies of the World Bank, risk increasing burdens on poor women by imposing user fees, sometimes for services that were at one time free when available, and diverting attention from the importance of investments in public health infrastructure.[34] Imrana Qadeer argues, for example, that despite evidence that maternal mortality is related to factors such as poverty, gender-based differentials in access to treatment, poor nutrition, and poor primary healthcare infrastructure, programs under the U.N. Millennium Development Goals in South Asia, which identified among health targets for 2015 the reduction of child mortality by two-thirds and the reduction of maternal mortality by three-fourths, have focused resources and technical assistance on reductions in a narrow set of measurable obstetrical complications: hemorrhage, sepsis, unsafe abortion, and eclampsia.[35] In addition, program emphasis has been directed toward strengthening public-private partnerships for the delivery of maternity services; therefore efforts build on other health care reform and structural adjustment policies which aim at shifting services from the public to the private sector. As Qadeer argues, improving emergency obstetrical and prenatal care is important, but it does not address root causes of maternal mortality through long-term prevention strategies and risks

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[33] Ruth Ojiambo Ochieng, "Supporting Women and Girls' Sexual and Reproductive Health and Rights: The Ugandan Experience," *Development* 46.2 (2003) 38–44. Ochieng notes that following the UN Conference on Population and Development at Cairo, Uganda initiated a program aimed at addressing the needs of at-risk adolescents. However, as of 2003, the program covered only 11 out of 56 districts, and lacked sufficient funding to hire and train health care workers.

[34] Rosalind Pollack Petchesky, *Global Prescriptions: Gendering Health and Human Rights* (London: Zed, 2003) 160–64.

[35] Imrana Qadeer, "Unpacking the Myths: Inequities and Maternal Mortality in South Asia," *Development* 48.4 (2005) 120–26, at 122. The Millennium Development Goals flow from the UN Development Program's Millennium Declaration accepted by 189 nations.

diverting attention from necessary investments in health care infrastructure.[36]

(2) *Lack of basic education.* Worldwide there are 121 million children not in school, of whom 65 million are girls. The highest concentration of unschooled girls is in sub-Saharan Africa. Education has important implications for health, not only because it provides a ready source for health-related information, for example, concerning risks for HIV/AIDS, but it also contributes to women's social status through the ability to enter the labor force, carrying with it the potential for greater financial stability and independence.

(3) *Economic disempowerment.* Pressure to provide an income for families leads some women into the sex trade or into relationships with older male partners. The rate of new infections among girls under 18 in many of the hardest-hit areas is five to seven times higher than among boys.[37]

(4) *Social-relational status.* The biggest risk factor of HIV infection for women in many parts of the world is marriage. Four-fifths of new infections in women result from sex with a husband or primary partner. Evidence indicates that the women who are especially vulnerable are those in a heterosexual marriage or a long-term union in a society where men commonly engage in sex outside the union and where women face abuse if they demand condom use or abstinence.[38] Referring to areas of Nigeria, Nkoli Ezumah points to cultural ideologies about women's passivity in sexual relations as a factor in their increased vulnerability as well as expectations concerning fertility. If a couple does not produce a male child, the woman may feel family and community pressure to have multiple sexual partners; sometimes young unmarried woman are expected to produce children for the family.[39] Women married to migrant workers, soldiers, and truckers also are at increased risk of infection. Thus, it is not enough for women to choose to be monogamous to prevent spread of AIDS; their vulnerability is tied to the behavior of their male partners and to their power/status within the relationship, that is, whether or not they can refuse dangerous or unwanted sex.

(5) *Ignorance or stigma around HIV/AIDS.* Unwillingness to address

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[36] Qadeer notes that maternity services are among the most privatized and highly profitable services in South Asia; ibid. 122–23.

[37] See Kaiser Family Foundation, HIV/AIDS Policy Factsheet, http://www.kff.org/content/factsheets.cfm?topic=hivaids (accessed October 2, 2007).

[38] See "Women and HIV/AIDS," Human Rights Watch, http://hrw.org/women/aids.html (accessed September 15, 2007).

[39] See Nkoli N. Ezumah, "Gender Issues in the Prevention and Control of STIs [Sexually Transmitted Infections] and HIV/AIDS: Lessons from Akwa and Agulu, Anambra State, Nigeria," *African Journal of Reproductive Health* 7.2 (2003) 89–99, at 90.

issues of sexuality and HIV publicly leaves both men and women unable to protect themselves and can foster inaccurate and dangerous beliefs, for example, that "sex with a virgin cures AIDS." Ezumah points to cultural and religious taboos and sanctions that contribute to a "culture of silence" around sexuality; when added to expectations concerning passivity in sexual relationships, women may be unable to "participate in meaningful communication about sexuality."[40]

6) *Child marriage.* The practice of child marriage has decreased globally over the past 30 years. However, it remains an entrenched practice in many rural areas and among the destitute poor. Because of the intersection of poverty and child marriage, the marriage relationship is typically characterized by large age differentials between spouses, limited social support and restricted mobility, limited educational opportunities, and increased risk of maternal and infant mortality. Because of both age and power differentials, child or adolescent brides can be unable to negotiate within the relationship or to call into question their husband's behavior; not unlike individuals in openly abusive relationships, therefore, they are at increased vulnerability to HIV/AIDS and other STIs.[41]

(7) *Violence.* Female victims of sexual violence are more vulnerable physically to contracting HIV during forced sexual intercourse. In addition, because of many of the reasons already given, women in abusive relationships frequently find it difficult to negotiate terms to protect themselves and/or their children. Poverty exacerbates risks under an abusive relationship as lack of financial security or the means to relocate can prevent even those women who so desire it from exiting such relationships.

What all these factors add up to, of course, is the recognition that technical fixes and approaches aimed at individual behavior in the AIDS pandemic, whether access to therapy or imposition of traditional rules and taboos concerning sexuality, will fail to protect those most at risk if there is no attempt to redress the social and economic realities (e.g., gender disparities, poverty, cultural, religious, and sexual norms based on inequality, lack of education, and violence) that determine choices individuals are able and likely to make. More than anything else, reducing women's risk of HIV depends upon: access to education, information and basic health care, improved economic status, and increased political power for implementing community priorities. All of women's basic human rights, therefore, are implicated in assuring a right to adequate health under the threat of HIV/AIDS.

Some of the most successful HIV/AIDS prevention and treatment pro-

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[40] Ibid. 91.

[41] See UNICEF, *Early Marriage: A Harmful Traditional Practice, A Statistical Exploration* (New York: UNICEF, 2005).

grams are based on this understanding of "pragmatic solidarity." Reach Out Mbuya Parish HIV/AIDS Initiative, located outside of Kampala, Uganda, provides free counseling, testing, and antiretroviral therapy (ARV) to all eligible patients at no cost, along with social, nutritional, and economic support.[42] Reach Out Mbuya began in 2001 with 14 clients as an outreach program of a Roman Catholic parish; today more than 2500 patients are served. Reach Out has four medical doctors on staff, but uses a network of community-based support (in the form of trained CATTS: Community ARV TB Treatment Supporters) to monitor health status and treatment regimes outside of the clinic. Two satellite sites (again building on existing religious community initiatives) increase the area they can serve.[43] According to the most recent report, 52.2 percent of Reach Out's clients were on antiretroviral therapy. Rates of adherence to therapy average 92 percent. Pregnant women are followed closely to lower the risk of maternal-fetal transmission of HIV; each is assigned a companion to accompany the birth and to lend support in case of family interference or the threat of domestic violence.

Reach Out Mbuya attributes its success in getting people to come for testing and to stick with treatment plans to its "empowerment" approach. More than 65 percent of their clients are women. Aware of the distinct multilayer vulnerability of girls and women to HIV/AIDS, Reach Out Mbuya offers a microfinance program, a grandmother's organization for community-building, a workshop where clients can learn either sewing or bead-making, a school fees program to make it possible for the children of clients to attend primary and secondary school, a food program for all patients on ARV, and educational outreach to raise awareness and combat stigma using drama and the arts. More than 60 percent of Reach Out's staff are clients, although program directors acknowledge that, as the scale of the program enlarges, employing clients is growing more difficult as most lack the skills to manage more complex budgets and other administrative tasks.

Programs such as Reach Out Mbyua are often described as "unique" or "impossible to duplicate." This is no doubt true, in the sense that the program grew out of and still depends on the commitment of a small faith community to respond with dignity to a situation of overwhelming suffer-

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[42] Eligibility for antiretroviral therapy is determined according to World Health Organization guidelines by clinical indications of the severity of the disease and blood cell counts indicating CD4 levels < 200 cells/muL. Reach Out's antiretroviral therapy program is funded mostly by PEPFAR (The President's Emergency Plan for AIDS Relief) and the Global Fund.

[43] Personal interview with Stella Alamo Talisuna, M.D., Executive Director, Reach Out Myuba, October 20, 2007. According to Talisuna, increasing the area of outreach is particularly important because economic development around the main site is pushing their client base farther out.

ing it faces on a daily basis. Still, it is hard to imagine why it would not be possible to bring the fundamental, strategic principle at work in such initiatives to bear on health care in general: promoting and protecting health is inextricably linked to efforts to improve socioeconomic stability and to secure the conditions for meaningful participation in one's community.

RETHINKING BIOETHICS

Above we saw that linking health and human rights shifts the center of gravity in public health analysis, giving weight to the constellation of factors at work in the social construction of health and illness. We have also begun to see the implications of a human rights focus for bioethics. In an article coauthored with Nicole Gastineau Campos, Farmer suggests what it would take to face up to the "unmentioned elephant in the room of medical ethics," that is, the growing gap in access to the fruits of modern science and medicine.[44] To change its subject, which long has been the more or less empowered individual in a Western clinical context, bioethics needs to turn its focus toward resource-poor areas, to engage the people and disciplines best equipped to speak to the realities at work in those settings, and to link research across steep economic gradients with the interventions demanded by the poor and marginalized.[45]

Echoing dos Anjos, Farmer and Campos point out that "subaltern populations within rich and middle-income countries have long been caught up in the key dramas of medical ethics . . . but to this day, the poorest people in the poorest countries are likely to appear only in the margins of the bioethics literature if they appear at all."[46] This is not surprising, given the settings in which bioethics developed as a field and the continued dominance of North American perspectives in its most influential journals. Bringing the voices of the most afflicted, those who "quite literally *embody* many of the ethical dilemmas stemming from injustices within medicine and public health," into the heart of bioethics is not only a way to expand its field of vision, to gain moral wisdom not otherwise available, but also to move analysis toward solidarity.[47] Many will regard with skepticism the assumption that encountering widespread poverty, starvation, and malnutrition as daily realities for millions of people leads inevitably to moral

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[44] Paul Farmer and Nicole Gastineau Campos, "Rethinking Medical Ethics: A View From Below," *Developing World Bioethics* 4.1 (2004) 17–41, at 29.

[45] Ibid. 17.

[46] Ibid. 20. Farmer and Campos point to the famous Tuskegee Syphilis Study (conducted in Alabama from 1932 to 1972) and the Norplant Trials in Brazil (1984–1986) as examples of studies involving marginalized populations that received significant attention in the bioethics literature.

[47] Ibid. 36.

conversion. It seems obvious, however, that failure to acknowledge the multiple and unequal worlds of health care that exist (within industrial democracies as well as across the so-called "developing" world) both distorts and impoverishes bioethics. If it is not to appear hopelessly academic—or worse, as dos Anjos warns, "mere casuistry for the economically privileged"—bioethics needs to turn to those who suffer most under current arrangements and to those disciplines that can illuminate the "social production and maintenance of that suffering," for example, anthropology, history, and economics. Yet, it is not enough simply to understand the realities of global health inequities. Increasingly, Farmer and Campos argue, bioethics needs to be linked through action to the struggle for social and economic rights. This is not merely a moral claim, but a pragmatic one: "If social inequalities persist and grow, we will no longer be welcome to conduct research or even to comment on it."[48]

One of the most interesting and provocative challenges made in *Pathologies of Power* is to universities (particularly those in resource-rich areas) to use their considerable economic and moral resources in service of the global movement toward health equity. Because they do not experience the same limitations (or political entanglements) as international institutions such as the United Nations or even international, highly visible NGOs (like Physicians for Human Rights), universities are uniquely positioned to engage in the sort of critical research that would follow from "rethinking bioethics" (and other fields of inquiry), and to explore the potential of partnerships for community-building. Farmer's call is echoed in a recent article by David Skorton, president of Cornell University, in the *Chronicle of Higher Education*; he argues for colleges and universities to take part in a "New Marshall Plan" for global outreach, participating in capacity-building by strengthening local education, research, and problem-solving skills:

> No single college or university, acting alone, can achieve what will be needed in tomorrow's world. Together, however, the nation's great research institutions—public and private, land-grant and Ivy League, working with the U.S. government, businesses, foundations, nongovernmental organizations, and, most important, our academic colleagues overseas—can offer a more focused application of our own resources to reach out, materially and directly, to assist and improve the quality of life.[49]

Many readers will be less sanguine than is Skorton about invoking "Marshall Plan" language to describe the potential contributions of colleges and universities, given the term's strong suggestion of American largess and

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[48] Ibid. 40.

[49] David J. Skorton, "A Global Outreach Plan for Colleges," *Chronicle Review* 54.4 (September 21, 2007) B28.

self-interest. Still, his practical proposal for harnessing the intellectual and moral power of higher education is both ambitious and achievable. Universities and colleges, he argues, should publicize and coordinate current efforts in capacity building already underway in the global South; "collaborate to develop a strategic research and education agenda that complements issues of concern to similarly oriented NGO's, corporations and foundations, and our counterparts overseas, in areas such as nutrition, global health, sustainable technologies, and conflict resolution;"[50] and be in a position to guide, influence and assist in the formation of domestic and international policy concerned with health equity.[51]

Many of the world's prestigious universities regularly engage in research with great potential for improving health, e.g., vaccine trials for tropical diseases; genetic modification of malaria-carrying mosquitoes; and bioremediation of water pollution, often in partnership with institutions in economically struggling areas. But we can imagine what would be possible through a committed, coordinated effort to bring the intellectual, financial and moral power of universities to bear on the problem of achieving health equity in the United States as well as across the global South. In this time of intense mission awareness, church-sponsored colleges and universities have a special challenge and opportunity. In whatever ways they come to define and communicate their identity, given commitments to social justice deep in the major religious traditions, it would be tragic if religious institutions of higher education—especially those with the greatest resources and highest visibility—failed to emerge as leaders and exemplars in this effort and in the broad movement for social and economic rights.

NEGOTIATING HUMAN RIGHTS

However apparent the place of health in a human rights agenda has seemed in this age of AIDS, or the promise of a human rights framework for bioethics, human rights—particularly social and economic rights—remain contested ground. An adequate treatment of all the issues and disagreements is beyond the scope of this note. However, it is important to highlight briefly three problems of relevance to bioethics.

The first concerns the complex relationship between human rights as instantiated in international law, conventions, and declarations, and human rights as a philosophy, a set of beliefs about the meaning of human dignity

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[50] Ibid.

[51] For an international perspective see Chitr Sitthi-amorn and Ratana Somrongthong, "Strengthening Health Research Capacity in Developing Countries: A Critical Element for Achieving Health Equity," *British Medical Journal* 321 (2000) 813–17.

and the contours of a just society. The goal of this note has not been to give an exhaustive account of the status of a right to health in international law, but rather to show how human rights principles provide a conceptual framework, a vocabulary, for describing societal factors in health-related vulnerability and a recognizable direction for social change.[52] One advantage of this approach is that it makes visible the sense in which human rights commitments and movements transcend the constraints of international politics. To borrow from Brazilian human rights advocate Sonia Corrêa, human rights are above all "a discourse that provides multiple spaces where women and other actors (excluded or misplaced by the existing social contract) . . . gain individual and collective agency."[53] In the language of many grassroots women's organizations, rights talk is not just a defensive strategy, a way to make visible women's vulnerabilities under various power regimes or to raise up many women's daily struggles for survival, but a claim for "a new vision of politics" and a "radical rethinking of the social contract."[54] Viewed this way, it is possible to see progress in the promotion of human rights (and the recognition of health as a human rights issue) in the form of emerging transnational movements for global health equity. Indeed, as Lisa Cahill points out, the place to look for evidence of a developing consensus about the priority of justice and the importance of action to meet the basic social and material needs of all people in a global bioethics is not at the UN, "at the top of the international governance pyramid," but rather in these transnational advocacy movements and the practical initiatives to which they give rise.[55]

At the same time, even if the signs of progress are more ambiguous, the importance of translating human rights commitments into law or policy cannot be ignored. One reason was suggested earlier: human rights play a critical role in the movement for social justice precisely because they are one of the principal forms in which perceptions of existing injustice become political claims. That law matters in this way is well illustrated by the intentional refusal of the United States to recognize a "right to health care." In a plenary address to the recent Catholic Theological Ethics in the World Church Conference, Henk ten Have suggests another reason.[56]

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[52] See Jonathan Mann, "Human Rights and AIDS: The Future of the Pandemic," in *Health and Human Rights,* 216–26, at 222.

[53] Sonia Corrêa, "Quandries at the Site of Human Rights," *Development* 46.2 (2003) 21–3, at 21.

[54] Temma Kaplan, "Women's Rights as Human Rights: Women as Agents of Social Change," in *Women, Gender, and Human Rights: A Global Perspective,* ed. Marjorie Agosín (New Brunswick, N.J.: Rutgers University, 2001) 125–51, at 132.

[55] Lisa Sowle Cahill, "Biotech and Justice: Catching Up with the Real World Order," *Hastings Center Report* 33.4 (2003) 34–44, at 42.

[56] Henk ten Have, "Universal Declaration on Bioethics and Human Rights," in

Statements such as the Universal Declaration on Bioethics and Human Rights, which was adopted by UNESCO Member States in 2005, are increasingly valuable, even when they are nonbinding, because they recognize the global character of both opportunities and dangers in contemporary science and medicine. Although how such statements influence policy varies widely, they nonetheless create a commitment on the part of governments that provides a framework for accountability. Still another reason explains the continued confidence of grassroots organizations, for example, groups working for women's rights, in efforts to forge international human rights agreements, despite setbacks and widespread suspicion concerning the motives of many of the actors on the international human rights scene. The protection and promotion of human rights, particularly social and economic rights, ultimately depend on national action; however, international human rights instruments are indispensable, especially for those not in a position to assert their human rights against deeply entrenched systems of cultural or religious discrimination. International human rights norms remain powerful because they "establish global standards, aid in interpretation [e.g., in local and regional courts] and serve as a final resort for those whose claims are not or cannot be vindicated on the national level."[57]

Moving forward, it will be important for ethicists to reflect on what forms of transnational governance are most valuable in securing the goals of health equity, as well as on the range of issues for which the framework of international law might prove crucial, for example, patenting of life forms and drug pricing. At the same time, advancing genuine international dialogue on human rights will require reaching beyond static or inductive conceptions of rights to envision rights as dynamic, fluid, and contextual, and to recognize rights discourses as "fields of on-going political struggle." Equally important will be the willingness to understand human rights treaties and declarations not as the culmination but as the initiation of a process in which shared moral values are translated into social policies and practices.[58]

A second problem encountered in making the link between health and human rights is the much-contested terrain of "women's rights." The last decade of the 20th century saw remarkable progress in raising the visibility of women's status as a human rights issue. Several international confer-

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Catholic Theological Ethics in the World Church: Plenary Papers from the First Cross-cultural Conference on Catholic Theological Ethics, ed. James F. Keenan (New York: Continuum, 2007) 29–34.

[57] Fitnat Naa-Adjeley Adjetey, "Reclaiming the African Woman's Individuality: The Struggle between Women's Reproductive Autonomy and African Society and Culture," *American University Law Review* 44 (1994–1995) 1351–81.

[58] Ten Have, "Universal Declaration on Bioethics and Human Rights" 33.

ences brought new attention to the importance of women's empowerment in achieving social stability and economic progress. The Plan of Action adopted at the International Conference on Population and Development (1994) explicitly recognized freedom from gender-based violence and access to education, health care, and political participation for women as cornerstones in sustainable development. But consensus on the question of women's rights as human rights has also foundered (and, in the case of some religious leaders, run aground) over deeply entrenched and well-known disagreements about abortion and over the meaning of reproductive health and agency.

Without denying the very serious moral questions involved in abortion, all that I have said earlier about the social construction of women's vulnerability to health threats such as HIV/AIDS should make clear the danger of reducing the question of advocacy for women's rights to a matter of abortion. For many women around the world, the struggle for human rights takes the concrete form of fighting for access to education, freedom from domestic and sexual violence, the right to refuse unsafe or unwanted sexual intercourse, and the means to provide for their children with dignity. Restricting access to abortion does not by itself address the complex social and economic factors that underlie and sometimes force decisions about abortion; moreover, reducing advocacy for women's rights to this single goal obscures the need to address those cultural and religious teachings and practices that contribute to worldwide discrimination on the basis of gender.[59] Where religious leaders are strong advocates for the protection of the unborn, but fail to call men to take responsibility for preventing the spread of HIV/AIDS, or fail to challenge aspects of their religious tradition that contribute to a "culture of silence" around issues of sexuality, their message is ultimately death-dealing. The movement to oppose abortion will have the potential to be empowering to women around the world only when "it comes in the form of strong, consistent advocacy for women's overall well-being, formulated in dialogue with women themselves."[60]

Finally, the meaning of a "right to health" might seem obvious in the context of the AIDS pandemic; however, when we consider what it involves as we look to potential advances in areas such as genetic medicine, the need to join a human rights framework with critical attention to health as a dimension of sustainable development becomes clear.[61] At its most

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[59] See Margaret A. Farley, *Compassionate Respect: A Feminist Approach to Medical Ethics and Other Questions* (New York: Paulist, 2002).

[60] Lisa Sowle Cahill, *Theological Bioethics: Participation, Justice, and Change* (Washington: Georgetown University, 2005) 193.

[61] For one view of the relationship of health, development, and human rights see

basic, to bring health, human rights, and development together is to understand how health and development are interconnected, and how investments in improving health care infrastructure contribute to the ability of individuals and communities to articulate and achieve goals. At the same time, a human rights lens challenges methods and measures in development theory, raising up the dimensions of structural violence highlighted above and making the connections between "orders of power" and "possibilities for empowerment." As we move into a future of immense potential for promoting health and enhancing human well-being, it will be all the more important to set questions about health care investments within a broader right to development and to call for dialogue over access to health care that is participatory, accountable to the common good, nondiscriminatory, and attentive to the conditions and relationships that create and maintain unequal vulnerabilities.

CONCLUSION

Rosalind Pollack Petchesky observed that it is no surprise that HIV/AIDS figures so prominently in the struggle to assert health as a human right; after all, "it most starkly locates the body at the crossroads of gender, race, class, sexuality and geography."[62] Among its legacies, the HIV/AIDS pandemic has pushed us to make new connections between a commitment to human dignity and strategic action on behalf of those who are socially, economically, and culturally marginalized. In its wake, it has generated renewed possibilities for exploring the interrelationships of health, development, and human rights and has posed a serious challenge of credibility to the field of bioethics. If Farmer is correct, we now stand at a decisive moment, when our political and moral choices about access to health care will define who we are as a people and shape our future within a global society.

Anne Donchin, "Converging Concerns: Feminist Bioethics, Development Theory, and Human Rights," *Signs: Journal of Women in Culture and Society* 29 (2003) 299–324.

[62] Petchesky, *Global Prescriptions* 116.