

The Language of Human Rights and Social Justice in the Face of HIV/AIDS

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The public language of AIDS is as important as the science.

– Albert Jonsen¹

We are two Roman Catholic priests (one an AIDS physician², the other an ethicist³) who have been working, lecturing and writing on HIV/AIDS since the 1980s. In order to do what we do, we have had to watch our language. For instance, when we address the question of condoms and HIV/AIDS prevention, we

¹ Albert Jonsen, "Foreword," *The Meaning of AIDS*, ed. Eric Juengst and Barbara Koenig, (New York: Praeger Publishers, 1989).

² Jon D. Fuller, "Priests with AIDS: What Lessons for the Church?," *America* 182 (2000): 7-9; "Needle Exchange: Saving Lives," *America* 179 (1998):8-11; "AIDS Prevention: A Challenge to the Catholic Moral Tradition," *America* 175 (1996), pp. 13-20.

³ James F. Keenan, ed. assisted by Lisa Sowle Cahill, Jon Fuller, and Kevin Kelly, *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2000), Philippine Edition: (Quezon City: Claretian Press, 2001); Keenan, "Prophylactics, Toleration and Cooperation: Contemporary Problems and Traditional Principles," *International Philosophical Quarterly*, 29 (1988), pp. 205-221; "Truth-Telling, Confidentiality and Fiduciary Responsibility in the Professions," *Theological Studies* 54 (1993), pp. 142-159; "HIV Testing of Seminary and Religious-Order Candidates," *Review for Religious* 55 (1996), pp. 297-314; "Making a Case for Casuistry: AIDS and its Ethical Challenges," Jon Wetlesen (ed.) *Hva er Kasuistikk?: Om moralsk laering og refleksjon i tilknytning til forbilder og eksempler* (Oslo: Oslo University Press, 1998), pp. 163-186; "Applying the Seventeenth Century Casuistry of Accommodation to HIV Prevention," *Theological Studies* 60 (1999), pp. 492-512; with Jon Fuller, "Tolerant Signals: The

always note that in the 1968 papal encyclical, *Humanae vitae*,⁴ Pope Paul VI condemned birth control but not in themselves either the pill (which can be used to regulate a woman's cycle) or the condom (which can simply function prophylactically to prevent the transmission of disease).

Language, we learned, sets agendas. When we talk about the condom, not as a contraceptive, but as a prophylactic, we detach ourselves from discussions about the legitimacy of the Catholic church's teaching on contraception and focus attention simply on HIV prevention strategies in a time of AIDS. As Dr. Peter Piot, Executive Director of UNAIDS has noted, "For years, Roman Catholics have been important providers of competent and compassionate care to people living with HIV infection around the globe."⁵ However, we have never found it easy to talk about HIV/AIDS prevention in Catholic settings, and Catholic institutions are often unable to work collaboratively with other social and health care agencies in this area. Recognizing this difference between Catholic institutional support for the care of those infected, and institutional obstacles to the work of HIV prevention, we worked on a three year project bringing the reflections of thirty-five Catholic ethicists from twenty six countries to bear on the question of the language of the Catholic moral tradition and HIV/AIDS prevention. This culminated in a book we edited, *Catholic Ethicists on HIV/AIDS Prevention*. Following that project, and being attentive to public language, we decided to examine how others are talking about HIV/AIDS. We discovered, for instance, that seven years ago the late Dr. Jonathan Mann proposed the language of human rights for those looking for a conceptual framework for public health workers.

Vatican's New Insights on Condoms for H.I.V. Prevention," *America* 183 (2000), pp. 6-7; with Jon Fuller, "Condoms, Catholics and HIV/AIDS Prevention," *The Furrow* 52 (2001), pp. 459-467; with Jon Fuller, "Catholic Answers to Aids," *The Tablet* June 30, 2001, pp. 942-943; with Jon Fuller, "Church Politics and HIV Prevention: Why is the Condom Question So Significant and So Neuralgic?," *Between Poetry and Politics, Essays in Honour of Enda McDonagh*, Linda Hogan and Barbara FitzGerald (eds.), The Columba Press, Dublin, 2003, pp. 158-181.

⁴ http://www.vatican.va/holy_father/paul_vi/encyclicals/documents/hf_p-vi_enc_25071968_humanae-vitae_en.html

⁵ Peter Piot, in *Catholic Ethicists on HIV/AIDS Prevention*, James F. Keenan, ed., (New York: Continuum, 2000), p. 1.

This use of language is very important. Having recently returned from the XVth International AIDS Conference in Bangkok, we heard time and again the language of human rights used. From the first plenary session to the last, we heard time and again: "Access to HIV treatment is a human right." That assertion was never accompanied by the complementary arguments that could morally compel the international community in general, and the industrialized world specifically, to make that access a reality. No ethical argument was made. Instead, we heard the language of "donor" nations, whose "generosity" was occasionally recognized. Elsewhere at Bangkok, Mann's prophetic call was expressed in two very different ways. Many from the industrialized world used human rights simply to assert every citizen's claim to certain goods. On one panel, for instance, a Harvard researcher insisted on the right to voluntary counseling and treatment, and two Canadian scholars claimed the right to microbicides. They failed to provide any analysis on how these rights could ever be attainable elsewhere. Here "human rights" were simply two words, not a language of analysis. Fortunately, the richness of the language was not lost on researchers from the developing world. On the same panel, a Ukrainian and a Nigerian scholar identified and examined the many goods and rights needing to be realized in order to make HIV prevention possible. They understood the rich resources that language provides.

In this article, then, we explore our findings and make our case for the need to attend to language as we work against the HIV/AIDS pandemic. We report first on our own experience with Catholic ethics, and then look to the "language" of epidemiology, clinical medicine, and public health. Examining these four different contexts, we find parallel though not yet concerted efforts to express somehow the needed "social" language for responding adequately to the pandemic. We conclude by noting not only that language has clarified and changed the ethical issues surrounding HIV/AIDS, but it has also empowered those working with this language to combat HIV/AIDS more effectively and to communicate with members of these four different but converging disciplines with greater facility and cogency.

Catholic Ethics

"AIDS is a social issue, not primarily a sex issue." With these words Boston College's Lisa Sowle Cahill opened her essay, "AIDS, Justice and the Common Good." Contrary to others who held that illicit private, sexual activity was the cause of HIV/AIDS, Cahill argued that "the primary cause of the spread of this horrendous disease is poverty." She added that "related barriers to AIDS prevention are racism; the low status of women, and an exploitive global economic system, which influences marketing of medical resources."⁶ Cahill provided readers with a relatively important hermeneutical shift: rather than addressing the pandemic through the conceptual framework of Roman Catholic sexual morality, she turned to its social justice teaching. There she found the concepts of common good, structural sin, subsidiarity, the dignity of the human person, and the preferential option for the poor. She saw that these terms could further empower and validate the commitment of Catholics and others to comprehensive HIV prevention strategies.

Though, as we shall see, other Catholic ethicists explored the language of social justice in order to respond to the AIDS pandemic, it is noteworthy that they not only eschewed the language of sexual morality, but also showed no interest in adjudicating these questions utilizing the traditional principles of bioethics: autonomy, beneficence, non-maleficence, and justice. The instinct of Cahill and others not to approach the pandemic with the tools of bioethics will also be shared by public health officials, and in particular by Jonathan Mann who specifically noted why the language of bioethics could not provide adequate traction.

Like Cahill, India's Clement Campos insisted on the urgent need to shift the context of discussion of Catholics about HIV prevention. Because of the inordinate attention being given to the use of condoms as prophylactics, he wrote, "the impression often created is that AIDS is essentially an issue of sexual morality. It is not. It is more an issue of social justice, involving human rights and the conflict between the rights of the individual and the protection of the common good." In a society where some persons are "untouchable," Campos reminded

⁶ Lisa Sowle Cahill, "AIDS, Justice and the Common Good," James F. Keenan, ed., assisted by Lisa Sowle Cahill, Jon Fuller, and Kevin Kelly, *Catholic Ethicists on HIV/AIDS Prevention* (New York: Continuum, 2000) 282–293, at p. 282.

us of the Roman Catholic tradition of social justice which calls for a solidarity with those who stand at the margins.⁷

Similarly, Egypt's Nader Michel took the language of Catholic social teaching and applied it in his essay, "Fighting AIDS in a Society Where We Egyptians Don't Talk About It." Facing the reality that "in Egypt AIDS is a taboo," Michel identified "social solidarity and the protection of the common good" as the goals of Catholic social organizations that work for health care. These goals would bring from the margins of society those most at risk. In this light he indicated that these organizations must serve "those who are at the margins of this society and...protect the members of the society from the dangers that it wants to repulse and hide. A healthy society is able to care for those who are rejected, to exorcise its taboos, to heal its wounded and protect its members."⁸

From their work in Haiti, Paul Farmer and David Walton argued that "the promotion of social and economic rights for the poor—central to the magisterium of the church, in the view of these two Catholic physicians—is the key missing ingredient in the struggle against a pathogen that makes its own preferential option for the poor."⁹ But Farmer and Walton took the relevance of the shift in language further by arguing that the terms of the Catholic social justice tradition—with its emphasis on common good, solidarity and the option for the poor—shapes not only a defense for the work of prevention, but also prompts an examination of the adequacy of the agenda of prevention strategies. Thus, they asked: "Are physicians and nurses and community-health workers responsible for the more equitable distribution of land and power?" While asserting that in many instances health care providers are not encumbered with this responsibility, still "those working within the institutions of the church and those adopting a faith-based approach to HIV/AIDS prevention have to answer to a more stringent mandate." In concrete terms this means recognizing "the imperative that HIV/AIDS prevention be linked to efforts to diminish

⁷ Clement Campos, "A Catholic Hospital in India is Asked to Cooperate with an HIV Prevention Program," *Ibid.*, pp. 199-211, at pp. 207-208.

⁸ Nader Michel, "Fighting AIDS in a Society where we Egyptians Don't Talk About It," *Ibid.*, pp. 155-161, at p. 159.

⁹ Paul Farmer and David Walton, "Condoms, Coups, and the Ideology of Prevention: Facing Failure in Rural Haiti," *Ibid.*, 108-119, at 109.

the poverty and inequality that serve as the most virulent co-factors for this epidemic. This means offering “pragmatic solidarity” to women’s groups, which in turn means putting resources directly into the hands of poor women.” While they acknowledged that “Haitian bishops have by and large failed to underline the connections between social inequality and HIV transmission,” the base communities of the church have, and so they concluded with the “hope that support for a social-justice approach to HIV/AIDS prevention will find its leading protagonists within the church.”¹⁰ The language of social justice prompts not only a new context of analysis, but also provides a framework for moving interested communities of faith forward to further the work of HIV/AIDS prevention.

Back in the United States, Georgetown University’s Diana L. Hayes explored the impact that discourse on HIV/AIDS has had on the African-American community. Reflecting on Beth Ritchie’s insight that AIDS “has the potential to cripple black people in a way that few other health or social forces have since slavery,”¹¹ Hayes turned not to the social justice tradition, but rather to the received understanding of the scriptures in the black community in order to focus on the need for solidarity in the time of AIDS. In the Gospel spirit of mercy and solidarity, she noted that church leaders’ discourse on HIV/AIDS all too frequently focuses on the sexual practices of gay men. She writes:

Traditional church teachings on HIV/AIDS have too often addressed the issue within the context...of homosexuality. With its dualistic emphasis on condemning the sin while caring for the sinner, the more critical perspective of prevention is often overlooked, especially among poor blacks and Latinos. Already overwhelmed by poverty, racial prejudice and discrimination, finding little or no support from overstretched government agencies, they turn to their church only to find that it is more interested in how they contracted the disease than in how they can be helped in their efforts to take care of themselves while not passing the disease on to others around them, especially their wives and children.¹²

¹⁰ *Ibid*, pp. 117-118.

¹¹ Beth Ritchie, “AIDS in Living Color,” Evelyn C. White, ed., *The Black Women’s Health Book: Speaking for Ourselves* (Seattle: Seal Press, 1990), p. 183.

¹² Diana Hayes, “Come, Ye Disconsolate: American Black Catholics, Their Church, and HIV/AIDS,” *Catholic Ethicists on HIV/AIDS Prevention*, pp. 96-107, at p. 104.

She goes on to ask: "Who, if not the Church, will speak for them, and prevent their further decimation, not only as individuals, but as members of a living community?" She answers this question by reiterating the words of Jesus: "I desire mercy and not sacrifice," and insists that "we should be engaging in acts of mercy, not requiring the sacrifice of those least able to fend for themselves." In a spirit of mercy and solidarity, she concludes that "to approach the individual as if her or his behavior were independent of economics, culture and politics, as independent of human rights and dignity, would be to deny the reality that we know."¹³

Though the contributors to our project greatly affected the discourse and subsequent agendas among Catholic ethicists and their colleagues, several years earlier a number of other Catholic ethicists had already noted the need to shift the context of ethical argument about HIV prevention. In the United States, Eileen Flynn,¹⁴ and later, Richard Smith,¹⁵ noted the need for a new hermeneutical context. Eventually, Spain's Marciano Vidal flagged the need for non-discrimination and solidarity in HIV prevention, as did Ireland's Enda McDonagh.¹⁶ Finally, based on the belief that sexual morality must recognize our contemporary era as a time of AIDS, England's Kevin Kelly recast all of Catholic sexual morality in the language of Catholic social justice. In particular, from his own experience of listening to HIV-infected women in many regions of the world, he argued that a sexual ethics which fails to address gender inequalities cannot in itself be considered ethical.¹⁷

Our project could not have been accomplished without these pioneering writings, but the reflections and perspectives of the thirty-five contributors to *Catholic Ethicists on HIV/AIDS Prevention*

¹³ *Ibid.*, at p. 106.

¹⁴ Eileen Flynn, *AIDS: A Catholic Call for Compassion* (Kansas City: Sheed and Ward, 1985).

¹⁵ Richard Smith, *AIDS, Gays, and the American Catholic Church* (Cleveland: The Pilgrim Press, 1994).

¹⁶ Marciano Vidal, "The Christian Ethic: Help or Hindrance? The Ethical Aspects of AIDS," José Oscar Beozzo and Virgil Elizondo, eds., *Concilium: The Return of the Plague*, 75 (1997), pp. 89-98. See also Enda McDonagh, "Theology In a Time of AIDS," *Irish Theological Quarterly* 60 (1994), pp. 81-99.

¹⁷ Kevin T. Kelly, *New Directions in Sexual Ethics: Moral Theology and the Challenge of AIDS* (London: Geoffrey Chapman, 1998).

confirmed and extended throughout the world the necessity of a social justice hermeneutic as foundational for Catholic ethicists reflecting on the HIV/AIDS pandemic. Today, Catholic ethicists writing on HIV/AIDS inevitably turn to the language of the Catholic social justice tradition, particularly developing three main concepts: the common good, solidarity, and the preferential option for the poor. These concepts not only validate the participation of Catholics in the work of HIV prevention, but more importantly—as Farmer and Walton noted—they help us to design even more comprehensive strategies for effective HIV prevention.

Epidemiology

Since it was first recognized in June, 1981, the HIV/AIDS epidemic has spread to every region of the globe and has impacted virtually every sector of society. Initially identified among gay men and injection drug users in the United States, from a global perspective HIV is spread predominantly through heterosexual transmission, with women now accounting for a majority of new infections in Sub-Saharan Africa. By 1999, AIDS had become the 4th greatest killer globally, accounting for 4.8% of all deaths, while in Sub-Saharan Africa it was the #1 killer, responsible for 20.6% of deaths (twice as many as the #2 killer: upper respiratory infections).¹⁸ More than 20 million persons have already succumbed to the epidemic, and annually 3 million more die (8,200/day). An estimated 42 million persons were living with HIV infection at end 2003, and each year 5 million more become infected (more than 13,000/day). The epidemic is currently poised to spread especially rapidly in Asia and in former countries of the Soviet Union (with 1% of the Russian population already being infected). Estimates for cumulative new HIV cases between 2000 and 2002 just in China, Russia and India range from 66-259 million, with cumulative deaths in those countries over the same period estimated to range from 43 to 155 million.¹⁹

¹⁸ The World Health Report 2000, WHO.

¹⁹ Nicholas Eberstadt, "The Future of AIDS," *Foreign Affairs* 81 (2002), pp. 22-45, at p. 35.

As the epidemic has expanded, the public health perception of it has evolved from being seen as a health condition chiefly impinging on individuals and families, to being viewed as a more broadly destructive force striking at all levels of social organization including the family, village, district, country and even continent.

By viewing projections for Botswana, the country with the world's highest HIV prevalence (where up to 35% of adults may be infected), one can appreciate the large demographic shifts being occasioned by the epidemic. Figure one shows Botswana's projected "population pyramid" for 2020 in the absence of the epidemic. Here is a healthy, wide-based population structure with a large number of younger persons at the bottom supporting a relatively smaller number of older persons in the middle and at the top. However, Figure 2 demonstrates the anticipated impact of the epidemic, in which a chimney-shaped or "cantilevered" population structure demonstrates not only a significant reduction in the total size of the population, but also anticipates that a relatively small number of younger persons will be supporting a larger number of middle-aged persons who will have the largest burden of disease. In a similar analysis from a global perspective, AIDS will by 2050 cause the populations of the hardest-hit nations to have 480 million fewer people than previously predicted (as compared with a projection of 300 million fewer persons anticipated as recently as 2001 by UN demographers).²⁰

Numerous reports have demonstrated the particular impact of the epidemic on important sectors of society. For example, according to the South African Democratic Teachers Union, nation-wide AIDS-related deaths among teachers rose by over 40% between 2000 and 2001. Swaziland has estimated that it will have to train 13,000 teachers over the next 17 years just to keep services at their 1997 levels—7000 more than it would have had to train in the absence of AIDS.²¹

AIDS-related teacher scarcity, families being unable to afford school fees (because of AIDS-related decreased family income), and students (preferentially girls) being pulled from school to compensate for lost labor of sick adults have all contributed to fewer children attending primary school. UNAIDS reports that as a result of AIDS in Uganda,

²⁰ Gautam Naik, *Wall Street Journal*, Feb 27, 2003.

²¹ Report on the global HIV/AIDS Epidemic 2002, UNAIDS, p. 53.

Kenya, Zambia and Zimbabwe, the primary-school-age population in 2010 will have been reduced by 12-24%.²²

Even before considering the possibility of providing expensive anti-HIV drugs to infected persons, studies in Uganda have shown that up to 65% of affected families were forced to sell property to afford traditional care for affected family members. The future for the children in many of these families is the prospect of being uneducated orphans without land or animals.²³

Military personnel have been shown to be particularly vulnerable to becoming HIV-infected, with resulting concerns regarding the ability of some countries to maintain their security structure. For example, as compared with a 5% HIV seroprevalence among the adult population in Nigeria, 11% of Nigerian military returning from peacekeeping missions in Sierra Leone and Liberia were infected.²⁴ In South Africa, 60-70% of military personnel are infected as compared with 20% of the general population.²⁵

In the face of significant increases in adult life expectancy that had been achieved in many Sub-Saharan African countries since the 1950's, many countries are noting a reversal of these trends. In Botswana, for example, life expectancy increased from 43 to 62 years between 1955 and 1985, but is anticipated to drop to 37 years by 2005.²⁶

As the wider impact of the epidemic on social structures, demographics, development and security has become clearer, an understanding of the fundamental problem to be solved has evolved from being viewed primarily as a health issue to one identified as being critically related to poverty, economic development, and gender power disparity. This can be seen from a structural perspective as the WHO's initial Global Programme on AIDS (a single agency which viewed the epidemic primarily as a health issue) became UNAIDS, a multi-agency consortium which could also address issues relating to children, development, population control, education, drug control, etc. (being

²² UNAIDS, p. 52.

²³ UN Study, cited in *CDC HIV/STD/HIV Prevention News Update*, May 15, 2001.

²⁴ *Nigeria AIDS bulletin* No. 15, May 20, 2000.

²⁵ *The Mail & Guardian*, Pretoria, March 31, 2000; UNAIDS/WHO 1999 estimate.

²⁶ UN Department of Economic and Social Affairs (2001), *World Population Prospects, the 2000 Revision*.

a consortium of UNICEF, UNDP, UNFPA, UNDCP, UNESCO, WHO and the World Bank). Peter Piot of UNAIDS has noted that the reasons for re-conceiving HIV/AIDS from being a “health issue” to a “development crisis” and a “security issue” include an appreciation of the epidemic’s destruction of social capital, its impact on the production sector (especially agriculture and industry), its weakening of societal institutions (governance, civil service, judiciary, armed forces, education, and health), and its inhibition of private sector growth, all of which lead to wider and deeper poverty.²⁷

Thus we observe an expansion of epidemiology’s appreciation of the pandemic from one initially interested in etiology, transmission patterns and subpopulations, to the contemporary one which recognizes the vast impact of the epidemic on social structures and development, and indeed which views as etiologic such factors as poverty, gender power disparity, discrimination and stigmatization. In making this transition, epidemiologists never invoked the language of medical ethics as helpful in moving from the clinical to the social, political and economic arenas. Instead, as their analyses evolved into more political, social and economic concepts, they elicited effective responses to the epidemic from leaders not only in public health and clinical medicine, but also from government and inter-governmental institutions. This conceptual shift has critically shaped the way issues related to the pandemic have been framed, and more importantly has made it possible to develop the comprehensive and effective prevention and treatment strategies that are needed today.

Clinical Medicine

Among the four fields we are examining, only clinical medicine has not yet found a coherent conceptual framework to capture adequately the “social” dimension of the pandemic. A variety of physicians have reflected on their own experiences, however, and have invoked either the language of individual personal rights or observations regarding socially relevant phenomena in attempting to move beyond a purely clinical apprehension of the epidemic’s impact. These two approaches

²⁷ Peter Piot, XIII International AIDS Conference, Durban, South Africa, July 2000.

have not yet melded into a language of social rights, however, and therefore the framework of clinical medicine in its analysis and in establishing its future agenda is hobbled by an inadequate hermeneutical context. Still, we see here the emergence of a significant shift in conceptualizing the relationship of clinical medicine to the AIDS pandemic which nods affirmatively toward its social dimensions. Once again, this acknowledgement of the social is not made through the language or concepts of traditional medical ethics. Like the Catholic ethicists and the epidemiologists, in order to express their experience of the pandemic, clinicians have bypassed classic principles of medical ethics in their search for a compelling conceptual framework that will have purchase within the social arena.

An example of the turn to the language of individual personal rights is found in England's Anthony Pinching's analysis: "This infection is so intensely private in its transmission, the disease so isolating and so personally devastating in its impact, it readily distinguishes the reality of what people are and do from the rhetoric of what others may feel they should be and do. AIDS has forced us to recognize that respecting individual rights is a critical safeguard for the health of the community, as well as for the person."²⁸

While he uses the terminology of rights, in his examples they are reserved to the personal as opposed to the social domain. Nonetheless, his rights language nearly moves into the social realm, but only when there is a perceived conflict between rights. Thus when he addresses the question of confidentiality, he teeters between a consideration of competitive individual rights and nearly finds himself in the realm of social rights and concern for the common good:

For clinicians, the most substantial tension has been in the potential or perceived conflict between the duty to the individual and the duty to protect others...Many clinicians are very uncomfortable with knowing that an HIV-positive patient is continuing to have unsafe sex with a person whom the patient is unwilling to inform. After attempting to influence the patient's behaviour or willingness to disclose his HIV status, the clinician

²⁸ Anthony Pinching and Kenneth M. Boyd, "The Impact of AIDS on Medical Ethics," *Journal of Medical Ethics*, February 2000, Vol. 26, pp. 3-8.

may be left either unable to act further because of confidentiality, or feeling obliged to breach confidentiality to protect the third party.

Pinching leads his fellow physicians to consider not only the patient but also those other persons with whom the patient interacts, with concern for secondary HIV transmission from the patient. Still, his rights language does not extend beyond the interpersonal ambit.

Pinching narrates the turn from physician-dominated to patient-centered decision-making by explaining how severe and rapidly progressing illness, limited treatment options, and uncertain outcomes and expectations for both physician and patient prompted physicians to authorize the patient as primary decision maker. This move entailed providing them with greater information and explanations about their treatments, and including them in the design and oversight of clinical trials. He concludes: "As treatments have improved, so the content of the debate between clinician and patient has shifted...Empowerment has shifted control back to the patient, giving the clinician a more appropriate role as guide and enabler."

The other shift in perspective occurs when physicians address the social phenomena surrounding HIV/AIDS and find themselves necessarily in the role of patient advocate. Although in this instance advocacy and the patient's social context are considered, without the language of rights physicians do not have the necessary leverage to further substantiate their agenda. Thus, as Pinching used rights language without a social context, these other physicians address the social without an adequate hermeneutical framework for analysis from a rights perspective, and without a proper vocabulary to form consensus. (When we turn to the achievement in public health, both framework and vocabulary will become crucial for engaging not only the personal but also the social context of the HIV/AIDS pandemic.)

Edinburgh's Kenneth Boyd describes the impact HIV/AIDS has had in motivating both patients and physicians to enter the advocacy arena. After recognizing that women in childbirth, parents of sick children, and patients with a variety of chronic conditions had already started down the path of advocacy, often with medical encouragement, "many people with HIV wished to go further and faster, forcing their clinicians to think through the ethical issues until they were able to

articulate a 'joined-up' rationale for what increasingly made practical sense to them... Their message about empowerment and partnerships (from AIDS specialists and palliative care specialists) began to sound increasingly credible."²⁹

Reflecting on the first 20 years of AIDS in the *New England Journal of Medicine*, New York's Kent A. Sepkowitz comments:

In the 1970s, Washington-based, organized advocacy groups that focused on particular diseases were few; now at least 150 organizations exist. Activism by patients with AIDS has influenced advocates for patients with other diseases, including breast cancer, Parkinson's disease, Alzheimer's disease, and juvenile diabetes. Using creative approaches rather than following the established rules of lobbying, AIDS activists created a new model... Today, patients are routinely consulted regarding the design of studies, and community-based research is conducted across the country.

This advocacy has had concrete results particularly in the development and approval of novel therapies, not only for AIDS but for other diseases as well. As Sepkowitz notes, "AIDS has radically altered the development of drugs. Before the AIDS epidemic, the US Food and Drug Administration (FDA) was often viewed as a remote bureaucracy. With the advent of AIDS and the community that formed around it, numerous innovative approaches were developed to expedite the development of new drugs and patients' access to investigational drugs. The FDA became substantially more efficient: in 1986 the average interval between a drug application and the granting of FDA approval was 34.1 months; by 1999, it had decreased to 12.6 months."³⁰

This entry into the advocacy arena is found not only in the industrialized world. At the opening ceremony of the XIVth International AIDS Conference held in Barcelona in July, 2002, Italy's Stefano Vela, President of the International AIDS Society, highlighted the unprecedented shift seen around the world in the self-understanding of physicians and scientists regarding their responsibilities: "I have

²⁹ *Ibid.*

³⁰ Kent A. Sepkowitz, "AIDS—The First 20 Years," *NEJM* 344, (2001), pp. 1764-72.

never seen in the history of medicine such a growing scientific activism in that all of us included access to medication and to care to the South of the world in our scientific agenda. This is something I think that never really happened in the history of medicine. I think that all scientists progressively understood that they should take the lead with the idea that the advancements of medicine should not be reserved to small numbers of people.”

Despite this noteworthy observation, without a conceptual framework and an attendant vocabulary to locate it within the political, social and economic domains as epidemiologists and religious ethicists did, Vela’s claim will have difficulty being translated into an adequately justified and sustained plan.

Like Vela, Los Angeles’ Michael Gottlieb recognizes the significance of worldwide advocacy, and goes beyond him to endorse more aggressive strategies. But, as with the other physicians we have read, he too lacks the linguistic tools and an overarching analysis that could make his call to action more politically realizable and philosophically coherent:

We physicians must continue to advocate aggressive programs for prevention...and we must ensure easy access to care and medication for people who are HIV-positive. We must convince the pharmaceutical industry, foundations, and the government that there is a moral imperative to provide humanitarian relief in poor countries, to make antiviral medication affordable, and to improve medical care delivery systems.³¹

Public Health

None of the four fields we have looked at has more intentionally and deliberately searched for a conceptual framework with its attendant linguistic tools for analysis and empowerment than has public health, particularly in the person of Jonathan Mann. In 1997 in these pages, Mann had the foresight to recognize the relevance of human rights for public health. He did this by first drawing attention to the connection between poverty and illness:

³¹ Michael S. Gottlieb, “AIDS – Past and Future,” *NEJM*, 344 (2001): 1788-91.

The vast majority of research into the health of populations identifies so-called ‘societal factors’ as the major determinants of health status. Most of the work on this area has focused on socioeconomic status as the key variable, for it is clear, throughout history and in all societies, that the rich live generally longer and healthier lives than the poor... A major question arising from the socioeconomic status-health gradient is why there is a gradient.³²

In response to this question, Mann reflected on the inability of public health to integrate into a solution what it realized was integral to the problem: “While public health may cite, or blame, or otherwise identify the societal-level or contextual issues—which it acknowledges to be of dominant importance, both for influencing behavior and for determining health status more broadly—it does not deal directly with these societal factors.” Mann then gave three reasons for this paradoxical inaction:

- “Public health has lacked a conceptual framework for identifying and analyzing the essential societal factors that represent the conditions in which people can be healthy.
- “Public health lacks a vocabulary with which to speak about and identify commonalities among health problems experienced by very different populations.
- “There is no consensus about the nature or direction of societal change that would be necessary to address the societal conditions involved.”

He concluded by ruing the ineffectual babble that public health officials inevitably uttered without these critical tools: “Lacking a coherent framework, a consistent vocabulary, and a consensus about societal change, public health assembles and then tries valiantly to assimilate a wide variety of disciplinary perspectives, from economists, political scientists, societal and behavioral scientists, health systems analysts, and a range of medical practitioners. Yet while each of these perspectives provides some useful insight, public health becomes thereby a little bit of everything and thus not enough of anything.”

³² Jonathan Mann, “Medicine and Public Health, Ethics and Human Rights,” *The Hastings Center Report*, 27 (1997), pp. 6-13.

Mann appreciated in the language of human rights its integral comprehensiveness and its moral urgency. That is, human rights language could link global campaigns for the right to access available medical treatments with equally effective and strategic movements to obtain greater equality in political, economic and social forms of life. He, therefore, proposed that public health had a desperate need for the conceptual framework of human rights to analyze and effectively respond to the unprecedented nature and magnitude of the HIV/AIDS pandemic: "Modern human rights, precisely because they were initially developed entirely outside the health domain and seek to articulate the societal preconditions for human well-being, seem a far more useful framework, vocabulary, and form of guidance for public health efforts to analyze and respond directly to the societal determinants of health than any inherited from the past biomedical or public health tradition."

We have wondered how well public health officials have received Mann's proposal, and so we have tracked over the past four years whether and how it has been integrated into the international public health agenda regarding HIV/AIDS. Specifically, we have looked at how the language of human rights has enabled public health officials to make their case to the United Nations (both in 2000 at the UN Security Council and at the 2001 United Nations General Assembly Special Session on AIDS (UNGASS), at the 2002 Barcelona International AIDS Conference, and in preparation for the 2004 Bangkok International AIDS Conference.

In January, 2000, the UN Security Council took up the subject of AIDS for the first time, and in doing so recognized the epidemic not just as a health issue but also as a security issue "that could decimate the economic, political and military establishments in many countries."³³ In testimony at this session, World Bank President James D. Wolfensohn noted that the epidemic "is being more effective than war in destabilizing countries."

The recognition of the scope and severity of the epidemic, and of the need for political leadership to form the basis of an effective response, led to the Declaration of Commitment on HIV/AIDS at

³³ Barbara Crossette, "Gore Presides Over Rare Security Council Debate on AIDS," *New York Times*, January 11, 2000, p. A3.

UNGASS on AIDS in June, 2001. The Declaration noted with deep concern that “the global HIV/AIDS epidemic, through its devastating scale and impact, constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights, which undermines social and economic development throughout the world and affects all levels of society—national, community, family and individual.” It recognized that “poverty, underdevelopment and illiteracy are among the principal contributing factors to the spread of HIV/AIDS,” and noted with grave concern “that HIV/AIDS is compounding poverty and is now reversing or impeding development in many countries and should therefore be addressed in an integrated manner.” It further noted that “stigma, silence, discrimination, and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations.” It stressed that “gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS.”

In light of its recognition of the causes and enabling conditions for the transmission of HIV/AIDS, the Declaration articulated first the right to physical and mental health: “Access to medication in the context of pandemics such as HIV/AIDS is one of the fundamental elements to achieve progressively the full realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” Based on this conjunction, it then invoked more general and equally universal human rights:

The full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic, including in the areas of prevention, care, support and treatment, and that it reduces vulnerability to HIV/AIDS and prevents stigma and related discrimination against people living with or at risk of HIV/AIDS.³⁴

In 2002, in Barcelona, strategists looked back to previous attempts at making antiretroviral drugs accessible in developing nations. They saw

³⁴ “Declaration of Commitment on HIV/AIDS, Global Crisis—Global Action,” United Nations General Assembly Special Session on HIV/AIDS, 25-27 June 2001.

how at the AIDS meeting in Geneva in 1998 advocates were ridiculed for focusing attention on the urgency of getting anti-retroviral treatments to developing countries, with pharmaceutical company representatives arguing that “differential pricing” would be a disaster for research and development. The 2000 AIDS meeting in Durban silenced the ridicule, and by the 2002 Barcelona conference concrete proposals for drug access were being sponsored by public health activists, economists and government officials. Successful programs in Thailand and Brazil were specifically studied and invoked as examples of normative solutions. Paolo Teixeira of the Brazilian STD/AIDS program explained why and how his nation came to the decision that antiretroviral therapies should be made universally available to all HIV-infected citizens, and singularly credited the language of human rights as the cogent means for validating the policy: “What we have been doing is to put into practice principles that have long been recognized by the international community. At their very core is the Universal Declaration of Human Rights, adopted more than 54 years ago.”³⁵

As the world community anticipated the XVth International AIDS Conference in Bangkok in 2004, it heard major participants like Joseph O’Reilly, National AIDS Trust, United Kingdom, summon the membership to consider the relevance of the language of human rights for responding to the pandemic:

In the lead up to the next conference in Thailand in 2004, we need to use the UNAIDS Guidelines on HIV and Human Rights and the undertakings on human rights in the UN’s Declaration of Commitment on HIV/AIDS to track the efforts of governments, UN agencies, international financial institutions and civil society organizations for implementing an HIV/AIDS and human rights agenda.

Not surprisingly, the language of human rights became at Bangkok the language to analyze public health HIV/AIDS’ strategies.

³⁵ Teixeira, Paolo, quoted in “One step ahead of us,” IAPAC (monthly publication of the International Association of Physicians in AIDS Care), reporting on the Barcelona AIDS Conference, October, 2002, p 285.

Conclusion

Certainly there continues to be debate about human rights language: whose rights, how are they articulated, how are they applied, who guarantees them, and—invariably—who determines the answer to any of these questions? Nevertheless, in responding to these central issues it is precisely the vocabulary of human rights and its conceptual framework that allow these critical discussions to occur, and makes possible the development of coherent, equitable and effective policies for HIV prevention and treatment. We cannot imagine that achievements attained thus far in responding to the pandemic could have been possible without this shift in conceptual framework. Its effectiveness has been proven, and for this reason we believe that the success of public health officials outdistances the noteworthy accomplishments of individual physicians. Public health officials have what physicians do not yet possess: a language with which to communicate within and across disciplines not only to properly analyze the socioeconomic conditions relevant to the transmission of HIV, but also to forge consensus and to galvanize the political will to respond effectively to these conditions.

The coherence and the application and relevance of traditional human rights language parallels in many instances the same coherence and application of the traditional language of social justice in Roman Catholicism. The wisdom of Jonathan Mann, then, parallels the wisdom of Lisa Cahill in turning to an existing, sustained and sustainable tradition that logically and experientially precedes the language of medical discourse. As they both recognize, medicine occurs in a social context. Likewise, epidemiologists are examining data best interpreted through the language of human rights or social justice. Finally, in reflecting on their own experiences and responsibilities that emerge as the pandemic expands, physicians are looking, it seems to us, for the type of coherent framework and vocabulary that public health officials like Mann and ethicists like Cahill have already employed. But, as can be seen, aside from the evident communication and collaboration between epidemiologists and public health officials, physicians, ethicists and public health officials seem for a variety of reasons to be on their own distinct, albeit parallel, linguistic tracks.

It is our hope that these distinctive conversations will overlap and might even converge, and that we will have found a resonance in

recognizing that the languages of human rights and of social justice are translatable. Of course, the possibility for translation hinges on the desire and willingness of each of these constituencies to dialogue with one another. But the possibility for that more comprehensive and inclusive dialogue has been greatly enhanced by the attempts of each to find the words and the means to work more collaboratively in effectively combating HIV/AIDS. ⇨

