

HEALTH AND HUMAN RIGHTS: AN INSEPARABLE SYNERGY

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Having the “last word” in a company of this experience and distinction would be quite intimidating, were it indeed the end of something — but the first and most important thing I have to say is that it must not be the last word! I hope this is the beginning of sustained dialogue and fruitful discussions between and among many of us who have newly or freshly recognized our common resolve in maintaining the connectedness of health and human rights. And I hope that those ongoing collaborations will be revitalized, at intervals, by the second — and then the third — International Conferences on Health and Human Rights...such that, years hence, we can look back at a record of accelerating progress and say “I was there when the first of these was held—where it all really began in earnest!”

So my task isn't quite so intimidating as it seems. What I will do is to try to draw from things I have heard at this conference, augmented by a few favorite passages I have read, to establish firmly and unequivocally — at least for those of us inspired

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by this participation — that we have moved, in a quiet but irrevocable way, from thinking of health *or* human rights to health *and* human rights...and that wherever we go from here, one of our tasks will be to help others to understand the inseparable synergy of those convergent themes.

Jack Geiger, in his plenary address during this conference, told a lovely story of the long friendship he has had with Dr. Nkosasana Zuma, now the South African Minister of Health, whom he first met when she was a little girl, eight years old, living in KwaZulu in conditions that defy the imagination of anyone who had not seen them. In his narrative he answered a question for me that had been lurking in my proximate memory since I got to know Dr. Zuma for the first time last November in Johannesburg.

It was not known then, of course, if the miracle of change would even succeed, much less that she would become Minister. She was a returned leader of the African National Congress, co-chair of the South African AIDS Consortium, and (for me) an inspiring new friend who had managed to bring her great talent to full flower, yet who had only recently returned from 14 years of exile with three bright-eyed children ages 11 and under who were learning to see their own country for the first time through a cloud of uncertainty, violence, and residual malevolence.

Over a leisurely dinner, while she and I compared notes on AIDS, on pediatrics, on public health and health care, on our children, and on the world in general—I kept wondering to myself “How in the world did she do all that? How could she possibly have survived? And, having survived, how did she build such strength as must have been necessary to decide to return from exile into incipient chaos and to help construct a new order that may well, in time, be an inspiration to us all?”

Jack Geiger’s reminiscence answered my question; she had told him—in response to a more direct query than I had figured out how to pose—that it had been crucially important for her, literally but also figuratively, to be able to see that there *was a road out*.

How strongly that resonates for me: for I have been regularly bemused by human miracles of resilience, and again and again have found myself wondering how people manage such personal miracles. I will tell just one story to extend the point, drawn against the backdrop of our own sad social scenery in the

United States. In 1991, when the US National Commission on AIDS was holding hearings in Chicago, focusing for the moment on issues of adolescence and HIV/AIDS, there was one session in which a group of teenage “peer-counselors” from around the country had been invited—to give brief vignettes of themselves and then to talk about the HIV-preventive work they were doing among their peers. It was a uniformly powerful and moving series of testimonies, especially so because most of the 10 young people who talked with us were, themselves, either HIV-infected or immersed in settings in which their risk was extraordinarily high.

But the session was engraved in my memory by the narrative of one young African-American woman (by then, age 19) who told her story as follows. She was the second of 14 siblings (she explained that her mother had a tendency to twinning). There had been, serially, two men on the scene, but by the time she was 13 years old, they were entirely gone, and her mother began to “do” cocaine. She said, without disingenuousness, that for about a year she thought that was very “cool,” for she and the other kids were entirely unsupervised for increasingly long periods while their mother stayed in her room “doing drugs.” But then, she said, after about a year she realized that it wasn’t cool at all—that *someone* had to take care of those kids and that her mother was upstairs killing herself in slow stages.

So, at age 14, she picked up the mantle of family and tried to support the kids, lying about her age in order to get a job at McDonald’s. But then, as she again said matter-of-factly and without guile—she realized that “you can’t feed 14 kids on McDonald’s wages. So,” she said, “I sold drugs. I never *used* them, for I had seen what they did to my mother—but I sold them.”

Ultimately, the wretchedly inchoate gears of the American inner-city social support mechanisms ground along and she managed, among other things, to end up doing HIV peer-counseling, which she then described with great joy and exuberance—how good she found it to be able to do something to help others! It came out, almost as an afterthought at the very end, that by the time we met her at age 19, she had also kept her life together such that she had completed high school and was an honor student in the second year of college!

During the years that I chaired the sessions of the Na-

tional Commission on AIDS, I usually tried to listen to people's stories without comment, for fear of misspeaking. But when she finished, I couldn't restrain myself, and asked in complete awe, "How did you *do* that?" She looked at me with genuine puzzlement—not to mention great dignity—and said "Do what?" I abandoned the question, suppressing the urge to say "Don't you realize that you can't possibly have gotten here from there?"

But an answer has taken shape for me over time—there is, at the foundation of all our mutual interests and effort, a truly magic dust of *dignity*, and with that magic all things are possible. Perhaps, in her case, it remains mysterious how she was touched by the first sprinkles (although embedded in the story is the real possibility that her mother, who bore and bred and kept together a family of 14 children before she broke, must have been rather special herself). But once she perceived a chance to enhance her own sense of self by caring for others, *she*, clearly, was protected by an increasingly effective armor of dignity—and issues of survival ultimately were supplanted by efforts at self-realization. By the time I met her, that had, in turn, been augmented by enthusiastic altruism. Clearly, she was well on her way along "the road out..."

So, part of my message as to where we go from here is that we must be diligent—whether our primary effort has traditionally focused on health or on human rights—in being sure, not of total success, but of making visible the fact that there is a road out. Health is affected deeply by that vision: the inseparable synergy of health and human rights works in both directions, as these rich days have shown us in profusion. Progress anywhere along our mutual road will help us all—and that is inspiring and energizing.

There is an important caveat: as my friend and colleague Eka Esu-Williams said, thoughtfully, what we undertake in the name of progress must actually turn out to *be* progress; and her words, underscored by Dr. Ramalingaswami, were that intervention into culturally entrenched practices, deeply embedded yet injurious to both health *and* human rights, must be approached gently, delicately and sensitively. As we have heard in other talks, our enterprise—by definition—must challenge the present distribution of power in relationships; and it is always best to be inconspicuous when sidling up to a bull, even if one's aim is to improve his ultimate lot!

One more point before I leave the topic of dignity—for that, if I have been too subtle, is what I propose is our hidden weapon for both the enhancement of health and of human rights. (We do, indeed, have magic on our side, for one taste of dignity changes the equation forever in our favor.) The point I want to make is about the debilitating and ultimately destructive effect of *indignity*, and my text—for in this case I want to borrow someone else's words—is from a wonderful new book just out in the United States called *Not All of Us Are Saints*, by Dr. David Hilfiker, which tells of his experiences and thoughts during several years practicing “poverty medicine” among the homeless.

He describes briefly his decision, a few years ago, to leave his primary care practice in rural Minnesota and to take up the challenge of practicing medicine in the inner city, joining with two or three other physicians to establish a subacute care facility that would plug one of the gaping holes in the tattered meshwork of options for the sick homeless of Washington, DC.

He admits to initial puzzlement and frustration when his efforts to help are sometimes rebuffed or negated by people in such conspicuous need, and then comments: “What caught me completely off guard was my patients’ internalization of their abandonment. Children who had not been adequately loved now saw themselves as unlovable; young people who had been inadequately trusted now trusted no one; adults who had been pushed down too many times now saw failure as inevitable; addicts for whom no treatment was offered had now—for practical purposes—given up on the possibility of a meaningful life. I was not prepared for the hostility, the seeming ingratitude, the noncompliance, the irrationality that is so much a part of the inner-city reality.”

But then he added detail to how poorly the official “system” actually works, citing horrifying examples of bureaucratic indifference and rejection; and he comments that “...people could cycle through the system of ‘care’ over and over without a caring result...”

In reflecting on these matters he remarks that: “The very poor have taken a particular beating in the last two decades [in the United States]. The undertow is powerful...in the inner city, overwhelming too many of those born into urban poverty, dragging away almost every chance for what the rest of us might call a ‘normal’ life. For every mother who courageously drags her

children out of the despair, two, three or four others are unable to escape their birth; anything that might make escape possible—adequate housing, basic education, jobs upon which one can support a family, accessible health care—is absent.... There is no breathing room left in the system.” He might well have said, to use the metaphor I have invoked today, that there is no visible road.

That is, of course, a terrible indictment of our rich country, and one we must struggle harder to face and to redress. But it also provides a lucid, lurid image of what can happen if there is loss of hope, if the magic touch of dignity never brushes across human lives.

In other sections, Dr. Hilfiker points out the entrapment of children in this poisonous and hopeless miasma, and then comments, “In time, the children cease to be the victims and become the perpetrators of what we deplore—the violence, and therefore the hopelessness, of their lives.”

That is a somber aspect of what we care about, as we all know—as we listen to debate about interventions postponed or health care deferred, it is desperately important to remember that childhood happens only once; that it may not happen at all if health care is denied; and that it takes both good health and at least a few years of life even to *perceive* that there is a road out, and that one can even contribute to the building of that road if one stays the course.

Enough! You know all that! I am preaching to the converted. But another analysis, that I heard for the first time at this conference and for which I am grateful to Lynn Freedman, is germane to all this. She talked about the phenomenon of fundamentalisms, which all of us here probably recognize as real or potential impediments along the road. Her generalizations, which I found very helpful to my thinking, embraced not only the obvious religiously derived movements but also ethnic and cultural fundamentalisms that share, at their core, a retrospective, selective embrace of the “good old days”—of the way things (actually) *never were* but which people with their own agendas assert must be “brought back.” Helpfully, she pointed out that fundamentalisms are intrinsically *political*, the activation of selective nostalgia for purposes of social control; and that, among other things, they are not necessarily (or even generally) a good representation of the tradition they purport to represent and protect.

That rings very true to me! The stridency and intransigence of the early days of the Cairo meeting is still ringing in our ears. And yet Islam, as interpreted by thoughtful Muslims I know, has a kind and compassionate theme consonant with what we, here, are about; and the most compassionate and effective religious groups in the initial response to the AIDS epidemic in the United States were not only the Episcopal Church but also the working Catholic clergy—hierarchy notwithstanding. The moral seems clear—we must be tolerant, and sensitive, and *very* slow to identify and name “The Enemy.” Rather, in both health and human rights, we must be patient and watch carefully for the sparks raised by the expanding magic of human dignity, for therein lies the energy necessary for our success.

That is not to say there is no *cause* for impatience; the worldwide phenomenon of the debasement of women alone is enough to set off a veritable tantrum. When one sees the acculturating and stabilizing role they regularly play, the peculiar so-called reverence of that role that is so often used to keep them in their place, and the way in which those dynamics are used to justify their genuine subjugation in many cultures—it is painful to recognize the pernicious mix of “tradition” with ulterior motives, with its cumulative impact to the terrible detriment of their health.

But here is where the moral comes in. If we accept that (one way or another) this struggle between fundamentalisms and progress involves a *political* process, prediction is a chancy business. Discouragement is hard to avoid, yet it is always difficult to know just how far one has managed to progress along a continuum toward success; a goal may seem very far off and yet be just around the next bend.

In that regard I must tell you a favorite joke—an anecdote entitled “On the importance of stamina in the political process,” related some years ago by American political commentator Daniel Greenberg. In the story, he told of the gala that was staged when the Lincoln Center for the Performing Arts in New York City was inaugurated. To help in the celebration, Victor Borge, the Danish piano-playing humorist and raconteur, had been asked to “do his thing,” which was a combination of music and commentary.

The Lincoln Center had been conceived and executed on a grand scale, and was lavishly plush—intentionally, so as to sig-

nify the opulence of human creativity by its very nature. So Borge went on at length about how sumptuous and elegant it was—pointing out the luxurious draperies and upholstery, the dazzling, glittering chandeliers, and so forth. At some point in his monologue he proposed to leave the stage and go down into the audience to elicit their reactions. But as he reached the edge of the stage, the microphone cord tugged. He presumed it was tangled and turned around to undo the knot, only to realize that he had reached the end of his tether—that was all the microphone cord there was. Turning to the audience and sighing loudly into the microphone, he said “Oh dear—and to think that for only \$1.29 more they could have gone *all the way!*”

The fact that we are now here brings that story to mind, for—it is all too easy to forget the importance of simple *stamina* in the political process. As Jack Geiger wisely said, we have had most of the facts in hand for more than a century. Progressively since the time of Rudolph Virchow, if not before, the evidence has been there for all to see that documents the intimate linkage between health and human rights. And as Jonathan Mann has reiterated so eloquently, we know without question (once the issue is posed) that a male-dominated society is inimical to public health. My point is that we may, in fact, be well along our road—that with this meeting and what it represents (to switch metaphors), we may be not so much at the initial seeding but rather at the budding and blossoming stage of the growth toward synergy—that our most important qualities may be sensitivity and stamina. Think “\$1.29 more.”

Finally, there is no question that having *heard* each other was important. The most useful skill I have ever acquired—and I’m still working on it—is to *listen*. To make that point as I close, I will again borrow the words of a powerful writer, in this instance Doris Lessing, who in the late 1980s wrote a set of essays and reflections entitled *The Wind Blows Away Our Words*. The book is primarily about the Afghanistani war of recent years, but in the opening chapter she revisits the Greek myth of the siege of Troy—the Trojan Horse and all that. She writes of Helen, who is eagerly anticipating new lovers arriving under cover of the disguise, and Cassandra, who sees what horror is coming. The two women, with their disparate perceptions and values, stand together in a tower and reflect as they watch the acquiescence of the Trojans to entry of the huge, secretly malevolent

Horse concealing warriors who will pillage the town.

Cassandra, in a quandary that has echoed through the centuries, sees the horror coming and tries to warn, but without avail. The traditional telling of her tale is classically sexist: that before the siege of Troy, the god Apollo had wanted Cassandra to give him sexual favors, and that when she refused he had cursed her *both* with the power to see the future *and* with the inability to be heard. Thus she was doomed to shout her warnings and yet not to have them perceived by those in danger.

But as Doris Lessing points out, blaming the gods is all too easy. It was, in fact, not the first sack of Troy but the seventh; and others besides Cassandra surely could hear men's voices within the huge wooden effigy of a horse—and almost surely, many others tried to shout warnings as well.

And then Lessing asserts that the interpretation has probably always been in error—the problem wasn't with Cassandra but rather with her *listeners*. She goes on to write a wonderful passage with which I will close. She says "...[I]magine...a secret conference called by the nations, who have agreed to set aside all the slogans and battle cries and the circling for better positions just for the duration of the conference, which will discuss 'What is the matter with us, what is wrong with mankind, that we can't listen to Cassandra? It is as if the world, as if we, were being dragged along by some undertow of stupidity too powerful to resist, and all the sharp, frantic, desperate cries of warning are like gulls glinting as they wheel over the scene and then dip and vanish, screaming, *If you do this, then that must follow*—Surely there must be something we can all do, together; perhaps we can learn to listen...."

Before I stop, let me take advantage of the microphone to compliment the remarkable staff who have put together such a rich and complex menu of information and inspiration for all of us over these busy days. Just as one feels overly ambitious when faced with a laden smorgasbord table of delectables, the only disappointment one can feel after these good days is that it was not possible to partake of it all. But that is another way of saying that the agenda is inexhaustible and that this is, indeed, just a beginning. Thank you for a memorable event, and for finding the way to bring out in ever more vivid relief the compelling mandate to weld together the efforts we all exert in the interest of health *and* human rights.

References

1. Hilfiker, David. *Not All of Us Are Saints: a Doctor's Journey with the Poor*. (New York: Hill and Wang, 1994).
2. Lessing, Doris. *The Wind Blows Away Our Words* (New York: Viking Press, 1987).