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MAKING THE CASE FOR THE RIGHT TO HEALTH

Maria May

On September 17, 2008, *Health and Human Rights: An International Journal* celebrated its recent re-release as an open access publication with a panel discussion on “Creating on Open Forum to Advance Global Health and Social Justice.” The panel included Dr. Paul Farmer, Editor-in-chief; Dr. Jim Kim, Publisher and Director of the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health which funds the journal; Dr. Agnès Binagwaho, Executive Secretary of Rwanda’s National AIDS Commission; Dr. Gavin Yamey, Senior Editor of *PLoS Medicine*; and Philip Alston, the John Norton Pomeroy Professor of Law and Director of the Center for Human Rights and Global Justice at New York University School of Law.



In his opening remarks, Dr. Kim challenged the audience to extend their rights-based framework beyond just conceptual clarity and advocacy to the level of implementation, noting that “effective programs are needed to ensure the human right to health.”

Dr. Binagwaho took the stage first and spoke of how Rwanda’s history, and particularly the role of state-controlled radio stations in the genocide, had demonstrated that the right to information was critical to protecting individuals. The Rwandan government sees information and communication technology as a top priority, and is working tirelessly to increase internet access nationally and achieve the goal of one laptop per child. This priority was clearly illustrated by the topic of last week’s Compton Lecture given at the Massachusetts Institute of Technology by His Excellency Paul Kagame, President of the Republic of Rwanda entitled Imperative of Science and Technology in Accelerating African and Rwandan Development.

Dr. Binagwaho reflected on the irony of research done in developing countries that is never available to the study subjects, and she applauded efforts like PLoS Medicine and Health and Human Rights for working to promote access to a wider audience. In addition, she stressed the need for intellectual exchange. She saw these discussions as “necessary

to make the best decisions.” Citing the example of GHDonline.org, she told of the value for herself and others in executive positions to bounce ideas off of each other (for example, should children of HIV-positive parents undergo mandatory testing?) and also the value gained by including field workers in the conversation. “People at the community level may not have the theories, but they have the knowledge,” she said. Finally, she outlined that the sum of these efforts, of fighting for access to health, information, and education, is to eliminate poverty.

Dr. Yamey focused on the need to change the way we look at medical publications. He pointed out that information is so expensive to access that patients, and many doctors and researchers, simply cannot afford to survey the literature and make fully informed decisions. “Only a tiny fraction of the intended audience can read a work. This paradigm is wrong — medical research should be a global public good.” The consequences of the current model are hazardous: often, doctors and patients are forced to rely on abstracts, which convey “dangerous half-truths.” Also, because researchers in the global south often have less access to literature than their counterparts in the north, a dynamic of inequality is introduced in their interactions. The world would benefit from a “knowledge commons,” which would better allow research and practice efforts to “build on the shoulders of giants.” Dr. Yamey was instrumental in getting the journal online in an open access format, and he applauded the journal’s new format.

Tracing the history of the human rights movement, Mr. Alston reflected that the discourse had been dominated by lawyers, resulting in a legal focus that often failed to garner enthusiasm or trust among social advocates. While the civil and political aspects are critical, Mr. Alston emphasized the need to link that with the right to health. He also challenged the journal not to let its focus waver from what he considered the ultimate task at hand: making the case for the right to health. “Until we confront the right of every individual to health and health care, then we are not looking at the central concern, and we are failing to achieve our objectives.” Changing the political dynamics and infusing society with a sense of moral outrage about violations of the right to health were objectives that he also lay out for the human rights community.

Dr. Farmer described his relationship with human rights as a “voyage,” and credited Haiti for being his greatest teacher. It was in conversations with his Haitian friends and colleagues almost 20 years ago that he saw a divergence between the goals and values of the academic community and those who did not enjoy their basic human rights. He observed “the limited faith of the poor in the non-poor’s promise to protect their interests, including health, housing, and food.” This rift, along with others between legal frameworks and social advocates as outlined by Mr. Alston, needs mending and harmonization. Citing an example of Russian prisons fighting TB epidemics and outcries that prisoners were starving to death, he said that “it is of utmost importance to get the diagnosis right in human rights. It determines whether we apply the right treatment.” His hope for the journal is that it will bring the discourses together in an “honest way,” and he was excited about the new format, adding, “The internet provides an opportunity to push through an agenda that is pro-poor.”

A reception in honor of Dr. Jonathan Mann, founder of the journal, concluded the event. Two of his children, along with Drs. Kim and Farmer, both of whom knew Dr. Mann very well as an early supporter of Partners In Health, shared some of their memories and told of his influence on their lives and that of many more, adding that he would be thrilled with the new direction the journal is taking.