

VIEWPOINT

A Letter to Young and Future Leaders in Struggles for Health Rights and Social Justice

ALICIA ELY YAMIN

Dear young and future leaders in struggles for health rights and social justice:

The world has changed tremendously in the almost 25 years since I had the privilege of studying under the late Dr. Jonathan Mann at what is now the Harvard TH Chan School of Public Health, and to witness the birth of a movement for health and human rights. You may be inclined to dismiss this collection of anniversary reminiscences as largely irrelevant to the issues faced around the globe today, but please resist that urge. We can only understand where we need to go and what to do in deploying human rights for health justice, if we understand how we got here. And, when the very idea of human rights is under such widespread attack—not just from self-serving authoritarians but also from progressives who argue that human rights has been ineffectual or worse with respect to stemming the rise of neoliberalism—it is imperative that you, and we all, try our best to understand how we got here.¹

By “here” I mean a context of growing distrust of democratic institutions and multilateralism; hyper-globalization and concentration of private wealth; ravaging inequalities within and between nations; impending climate cataclysm; mass migration and displacement; toxic synergies between ethno-nationalism, racism, and misogyny—and all of the ensuing impacts on the distribution of population health and human dignity. There is important “evidence for hope,” but it is clearly “not enough.”² This is not a time for self-congratulation; nor can we afford “business as usual” in efforts to apply human rights to advance health and social equality. It is a time for critical reflection in order to permit reconstruction of our aspirations, creative adaptation of our strategies—and disruption of some of our cherished certainties.

In *When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality*, I engage in that critical (self) reflection.³ Based on experiences living in multiple regions and bridging academia and advocacy over the last few decades, I offer my own subjective and invariably partial account of efforts to change a narrative of health deprivations as misfortunes to be endured into one of injustices to be remedied.⁴ I argue that over these years, advocates for health and other economic, social, and cultural (ESC) rights have faced three principal challenges: (1) subverting entrenched ideas that these were not real rights, but mere programmatic aspirations; (2) articulating a vision for taking health-related rights seriously in laws, policies, and practices; and (3) demonstrating that doing so could achieve meaningful progress toward social justice in national and global orders, which was particularly essential in global

ALICIA ELY YAMIN, JD MPH is a Senior Fellow at the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School. Yamin has lived half her professional life in Latin America and Africa and worked extensively with advocacy organizations in those regions. Email: ayamin@hsph.harvard.edu.

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health. While much has been achieved in terms of the first two challenges, as the contributions to this journal over the years attest, we who have been engaged in these struggles since the beginning need to collectively acknowledge that we have failed with respect to the third.

Why have we failed in this regard? And what does that mean for moving forward?

Answering the why question, in my view, requires examining how an array of opportunity structures evolved and were perceived by different sets of actors as the law changed, public health evidence was built, global economic and political configurations shifted, and technologies advanced over the last decades. In *When Misfortune Becomes Injustice*, I argue that the duality of the historical narrative becomes easier to understand in this way. That is, over these years we have theorized health-related rights and what they implied in terms of social contracts, institutional arrangements, and the conditions necessary for diverse groups facing intersectional disadvantages to effectively enjoy them. And arguably nowhere has evolution in normative frameworks been more dramatic than in relation to sexual and reproductive rights (and nowhere has the backlash been more brutal). Yet, just as health-related and other ESC rights were being articulated, increasingly intrusive global economic governance, often in synergy with anti-democratic centralization of power at national levels, was limiting the political possibilities to realize them.

Nonetheless, there is no cause for fatalism and no room for despair; this unpacking of the temporal sequence allows us to see that alternative socio-legal narratives and social mobilization strategies might have led us down other paths—and they can open new possibilities for advancing health and social equality today. Without conceding the extraordinary achievements and critical ground gained in so many respects, we can and urgently must re-energize the original human rights aspirations of a social and international order based upon equal dignity of diverse human beings, which includes economic justice.⁵

What does this mean for you young advocates and future leaders?

There is of course no single response, and even as I suggest some points of departure in *When Misfortune Becomes Injustice*, I argue we should eschew facile formulas. Advancing rights with respect to any particular health issue in our deeply interconnected, but simultaneously fragmented, world demands collective deliberation, and collective efforts. And that in turn calls for broadening the circle to include cross-disciplinary dialogue with progressive economists, among others, and forging alliances with varied social movements.

When Jonathan Mann, together with colleagues, founded this journal and held initial conferences on health and human rights at Harvard in the 1990s, he envisioned fostering a broad movement that would bridge the fields of health and human rights through both scholarship and advocacy, in order to challenge the status quo in public health. And arguably no single person has done more than Paul Farmer, through Partners in Health and across many other spaces, to inspire people around the globe to challenge orthodoxies not just in medicine and public health, but also in human rights.

I was privileged to be part of the team that Farmer assembled when he initially became Editor-in-Chief of this journal over a decade ago. In that 2007-2010 re-envisioning, we understood that learnings in relation to applying rights to health needed to be far more accessible, and so the journal not only went online, but was an early adopter of completely open access. Recognizing the barriers language presented, we included articles in other languages, together with translations. We also thought it imperative for such a forum to include the voices of those on the front lines, and dedicated one of two principal sections to writing “from practice.” The other principal section highlighted critical concepts, as well as contestations, in the multiple intersecting fields related to health and health and human rights in order to inform reflective and innovative practice.

Needless to say, that sweepingly ambitious endeavor faced enormous practical obstacles,

including funding, and the fact that meaningful social impacts are rarely measurable in algorithmic “factors.” Nonetheless, it was an experiment worth undertaking; under Farmer’s leadership, as reflected in the mission statement that remains on the website to this day, we were committed to developing a platform for human rights praxis that would be relevant to the health and related struggles of those whose lives are shadowed by structural injustice.⁶ The journal’s entry into another exciting phase provides an invitation to once again consider the possibilities this forum might offer. At this critical inflection point, we should all challenge ourselves to enlarge our imaginations beyond the aim of sustaining a professionalized “health and human rights field,” which can all too easily reproduce the very global, institutional, and epistemic hierarchies that we claim to challenge.

But it will be up to you young advocates and future leaders to hold those of us who have been at this for a while to account. Consider whether we are asking the right questions, deploying effective strategies and using metrics that are fit-for-purpose in our current age of neoliberalism. And please don’t hesitate to raise “difficult” issues, dissent from majority views, and surface contestation. We all need to reflect on how political and epistemic colonialism in global health and international human rights shape the politics of agenda-setting, the production of social meanings, and the dynamics of privilege and power within which we all operate. Likewise, all of us need to grapple with the complexities of promoting a universal understanding of human being in a world, and within representations of that world in both law and biomedicine, constructed by (and for) men. And we all—in global governance as well as at national level, in academic institutions as well as in advocacy organizations—need to confront how the control and uses of funding are (mis)aligned with progressively reshaping the political economy of global health.

Further, while lawyers and development economists, physicians and biomedical researchers, and other professional disciplines play critical roles, please don’t be cowed by labels of technical exper-

tise. Be skeptical of technologies of knowledge that enable governance at a distance, disconnected from the contexts in which institutional actors need to be mapped, relations need to be (re)shaped, and politics need to be contested in order to produce social change. Beware of the “technical” policy-making exercises that exclude or diminish the lived realities of activists or abuse survivors, of health system users or community health workers, or of any other variant of ordinary human being.

If health is largely socially constructed, it can be reconstructed and democratized. But the only way to democratize health is to actually democratize health. And democracy depends upon “ordinary” political energy, when diverse people whose lives are affected come together to participate meaningfully in identifying ways forward and mobilizing for change. “Ordinary” people have always been, and will always be, the drivers of extraordinary social transformations in relation to health and more broadly—from movements for labor rights and social protection to sexual and reproductive health and rights, from movements for the rights of persons living with HIV/AIDS to movements for climate justice and planetary health.

Using human rights for social change in health and beyond is a relentless and often anguishing struggle, so choose your mentors and companions on this journey well. The exuberance of victories will often be short-lived because the goal posts, and indeed the fields of play themselves, are constantly shifting. There will be times when you sink into despondency at the vastness of needless suffering that is so normalized, and the hopeless inadequacy of our efforts to remedy it. But, in the end, it is the struggles we most passionately pursue that define our lives. And what is at stake here is nothing less than what we owe to one another and to future generations, as diverse but equal human beings sharing one irreplaceable planet.

So, please: learn from our many hard-won achievements—and from where we have fallen short. Be bold, be creative, be disruptive. The future that you will leave to the young advocates who are emerging in 25 years depends upon it.

References

1. For example, see: Samuel Moyn, *Not Enough: Human Rights in an Unequal World* (Cambridge, MA: Harvard University Press, 2018); Stephen Hopgood, *The Endtimes of Human Rights* (Ithaca, NY: Cornell University Press, 2015); Naomi Klein, *The Shock Doctrine: The Rise of Disaster Capitalism* (Toronto, Canada: Knopf Canada, 2007).
2. See: Kathryn Sikkink, *Evidence for Hope: Making Human Rights Work in the 21st Century* (Princeton, NJ: Princeton University Press, 2017); Moyn, *Not Enough: Human Rights in an Unequal World*, (see note 1).
3. Alicia Ely Yamin, *When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality* (Palo Alto, CA: Stanford University Press; forthcoming 2020).
4. See *S. v. Baloyi and Others 1999 (1) BCLR 86 (CC) 29/99* ¶ 12 (Sachs, J.) (S. Afr.).
5. Art 28, Universal Declaration of Human Rights, 1948, available at <https://www.un.org/en/universal-declaration-human-rights/>.
6. "*Health and Human Rights* is an international journal dedicated to scholarship and praxis that advance health as an issue of fundamental human rights and social justice. It seeks to provide a forum for academics, practitioners and activists from public health, human rights and related fields to explore how rights-based approaches to health can be implemented in practice. In so doing, it contributes to fostering a global movement for health and human rights." See "Mission Statement" at <https://www.hhrjournal.org/about-hhr/>. Accessed October 15, 2019.