A Wake-Up Call in Our Upside-Down World: Three Starting-Points for Advancing Health Rights and Social Justice in a Post-Pandemic Future

Alicia Ely Yamin *

Abstract

What the world and our health systems and societies look like in the future depends on the meaning(s) we take from this pandemic, and in turn how we collectively respond. Before the pandemic, we were living in a scandalously unequal world in which one per cent owned as much wealth as the rest of the globe’s population. Worse yet, as Eduardo Galeano suggested, in our upside-down world, this injustice had come to be accepted as a law of nature. This calamity has ravaged the planet with added suffering—some from the disease itself and more that is the result of structural injustice and policies adopted in response. But the disruption in the lives of tens of millions, as well as in the organization of our societies, provides an opportunity for subverting a number of pillars of the upside-down world, and we in the overlapping fields of health justice and human rights have a responsibility to think and act boldly on transformative political possibilities now. In this essay, I set out three lessons and the implications of those lessons. First, we must hold governments to account for the disparate impacts not only of the virus but of governmental responses to the virus. Secondly, if we hope to emerge from this pandemic with meaningful social contracts, it is imperative that we understand health and health systems as integral to democracy. Thirdly, we need to reimagine the architecture of aid, as well as global health and economic governance.

Keywords: aid architecture; COVID-19; democracy; global health governance; health rights; health systems

* The author is the senior advisor on human rights at Partners in Health, a global health and social justice organization committed to improving the health of the poor and marginalized as a matter of justice, and senior fellow on ‘Global Health and Rights’ at the Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School.
Susan Sontag famously referred to illness as a metaphor (Sontag 1979). What the world and our health systems and societies look like in the future depends on the meaning(s) we take from this pandemic, and in turn how we collectively respond. Before the pandemic, we were living in a scandalously unequal world in which one per cent owned as much wealth as the rest of the globe’s population. Worse yet, as Eduardo Galeano suggested, in our upside-down world, this injustice had come to be accepted as a law of nature (Galeano 1998). This calamity has ravaged the planet with added suffering—some from the disease itself and more that is the result of structural injustice and policies adopted in response. But the disruption in the lives of tens of millions, as well as in the organization of our societies, provides an opportunity for subverting a number of pillars of the upside-down world, and we in the overlapping fields of health justice and human rights have a responsibility to think and act boldly on transformative political possibilities now.

In this essay, I set out three take-aways and their implications for health, rights and social justice. First, we must hold governments to account for the disparate impacts not only of the virus but of governmental responses to the virus. Secondly, if we hope to emerge from this pandemic with meaningful social contracts, it is imperative that we understand health and health systems as integral to democracy. Thirdly, we need to reimagine the architecture of aid, as well as global health and economic governance.

1. Accountability for diverse impacts of the virus and of governmental responses; progressive social and legal agendas

By now it is painfully clear that far from being an ‘equalizer’, as it was initially widely dubbed, COVID-19 is in reality a social x-ray that illuminates the fragmentation and social inequalities within and between our societies, and the health systems that purport to serve them. We know in human rights that gender, race, caste, class, disability, ethnicity and other axes of identity determine our inclusion within society and by extension, our vulnerability to epidemics (Virchow 1985; UN CESCR 2009). Even when measures may seem neutral on their face, public health tends to follow an inexorably utilitarian logic, which can often lead to inadvertent discrimination. And of course poverty intersects with other axes of identity in defining both risk and access to care. For example, after 150 years of neglect and disinvestment by the federal government, the Navajo Nation has among the highest infection rates in the United States (Morales 2020).

Advancing the right to health requires challenging the widespread understanding of health as merely a product of random or individual biological factors. It is imperative we understand the difference between biological and socially-constructed vulnerability in this pandemic—and more broadly. Homeless people, prisoners and those in any form of overcrowded housing or institutional settings are more susceptible (Balsamo 2020). And there are vast swathes of people across low- and low-middle income countries (LICs and LMICs) who don’t even have regular access to soap and water (Burki 2020).

Similarly, the impacts of governmental responses are not equally distributed. Women suffer disproportionately from displacement of other services, such as reproductive health care, as well as from indirect effects. They bear the greatest burden of care in most societies, both within families and in wider society, and are disproportionately affected when serious social disruption occurs. And women are overwhelmingly the victims of the ‘shadow pandemic’ of domestic violence, as millions find themselves confined with their abusers (Tang et al. 2020).
Among the most vulnerable are refugees, who find themselves unable to ‘social distance’ in crowded camps with weak or non-existent water and sanitation, and vulnerable to punitive and xenophobic responses by states. While large outbreaks in most of these settings have yet to be observed, models of the epidemic in Cox’s Bazar, a Bangladeshi site for Rohingya refugees, have predicted health-care capacity to be exhausted within 58 days and a death toll of 2,000 among the camp’s 600,000 individuals (Subbaraman 2020). Under the guise of ‘protecting the state’ from potential terrorism, Malaysia has begun raiding the homes of migrants in spite of the UN’s recommendation that their detention in overcrowded centres would only further the spread of the outbreak (Ahmed 2020).

In short, advocacy for health rights and social justice must demand measures in the short term that respect and protect the effective enjoyment of rights by diverse human beings who are differently situated, and must hold governments accountable for justifying any formalistic measures that fail to address substantive inequalities. We should take a lesson from the HIV/AIDS pandemic, in which millions of marginalized persons across the world literally ‘acted up’ collectively to claim their rights and declare their health and lives were not expendable.

But the effects of this pandemic are so sweeping that it is not one minority, or set of populations, that will be excluded, and that calls for another set of strategies. Think of the millions of workers who have lost their livelihoods as economies are closed down (Kawol and Nordt 2020). As Philip Alston, former UN Special Rapporteur on extreme poverty and human rights, has noted, the grossly inadequate responses to the pandemic are likely to thrust more than half a billion into poverty and even starvation (Alston 2020).

2. Health, health systems and democracy

The world’s attention has suddenly been riveted on the connections between population health, democratic functioning and health system response. Advancing health rights and social justice in health requires understanding that health systems are not just delivery systems for health goods and services, which can be allocated by market principles alone. If health is a right, the health system cannot treat access to diagnostics, treatment, and an eventual vaccine as any other commodities.

Rather, health systems function as core social institutions—just as criminal justice systems do. And just as the Black Lives Matter protests have underscored that too often policing and criminal justice systems exacerbate patterns of racial and other discrimination in the overall society, so too have racial disparities in COVID-19 mortality laid bare how the US health system plays a similar role.

If health is a right, the central institution designed to protect and respect it can and must function to mitigate exclusion and reaffirm normative principles of equal concern and respect—from financing to priority-setting to organization and delivery of care. In countries where health systems are publicly funded and universally accessible, this pandemic is playing out very differently in terms of its material and symbolic impacts. In moving towards the world we want post-pandemic, advocacy for health rights needs to take seriously the role of institutional arrangements regarding public health and health care as part of the fabric of a democratic society (Yamin 2020).

Democratic legitimacy requires input from the people whose lives are affected by health-related policies and programmes. For example, Alex de Waal argues that in Africa governments can draw on experience with HIV and the Ebola epidemic, and engage in
meaningful ‘community consultations driven by evidence exchange—scientific evidence from the experts, contextual realities from the people’ (de Waal 2020). There is both inherent and instrumental value in understanding the perspective of ‘non-experts’, which was demonstrated repeatedly in the AIDS crisis (Kearnes 2020). Not only has every experience with past outbreaks shown that the agency and engagement of individuals and communities are essential for effectively managing the spread of disease, but also that people are not passive targets of delivery programmes. In a human rights framework, people are active agents who need to have a voice in decisions that affect their lives, during and beyond this pandemic.

It follows that we cannot be seduced into believing that technological and clinical innovation—while critical—is the solution. Perhaps the most critical aspect of health systems, public health, has long been systematically neglected as health systems were driven ever more by neoliberal imperatives. The United States spends approximately 10,000 US dollars per person per year on medical care but only a matter of hundreds on public health (Himmelstein and Woolhandler 2016; Dieleman et al. 2020). This pandemic has laid bare the deadly toll of a lack of public health infrastructure in the United States, as well as in other highly medicalized health care systems, where there is little capacity for contact tracing or community outreach.

People are the backbone of any health system, and salaries as well as the necessary investments to make working conditions safe are perpetually under-funded in top-down global health funding. In Sub-Saharan Africa, the shortages of trained, equipped and fairly compensated health workers will likely exacerbate the toll of the pandemic. As Zambian physician Naeem Dalal notes during the pandemic, ‘one doctor’s death in Africa is a loss to more than 10,000 people’ (Dalal 2020).

In short, in evolving struggles for health rights, we have had an ambivalent relationship with both biomedicine and health technology. We can expect risks and opportunities to be heightened in a post-pandemic world. Artificial intelligence and telehealth, for example, can extend primary care—especially where human resources are scarce and transportation networks are difficult (Wahl et al. 2018). Yet health technologies can reinforce underlying patterns of discrimination in health and make them less challengeable as biased premises and poor data become cloaked in mendacious algorithmic certainty (Gerke et al. 2020). As laws and institutions invariably lag behind the breathtaking pace of technological innovation, human rights advocates need to be vigilant about the distributional aspects of rules governing these technologies. Further, we need to call out the implications of the dominant logic of market-based solutions to social problems, and the impacts on how we conceive of health systems and in turn rights to health.

3. An opportunity to reimagine aid architectures and global health and economic governance

Movements for health justice must be based on understanding that we live in an inexorably globalized world and we require a reimagined multilateral rules-based order. People travel, goods move, and economies rely on an infinity of networks of exchange. For the most part that’s good. Closing in on ourselves has always been a xenophobic move, and we’re seeing the pandemic used as an excuse for furthering hateful exclusion today in places from the United States to Israel.
The International Health Regulations (IHR), binding on the 196 member states of the WHO (World Health Organization), are an artefact of that globalized reality. The IHR—which were overhauled after SARS—were meant to guide policies that would reduce the spread of disease while minimizing disruptions to travel and trade (WHO 2004). They have been widely flouted in the current pandemic and, if they are to remain relevant to the behaviour of governments, the IHR clearly need to be revised in light of this pandemic to take into account not only the spread of different kinds of infectious disease, but also other threats that invariably cross borders such as the impacts of climate change, as well as clarifying international cooperation and embedding far better monitoring along with dispute resolution.

But fixing the IHR is not nearly enough; we should take the opportunity to re-evaluate global health governance more broadly. The growing influence of transnational corporations; increased privatization of previously government-owned or administered services; waning resources in multilateral institutions; the power of private philanthropies, coupled with the baroque architecture of global health governance and the opaque accountability relationships that lie therein all need to be radically rethought (Bull and McNeill 2007). For example, the Global Fund and GAVI (the vaccine alliance) not only represent targeted vertical approaches to specific diseases/conditions, as opposed to horizontal approaches across health systems—vertical approaches which are ill-suited to responding in a pandemic or to strengthening public health in general; these funds also reflect the outsized importance of corporate and philanthropic influence over global health governance as well as other aspects of health care (Clinton and Sridhar 2017). Moreover, even on the terms of its own narrow mandate, the buy-in to corporate premises around intellectual property and control exercised by philanthro-capitalists such as Gates fundamentally undermine GAVI’s role in making an eventual vaccine for COVID-19 available.

More broadly, the colonialist premises of global health and development, in which many in the economic North saw themselves as exempt from such massive upheavals and health system failures and peddled ‘resilience’ for the poor in the global South, have also been shattered. This is an opportunity to reimagine the architecture of global aid as well as rethink the assumptions about ‘progressive achievement of the right to health’ as a linear path to some fixed version of Universal Health Coverage (UHC) available in the economic North. The priorities of donors dictate the aid agenda, displacing democratic accountability and too often reinforcing rather than ameliorating the underlying systemic health and social inequities.

But just as it does at national levels, the devastation of this pandemic opens the possibility for a wider rethinking of aid architectures and the global economy. A survey just before the pandemic found mistrust in the global order being driven by ‘a growing sense of inequity and unfairness in the system’ (Edelman 2020). The United Nations Secretary-General highlighted global mistrust as one of the greatest threats facing the international community in a speech of January 2020 (Guterres 2020).

To do that, we need a new model of global public investment which is universal and based on solidarity, not charity (Glennie 2019). But we also need to address the structural relationships that deprive governments of fiscal capacities and resources. The political economy of global health and global equality is deeply shaped by both legal rules and informal practices regarding debt, multinational taxation (and inter-state tax evasion), and intellectual property and trade rules, among others. One avenue to begin to remedy systemic asymmetries in the global order is through expanding extraterritorial obligations of states, where a state would be held responsible for its own transboundary impacts (bilaterally and
through multilateral institutions such as the World Bank) as well as for regulating the actions of private entities, such as transnational corporations, over which the state has effective control. In addition to the Committee on Economic, Social and Cultural Rights, the Committee on the Rights of the Child, the Committee on the Elimination of All Forms of Racial Discrimination, and the Human Rights Committee have all referenced extraterritorial obligations, as have domestic courts (UN CESCR 2017; UN CRC 2013; UN CERD 2011; UN Human Rights Committee 2012).

Recently, in a dramatic victory for multiple actors across borders and in different fields, the International Finance Corporation of the World Bank agreed to stop financing private educational institutions in the global South (Oduor-Noah 2019). We must seize the opportunity offered by this ravaging pandemic to insist on similar restraints around privatization of financing and provision of health services. Indeed, if there were any remaining doubt as to the critical role that universal access to publicly-financed and regulated health systems play in democracies, this pandemic should put those questions to rest (Goldhill 2020).

4. Conclusions

Implicit throughout this essay is that COVID-19 is not just a health crisis, or an economic crisis; it perhaps most fundamentally is a crisis for demonstrating the legitimacy of both human rights and democracy. Even before the pandemic it was clear that too many of us had become complacent about democracy and the continual struggles needed to sustain and deepen it, in health and beyond. As the Spanish philosopher Maria Zambrano argued, democracy does not merely permit people to be fully human, it demands that they be so (Zambrano 1988). This robust understanding of democracy, and its relation to humanness and rights, requires not merely civil and political rights protections—which are being trampled in many cases during this pandemic. It also requires bringing diverse people together in mutually humanizing interaction, which is impossible with such extremes of inequality and governance by technocratic elites.

We must ensure that ‘social distancing’ does not become a lasting metaphor for the segregation of classes and populations that had already been well-entrenched in many societies before the pandemic. On the contrary, this is the time for understanding that our actions affect others’ lives and well-being, sometimes in our neighbourhood and sometimes across the globe. Now is the time for advocates in health rights and social justice to join together with advocates from many other movements to shape the social learning we will take from this horrific calamity.

The power of human rights has always come from the energy of real human beings, struggling for the seemingly impossible and acting collectively to make it possible. As Galeano writes, ‘the process is anything but spectacular and it mostly happens at the local level, where across the world a thousand and one new forces are emerging. They emerge from the bottom up and the inside out . . . they shoulder the task of reconceiving democracy, nourishing it with popular participation and reviving it with the battered traditions of tolerance, mutual assistance, and communion with nature’ (Galeano 1998: 321).

Acknowledgements

I am hugely grateful to Richard Carver for his valuable comments, as well as to Neil Thivalapill for his assistance with the preparation of this article.
References

Ahmed, K. 2020. Malaysia Cites Covid-19 for Rounding Up Hundreds of Migrants. The Guardian. 2 May. https://www.theguardian.com/global-development/2020/may/02/malaysia-cites-covid-19-for-rounding-up-hundreds-of-migrants.

Alston, P. 2020. ‘Responses to COVID-19 are Failing People in Poverty Worldwide’ – UN Human Rights Expert. United Nations Human Rights. 22 April. https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25815&LangID=E.

Balsamo, M. 2020. Over 70% of Tested Inmates in Federal Prisons Have COVID-19, Official Figures Show. AP News. 30 April. https://apnews.com/fb43e3ebc4f7355a4f71e3563dbca4f.

Bull, B., and D. McNeill. 2007. Development Issues in Global Governance: Public-Private Partnerships and Market Multilateralism. Routledge.

Burki, T. 2020. COVID-19 in Latin America. The Lancet 20(5): 547–8.

Clinton, C., and D. L. Sridhar. 2017. Governing Global Health: Who Runs the World and Why? Oxford University Press.

Dalal, N. 2020. Africa Cannot Afford to Lose Doctors to COVID-19. World Economic Forum. 9 April. https://www.weforum.org/agenda/2020/04/africa-cannot-lose-doctors-covid-19.

de Waal, A. 2020. COVID-19 in Africa: ‘Know Your Epidemic, Act on its Politics’. London School of Economics Blog. 31 March. https://blogs.lse.ac.uk/crp/2020/03/31/covid-19-in-africa-know-your-epidemic-act-on-its-politics.

Dieleman, J. et al. 2020. US Health Care Spending by Payer and Health Condition, 1996–2016. Journal of the American Medical Association 323(9): 863–84.

Edelman. 2020. Edelman Trust Barometer 2020. https://www.edelman.com/trustbarometer, Global Results (referenced 25 June 2020).

Galeano, E. 1998. Upside Down: A Primer For the Looking-Glass World (M. Fried, trans.). New York: Picador.

Gerke, S., B. Babic, T. Evgeniou, and I. Cohen. 2020. The Need for a System View to Regulate Artificial Intelligence/Machine-Learning-Based Software as Medical Device. NPJ Digital Medicine 3(1): 53.

Glennie, J. 2019. Global Public Investment: Five Paradigm Shifts for a New Era of Aid. Joep Lang Institute. https://www.joelangeinstitute.org/wp-content/uploads/2019/10/Global-Public-Investment-FULL-REPORT-Sept2019.pdf (referenced 18 July 2020).

Goldhill, O. 2020. How At-Home Coronavirus Testing Could Contribute to Healthcare Inequalities. Quartz. 29 April. https://qz.com/1845635/at-home-covid-19-tests-could-contribute-to-health-inequalities.

Gutierrez, A. 2020. Secretary-General’s Remarks to the General Assembly on his Priorities for 2020. United Nations Secretary-General. 22 January.

Himmelstein, D., and S. Woolhandler. 2016. Public Health’s Falling Share of US Health Spending. American Journal of Public Health 106(1): 56–7.

Kawol, W., and C. Nordt. 2020. COVID-19, Unemployment, and Suicide. The Lancet 7(5): 389–90.

Kearnes, M. 2020. We Should Listen to Coronavirus Experts, But Local Wisdom Counts Too. The Conversation. 1 April. https://theconversation.com/we-should-listen-to-coronavirus-experts-but-local-wisdom-counts-too-134034.

Morales, L. 2020. Navajo Nation Sees High Rate of COVID-19 and Contact Tracing is a Challenge. National Public Radio. 24 April. https://www.npr.org/2020/04/24/842945050/navajo-nation-sees-high-rate-of-covid-19-and-contact-tracing-is-a-challenge.

Oduor-Noah, L. 2019. World Bank’s Accountability Body Raises ‘Substantial Concerns’ Regarding IFC’S Investment in Bridge International Academies. East African Centre for Human Rights. 25 October. http://eachrights.or.ke/?press-releases=world-banks-accountability-body-raises-substantial-concerns-regarding-ifcs-investment-in-bridge-international-academies.
Sontag, S. 1979. *Illness as Metaphor*. New York: Vintage Books.
Subbaraman, N. 2020. ‘Distancing is Impossible’: Refugee Camps Race to Avert Coronavirus Catastrophe. *Nature News*. 24 April. https://www.nature.com/articles/d41586-020-01219-6.
Tang, K., J. Gaoshan, and B. Ahonsi. 2020. Sexual and Reproductive Health (SRH): A Key Issue in the Emergency Response to Coronavirus Disease (COVID-19) Outbreak. *Reproductive Health* 17(59): 1–3.
UN CESCR (Committee on Economic, Social and Cultural Rights). 2009. General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights). E/C.12/GC/20. https://undocs.org/en/E/C.12/GC/20.
———. 2017. General Comment No. 24 on State Obligations under the International Covenant on Economic, Social and Cultural Rights in the Context of Business Activities. E/C.12/GC/24. https://undocs.org/en/E/C.12/GC/24.
UN CERD (Committee on the Elimination of Racial Discrimination). 2011. Concluding Observations: Norway. CERD/C/NOR/CO/19-20. https://undocs.org/en/CERD/C/NOR/CO/19-20.
UN CRC (Committee on the Rights of the Child). 2013. General Comment No. 16 on State Obligations Regarding the Impact of the Business Sector on Children’s Rights. CRC/C/GC/16. https://undocs.org/en/CRC/C/GC/16.
UN Human Rights Committee. 2012. Concluding Observations: Germany. CCPR/C/DEU/CO/6. https://undocs.org/en/CCPR/C/DEU/CO/6.
Virchow, R. C. 1985. *Collected Essays on Public Health and Epidemiology*. Vol 1. Boston, MA: Science History Publications.
Wahl, B., A. Cossy-Gantner, S. Germann, and N. Schwalbe. 2018. Artificial Intelligence (AI) and Global Health: How Can AI Contribute to Health in Resource-Poor Settings? *BMJ Global Health* 3(4): E000798.
WHO (World Health Organization). 2004. International Health Regulations, WHA58.3 Revision of the IHR. https://www.who.int/ipcs/publications/wha/ihr_resolution.pdf (referenced 25 June 2020).
Yamin, A. E. 2020. Power, Politics, and Knowledge. In *When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality*, pp. 75–201. Stanford University Press.
Zambrano, M. 1988. *Persona y democracia: La historia sacrificial* (1a ed.). Barcelona: Anthropos.