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## FROM THE EDITOR

### HUMAN RIGHTS AND HEALTH SYSTEMS DEVELOPMENT: CONFRONTING THE POLITICS OF EXCLUSION AND THE ECONOMICS OF INEQUALITY

*Duncan Maru and Paul Farmer*

#### ABSTRACT

*The social movements of the last two decades have fostered a rights-based approach to health systems development within the global discourse on national and international health governance. In this piece, we discuss ongoing challenges in the cavernous "implementation gap": translating legislative human rights victories into actual practice and delivery. Using accompaniment as an underlying principle, we focus primarily on constructing effective, equitable, and accountable public sector health systems. Public sector health care delivery is challenged by increasingly exclusive politics and inequitable economic policies that fundamentally limit the participatory power of marginalized citizens. Finally, we discuss the role of implementation science in closing the delivery gap in human rights practice.*

#### INTRODUCTION: THE RIGHT TO HEALTH

The human rights approach to public health systems development has been a central theme to emerge from the explosive growth in global health awareness and funding in the last two decades.<sup>1</sup> The notion that health care systems are both national and international public goods protecting the essential rights of all citizens, while not wholly embraced, has gained traction in global debates about health care financing, governance, and implementation.<sup>2</sup> In this piece, we discuss challenges in translating consensus around health as a human right into one particular aspect of the right to health: namely, access to effective health care systems that reach the most vulnerable.

The Universal Declaration of Human Rights was published in 1948, marking the start of the modern human rights movement.<sup>3</sup> The poles of civil and political rights versus social and economic rights established during the Cold War era prevailed until the early 1990s, when a relative consensus emerged that the different human rights domains should be integrated. The global movement to combat HIV/AIDS represents the broadest, deepest, most concerted effort to date to forge a link between health and human rights. It is no coincidence that this movement was initiated, expanded, and sustained by individuals from communities bearing the highest burdens of HIV disease. The movement was successful because it was driven and led by individuals directly affected by the epidemic. This movement both globalized public health and connected it to the rights agenda.<sup>4</sup>

A major challenge in translating the successes of the HIV/AIDS movement into broader health systems change is deepening the involvement of citizens who would be most impacted by such changes—often the most marginalized populations. Wealthier citizens tend to be able to rely on for-profit, privatized health services and therefore have little incentive to partner with poorer citizens to advance public sector health systems change.

Herein lies a paradox in health and human rights. At no time in human history has health as a human right been as prominent in international and national health discourse as it is now. Yet we also face ongoing expansion of the politics of exclusion and the economics of inequality, which pose immense challenges to implementing human rights-based advances. Human rights legislation without effective delivery systems is impotent; effective delivery systems without human rights protections (for example, legislative guarantees) will fail to deliver to the most vulnerable.

For health systems development, why does the rights-based view remain relevant today? While much has changed, the underlying forces driving health inequity remain the same. We believe that effective health care systems must guarantee the right to health for our most vulnerable citizens. While this is a sweeping statement, it is important to differentiate this rights-based approach from other approaches that seek merely to reduce population disease, maximize cost-effectiveness, or facilitate rational private investment in health. Our stance is a fundamentally moral one, rooted in the lived experiences of our patients, but it is also deeply pragmatic. To free the world's poor from the diseases that continue to stalk them, we must build better public sector systems.

### *Public sector accompaniment*

The private sector cannot by itself guarantee the health of the poor, whose right to care is so routinely violated.<sup>5</sup> The private sector can deliver dignified care to significant segments of the world's population, but cannot guarantee access to the poorest. Private corporations are key partners in innovation, including the development of diagnostics, and therapeutics, but it is neither their role nor their business model to guarantee health to the poor. Note that we are not discussing which types of health care delivery sys-

tems are used on the spectrum of purely nationalized health services to purely privatized ones. Rather, we posit that within any mechanism of care delivery, the government is responsible for ensuring that the poorest get the treatment that is their right.

This is why so much of our work in global health delivery is centered on accompanying the public sector.<sup>6</sup> The destitute sick rely on governmental protection for their survival. If our goal is to reach these most destitute, we must then accompany governments—that is, we must strengthen and support the public sector, rather than provide parallel services. Patients may receive care, services, and goods from private companies or organizations, but these institutions cannot themselves provide the basic social protections the poor need to survive. Accompaniment, in a rights-based approach to public sector services, has two elements: working with governments to build their capacity to deliver services, and simultaneously working with communities to hold governments accountable for the quality, equity, and effectiveness of those services.

This intersection—of human rights theory and policy, and health care delivery—is where we have worked as physicians and implementers for, collectively, decades. We transition here to more personal narratives, focusing on South Asia, a region home to 33.9% of global child deaths, 30% of maternal deaths, and 55% of tuberculosis cases.<sup>7,8,9</sup> South Asia also continues to have the highest rates of malnourished children; in India, Bangladesh, Afghanistan, and Pakistan, prevalence rates of under-nutrition are much higher (38 to 51 percent, respectively) even than those in sub-Saharan Africa, which stand at 26 percent.<sup>10</sup> We were fortunate to share a trip to the region, to Nepal, in July 2012.

### **DR. PAUL FARMER: HEALTH AND HUMAN RIGHTS – A VIEW FROM NEPAL**

*(Note: Dr. Farmer's personal narrative builds on his article *Reflections on Nepal*)<sup>11</sup>*

On a map of the world and to a doctor's eye, Nepal is a rib-shaped slice of a country stretched laterally between two giants, hemmed in to the north by the Himalayas and to the south by India. In the words of anthropologist Dor Bahadur Bista, “Nepal is such a complex social conglomeration seeking perpetu-

ally to accommodate, if not synthesize, its diverse discrete parts.”<sup>12</sup> In spite of close to three centuries of national identity, groups defined variously by class, caste, ethnicity, language, region, and religion jostle for the rights that people everywhere want: access to health care and education, the chance to make a decent living without risking life and limb. In much of the country, and among the poor, precisely such risks are faced every day. Although the rules of feudalism have been abolished, landless poverty keeps millions in profound dependence. Some recent estimates peg the number of Nepalis who live on less than \$2 a day as high as 80 percent.<sup>13</sup>

Physicians are trained to expect an often-grim universality from pathophysiology. A bad chest x-ray looks familiar in Boston or Rwanda or Kathmandu; lungs and hearts sound the same across the globe; a fracture is a fracture is a fracture. Yet whether among the poor and marginalized in wealthy or developed countries or among the great majority in the world’s poorest countries, the concept of justice in action—of actually delivering on lofty concepts regarding the right to food security, safe schools, housing, water, and health care—remains as powerful and important now as ever.<sup>14</sup> Perhaps more powerful: it’s impossible to argue, in the 21st century, that any of these challenges are somehow technically insuperable. They’re not, and we all know it.

A few years ago, a group of medical students, trainees of mine, founded Nyaya Health, working in partnership with local groups and public health authorities to promote the right to health and help break the cycle of poverty and disease.<sup>15</sup> They opened a health center in a warehouse in a small town, and brought in Achham district’s first biomedically trained doctor. Until recently, the district counted a quarter of a million people but not a single physician.

Their work isn’t easy. It’s well over 100 degrees in summer and humid enough to make one wish for rain. Inside the clinics and wards, the mortal dramas are all too familiar. Women with third-trimester catastrophes. Abscesses from injuries. Rheumatic heart disease. Enteric fever. Childhood malnutrition and its companion diarrheal disease. All manner of waterborne ailments. Tuberculosis and AIDS. (Achham probably has Nepal’s highest rates of these two chronic infections, long associated with poverty, gender-based disparities, and labor migration, all of which are also associated with conflict). Of course,

there are non-communicable chronic diseases, too: congestive heart failure, renal insufficiency, many cancers, mental illness. It’s a well-known catalogue, seen in every impoverished corner of the world.

Every one of these problems can be prevented or palliated or cured by the basics of modern medicine and public health. By basics, I mean clean water and safer roads, of course, but also a fairly modest array of vaccines and diagnostics and treatments. In an era in which we talk glibly of “value for money” or “cost-effective interventions,” it would be hard to argue that the work at hand in Achham doesn’t offer a terrific bargain—to push the metaphor crassly—for those wishing to make a difference in a world riven by inequality and its attendant suffering.

Taking on the noxious synergy of poverty and disease is tedious and full of pitfalls and disappointments. But many have fought hard and made great sacrifices in order to insist on something as simple as a hospital in a place such as Achham district in far-western Nepal. Those sacrifices include the lives of six people killed during a demonstration in 1976; people in the region were agitating for a hospital and the protest turned violent. Six more people went to jail, some as far away as Kathmandu. Some of those who served time returned to see the hospital reborn and growing. The vigor of purpose in providing a preferential option for the poor has remained unwavering. The challenge we face is not lack of conviction, just as it is not lack of available technology. Delivering on the promise of the right to health care is, some have argued, the ranking human rights challenge of our time.

Over the past quarter-century, I have been asked a thousand variants of the following questions: “This work to provide health care as a right is a good thing, but is it sustainable? Can it ever be brought to scale?” And we’ve said a thousand times, especially to our own students, that it’s possible to tell whether these questions are asked to start the conversation or to end it. For those seeking to start conversations about sustainability and scale, or about the right to health care, we have learned a great deal. To sustain such efforts requires that a new generation of practitioners, policymakers, scholars, researchers, and advocates take up the mantle of human rights and global health equity. It requires investments in training on both sides of the great divide between rich and poor.<sup>16</sup> To bring such efforts to scale requires that

we engage the public sector, since only governments can confer rights to those living within their borders.

If you do this work long enough—I've worked with the same people in Haiti and at Harvard for nearly thirty years—life starts to be defined by tension between the general and the specific, the universal and the particular, and is always linked to the mortal dramas mentioned above. These dramas can be hidden away, and often are, but they exist whether we acknowledge them or not. And yet, acknowledging injustice is not enough; linking knowledge to reparative action is what we're all called to do, together. It's the heart of the matter for all partners in health, lower case. As I have learned from Amartya Sen and from colleagues at Nyaya Health, the Sanskrit-based word *nyaya* means "justice in action"—it's perhaps a shorter and more elegant term for global health delivery and for human rights.<sup>17</sup> No single group can possibly bring services to all who need them. But the lives of those we never see or meet are just as valuable as the lives of those we meet directly, and their health just as much a right as our own.

#### DR. DUNCAN MARU: SOUTH ASIA: GROWTH AND INEQUALITIES

My own thinking about health and human rights is driven by my experiences in India, South Asia's most wealthy and populous country, and Nepal, its most impoverished. One can only understand health and human rights, or the lack thereof, in the context of the politics of exclusion. Over the last 15 years, India has enjoyed one of the world's most impressive economic growth rates.<sup>18</sup> A largely privatized health care system has flourished during this time, building shining new hospitals and developing a lucrative medical tourism industry. Yet measures of infant mortality, maternal mortality, sanitation, and pediatric malnutrition stubbornly remain at levels far higher than many other countries of similar wealth.<sup>19</sup> India is home to three of the world's top 10 wealthiest individuals and 400 million of the world's poorest quintile.<sup>20</sup> This inequity is perhaps most striking in the capital city of Mumbai, the financial capital of India and the engine of growth on the subcontinent. It is one of the earth's most cosmopolitan cities, driven by mass migration from rural areas throughout the subcontinent.

Nepal is a microcosm of the South Asia-wide issues presented by India. For the last six years, I have been working on public sector accompaniment in Nepal

with our organization Nyaya Health. In the wake of a decade-long war that ultimately deposed the king and created a constitutional democracy, health care policy was written to include, for the first time, bold rights-based language.<sup>21</sup> The People's War, as it is often called, had its roots in the exclusion from economic, political, and social power of several groups, based on caste, ethnicity, and geography. During the war, the Maoist insurgents captured the hearts of the countryside, with troops some ten times fewer than those of the Royal Nepalese Army, through promises of basic protections for excluded groups.<sup>22</sup> Since the mid-18th century, when the Gorkha empire consolidated power over numerous linguistically and ethnically diverse communities, the Nepali nation has been defined by exploitation of the rural, landless, and ethnically marginalized citizenry by the rich, land-owning, upper caste rulers.

Inequality in Nepal has deepened during and following the civil war. Prior to the war, Nepal's Gini coefficient was close to the global average; subsequently, however, its coefficient has grown faster than that of any other country in Asia.<sup>23</sup> Today Nepal is one of Asia's most inequitable countries, second only to China. This was driven by multiple factors, including the decrease in remittances to and increase in migration from rural areas out of security concerns, as well as the ongoing consolidation of political leadership of the governing parties by the elite classes.<sup>24</sup>

In the aftermath of the civil war, Nepal integrated strong rights-based changes into their approach to health care delivery in the public sector.<sup>25</sup> Over the course of two years, a policy was established that calls for free care at all health posts and sub-health posts (clinics typically staffed by non-physician providers) designates 40 essential medicines to be provided free of charge at the district hospital level. Other services, such as deliveries, were not only provided free of charge; patients also received a small stipend to incentivize the use of those services.<sup>26</sup>

The new mandate on the right to free health care has, unsurprisingly, been difficult to translate into actual advances in the right to health for Nepal's excluded populations. Much of this has to do with the inherent implementation challenges of delivering care to the excluded. Fifty-five percent of the richest quintile births were conducted in a health care facility, compared with only 4% of the poorest.<sup>27</sup> One review of Nepal's free health care policy showed that 85% of

hospitals suffered medication shortages and 24% of health care facilities were understaffed owing to absenteeism and competing work by staff in the private sector.<sup>28</sup> Improving these realities is made difficult by patterns of health care utilization in the post-free-care-era: 84% of the poorest quintile utilized public sector services and 10% went to private sector, compared with 64% and 29% in the highest.<sup>29</sup>

Our own operations in Far Western Nepal, home to some of the country's most marginalized and impoverished communities, have been challenged by the politics of exclusion and the economics of inequality. Exclusion based on caste and gender looms large. The Dalit caste makes up 47% of our patients.<sup>30</sup> Over 50% of women remain illiterate in our district, and the majority of them are still forced to practice *chau-padi gauth*, or isolation in cow sheds during menstruation.<sup>31</sup> The geographic exclusion is powerful and tangible in daily life here. Where we work, it takes over 30 hours by road to reach Kathmandu, the political and economic capital of the country. The nearest functioning airport is more than 10 hours away. A single, poorly maintained road winds through the hills as the lifeline for essential supplies for our work. When that road is cut off by strikes, which are often motivated by the politics of exclusion, our services suffer.

We have confronted political exclusion as well. We have worked closely with the central government, and they have provided funding as well as land and facilities. However, their motivation to assist is minimized by the lack of an active constituency that has the power to advocate. Building a solid base of citizens engaged in political advocacy takes time, and in settings of deprivation, actual services. In the face of a hospital crisis led by individuals from outside our district, community members rose to the occasion to protect the hospital and keep services going, a process we describe elsewhere.<sup>32</sup> This is the power of strengthening direct services—citizens come to have hope and belief in the very human and physical infrastructure they need to improve.

Human resources themselves are challenged by political and economic exclusions. There are few doctors willing to work in the Far West, which is a reality that cannot be fixed by legislation. Ultimately, any legislation, such as mandatory rural service, incentives for rural providers, and protections against absenteeism, cannot alter the realities of the Far West that make

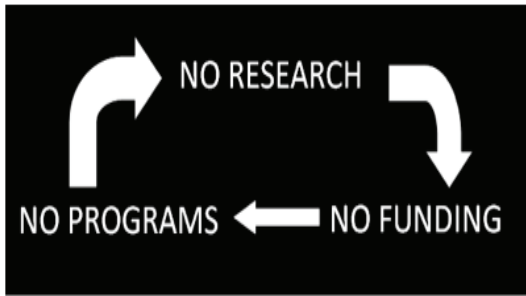
it currently unlivable for many doctors. While the first medical director of our organization was from Achham, he was one of the only physicians ever trained from the district. Subsequent to his two-year commitment, the longest period of time for any physician at our hospital has been one year, and it is typically far less. We have gone through some ten medical directors in the last two years. This stands in contrast to our excellent retention of mid-level providers, nearly all of whom come from the region.

We have seen these forces at play as we have tried to work with the government to implement another one of Nepal's important right-to-health legislative achievements: the 2004 legalization of abortion through 12 weeks of gestation. Operationally, we have prioritized abortion as one of the most life-saving services we provide, yet we have consistently run into problems with staffing. Abortion provision requires government-sponsored training by a physician, and because of the aforementioned physician recruitment and retention problem, our abortion services have been intermittent. We have discussed at length with the government's Family Health Division, though there is little, logistically, that they can assist us with in absence of legislative changes. Thus, the realization of this essential human right is incompletely implemented.

### *Implementation science and social action*

Implementation science is a relatively new discipline that aims to scientifically develop and test innovations to improve the delivery of evidence-based interventions that improve the health of patients and populations. Much has been written about implementation science, its approaches and methodologies. One notable gap in the existing dialogue around implementation science is discussion of its relationship to social action. This is critical in settings of extreme poverty, where the social and historical and cultural roots of under-utilization or under-implementation are fundamentally tied to lack of access to economic resources. It is impossible, for example, to ignore social action in implementation science research when studying the implementation of evidence-based interventions for child survival within the government sector in a marginalized and economically depressed area. Excellent implementation science studies without political and social backing from constituents to policy makers will have little impact. Indeed, if the goal is to break the vicious cycle in which a lack of programs precludes





research, which in turn restricts funding (figure), then implementation science must be combined with social action.

However, when effective implementation is combined with rigorous study of interventions and sound policy, the vicious cycle described above can become a virtuous one:



In settings of extreme poverty, economic deprivation and social exclusion are often the roots of the implementation gap. Given this reality, implementation scientists should incorporate clear post-study social action plans into their protocols. These social action plans should describe the key actors and main strategies in changing policy and mobilizing resources to implement the findings of the research. Here, we describe the rationale for this approach and develop a structured method for developing social action plans within implementation science protocols.

The social action strategy plan should have the following components: 1) background to the current political, policy, and economic barriers to implementation; 2) key constituents, actors, and partners

**Background to the current political, policy, and economic barriers to implementation**

What are the major constraints to implementation? What are the data on utilization, financing, staffing, and supplying for the targeted services? What are the major institutions and actors that may have a stake in the status quo?

**Key constituents, actors, and partners involved in overcoming these barriers**

Who are the individuals and groups who are capable or otherwise essential in overcoming these barriers? At a local level these may be private sector providers, government staff, local politicians, and supply companies. At a national level, these may include politicians, policy makers, non-governmental organizations, and aid agencies.

**Concrete plan for dissemination of findings and action around their implementation**

What will be the immediate next steps post-publication? Who will receive email and paper copies of the publication? Who will receive an in-person meeting? Where will community or public meetings be conducted, and who will be invited?

involved in overcoming these barriers; 3) concrete plan for dissemination of findings and action around their implementation.

*Lessons learned and a path forward*

We have presented here both personal reflections and a possible way forward in realizing—and delivering on—health as a human right. The direct corollary of the application of human rights to health systems development is that the government must be deeply involved in and ultimately responsible for ensuring its poorest citizens have access to health care. Accompaniment of the public sector therefore means working with governments to build their capacity to deliver services, and simultaneously working with communities to hold governments accountable for the quality, equity, and effectiveness of those services. This is central to translating human rights declarations into effective implementation. Moreover, the relation of implementation to social action, as dictated by implementation science, emphasizes the need for social and political backing from local citizens and clear post-study social action plans. By building off the remarkable advances of the right-to-health movement, not only can the politics of exclusion and the economics of inequity be

overcome, but effective healthcare systems can be developed, and high-quality health care delivered to the global poor.

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