Introduction to *To Repair the World**

Jonathan L. Weigel

October 24, 2012

Anyone who has heard Dr. Paul Farmer speak knows the pull of his stories, the speed of his wit, and the force of his vision. When he describes the work of Partners In Health (PIH) in Haiti or Rwanda or Russia, we can't suppress the feeling that he's figured out what it means to do the right thing, to make the world a better place. It's inspiring. It's also uncomfortable because that right thing rarely resembles what we do every day. He makes us face poverty and injustice, which most of the time we are content to ignore. He makes us pay attention to people suffering, sometimes dying, from diseases for which we could pick up treatments in a corner pharmacy. We can't help asking ourselves what we, each of us, might do to help lessen such towering inequity.

This book is a collection of some of Paul's most memorable speeches, at university graduations and other public venues. Unlike many of his writings in clinical medicine, global public health, and anthropology, these are written principally for a general audience and especially for young people considering what path to tread in the years that await them.[1] We hope this volume will make Paul's vision of equity and radical solidarity with the world's poor accessible to readers from all walks of life.

*Farmer, P. 2013. To Repair the World: Paul Farmer Speaks to the Next Generation. University of California Press.

[1]Many of his academic writings are collected in *Partner to the Poor: A Paul Farmer Reader* (Berkeley: University of California Press, 2010).

1 "You guys are my heroes"

I met Paul when he came to speak at my high school in 2005. We were excited to meet a person of such stature and were prepared to be impressed and inspired. But we were not at all prepared for how funny he was, how he seemed to look each of us straight in the eye with full force of his big personality, how he got away with being so sincere and so passionate, how he got complicated ideas across in ways we could understand, how he made us feel important.

His presentation detailed PIH's efforts to provide AIDS treatment in an impoverished squatter settlement in rural Haiti. I was moved and inspired and more than a little uncomfortable. My planner was filled with biology classes, piano lessons, cross-country practice, and other things wholly alien to the hardscrabble life Paul described in Haiti. My main goal was getting into college. Should I harness the good fortune of my privileged upbringing to work on behalf of those born in less fortunate circumstances thousands of miles away?

At one point, someone asked him an awkward, perhaps impertinent question: what is it like to be a hero? "Well," he said without hesitation, "you guys are my heroes," referring to all of us packed in the auditorium, which was overflowing into the hall. "In fact, you're my retirement plan." Maybe it sounds trite now, but we could tell he meant it. Paul Farmer was in high demand as a speaker nationally and internationally; he wouldn't have made the effort to come to our high school if he didn't believe that students had a key role to play in the movement for global health equity.

This realization—that students were protagonists in Paul Farmer's vision of a more humane world—became clearer when I arrived at Harvard College a year later. In between running a department at the Medical School, a division at Brigham and Women's Hospital, a center at the School of Public Health, and of course continuing the work and expansion of Partners In Health, Paul and PIH cofounder Dr. Jim Yong Kim made time to advise a global health student group I joined. Sometimes they asked us to organize events; sometimes they solicited our advice about new courses they were developing; always they were eager to learn how to draw more students toward global health. The point is that they took us seriously. We weren't just pesky students asking for good grades and recommendation letters (though we were that, too); we were partners in something big and important.

My senior year, Paul, Jim, and Dr. Arthur Kleinman, who taught Paul

and Jim as doctoral students, offered a new class.[2] It was just what we had asked for: a comprehensive introduction to global health. The professors' office hours had lines out the door every week, but they stuck around until all of our questions had been answered. (I would later learn that, much to the bewilderment and occasional consternation of his staff, Paul regularly delayed "real" meetings and flights to stay in office hours until we students had had our fill.)

I started working on Paul's team at Partners In Health a year later. Orientation consisted of a one-line Blackberry-typed email from the doctor himself: "It's going to be a baptism by fire." No one could have said it better. Paul is all in, all the time. And everyone who works with him feels inspired—compelled—to do the same. I soon found myself helping Paul prepare for lectures, editing books and articles, and accompanying Paul as he traversed the globe, building an army of young people dedicated to fighting social injustice.

2 Countering failures of imagination

Six weeks on the job, cholera appeared in Haiti for the first time in at least a hundred years. This nineteenth-century disease persisted throughout the twentieth and early twenty-first centuries in many settings where poverty also persisted. But somehow Haiti—long labeled the "poorest country in the Western Hemisphere"—had been spared until October 2010, nine months after a magnitude 7.0 earthquake leveled much of the capital city, Port-au-Prince. Within days of the outbreak, it looked unlikely that the local and international response to cholera in Haiti would be sufficient to prevent great suffering and death. Paul immediately got to work, seeking to reverse the cruel fate that seemed to await this beleaguered country in which he's worked for three decades.

In Paul's class, we learned how failures of imagination undermined global efforts to respond to AIDS, tuberculosis, cancer, and other modern plagues.[3]

[2]The course is currently in its fifth year and continues to attract hundreds of students each term it is offered. An introductory global health textbook, which was modeled on this course, will also be published in 2013. See *Reimagining Global Health: An Introduction* (Berkeley: University of California Press).

[3]For more on this topic, see Paul's book *Infections and Inequalities: The Modern Plagues* (University of California Press, 1999).

When dealing with the health problems of the poor, public health policymakers often adhere so strictly to the doctrine of "cost-effectiveness"—a valuable tool for setting priorities, but just one tool among many—that responses to the big challenges in global health are anemic. Only inexpensive medical care is deemed appropriate for settings of poverty. Paul has a pithy expression for this perverse outcome: "cheap shit for the poor." (He left that one out during class.)

When used in a vacuum, cost-effectiveness analysis at times produces incorrect and unethical claims. To cite just one example, a 2002 study concluded that in Africa it is 28 times more cost-effective to prevent new HIV infections than to treat people who already have AIDS.[4] The authors thus effectively recommended letting 25 million people—all those living with AIDS in Africa at the time—die because they thought it would be too expensive to save them. How could well-meaning people make such a monstrous (and ill-founded) suggestion? Is anyone authorized to wield instruments like cost-effectiveness analysis with such certainty when so many human lives are at stake? These are questions Paul takes up throughout this volume.

The short answer is that claims such as these are failures of imagination. The authors of the 2002 paper arrived at their conclusion by treating "cost" and "effectiveness" as givens, but both turned out to be highly variable. Consider cost. Within a decade, the cost of AIDS therapy dropped from $10,000 per patient per year to less than $100 per patient per year. Meanwhile, AIDS drugs proved more effective than initially thought. Not only do multidrug regimens suppress the virus indefinitely, they also reduce transmission by 96 percent.[5] Put simply: treatment works as prevention, too. Today more than 8 million people are on treatment worldwide; some 6 million of them live in Africa.[6] Few experts of any stripe could have imagined in 2002 just how cost-effective AIDS treatment really is.

As this example reveals, global public health experts have sometimes become the tool of their tools, to paraphrase Thoreau. This is a problem when dealing with lethal infectious diseases that cross borders and burn through the ranks of the poor. The quick fix will never be enough to contain the really difficult diseases or protect the populations most vulnerable to

[4]E. Marseille, P. Hofmann, J. Kahn. 2002. "HIV prevention before HAART in sub-Saharan Africa," The Lancet. 25; 359 (9320): 1851–56.

[5]Myron Cohen et al. 2012. "Prevention of HIV-1 Infection with Early Antiretroviral Therapy," The New England Journal of Medicine 11; 365: 493–505.

[6]UNAIDS. Together We Will End AIDS. 2012.

them.

We learned this lesson, once again, in Haiti. In late 2010, the World Health Organization and other public health heavyweights got to work making policy recommendations about cholera in Haiti. Instead of using every weapon in the arsenal, as would have happened had the disease appeared in the United States or any other wealthy country, the post-quake aid apparatus balked, opting to promote certain interventions over others. In particular, oral cholera vaccine was ruled out as "too expensive" or "too complex to deliver" in Haiti. As Paul's students know, these are precisely the arguments used to low-ball the global response to malaria, drug-resistant tuberculosis, AIDS, heart disease, mental illness, and many other afflictions of the world's poor. And they are spurious arguments: the vaccine is administered orally and costs only $3.70 for the two required doses; increased production would lower prices even further. Providing health care doesn't get much easier than that. Accompanying Paul from policy meetings in New York to cholera treatment facilities in Haiti, I felt like I had a ringside seat as the latest installment in the sorry history of global health ran its course.

Predictably, the cheaper approach did not stop cholera. Within weeks, the epidemic had spread across the country, tracing a grim map of the scarce access to safe drinking water and modern sanitation across Haiti. Thousands have since perished from a disease that can in most cases be treated with simple rehydration, and transmission continues at alarmingly high rates. The epidemic in Haiti is now the world's largest in half a century.

Could a more forceful and a truly comprehensive response—one that integrated the cholera vaccine with other interventions—have stopped cholera? We'll never know, but surely it would have slowed the pace of the epidemic and potentially saved thousands of lives.

A year and a half after cholera hit Haiti, PIH finally got the green light to roll out a modest vaccination campaign in conjunction with its Haitian sister organization, the Haitian Ministry of Health, and another Haitian medical nonprofit. From April to June 2012, about 100,000 Haitians received the two-dose vaccine course in rural and urban Haiti. It is too early to claim success, but the news has been only positive to date: demand for the vaccine is high in the population, and the Ministry plans to scale up the campaign across the country with support from the United Nations and many other organizations. The World Health Organization recently endorsed the initiative, too. Long-term control of cholera will require building robust water and sanitation

systems across Haiti, which will take time.[7] In the interim, it would be foolish not to use every weapon we've got to help slow the world's worst cholera epidemic in recent memory.

Failures of imagination—claiming that you can't treat AIDS in Africa or that you can't deliver cholera vaccine in Haiti—and what we can do to reverse them are, in my mind, what this book is all about.

3 Accompaniment

Why is it acceptable to lower our standards when considering the health problems of the poor? How might we usher in a bolder, more humane chapter in the history of global health? The speeches in the first section ask readers to think hard about these questions. Paul encourages us to reimagine equity: what kind of world do we want to live in? What might our world look like if the next generations take poverty and inequality seriously? What kind of movement will it take to bring this vision into being?

One necessary part of a movement for global health equity is a cohort of medical professionals dedicated to serving the poor. In Paul's commencement speeches at medical schools, many of which appear in the second section, he asks new doctors to keep in mind the big picture: all that lies beyond cutting-edge laboratories and clinical facilities. The upper echelons of health research and practice in the wealthy world embody the promise of modern medicine. But without an equity plan, that promise remains unrealized to billions of people around the world—the very people who shoulder the lion's share of the burden of disease. Paul isn't calling for everyone to drop what they're doing and start working on the frontlines of global health. He's always been a stalwart cheerleader for scientific innovation, and commends all those who devote their lives to pushing the frontier. He just asks that every member of the medical professions, broadly defined, remember that even the greatest

[7] Vaccination is an imperfect tool, and an expanded vaccine effort must not undermine the treatment of patients and the provision of clean water and modern sanitation. Strong public-sector water and sanitation systems would halt transmission of cholera and also that of other waterborne pathogens, such as typhoid fever and hepatitis A, which also claim many lives among the poor, especially among children. Paul and I wrote a longer piece exploring some of the claims of causality about cholera control in Haiti and elsewhere in *Americas Quarterly*, available here: `http://americasquarterly.org/cholera-and-the-road-to-modernity`.

therapeutic or diagnostic breakthroughs will mean little unless they reach the people they were designed to help.

Paul also encourages new doctors to remember the importance of old-school caregiving.[8] He sums up the simple business of caring for others—visiting them in their homes, helping them fill prescriptions, washing their dishes—in a word that appears throughout this volume: accompaniment. Doctors and nurses and community health workers should, Paul suggests, be accompagnateurs (a word adopted from Haitian Creole) to their patients. The practice of accompaniment is one of main reasons why PIH achieves outstanding clinical outcomes when treating complex diseases like cancer, drug-resistant tuberculosis, AIDS, and depression in some of the poorest parts of the world.[9] By attending to the basic deficits that deny billions of people fundamental human rights—the topic of this book's third section—PIH teams attack ill health at its root: poverty, joblessness, homelessness, hunger, decrepit schools and hospitals, a lack of municipal water and sanitation systems. As Paul reminds medical school graduates, accompaniment isn't just humane practice; it's best practice.

But, as the speeches in the fourth section make clear, accompaniment goes well beyond the clinical realm. Paul sees in it a new model for all "aid" work. What does "accompaniment" really mean? Although it might at first seem simple, I think it is among the most difficult concepts to grasp in the speeches that follow. But there might be no more important principle animating Paul's work and vision. In his own words, then:

> 'Accompaniment' is an elastic term. It has a basic, everyday meaning. To accompany someone is to go somewhere with him or

[8]See also Arthur Kleinmans work on the moral dimensions of caregiving, for example: "Caregiving: the odyssey of becoming more human," The Lancet (2009) 373; 9660: 292-293.

[9]See, for example: Carlson JW, Lyon E, Walton D, Foo WC, Sievers AC, Shulman LN, Farmer P, Nos V, Milner DA. Partners in pathology: a collaborative model to bring pathology to resource poor settings. American Journal of Surgery and Pathology 2010; 34(1):118-23; Carole Mitnick, et al. "Community-Based Therapy for Multidrug-Resistant Tuberculosis in Lima, Peru," New England Journal of Medicine 2003, 348; 2: 119-122; P. Farmer, F. Landre, J. S. Mukherjee, M.S. Claude, P. Nevil, M. C. Smith-Fawzi, S. P. Koenig, A. Castro, M.C. Becerra, J. Sachs, A. Attaran, J. Y. Kim. "Community-based Approaches to HIV Treatment in Resource-poor Settings," The Lancet 2001, 358:404-9; Giuseppe Raviola, Eddy Eustache, Catherine Oswald, Gary Belkin. "Mental Health Response in Haiti in the Aftermath of the 2010 Earthquake: A Case Study for Building Long-Term Solutions. Harvard Review of Psychiatry 2012, 20(1):68-77."

> her, to break bread together, to be present on a journey with a beginning and an end. There's an element of mystery, of openness, of trust, in accompaniment. The companion, the accompagnateur, says, 'I'll go with you and support you on your journey wherever it leads. I'll share your fate for a while'—and by 'a while,' I don't mean a little while. Accompaniment is about sticking with a task until it's deemed completed—not by the accompagnateur, but by the person being accompanied.[10]

Accompaniment is different from aid. "Aid" connotes a short-term, one-way encounter: one person helps, and another is helped. Accompaniment seeks to abandon the temporal and directional nature of aid; it implies an open-ended commitment to another, a partnership in the deepest sense of the word.

Partners In Health was founded on the notion of accompaniment. Paul, and everyone at PIH, pledged to take this longer, more unpredictable road in serving the poor. They brought resources—medical, human, financial—but instead of imposing their own agenda on their intended beneficiaries, they formed partnerships and resolved always to accompany, not to lead. PIH sought to replace the hubris of traditional foreign assistance with humility, trust, patience, and constancy—to replace aid with accompaniment.

This is not an easy approach. It entails radical availability. (Paul rarely stops working, despite frequent attempts by friends and family to get him to take a vacation.) It means investing in ambitious projects that take years to complete and are unlikely to produce frequent bursts of measurable outcome data, as demanded by many donors concerned with impact evaluation.[11] And it means always trying again when projects fail. "It's not easy to admit, even today," Paul writes in one of the last speeches in this volume. "We tried and mostly failed. Haunted by mediocrity, we keep returning to the task of raising

[10]Paul Farmer, "Accompaniment as Policy," Harvard Kennedy School of Government Commencement Speech 2011.

[11]For example, many donors favor so-called "vertical" programs that target specific diseases. While such efforts can make inroads against major causes of mortality and morbidity, they reflect priorities cooked up in boardrooms in Washington or Geneva, not necessarily the priorities of the poor. By adopting an accompaniment approach, PIH learned that initiatives to combat leading killers like AIDS and tuberculosis could be improved by providing of primary health care and wraparound social and economic services, such as food support or improved housing. Strengthening health systems is a taller task than tackling a single disease, but one that surely brings greater long-term return on investment in terms of stemming death and disability, not to mention generating beneficial spillover effects on local economies.

the standard of care."[12] This dogged commitment to doing whatever it takes to give the poor a fair shake is the essence of accompaniment.

Over the last two years, I've learned a little bit about what it means to be an accompagnateur. Paul is the first to say that everyone needs accompaniment, and that includes Paul, the consummate accompagnateur himself. Beneath his irrepressible good humor lie enormous cares and, as he describes in the speeches that follow, doubts and fears. Trying to be his accompagnateur isn't easy for any of us on his team. Despite regular all-nighters and feverish last-minute scrambles, it is hard to catch up to Paul's steady, burning commitment to fighting injustice and advancing equity. We struggle with feeling inadequate, frustrated, and trivial; sometimes we want to leave work with an evening ahead. "Radical availability" is a physical, mental, and emotional challenge. With time, however, I realized that even small steps toward a more inclusive and compassionate vision, toward accompaniment of any measure, can earn you membership in Paul's army.

Probably none of us can do as much as Paul Farmer has done to bend the arc of history toward justice. But as Paul reminds us throughout this volume, no matter what paths we tread, each of us can strive in some way, however small, to be an accompagnateur to those who have not been blessed by good health and good fortune. And in so doing, we are, one baby step at a time, helping to "repair the world." If my generation and the generations that follow take Paul's entreaty to heart, I have little doubt we can expand the promise of modernity—the chance at a life free from poverty and premature death and unnecessary suffering—and move the world toward equity, peace, and prosperity.

[12]Paul Farmer, Countering Failures of Imagination, Northwestern University Commencement Speech 2012.