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Keynote Address

The Ethics of Health Reform: Why We Should Care About Who is Missing Coverage

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NORMAN DANIELS*

I want to bring a somewhat different perspective to the discussion of recent U.S. health reform from the focus of this Symposium. My field is in justice and health policy. I’m not a lawyer, and I’m not going to try to pretend to be. And, although I chair an ethics concentration for the Health Policy Ph.D. at Harvard, my work in policy is not quantitative. Primarily, I want to discuss the ethics of health reform.

One of the foci of concern has to do with the number of people in the U.S. who are uninsured. I want to take up the question: "Why should we care about who is missing coverage?"—which was the focus of the Affordable Care Act. I want to emphasize that we are talking about roughly fifty-one million people who are uninsured,¹ and this is a number that has increased by fifty percent since the Clinton efforts at reform in the early 1990s.² This population of fifty-one million people is larger than the nation of South Korea, a middle income country that instituted universal coverage years ago.³ The second issue I want to discuss is the efficiency of the American system and the high cost of health care in the United States.⁴ I will address why we should think about efficiency as an ethical issue and not simply as an economic concern. Finally, even with our very significant spending on health care, we still cannot meet all of our nation’s health needs. This is a general problem across the world. Every country struggles with how best to utilize resources that are insufficient to cover all of its health care needs.

Before I discuss issues particular to the United States and how the

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¹ Mary B. Saltonstall Professor of Population Ethics and Professor of Ethics and Population Health, Harvard School of Public Health.
reform might address them in some cases, I want to talk about what justice requires in the provision of health and health care in society. I first ask a general question: What do we owe each other? I then divide this general question into three sub-questions. I also want to speak about the implications for health protection of the answers that I give to the three sub-questions. Finally, I will briefly touch upon ethical issues in health reform.

The first sub-question, to the general question about what we owe each other as a matter of justice, is why is health of special moral importance? What actually drew me into the area of health (from a more general orientation on justice) was the idea that all developed countries in the world had robust forms of universal coverage, despite the fact that there were many kinds of other inequalities that those countries celebrated and did not oppose. Why distribute health care equitably when other goods are so differently distributed? This is how I thought about the question originally.

The second question, then, is why are health inequalities unjust? The third question is how can we meet health needs fairly when we cannot meet them all? I originally thought that these two questions were answered by my answer to the first question; however, one of the things that I have learned over the last couple of decades was the naiveté of that viewpoint; that is, we actually need more independent answers to these questions. These questions arise independently, or in addition to, the issue about universal coverage. Every society, whether it has universal health care or not, has a problem of using its resources to meet health needs, and even countries with universal coverage have significant health inequalities. We need to know when those inequalities are unjust. Furthermore, justice requires us to allocate the resources fairly among people even if we are not meeting other requirements of justice, such as the provision of universal coverage.

Now, I said that there are three questions, instead of one. In a book I wrote about twenty years ago, I thought I had answered the first question in a way that had also answered the other two questions.\textsuperscript{5} My answer to the first question is that health is morally important because of its impact on the opportunities we can have in life. And then I thought, perhaps in the grips of a false myth about health care and its social importance, that if the main determinant of health in a population is health care, broadly understood to include traditional public health measures, then unequal access to health care, including unequal provision of those public health measures to parts of the population, would be the main way in which we get inequality.

\textsuperscript{5} Norman Daniels, Just Health Care 56–58 (1985).
But I now think, following some of the social epidemiology literature, that there are actually many sources of inequality in health in a society—the distribution of many determinants of health that affect the health of the population. And if that is true, then inequalities in health are not only about injustice in the distribution of health care. That may be one reason, but there are other reasons as well.

The answer to the third question I also thought followed answers to the first two. I thought that if health was important, especially because of its impact on opportunity, then we could decide which health needs were most important simply by their relative impact on opportunities. But, it turns out that the story is much more complicated and reasonable people will disagree about how to distribute the goods that meet the health needs of society. So I began to think that we needed a different kind of answer from the one I had given.

My basic—and unrevised—idea is based on the simple intuition that if we take a notion like normal functioning in society, then disease and disability, or pathology more generally, can be thought of as departures from normal functioning. If we understand that departures from normal functioning can lead to more deficits in things that we can do or be, then what we have done is create an account of the range of opportunities that we lose as a result of disease and ill-health. So, if you think society has some social obligation to protect opportunity and its distribution, then you have a framework for thinking about justice and health care, or health more generally.

I borrow my justification for why we might think that we have an obligation to protect opportunity from more general theories of justice. For example, in the early 1970s John Rawls published what has probably emerged as the most important piece of literature in legal and political philosophy in the twentieth century, a book called *A Theory of Justice*.6 Very modest—a theory of justice.

It is a contractarian view that says that we need to decide what a fair choice situation is from which we can select fair terms of cooperation from society. Rawls made a simplifying assumption: namely that everyone who participated in this choice situation was fully functional over a normal life span.7 In effect, nobody gets sick; nobody dies early. This simplification was pounced upon by a number of people, including two Nobel economists, Amartya Sen and, earlier, Kenneth Arrow.8

Arrow asked: What kind of a theory is this? It does not even tell us

7 *Id.* at 14.
who is worse off, a rich but sick person or a poor but healthy one. Truly, if welfare is to count, we can look at how well off the individuals are and answer that question. But Rawls simplified his theory so he was not talking about health. Of course, it is not that he never wanted to talk about it. Rather, he put that off as a second stage or extension of the theory.

In his theory, Rawls wanted to say that we measure inequalities between people by how well off they are by reference to an index of “primary social goods”—all-purpose means that include income, wealth, opportunities, liberties, and rights. He then decided that in the choice situation he was describing, which was hypothetical and involved what became known as the “veil of ignorance,” deliberators would choose two fundamental principles of justice: first, to distribute basic liberties equally to all people; and second, to arrange social and economic inequalities to everyone’s advantage while at the same time keeping positions of responsibility and authority accessible to all. The second principle has two clauses. The first says that we should require jobs and offices be open to everyone (this is the equality of opportunity clause), and the second that we should compress inequalities in a significant way, allowing only inequalities that make the worst off as well off as possible.

This general theory of justice did not talk about health, but I have tried to extend it by broadening the notion of opportunity in such a way that we can capture the concerns we have about people’s motivation to protect health. And Rawls bought into this. Nevertheless, one of his critics, Amartya Sen, tried to suggest that this account did not quite capture what we ought to be concerned about when we are concerned about equality. I think it does, and Professor Sen and I have had a lot of discussion over

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9 Arrow, supra note 8, at 251–52.
10 RAWLS, supra note 6, at 92.
11 See id. at 136–37 (explaining the basic assumption of his theory, namely that “parties are situated behind a veil of ignorance” such that “[t]hey do not know how the various alternatives will affect their own particular case and they are obligated to evaluate principles solely on the basis of general considerations”).
12 Id. at 60–61.
13 See id. at 83 (describing the two clauses of the “difference principle,” which provides that “[s]ocial and economic inequalities are to be arranged so that they are both (a) to the greatest benefit of the least advantaged and (b) attached to offices and positions open to all under conditions of fair equality of opportunity”).
14 See id. at 83–84 (commenting on the “principle of fair equality of opportunity” and describing the rationale of maintaining open positions as “express[ing] the conviction that if some places were not open on a basis fair to all, those kept out would be right in feeling unjustly treated even though they benefited from the greater efforts of those who were allowed to hold them”).
15 See AMARTYA SEN, INEQUALITY REEXAMINED 77 (1992) (“The definitional exclusion contained in Rawls’s ‘political conception’ limits the scope of the concept of justice drastically and abruptly, and it would often make it hard to identify political rights and wrongs that a theory of justice should address.”).
This brings us to the second question of justice: When is a health inequality between socioeconomic or other demographic groups unjust? A thesis I will mention briefly is that the principles of justice, as described above, capture the key social determinants of health that we know about from the social epidemiological literature. More equitable distribution of income and fair participation in the political process can reduce the inequalities in health status across the population.\(^\text{17}\)

An interesting figure identifies one line of argument about wealth and health.\(^\text{18}\) The dots represent countries, the horizontal axis indicates the per capita gross domestic product, and the vertical axis shows the life expectancy at birth. What you see is a rapidly rising curve, which is generally interpreted to mean that the gross domestic product per capita, a crude measure of average income, has some effect on the health of the population, but only up to a certain modest level—approximately six to eight thousand dollars per capita—which is representative of the lower end of middle income countries. Beyond that income range, the curve tends to level.

But there is another feature of the graph that deserves attention: the variation among equally poor countries on the left side of the graph. The implication is that equally poor countries might have different policies about how they pursue the distribution and use of their resources, and that this may have a different effect on health.

Cuba, for example, has a life expectancy roughly equal to the United States, despite being much, much poorer than the United States, to say nothing of being the focus of economic attacks by the United States for decades. The state of Kerala, in India, is much poorer even than Cuba, but its health measures are the best of any state in India, and rival those of richer developed countries. How is that possible? What this says to me is that policy differences across countries matter a lot. What you see in the graph are countries with a lot of variation in health outcomes, even among wealthy countries. It is a well-known fact that the United States ranks only about fiftieth in life expectancy in the world.\(^\text{19}\) Even among other industrial countries the United States does not compare well. This can be attributed to several factors. In particular, significant economic inequality in the United States produces health inequalities, and that means that

\(^{17}\) Norman Daniels et al., Why Justice is Good for Our Health: The Social Determinants of Health Inequalities, DAEDALUS, Fall 1999, at 215, 241–42.

\(^{18}\) See Norman Daniels et al., Health and Inequality, or, Why Justice is Good for Our Health, in PUBLIC HEALTH, ETHICS, AND EQUITY 63, 66 fig.4.1 (Sudhir Anand et al., eds. 2004) (illustrating the relationship between country wealth and life-expectancy).

economically disadvantaged people in the United States have a lower health status and that equals out to a lower life expectancy.

Nonetheless, life expectancy is really somewhat independent of universal coverage as an issue. The Whitehall Studies in the United Kingdom are illustrative. Whitehall is the headquarters for the British Civil Service. Starting about twenty years after the introduction of universal coverage in Britain, people began to ask the questions: What difference does universal coverage make? Is it reducing health inequalities in society? Whitehall then began large studies of typical parts of the population, including all the workers in the British Civil Service.\(^{20}\)

What is striking about these data is that these are all individuals with universal coverage in the British health care system. They are all people who are not so poor that they are deprived, regardless of their occupations. They are people with basic levels of education, and yet, researchers found what is called a socioeconomic gradient of health. People with almost twice the relative mortality rate, but who are in the blue-collar group fared much worse in longevity and health status than people who are in the best-off groups—administrative occupations consisting of professionals, executives, and clerical workers. This forms a socioeconomic gradient of health.

Put into words, that gradient says something like, “the richer you are, or the higher your occupational status, the longer and healthier your life.” That kind of gradient is present in every age group in the study in the United Kingdom.\(^{21}\) It is also found in every country in the world where it has been measured. This is a very robust finding, and one that no one challenges, so then the questions become: What is causing it? Why are we getting this result? This socioeconomic gradient of health is, after all, just a correlation; it doesn’t show causation. Some part of the gradient may be explained by sicker people being selected for lower status and worse paying jobs, but that is not the majority of the story, especially if the gradient includes education and occupational status rather than just income.

If we go back to my earlier thesis and look at those three principles of justice that Rawls said came out of his theory,\(^{22}\) we actually get a model for what health would look like for one part of the world, given the distribution of some of the social determinants. But what I did not mention was some of the data about what those determinants are. They include things like income and wealth inequality in society, educational inequality,

\(^{20}\) M. G. Marmot et al., Employment Grade and Coronary Heart Disease in British Civil Servants, 32 J. EPIDEMIOLOGY & COMMUNITY HEALTH 244 (1978).

\(^{21}\) Id. at 245 fig.1.

\(^{22}\) See RAWLS, supra note 6, at 266 (enumerating his three principles of justice as: (1) equal basic liberties; (2) constraints on inequalities; and (3) equal opportunities).
inequality in participation in political activities, lack of access to health or health care, and inequalities in that access depending on wealth. What one finds in every country are variations in the distribution of these kinds of goods, and they produce health inequalities in those societies.

What I am suggesting is that if you had a just social arrangement, it would shrink the inequalities, flatten the socioeconomic gradient, and it might in fact help improve the overall health level of the population by improving the bottom line. That would be a very good outcome if it were true. The way I think of this is through the slogan "social justice is good for our health."

Another issue concerns meeting health needs fairly when we cannot meet them all. We have an enormous ethical controversy about how to distribute health care resources. It is illustrated, for example, in the strong public reaction that sometimes is triggered when countries will fairly and firmly try to adhere to a rationing principle, such as the claim that we should only include services that are effective (and safe) in our benefit packages. All countries have this issue, which is basically a distinction between proven and unproven treatments.\(^{23}\)

The basic idea is that we should only distribute things that we know work. That is, we should not be engaged in distributing things that might not work at all, or might harm people. That principle has a lot of plausibility, but when it comes down to excluding, for example, a child dying of cancer from an experimental therapy that is not entirely proven, some people will say "let's try it." That already pits values against each other: conserving resources in order to be used in a broader way by the population and to help as many people as possible, versus the compassionate use of scarce resources to try a last-chance therapy for an individual.

People will trade these values in different ways, depending on who they are, and that is what I mean by reasonable disagreement. We do not have a clear agreement on how to allocate resources for proven and unproven treatments. What I am suggesting is that we need a fair process, and a lot of my colleagues dislike this part of my proposal, because it says that professors sitting in armchairs cannot answer all the questions, at least not in a reasonable time. The basic idea is that we need a form of procedural justice to address the reasonable disagreements people have about how to allocate resources. My answer to this question—how can we meet health care needs fairly when we cannot meet them all?—is to create a fair process to adjudicate disputes. That is my version of what Sarah

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\(^{23}\) For discussion on this issue in the United States, see Norman Daniels & James Sabin, Setting Limits Fairly: Can We Learn to Share Medical Resources 67–84 (2002).
Palin calls the "death panels." I think we should instead call them the "access to life panels."

The general implication of this account is that access to life panels serve to protect opportunity by promoting and protecting population health, and that this is a social obligation that we have. So I want to borrow the obligation to protect opportunity from more general accounts of justice. The social obligation implies adequate protections against risk, and I think it implies universal coverage, that is equitably financed. This obligation to protect opportunity is what underlies the special moral importance of health and health care.

Turning to my second question about justice and health, I think justice also requires the elimination of unjust health inequalities. I do not think the current reform proposal addresses this issue in a significant way. It turns out that access to health care, while of some importance in distributing health, is dwarfed in its importance by other social determinants of health. Unless one was dealing with a comprehensive reform that made other things more equal in the United States—the distribution of education, the distribution of income and wealth, and so on—only then would worse off groups have more access to health. This is not to say universal coverage is not an important goal—the first point says it is, just that it is not a singular solution.

The last question I raised about justice and health is: What does it mean to say that we might have a right to health or health care? I think it means that health, or health care, is a special case of a right to equality of opportunity in society. Protecting health is one way to assure that people have a fair distribution of opportunities. Obviously it is not the only one—income, wealth, and other things affect the opportunity gradient—but health does too. If one asks: What should your entitlements be? with regard to health or health care, my suggestion is that we should use a deliberative democratic process to arrive at what those entitlements consist of, especially given the resources and technological capabilities that we have and the distribution of competing needs in a particular society. That is a fairly abstract answer, though.

Let me return, by way of conclusion, to some of the issues with which we started. In the United States, there are around fifty-one million people lacking health insurance. The number was forty-six million before the recession, and roughly fifty-one million now. If we look at the outcome of the Affordable Care Act, it turns out that it covers between roughly thirty-two and thirty-four million people, at our best estimates, and leaves

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25 Mullaney, supra note 1.
out many immigrants and undocumented individuals. Is this fair? Should we close this gap permanently, in order to get this universal coverage? If we ask the legal question about the Affordable Care Act and its individual mandate, then we are talking about the specific context of the Affordable Care Act. A more basic issue is whether we should ethically adopt a reform that guarantees universal coverage, and that is what most of my argument has addressed. I am not a lawyer, though I have my opinion about the constitutionality of the Affordable Care Act. I hope the Act is constitutional because it is now the only politically available way to provide access to coverage in this, the largest privately-based insurance country. If you had publicly funded insurance, using social security as a model, the whole issue of an individual mandate goes away, because everybody already has coverage, and because there is a mandate to pay taxes. That is, the worries about why you need an individual mandate in a private system go away because in a private system you are worried about adverse selection, where individuals, who for some reason do not want to get insured or they think they are going to pay too much for insurance given their possible health needs, might not want to participate. They might be free riders and they might expect that when they do need health care, the public will step up to the plate and cover them.

So in a private system, the fear of insurers is this concern about adverse selection. How do you guard against it? Well one way is through an individual mandate. Let me remind you there was a spirited debate about whether there ought to be a publicly funded provision in this health reform—although there never was a serious single payer proposal on the agenda for public debate during the reform effort. Even the much weaker public component of a reform was rejected in the political process, and so we were pushed to a private system in which an individual mandate is necessary. If you asked the American public, do they want a system in which nobody is excluded because of prior conditions, they all would almost overwhelmingly say yes. But you cannot have that in a private insurance scheme unless you have an individual mandate. For example, Germany has a mixed public and private system and everybody is required to have some kind of coverage or other. That kind of coverage is a mandate, in effect.

The ethical issue here stems from the fact that we do need an individual mandate in order to avoid free riders and adverse selection (health people do not get insurance but others cover their needs when they

26 CBO's Analysis of the Major Health Care Legislation Enacted in March 2010 Before the Subcomm. on Health of the H. Committee on Energy and Commerce, 112th Cong. 1 (2011) (statement of Douglas W. Elmendorf, Director) (estimating increased number of Americans to be insured by 2021 and stating one-third of the remaining uninsured will be unauthorized immigrants).

are urgently ill). Moreover, the dependence in the Affordable Care Act on an employer-based system is going to have significant cost implications. If you are going to have a system that requires individual coverage, then it must be affordable. You cannot make people do something that they cannot do. That requires subsidence and some account of affordability. And one needs that to be fleshed out.\textsuperscript{28}

Another issue that I wanted to pick up is the question: Why is efficiency and cost an ethical issue, and not simply an economic one? My answer to that is that if you want to meet everybody's needs in a fair way, you are going to want a system that meets, per dollar spent, as many needs as possible. It has to be efficient. If you do less than that, then it is less fair than a system that meets more needs. Efficiency is then an ethical concern, not simply an economic concern. Currently, the U.S. system has bizarre incentives that create the highest unit prices in the world for health care.\textsuperscript{29} This is a real issue. The theory is that, if there is a highly competitive economic system, then there should be lower prices. Although the United States appears to be a competitive system, we have higher prices. To determine why this is so, one must look at the incentive schemes. While there have been some efforts made to address the issues of cost, they are largely pilot programs and experiments.\textsuperscript{30} Thus, at this point, it is unclear what their total impact will be.

This model closely resembles what was done in Massachusetts to secure nearly universal coverage; it is the very same model on which the Obama plan is shaped. In the Massachusetts model the cost issues were not initially addressed, which produced significant strain in the system.\textsuperscript{31} The model, however, did manage to produce approximately ninety-seven

\textsuperscript{28}See, e.g., Brendan Saloner & Norman Daniels, The Ethics of the Affordability of Health Insurance, 36 J. HEALTH POL. POL'y & L. 815 (2011).


\textsuperscript{30}Peter R. Orszag & Ezekiel J. Emanuel, Health Care Reform and Cost Control, 7 NEW ENGL. J. MED. 601, 602–03 (2010) (discussing the pilot programs and proposals to address the cost issues of the Affordable Care Act).

\textsuperscript{31}See Kevin Sack, In Massachusetts, Universal Coverage Strains Care, N.Y. TIMES, Apr. 5, 2008, at A1 (explaining that the increase in insurance coverage in Massachusetts consequently increased the number of patients able to see doctors without actually increasing the number of doctors in the Commonwealth); see also Peter Suderman, Massachusetts Health Program, Model for Obama's Reform, Strains State Budget, DAILY CALLER (Jan. 10, 2010, 8:00 PM), http://dailycaller.com/2010/01/10/massachusetts-health-program-a-model-for-obamas-national-reform-strains-state-budget/ (explaining how the state mandated increase in insurance coverage means health care spending will increase faster than the state's GDP).
percent coverage, a very respectable number.\textsuperscript{32}

On the other hand, there are real cost issues, which must now be addressed. The current worry in the U.S. system is that the cost issues will be much greater than those seen in Massachusetts, in part because, at the time, Massachusetts had a higher level of insurance coverage than most of the United States when its model was put in place.\textsuperscript{33} So if you go to places like Texas, Alabama, and Mississippi, they have much higher levels of uninsured,\textsuperscript{34} and the impact on the budgets of Medicaid expansion is going to be huge. There are many complaints about the costs in the short run if you do not address the overall costs. One of the devices for addressing costs in the Affordable Care Act is the introduction of significant funding for comparative effectiveness research.\textsuperscript{35} But—this goes to the third issue, the issue about death panels—built into the law were restrictions on using the information that comes out of this research for coverage decisions.\textsuperscript{36}

We are investing in, and producing, a lot of information about the comparative effectiveness of different technologies, but we cannot use that information to make plausible coverage decisions in the system. This is a little crazy in my opinion—why invest in information if you are not going to use it?

Another puzzling issue about the Affordable Care Act is that it does not address some of the problems about fairness in financing in a serious way. I will not say much about this, but one has a fairer financing arrangement when people who can afford to pay more, do pay more—not just in absolute numbers, but perhaps even at higher rates. But even more progressive financing was not something likely to happen given the enormous pressures in our system to reduce tax rates for the wealthy and to make the system more regressive in its overall financing. The impact of cost reduction measures of the Affordable Care Act is minimal; it is not going to change much regarding the way things are done in the system. That is a battle for down the road if the Affordable Care Act survives court challenges. As far as whether people will have more equitable benefits,

\textsuperscript{32} COMMONWEALTH HEALTH INS. CONNECTOR AUTH. & EXEC. OFFICE OF HEALTH & HUMAN SERVS., THE TOP TEN FACTS ABOUT MASSACHUSETTS HEALTH CARE REFORM (2011) (noting that with ninety-seven percent coverage, Massachusetts' coverage was by far the best in the nation).

\textsuperscript{33} Id. ("Massachusetts now has a 98% coverage rate, the best in the nation, by far. . . . Access to care is far better in Massachusetts than nationally. For instance, in 2007, about 20% of the U.S. population reported not getting or delaying needed medical care at some point in the previous 12 months.").


\textsuperscript{36} Id. § 1320e-1.
there is a commission trying to figure out what would be the essential benefits of the exchange-based plans. Whether it meets my concerns about what a fair process would look like remains to be seen, we simply do not have much access to that information yet.

Finally, let me just say that the Affordable Care Act itself does not explicitly address the inequalities in health status, except by pretending that providing universal coverage will in fact flatten the gradient of health in a society. But that pretense helps blind us to other factors affecting the distribution of health in our population that are not addressed by the reform at all.

In summary, I think we have improved coverage, but it is not universal; immigration, for example, is one of the big holes. The cost reduction involved in the process is modest, and I think inadequate. Eventually, much stronger measures will have to be taken. I emphasize that because the system is largely private we avoid what most European systems would use as the main way of controlling costs, which is a better balancing of monopoly and monopsony powers in a society. In the United States, the pretense is that if we have a lot of separate insurance companies competing with each other then we will be more competitive, but the fundamental way in which most European countries have kept their costs roughly fifty percent lower than U.S. costs is through this balancing of monopoly and monopsony powers. We just do not do that. Indeed, in the original Medicare Part D, the drug benefit that was passed under Bush, this was prohibited. So, we explicitly say that you cannot do what all countries do to keep their costs manageable.

There are some loose ends in the reform, like what to do about abortion and birth control coverage, and these are going to be ongoing issues given the political controversies in this country. But on the whole, I do not think that there will be big battles about the benefits package that is modeled, for the most part, on employer-based schemes that we already have.

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