

Re-Designing the US Health Care System: Think Universally, Design Locally

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This paper picks up the dialogue started by Paul Starr with The Social Transformation of American Medicine, in which he noted “The dream of reason did not take power into account.”

With gratitude to Patch Adams MD, Gesundheit Institute, for conversations on health care system design and political activism.

We see two positions that already exist in the dialogue around the crisis in the US health care delivery system.

The first position is the status quo: the health care system as developed by entrenched health system industries (hospital, insurance, pharmaceutical, information technologies—with government primarily acting as their watchdog). The medical profession of doctor—its history of professional sovereignty—now no longer provides the bottom line in health care. The bottom line belongs to a different bottom: Big Business.

The second position is single-payer/universal coverage, functioning as a challenge (perturbation) to Big Business-dominated health care. Single-payer’s premise fundamentally differs from corporate-controlled health care: access to health care is a right for all people (a premise we whole-heartedly share). It proposes a system of health care financing/delivery that alters the financial incentives alive in American health care and provides access for all: one payer, single tier, universal access.

If enacted in legislation, single payer/universal coverage would be a crucial macro-level policy change in the US. While single-payer is a much needed mechanism that would enable all people to have *access to* health care, it is not meant to serve as a *design* of the whole system, itself.

We add a third position—whole system design—our frontline, can-do position:
Do it local, do it now, do it small, link with all.

Whole system design considers the big question, “What is it we want in a health care delivery system?” and then applies can-do-ism to the next question, “What *can we do*, now?” These questions unearth possibilities for change in the whole that are often neglected by focus on the part (funding/access).

Meant to work side-by-side with single payer/universal coverage efforts, whole system design is a call to think universally, design locally: to design local contexts that *protect* the distinguishing core of the health care relation—that simple relation between doctor/nurse and patient, with some tools. We need to design so that the health care relation is *protected* by the health care system.

We want to wrest neglected aspects of health care delivery out of the control of market capital, into designs of pockets of care. These local pockets of variety would run parallel to mainstream market care and be loosely linked with one another to act as perturbations to the system.

This brief position paper, and its more fulsome 30-page background paper, describes this third position and the contexts of our thinking.

Statement of the problem: Fortune 500 Health Care and Its Frames

United States 2006: When the financing of health care upstages the delivery and culture of health care, we're in trouble. Big Business market behavior and its inherent opportunism has damaged the delivery of health care, has *co-opted* its culture, and—most ominously—has become THE frame.

What do we mean, 'frame'?

'Frame' is short for framework—frameworks are those contexts that enable us to make sense of something. Frames are carried in language. Linguistics professor George Lakoff, in his book *Don't Think of an Elephant*, writes:

Frames are mental structures that shape the way we see the world. As a result, they shape the goals we seek, the plans we make, the way we act . . . To change our frames is to change all of this. Reframing IS social change.

Let's look at the language around the crisis in the US health care system. This from Joe Paduda, a health policy analyst, spring 2006:

Major change in US health policy is imminent . . . The question has changed from "should we do something different about health care?" to "what should we do about health care?" Who should pay? What should we pay for? Does a single-payer system make sense, or should individuals buy their own health insurance? What role, if any, should employers play? How much can technology help? What should we be investing in?

The language of this writing looks sensible: aren't these, after all, the crucial questions? At second look, however, notice that almost every sentence focuses on the financing of health care: "who should pay?" "what should we pay for?" "what should we be investing in?"

This single-minded focus on financing to the neglect of other aspects of social design is a fingerprint of the frame of market capitalism.

What's the problem with market capital?

When we object to market capitalism and its frames dominating the US health care delivery system, we object to market capital's fundamental operating structure, that being to streamline health care to show profit, thus attracting/rewarding investment capital. In this context short-staffing of nurses (a recurrent problem in the present system) is not an accident but part of streamlining, the staffing figured in simply as a dollar amount. If short staffing causes problems in any other dimension besides profit, this is not registered as significant by market capital, as there is little quantification of other dimensions besides costs. Loss of quality of care?—not figured in; loss of continuity of care?—not figured in; burn out of staff?—not figured in.

For Big Business, “Who pays?” and “How much?” are the fundamental operating questions, and the frame.

That entrenched health system industries focus on the question “Who pays?” makes sense from their point of view: corporations are legally obligated to protect investors' interests.

But for those of us who oppose this? Does it make sense for us to use the terminology, reasoning, bottom lines, behaviors, decision-making, and ultimately the value system of the market—in short, the frame—when we oppose Wall Street's control over health care?

No.

Someone could ask at this point, does this mean you think that financing is *unimportant*? No, we don't think it's unimportant. But we—as well as single payer activists—*do* consider its importance to be part of the *problem*, and wish to change that positional value in the scheme of things.

While single payer's strategy is to take the question “Who pays?” and use it as leverage point to radically change the funding structure, our strategy is to be wary of the dominance of this frame, and to pursue other neglected questions of social design.

We say, while Wall Street/K Street dynasties as yet control the economics of health care, why would we let them also control the language and culture of health care delivery—to control the frame—especially when that frame is used in the discourse around fundamental change?

Why use their framing?

The Frame of Whole System Design

Our frame goes like this: Given that there's a call for fundamental change in the US health care system, we respond by saying---that means, design something that DOESN'T act like a corporation.

How do we play this out?

While global corporations focus on homogeneity of language and culture, on hierarchies, on profit, and on restricting participation, we focus on a call for variety and creativity—with an edge. We're asking people who care about care to design those many areas in health delivery systems that *are* open to change, *are* open to design.

Design is the connection between what I want and a resistance to settling for. It refuses the idea of it-can't-change. A person designs when she connects things in ways that haven't been connected before, according to her desires and intentions.

In asking people to design, we're attempting to seed a variety of local pockets and pockets of local variety in health care systems.

And the edge? We want these pockets of variety to run parallel to the current health care (disease management) systems, and to be loosely linked to one another so as to act as perturbations to the system.

Perturbations are ideas/actions that put the system on the spot with the aim of destabilizing it, of making it trip on itself. When thinking of perturbations, we aim at the system's moving itself in a new direction under its own weight and inertia, as it attempts to compensate for our putting it on the spot. This is different from reforming or improving a system, where we aim at ourselves moving the system.

Why perturbation rather than simple direct improvement and reform?

We turn to perturbation when we humbly admit that folks, we're in a David-and-Goliath position here as regards to change of health care system, in that:

1. the system we want to change is in the control of people/institutions who have power over us;
2. the system as is—unchanged—benefits them enormously;
3. these people/institutions have no intention of allowing change of that system, no matter how reasonable and ethical the arguments for change, no matter how compelling the evidence of human suffering and human waste, no matter how many compromises activists are willing to make towards these people/institutions.

Unlike our friends, the single payer activists, who work toward directly affecting outcomes, we humbly submit that given our understanding of systems change and of the dynamics of the US health care system in 2006, we can only hope to trip the system up. In short, to perturb it, to put it on the spot. In terms of perturbation, we do have a chance: the health care system in the US is so big, so complicated, so bureaucratic, with parts unable to connect to other parts, so insensitive to the mood of its environment, so unable to see its consequences—that falling by means of its own weight is a possibility.

How to bring that about?

Perturbation is the action of desperate and thoughtful people.

“Who will pay” is such a volatile question to Big Money corporations as it hits them in the pocket book which is about the only book they read, that we think the question better addressed if we sneak up on it from the back door than rather than coming in on it squarely from the front. “Sneaking up on something from the back door” is a folksy way of saying, perturbation.

The back door in this context means whole system design: inviting people who participate in health care on the day-to-day level (front lines) to design health care delivery systems.

Whole System Design, in Order to Perturb (can-do-ism at work)

Do we have a choice about anything in health care systems? Yes. Where we have a choice, there we can design.

Selected items from our checklist, open to choice:

1. **Hierarchy, rank abuse** Health care interactions inherit a culture of hierarchy, rank abuse, posing. This is something a group of people, in shaping their health care facility along the lines they want, can support, oppose, change, alter.

—this is something that can be designed

2. **Health of individual nested within a larger group** In our consumerist culture, health/sickness is identified as being an individual property—a person sees her health as her own individual state, she battles against her disease, alone. (This, in the face of many studies that show a person has better health outcomes if she feels her well-being integrated within that of a larger group.) A group of healers/designers can come up with a language—frames and metaphors—that oppose this isolationist consumerist tendency, and situate the health of the individual with the health of a group.

—this is something that can be designed

3. **Health of the staff as important as the health of the patient** In Patch Adams’ design of his hospital project, *Gesundheit*, he insists that the health of the staff needs to be just as much a priority as the health of the patient. Just as the patient needs to feel her well-being is nested within the well-being of a larger group, so does the staff.

—this is something that can be designed.

4. **Participating in health as a people’s popular movement** Commercial culture names a patient as consumer and a doctor/nurse as provider. Given this framing, health care interactions are experienced as a form of shopping, for both patients and healers. Beyond stopping at the counter to get a pill, patients in the United States do not participate in health, health care, or health care systems. Designers can oppose this state of affairs and make elements in their facility (by means of language, imagery, structure) that enable popular participation in all aspects/levels of health, health care, and health care system.

–this is something that can be designed

5. **Nesting** Currently health care has been nested in bureaucratic and financial institutions. This can be counter-acted: healing interactions need to be protected by nesting them in larger *beneficial* social groups.

–this is something that can be designed

6. **Solidarity** We need to rescue the concept/feeling/action of solidarity from North America's garbage heap. In the current culture, each person feels "you're on your own", "everyone for himself". Thus under-staffing of nurses is experienced as the nurses' problem, not the problem of the doctor, medical student, patient, family, technician. This reveals a lack of solidarity between people whose interests are fundamentally in common. How is it that some doctors have been wooed to invest in hospital corporations, to see themselves as part of the opportunistic entrepreneurism? This reveals that the lines of solidarity need to be refreshed and redrawn. There need to be discussions about whose interests are being represented. Does the design move in the direction toward creating constructs in which solidarity between the greatest number of different people/groups is supported?

–this is something that can be designed

7. **Decision-making** Who makes decisions? Is decision-making about health care system dilemmas communicated to/from the people? Does the health care system *listen*, in addition to *talk*?

–this is something that can be designed

8. **Communication** How is information communicated and disseminated? Where is it? –to be designed

9. **Motivation of actors** Who stands to benefit? In whose interests are decisions made? Are the motivations of the others clear to each? Differences of power?

–to be designed

10. **Seek out, comes to** Do people seek out health care, or does health care come to them? Is the health care system visible only when a sick person looks for it, or does a person have the sense she is nested in care?

–to be designed

11. **Cure or care?** In the health care facility, is there a behavior which values cure over a commitment to care?

–to be designed

12. **Spaces** Does the space (rooms, hallways, waiting rooms) support the values we want?

–to be designed

13. **Presentation of self in everyday life** The way healers, staff, and patients act in everyday life is a choice and can be a tremendously valuable input to desirable health care interactions. There is no neutral interaction.

–to be designed

No One Else Is Doing This!—Good, Let's Try It

Calls for change in the US health care system are, amongst other things, calls for creativity. We need a variety of new ideas, projects, designs, configurations, proposals—alternatives to look at and weigh.

There are some problems where the solutions *are not there yet*. Action to be taken: we have to make up solutions.

Why is there so little call for creativity and variety in relation to the US health care crisis? I consider it symptomatic of the stuckness of the situation and the identifying signature of those who consider themselves the players. Entrenched industry is not creative, nor is it looking for creativity. Rather, under the guidance of these players the discussion is pitched at the level of choosing between already available policy options within market capitalism.

The health care crisis is, amongst other things, a crisis of bankrupt ideas. People recognize that things need to change; they do not recognize that something has to be *made up*.

Under the control of the market, mesmerized, we obey a homogeneous culture of disease management, instead of creating and supporting a variety of cultures of health care and alternatives to market-driven care.

Political Strategizing in 2006: Entry-Points in Changing the Health Care System

Changing a system means deciding where to enter it—deciding which entry point, if changed, would have the most likelihood of radically transforming the whole system. Systems are circular; something which seems to be a cause turns out to be an effect of something else, and so on. Where to start?

We see that single payer/universal access offers one entry point in change of system, and we wish to offer an additional one.

Single-payers' entry point is the funding structure—to begin by changing that, so that profit is not the motor that drives the health care system, so that administrative costs are significantly reduced, so that all people will have universal access. If a system of one payer, single tier, universal access is created, then hopefully that will lead to a significant change in many other aspects of the culture of care in the system.

In contradistinction to this, we start with designing towards the culture of care—that's our entry point. We meet with health care providers to discuss here-and-now aspects of their health care delivery situation, working on bi-directional designing—designs where the health care relation *shapes* the system, and where the system *protects* the relation. If a group of health care providers at a clinic are involved in designing their practice, our hope is that a change in the culture of care will open the way to a change in the funding of it, or at least make people more susceptible to that change.

Local hosts universal: campaign universally, design locally. While many many people want a fundamental change in the US health care system, quite a few have lost confidence in large government programs taking over. Yes, universal coverage sounds

good—but, many say, run by the government? Aren't Democrats just as much in bed with Big Business as Republicans? Can we trust millionaire politicians to pay attention to us?

We say—local initiatives for the good of the public renew the sense of confidence in a group of people governing. Campaign universally, design locally.

Oppose/Expose the Undesirability of Market-Controlled Health Care

Single payer activists, our friends, are making coalitions with health system industries in order to enact health care reform legislation on the state level.

We admire our friends' integrity, we admire even more their tenacity, but we don't share this strategy. (However, every David supports the efforts of every other David in the fight against this Goliath! So—good luck, friends!)

Our strategy is this—rather than priding ourselves in working with organized business, we want to oppose and expose the undesirability of market-controlled health care and to popularize a hands-off-health care, corporations!! sentiment in Americans and in business-people themselves.

We take our cues from an historical analysis made by economist Robert Kuttner, re-introducing the term 'passive intervention'. Kuttner writes:

In 1965, armed with a rare working majority, the Democrats were able to enact both Medicare and Medicaid. . . Though the AMA was implacably opposed to the whole idea, Congress and the Johnson administration offered doctors a costly sweetener—and found sugar coating for the hospital, insurance, and drug industries as well: The government would do almost nothing to alter the existing structure of the private health care system. It would simply pay the cost of bringing new subscribers into it—creating new profit opportunities for these powerful industries. . . All this created a huge new market for the medical-industrial complex, and increased the inflationary bias.

My colleague Paul Starr terms this characteristically American approach to social reform 'passive intervention'. Organized business has immense political power in the United States. Occasionally, reformers muster enough countervailing power to extend social benefits to new groups of citizens—but not to challenge the structural power of dominant industries. This brand of reform, then, comes at a terrible price, since it reflects and inflates existing inefficiencies. In the 1960's, this failure to challenge entrenched provider groups and the structure of their system led the Johnson administration to enact a medical-insurance program with a profound inflationary bias. In the 1990s, the same failure to confront entrenched industry structures led the weaker Clinton administration to a spectacular political failure. *Everything for Sale—The Virtues and Limits of Markets*

An Error?

We see that certain outcomes and patterns are conserved in the medical system—whether they are unethical or not—because they benefit a small group of people who hold power in that system.

The lack of medical care for all people is not an error in the system, something that

had been overlooked and now needs to be fixed. The lack of medical care for all people is an *intended consequence* of the current system. The abundance of bureaucracy in the medical system—the paperwork, the overseeing of diagnostic decisions by insurance companies, etc.—is not an error in the system. It is the *intended consequence* of the current system. If the system is so constructed that 15 cents out of every dollar spent on health care goes to administration, then this plays itself out in our everyday experience. The system is being maintained at the expense of the well-being of its members.

When we Americans say we want fundamental change of the US health care system, this means we want a change of fundamentals: we no longer allow market forces to control health care. Hey, Big Business—Hands off health care! It's not good business to make health care a business!

Talking Points

1. We question at every opportunity the appropriateness of market capitalism to control (nest) the delivery of health care. We discuss the limits of free markets and the need for non-market regulation of experiential goods (a term in economics for services whose outcome is uncertain). We point out that in the case of a relationship-dominated good such as health care, cutting costs in overhead results in cutting care itself.

2. We debate the assumption that health care is (needs must be) expensive. The expense of health care is not a property of health care in itself; the expense is an engineered condition, a consequence of the present design. We debunk the framing that health care will always be costly by making reference to counter-examples.

We invite media and wireless activists to demonstrate how the use of technology in health care can be free.

Every time the question, “Who will pay for this expensive system” is asked, we balance this with our question, “Who has been profiting such that this system is expensive?”

Health care, by its nature, is inexpensive—it's primarily a relationship along with some tools. We keep that image in mind so that we avoid playing into the assumptions of the market. The “high cost of care”, the “complexity of the system” are frames that fuel the symbolic capital of the current system.

3. We caution that when big business says “we're committed to cutting costs in health care” this DOES NOT mean “we're committed to making health care inexpensive”. It doesn't mean that. Within market capitalism cutting costs means lowering overhead (workers' wages, resources) to keep profit at margins attractive to investment capital. It *does not* refer to lowering the cost of health care so that it's easily available to us who need it. Market forces always say they want to cut costs; the question of reducing their profit margins is never brought up.

4. We rename the health care system the ‘disease management system’. When a

person gets into the medical system, that person is getting disease management not health care. Disease management is a far smaller domain than the domain of health care. Health care is a huge domain of interactions, happening primarily outside the medical system, available to all, only not organized. John Glick, MD says, “Every moment is a health care moment”. When does health care “start”—when you decide to take a walk early in the morning? When you feel like you’re getting a cold and a friend gives you echinacea drops in a cup of tea?

What is health care at its indispensable minimum? Against the noise tunnel of the expensive and complicated disease management system we need to keep in mind the simplicity of a desirable health care relation: it’s a bi-directional relation of care, always available, always findable—as a matter of fact you don’t have to look for it, it looks for you. One has a sense of being inside caring, of being nested in care—there’s someone to turn to, to talk to, they suggest a few things to do, you do them, you turn to them again.

The protection of this simple relation, of its friendly permeating steadfast thoughtful presence, is the primary function of any system/culture built around it. Thus the system/culture would be so designed that this relation is either freely offered or offered at a low cost (supported by communal and social structures in a variety of ways); that the formation of any bureaucracy around it would be a sign of malfunctioning or predators, and steps would be taken to eliminate that; that creativity and variety would go into the design of the supporting nest into which the relation is put, and into the relation itself. So einfach.

5. Do we attempt to work with market institutions to change health care? Organized business is interested in discussing financing and administration, not health or health care. Thus, to sit down at the table with these major players in health care industries means to sit down with people who frame every discussion of health/health care as a discussion of money and administration. If any other consideration is brought up, they will look at you with a patronizing eye—after all, they know their business—and turn it back into a discussion of financing.

So we *can* sit down with them at the table, but we have to realize we’re sitting down with opponents to any direction of creating a desirable health care system available to all.

6. We need to garner support from business people, on a person-by-person basis, for hands-off-health-care initiatives. To appeal to faith communities whose morals lead them to ethical political positions. Every businessman has his fatherhood looking over his shoulder; has his son-hood, brother-hood. Every businesswoman is also a mother, daughter, sister, friend. Do they want to overhear, in the waiting room, that cutting costs was a factor in why their grandchild died on the operating table? At some point in their lives, someone they care about will be in the system too. Their own pricey insurance policies cannot be transferred to everyone they care about.

7. We consider what is happening to health care in the US a local version of the same market theories that initiated Structural Adjustment Programs across the globe by WTO and World Bank. (Structural adjustments’ primary focus is to shape

institutions/countries so that they're attractive to long distance investment capital.)

Structural adjustment policies have been tried in South America, and met, in an increasing number of cases, with resistance. Let's link our resistance to structural adjustment policies at home to the resistance made by allies across the globe who are also fighting these policies.

Final Remarks

The components of what we're calling 'Whole System Design' are two calls: one is a call for a variety of designs of those elements that will become the culture of health care; and the second is a call for the sentiment: "hands off health care, big business" to become infectious in the Americas. Both these calls are efforts to perturb the current system.

In 2006, people in the United States have a diagnosis of the problem of our health care system that is clear and intelligent. If you read blogs/letters/emails from the common person they articulate their discontent with the health care system in a sophisticated way. (See membership polls conducted in spring, 2006, by MoveOn.Org).

People want a fundamental change in the health care system. This means, we want a change in the fundamentals.

We need to be prepared for the language/framing in response to this desire for change. When Medicare Plan D came out in May 2006, it was a 122-page document with lots of complicated sections, written for older Americans, telling them how to get pharmaceutical drugs. 122 pages? Huh? How was this allowed? Did the writers lack schooling, lack funding, lack time to do a better job? We don't think so. Plan D was a linguistic display of 'passive intervention'.

We need to watch out. The existing players (entrenched industries, along with their current protectorate: the government) will respond to our clear desire for fundamental change with an engineered Tower of Babel. The column of language is coming at us now: fundamental change in the health care system is re-framed as the question "who will pay for this expensive system?", as a debate between various complicated payment schemes, as a mandate for consumer choice. 'Universal insurance' will be used, to confuse us into thinking this means 'single payer'.

The language will befuddle us, discourage us.

The temptation will be to leave the discourse around health care to the experts. They seem to know what they're talking about, right? None of these experts will challenge the structural power of the entrenched industries, the huge salaries of the health care corporations CEO's, the fact that pharmaceutical corporations top the chart for profit returns, etc.

Will we permit 'passive intervention', again?

The statistic is cited, over and over again, that in the richest country in the world, nearly 48 million Americans do not get health care.

We say that in the richest country in the world, 300 million Americans do not get health care. Yes, of these 300 million, many people do get into the disease management bureaucracy, as they have insurance. But what is happening inside the medical system is no longer care; the 567,000 licensed doctors are not permitted to doctor; the 2.4 million nurses are being thwarted at nursing. The culture of health care in America is being morphed into something else.

When hospitals and clinics are businesses, and doctors/nurses become business people, who will we then turn to for health care?

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