

## **Planting the Seeds of Tomorrow**

### **The Case for Demanding Value in the Health Care Debate**

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When I was an intern, I watched a baby die. His name was Sam—or at least that is what we called him—and he didn't have much of a chance from the start. He was delivered in the emergency room to a young woman who showed up late at night in labor. She was both malnourished and anemic. Baby Sam weighed less than three pounds and wasn't breathing when he emerged into this world and had to be resuscitated before he was transferred to my service in the neonatal intensive care unit. I was part of his short life from the time he was born until the moment of his death two days later. I remember standing beside him during the final hour, knowing what was going to happen and feeling depressed and helpless.

He was so small with pale pink skin. His nose and mouth were covered with a clear plastic mask which carried oxygen and warm mist through a green plastic tube. His little stomach was hugely distended and when he tried to inhale the skin between his ribs was sucked in with the effort. His tiny fist gripped the green tube, which carried the oxygen as if he wanted something stable to hold on to. And his bright black eyes stared out at me as if from a great distance and seemed to concentrate the desperation of his struggle and reflect it out into the room.

I knew he was going to die; his chest was becoming exhausted and couldn't move air through his lungs for much longer. He still watched me as his chest heaved up and down— but gradually the rise and fall slowed and became almost imperceptible. Then his eyes flashed bright as if calling to me, asking me to join him, giving me one last chance to come with him beyond the struggle . . . and then he was gone. There was only the soft hiss of the oxygen and the mist drifting up around the mask.

Sam died in the ICU of a modern hospital. He didn't die from lack of access to the U.S. medical system. His mother was on Medicaid, so he didn't die from a lack of coverage either. He died because he lacked access to the most basic social investments necessary for healthy pregnancies, stable families and safe communities—the basic social investments that could have given him an equal opportunity to succeed; indeed, an equal opportunity to live.

I remember how quiet his death was. There was no one there but his mother, a nurse, and myself. Nobody else knew about Sam and his two-day struggle to live. It never made the papers or the evening news. It was an anonymous tragedy that touched the lives of no one but those in the room. And yet now, over 45 years later, the same anonymous tragedy is played out over and over in our wealthy nation ... and every time we are all diminished and we lose a little more of the soul of America.

Those of you gathered here are the most powerful voices in our nation for consumers, for children and families for equity and opportunity; and for social justice. I am honored to be with you to share a few of my thoughts. I thank you for your passion, your persistence, and for your steadfast commitment to a more just and equitable society. And I applaud your fierce advocacy for universal coverage.

At the same time, I want to ask if your advocacy may be incomplete—to ask if a moral and fiscal imperative to improve value may be just as compelling and as urgent as the imperative for universal coverage. We all understand “coverage”—it means having the ability to pay for the cost of the health care you need—without suffering economic hardship, without crippling copayments and deductibles, without having to choose between paying for prescriptions and paying for rent, without fear of surprise billings.

“Value” is something else entirely. Value is the recognition that the purpose of our health care system is not just to finance and deliver medical care; it is to keep people healthy. Value is the recognition that not only must all Americans have coverage—the ability to pay for their medical care—but that the care they receive and the system through which they receive it must add value; that is, it must produce positive health outcomes and that we should not be spending our public resources on overtreatment, unnecessary care, inflated prices or care that is inefficient, uncoordinated or ineffective. Most of all, value is the recognition that the things that have by far the greatest impact on the health of our people, have little to do with our health care system and everything to do with the conditions of injustice which underlie disease—poverty, hunger, unemployment, the erosion of community, the lack of hope.

My message to you is that universal coverage, by itself, will not achieve the level of social justice, or the degree of equity and opportunity, which should be the birthright of every person in this country. To truly lift up those for whom we advocate, expanding access must go hand in hand with improving value.

Let me elaborate with an example that touched me deeply. I have only changed the names to protect their privacy.

This is the story of Susan and her daughter Patty. Susan was born into an abusive family. She was sexually and physically abused by her alcoholic father and fled from her home to the streets of Portland. Alone, homeless, looking for love and somewhere to belong, she continued to be victimized, abusing alcohol herself and becoming pregnant at 17. Without any prenatal care or emotional support, she continued to use alcohol and drugs during her pregnancy. Giving birth to a child – surely one of life’s greatest joys and greatest gifts – was, for Susan, a nightmare.

When her daughter Patty was born, she was both premature and suffering from fetal alcohol syndrome. Susan returned to the streets and today remains homeless, transient and addicted. At the young age of 19, any hope she might ever have had for a healthy nurturing life – a life of contribution, accomplishment and satisfaction – has all but evaporated.

Her daughter Patty is today a ward of the state. She has been diagnosed with depression and multiple mental disorders including Attention Deficit Disorder. Her original adoptive parents gave her up because of her severe mental disorders. She had 26 different foster placements—twenty-six—before being admitted to a residential mental health facility where she now lives.

All of this happened before her tenth birthday.

I know of no yardstick that can measure the depth of this tragedy. The tragedy of mother who is still drug addicted and who will never know her daughter. The tragedy of a young girl who is severely mentally ill and who will live out her life within the walls of an institution. And the tragedy of knowing that we could have prevented this outcome – but failed to do so.

My point is that none of this has anything to do with access to our acute care medical system. Nor would a system of universal coverage have materially changed the outcome or the tragedy. In fact, dramatically expanding access without, at the same time, demanding value, will actually exacerbate, rather than mitigate, the circumstances that lead to these tragic outcomes. Why? Because among the factors that contribute most to lifetime health status, our medical system is a relatively minor contributor. Far more important are things like healthy pregnancies, housing, nutrition, stable families, safe communities, education, good jobs and the other “social determinants” of health.

I deeply believe that universal coverage—actually universal access—to quality, affordable medical care, delivered where and when people need it; is not only a basic measure of a just society, it is essential to the health of our nation. At the same time, blindly pumping more public dollars into our health care system without demanding value, undermines our ability to invest in the very things that contribute most to health; the investments in our communities and in our children and families, investments that form the very threads from which is woven the fabric of social justice.

As Robert Kennedy pointed out over 50 years ago: “Health care and poverty are inseparable issues and no program to improve the nation’s health will be effective unless we understand the conditions of injustice which underlie disease. It is illusory to think that we can cure a sickly child and ignore his need for enough food to eat.”

One of the central reasons we have been unable to break the logjam on health care is because the current political debate is primarily about coverage, not value—and it needs to be about both. Neither the Democrats nor Republicans assume any change in the underlying health care business model or cost structure: we either pay for it or we

don't—which creates the logjam; a zero sum, false choice between cost and access. Focusing primarily on coverage—as important as that is—does nothing to address the total cost of care or to hold the *delivery system* accountable for quality and outcomes. Universal coverage without demanding value may give all Americans financial access to the health care system—but to a system which, by even the most conservative estimates, *wastes* thirty percent of the money it spends. This is not value and it should not be acceptable to any of us.

This is not an either-or choice—it is not a zero-sum proposition. It is a matter of demanding *value* for each and every public dollar we spend on health care; it is a matter of holding the delivery system accountable for quality and outcomes; it is about putting downward fiscal pressure on a delivery system and cost structure that has become obsessed with the delivery of medical care as an economic commodity at the expense of the health of the American people; it is about rooting out those aspects of the system that are focused solely on maximizing revenue, increasingly financed with limited public resources.

Our precious public resources are just that: *public* resources. They represent a “*fiscal commons*”—they are resources that have been raised from *all of us* and should be spent in a way that *benefits all of us*, not just some of us. They are also finite—which means that public resources spent on one set of services are not available to be spent on other services. It means that failing to demand *value* for the public dollars we spend on health care amounts to embracing the thirty percent waste that is baked into the system. That is over a trillion dollars a year—a trillion dollars a year that does not add value. The fact is, that the *only way* to make room in the federal budget for sustainable universal coverage and to invest seriously in the social determinants of health is demand *value* by *capping the total cost of care* through a global budget indexed to a sustainable annual growth rate; and requiring providers to assume financial risk and accountability for quality and outcomes.

Those of you gathered here today hold the moral high ground on coverage, on access to the U.S. health care system. This morning, I am calling for you to also claim the moral high ground on value. As you advocate to commit trillions of additional dollars to finance universal access, there is, I believe, a moral and fiscal imperative to also demand that those dollars are not simply buying access to the current dysfunctional medical business model, but to a model that does *not* waste thirty cents on the dollar, undermining our capacity to adequately invest in healthy pregnancies, housing, nutrition and stable families—in those things that form the scaffolding of social justice.

Let me turn once more to Robert Kennedy, whose untimely death on June 6, 1968 was the inspiration for my own career in public service. The day after Dr. Martin Luther King was assassinated—Kennedy delivered some brief remarks to the City Club of Cleveland. His speech was about the stain of violence in America, but then he said: “For there is another kind of violence, slower but just as deadly, destructive as the shot or the bomb in the night. This is the violence of institutions; indifference and inaction and slow decay. This is the violence that afflicts the poor, that poisons relations between men because their skin has different colors. This is a slow destruction of a child by hunger,

and schools without books and homes without heat in the winter.”

Schools without books, and homes without heat in the winter ... and hunger and homelessness, and families under economic stress, disintegrating neighborhoods, unemployment, and the creeping menace of despair and fading hope of a better future. These are cancers on the body of our community and they have nothing to do with lack of access to the health care system—but rather to the cost of that system. And it is our failure to demand value for the public dollars that support that system, which is directly responsible for our inability to invest in those things that can bring relief to these struggling Americans...that can lift them up and give them *health* and hope and an *equal opportunity* for a better life.

Ensuring that all of our children have an equal opportunity to succeed—is the single most important domestic challenge we face today. Contrary to what we are being told by our current political leadership, the greatest threat to America is not terrorism, immigration or our trade deficit with China. It is the fact that nearly sixty percent of our children are exposed, at a very early age, to one or more risk factors that can severely and profoundly compromise their ability to succeed. We cannot solve this problem by investing more money in medical care, but only by investing in our communities. Our children cannot be shielded from these risk factors by building a wall; but only by building strong, successful families.

The consequences for a child of toxic stress during his or her mother’s pregnancy—whether that stress is from hunger or homelessness or alcohol or despair—may not be as visible or as dramatic as the consequences of someone who lacks access to the acute care medical system ... but as Bobby Kennedy pointed out, it may be “slower, but [it is] just as deadly destructive.” In our political system we tend to pay for what is visible and compelling; we prioritize immediate problems over investments that could prevent those problems in the first place. If given a choice between funding prenatal care—or paying to resuscitate a 500-gram infant in the neonatal intensive care unit—the emotional and political imperative always puts money into the hospital rather than into the community. To policy makers and to the political system, the neonate is highly visible while the thousands of women who lack prenatal care are anonymous and therefore invisible.

Our challenge, and indeed our responsibility, is to move the national conversation beyond this either-or choice—by giving voice to the voiceless and making visible those who are now unseen—by demanding value for the public resources we commit to expanding access; by calling out that the thirty percent waste in our health care system is a trillion dollars a year that could and should be invested in healthy families.

Today I am calling on you to assume the leadership in redefining the terms of the national health care debate. I am calling on you to grow your mission—to continue your fierce and unrelenting advocacy for universal coverage, yes—but to temper and hone that advocacy by becoming this nation’s most powerful and compelling voice for value in the allocation of public resources; and for the proposition that everyone in this country deserves, indeed has the right, to an equal opportunity to be healthy.

Let me leave you with a story told by Oregon Poet Laureate Kim Stafford ... a true story, and one that offers a metaphor for what I am calling on you to do today.

Lloyd Reynolds, the international citizen of Portland, spent his last days in pain, silent, unable to speak or to write, lying in his hospital bed. On his last day at home, as his wife scurried to pack his suitcase for the hospital, Lloyd made his way outside to the garden and there she found him on his knees, with a spoon, awkwardly planting flower bulbs.

“Lloyd,” she said, “you will never see these flowers bloom.” He smiled at her. “They are not for me,” he said, “they are for you. The salmon coming home? They are for you. The calls of the wild geese? They are for you. The last old trees? They are for you and your children, to the seventh generation and beyond. They are all blooming into being for you.”

When we structure the full benefit of health care around value, those benefits too belong to all of us: to you, to me, to our children and our children’s children to the seventh generation and beyond. Our responsibility is to plant the seeds of tomorrow by having the courage to create that fertile ground in which our children and families can thrive.

So, look with me once more into Sam’s eyes, and promise ...we will do better.