

**Remarks Upon Acceptance of the  
Terrance Keenan Leadership Award in Health Philanthropy**

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Thank you, Susan, and my thanks to the Terrence Keenan Award Committee for this recognition of our work.

Today my thanks also go:

To Lauren LeRoy. It is an honor to be here at the tenth anniversary of her tenure at GIH. I have been her supporter all along. My thanks also to entire GIH staff.

To the Health Working Group in Washington.

To the Board of the Public Welfare Foundation. I am especially grateful to those board members who, in those long years before we said the “A” word – advocacy - approved my programs with a twinkle in their eyes.

To all my colleagues at the Foundation, especially...

Deborah Leff, Public Welfare’s President, for her strong support of our health work, and Ria Puggeda, my everyday partner in this work, and Adisa Douglas, my “sistuh” in social justice funding.

To Susan Sherry and Rob Restuccia of Community Catalyst for their partnership in all of this work. And to Kate Villers who is here today – her tireless work and generosity are exemplary.

To Stephan, my husband, and Nathan, our son:

Better to be loved than to be understood  
For we can never be understood  
But we can be loved.

One evening during a recent meeting of advocates in Atlanta, we watched the movie “Amazing Grace” about how a small group of citizens in England helped abolish the slave trade. When we look back now, it’s hard to fathom that the slave trade was a huge industry that involved the economies of several nations.

There was a time when people thought, “How could nations prosper without it?” Unbelievably, the cruelty of the practice was secondary to economic interests.

But there came a time when we looked back and asked, “How could the slave trade have ever been?”

There was a time when a little girl in South Carolina noticed that there were water fountains for whites and separate ones for blacks.

There came a time when her son – my son - would vote for the first time and would favor a black man for President.

There was a time when most of the elderly lived their last years in poverty without medical care.

There came a time when public programs would lift those indignities largely out of their lives.

It’s what Chief Justice Earl Warren in 1958 called “the evolving standards of decency that mark the progress of a maturing society.”<sup>1</sup>

All of that progress has been spurred on by the voices of the people.

And surely...

There will come a time when we will ask, How could we have denied children health care?

There will come a time when we will ask, “How could we have denied anyone health care?”

Let’s think about “the progress of a maturing society.”

Let’s think in terms of a Big Round Table – within communities, cities, states, the nation – a Big Round Table where people with different interests and contributions see each other as equals and work things out.

That table must include the voices of the people. No matter where you sit at the table, none of the key aspects of health reform – coverage, quality, delivery systems, costs or disparities – none can be properly addressed without asking people what they want and need.

In his book Health Care Reform, Now!, George Halvorsan of Kaiser says health care in America is siloed. We deliver it one unit at a time and we don’t make the linkages. Health care lacks “systems thinking.”<sup>2</sup>

In health advocacy, we are making progress with a useful concept called “Systems of Advocacy.” This entails the collaboration of different organizations with different contributions to make. Together, they insure that the voices of the people served by the health care system are informed and permanent. The 2006 report by Community Catalyst on consumer health advocacy in the states articulates the concept.<sup>3</sup>

Over the past fifteen years, the Public Welfare Foundation has nurtured a national network of health advocacy organizations. The seed organization for this work was Health Care for All, established by the Villers Foundation. Villers played a pioneering role in organizing people in Boston and throughout the nation. Health Care for All’s work ultimately resulted in the federal Children’s Health Insurance Program, in federal

programs for disabled children and adults, and in the 2006 health reform plan. For all of this, the System of Advocacy in Massachusetts was ready as an instigator and an implementer of reform. I must take exception with our speaker from this morning: advocates absolutely do have the language, the ideas, the model legislation – they just don't get paid like lobbyists....they don't get paid like we do. Maybe we could do something about that.

### **What do Systems of Advocacy provide?**

First, they provide the permanent presence of people's voices at the table. Paul Cillo served as House Majority Leader in Vermont for several years. Paul now runs Vermont's fiscal analysis organization assisted by the Center on Budget and Policy Priorities. He says we can never be sure when policy opportunities may present themselves, so advocates must always be ready. More poetically, Jim Payne of Virginia says, "Public policy in Virginia just smolders and smolders, but once in a while, it'll burst into flame."<sup>4</sup> A System of Advocacy needs to be there when it bursts into flame.

Advocates can also fan those flames: When Scott Harshbarger was Attorney General of Massachusetts, a group of advocates informed him about the planned conversion of a non-profit health plan. Having listened to their request for intervention in the public's interest, he replied, "You're absolutely right. Now go out and make me do it." You see, he was asking for constituency pressure in the great activity of politics.

*Politics is simply the way a society decides who gets what, when, where, how and why - without resorting to violence.*<sup>5</sup> And that's a good thing.

Many people assume that advocates are too adversarial. But it's often the opposite. Officials who truly work for the public encourage advocates to bring the interests of the people into the political and policy process.

**And policy: policy is the rules that govern who gets what, when, where, how and why.** <sup>6</sup> And that's a good thing, too.

The private sector also needs to hear from the people. A person saddled with medical debt sits down face-to-face with the CEO of his local hospital. This has happened recently in Ohio and Oregon. The results? Charity care policies, forgiveness of medical debt, and a deep knowledge of how our health system is failing people.

Systems of Advocacy provide a chance to test policies in reality. The Governor of Illinois spoke in 2006 about his new All Kids program. In the question period, Claudia Lennhoff of Champaign County Health Care Consumers congratulated him on the policy, but explained that it would not help children in Champaign County. The public clinic couldn't take any more patients. The two remaining clinics were for-profit, employed 93% of the county's physicians, and refused Medicaid. At that moment, the Governor saw the rubber of public policy meet the rough road of access. After that, the state's Attorney General worked with Claudia on a more open arrangement with the providers.

Systems of Advocacy must also include communications. Advocates have long thirsted for better ways to reach out to a broader base of people. In response, a group of advocates started the Herndon Alliance to work on American values and communications. Here I agree with our speaker earlier: it is important not just to listen to the like-minded, to preach to the choir. We do need to find the kernel of truth in others'

opinions and to understand their values. Frankly, sometimes the findings of the Herndon Alliance make me cringe, but that's good. I need to hear those opinions.

Systems of Advocacy include organizing. Political will must precede all policy. Organizers have the ability to bring people to the table. And inclusion in a System of Advocacy helps organizers to be more transparent, informed, and politically realistic. In the states, we are also seeing the power of interfaith organizing.

First, let say what interfaith organizing is NOT: It's not about electing anyone. It's not the promise to keep us from what Dr. Arthur Flemming used to call the "vicissitudes" of life. It's not even about the role of religion in public life.

Gordon Whitman of the PICO National Network explains this best: "Community organizing does not have a dog in the fight over the role of religion in public life. (Gordon was on the Harvard Law Review – that's why he can write like that). Religion is not a strategy or a tactic or a position. It is a reality in the lives of most Americans. Most people in the country continue to draw on religion and faith values to make sense of the aspirations they have for their own lives, their communities and the broader society."<sup>7</sup>

On January 15, Dr. King's actual birthday, I visited the Virginia Interfaith Center on Public Policy in Richmond for their "Day for All People at the General Assembly." Even in the South, that day wasn't about preaching or singing *Cum Bai Ya*. It was about people who care about their fellow man and who understand democracy. It was about informed citizens speaking with their legislators. Governor Kaine also spoke at the meeting and, by the way, gave one-third of his speech in fluent Spanish.

Organizing builds hope where there is a profound absence of it – that’s why we support organizers, especially in those places where the people are afraid and have lost hope in their government.

### **What do Systems of Advocacy need from foundations?**

To begin to answer that question, permit me for a moment to go back to 1988, to a cold and rainy night in Princeton, New Jersey, as Terrance Keenan drove me to the train station. He and I had spent the afternoon at the Robert Wood Johnson Foundation. A couple of months prior to that, I was sitting in my office, trying to figure out what a program officer did, and I got a call: “Ms. Langston, I am Terrance Keenan, Vice President of the Robert Wood Johnson Foundation and I need your help.” He went on to explain his work on school-based health clinics. There was one in Washington Heights, New York City, in a – well, as Terry said, a “difficult” neighborhood – (On the site visit, I learned from a cabdriver that it was called “the crack capital of the world”). The clinic needed more space and Terry could not fund the \$51,000 needed for the renovations. Terry had the operating costs and he had his heart set on this. I went to Washington Heights, took the request to our board and Terry Keenan got his clinic. I pulled the file out of archives the other day and read my comments that had closed it, “This was a good example of how foundations can work together. Terrance Keenan was particularly happy...the grant provided health and family planning services to young people, among whom poverty, drugs, and teenage pregnancy run rampant.”

On that rainy afternoon in Princeton, Terry had introduced me to a young colleague of his – another Vice President – (I can’t remember his name -- he wasn’t there long). That afternoon, he reared back in his chair and threw his feet up on his desk – now

those of you who know Terry will be amused at that – Terry is a genteel New Englander, the kind of Yale-ie like they used to make them – and you just didn't throw your feet on the desk when a guest was present. Then the young man told me that Public Welfare Foundation was not on his radar screen. Terry was mortified and let him know how much we had helped him in Washington Heights. You see, foundation arrogance was never acceptable to Terry – not toward each other and certainly not toward grantees.

**So, what do advocates need from foundations?**

They need for us:

First, to be in it for the long haul. You have to build capacity so that the voices of people and their advocates are fixtures in their community. We can work hard on sustainability. But the truth is that if foundations do not support those voices, I don't know who will.

Second, they need us to be flexible: On February 1, Public Welfare approved \$5 million in grants to 17 organizations in 10 states of the South. When I was putting together this work last fall, I was talking with the leader of Alabama Arise. As he described their projects and funding, I began to listen to his pauses as much as to his words and finally asked him outright, “Kimble, do you feel like you're being jerked around by foundations?” Yes indeed, he did. At that point, the real communication began. Another foundation – a non-health foundation – was requiring a lot of time and effort. Kimble explained to me that Arise wanted to work on Medicaid, but really couldn't until they made headway on their advocacy toward restructuring the state's budget. OK, I said, then I'll recommend support for budget work to be followed by Medicaid work. To him, that was “too good to be true.” To me, it was flexibility. Saul

Alinsky articulated to his organizers a principle that applies to foundations, too: *Start people where they're at.*

Third, they need us to be grantmakers: I admit to feeling a little queasy when I hear foundation people say, “Ya dee da...This shows that we can do so much more than just make grants.” That really must be kept in perspective – those other activities should never trump getting the money out. They need us to be short on process, quick with our decisions, and more interested in them and their issues, than in ourselves and our motivations. We are not procrastinators in health, we are grantmakers in health.

Fourth, they need us to collaborate: This is more important now than ever. Recently, Robert Wood Johnson’s *Consumer Voices for Coverage* staff, Nathan Cummings, Kellogg and Public Welfare are exchanging information and complementing each other’s work. Robert Wood Johnson and Packard have coordinated their recent efforts. The California Endowment, Nathan Cummings, and Public Welfare helped start the Herndon Alliance. And I would not have acted so quickly on supporting PICO’s national expansion had I not heard strong support from the California Wellness Foundation and the California Endowment. In the South, Health Care Georgia Foundation is working with us on developing health advocacy in Georgia. It was striking to me to hear Martha Katz say she does this work “for the young people.”

A couple of weeks ago, I talked with board and staff members of the Foundation for Community Health in western Connecticut. They are doing a mix of services and advocacy; first, addressing pressing needs and then asking why those needs go unmet, and what can be done through advocacy and public policy. It’s interesting, some of the small foundations are much less afraid of advocacy than some of the larger ones.

Collaboration needs to happen between funders and advocates, too. It's happening on the national level, but it also needs to happen on the state and local level.

State and local foundations, please look beyond the vested interests in your communities. There is a crying need to do what you can do better than anyone else: to collaborate with local advocates and to support the voices of the people in your state.

A final word about collaboration with operating foundations. Your wonderful information has far less effect if it does not reach those who can bring about change – and I don't just mean policy makers. We need to forge the links between your information and the advocates on the ground. It is critical for them to have the right information at the right time.

**You know, we don't need trickle down...because it doesn't. We need justice to flow down – all the way down – and to well up.**

Advocates nurture what one young writer calls “the nascent political mind”:<sup>8</sup>

*... the nascent political mind casts off politeness and tradition, refuses to blame itself for adopting a contrary stance and asks, with all the innocence of a child and the tenacity of a trial lawyer, ‘Does this have to be?’*

The failure to provide for health care for children....the failure to provide health care for everyone in this country: *‘Does this have to be?’*

Recently, the pianist Leon Fleisher wrote about a dilemma he faced. He was honored by the Kennedy Center for the Performing Arts and he was also required to attend a White House reception. At both events, a code of silence was required. He wrote in the *Washington Post*, “Turning a blind eye to the political undercurrents of the event

dismantles the very force of arts in this country that the honors celebrate: the freedom, nay, the obligation to express oneself honestly and without fear.”<sup>9</sup>

At our Atlanta meeting, Roy Mitchell from the Mississippi Health Advocacy Program told that last year Governor Haley Barbour cut elderly and disabled people out of the state’s Medicaid program – 65,000 of them. The advocates held town meetings for the people to talk with state officials. The Mississippi Justice Center and the National Health Law Program also had occasion to add their opinions to the fray – as those wonderful legal advocates can do. Finally, the state cancelled the cuts. Roy smiled and said, “Before that, we had been afraid of Haley Barbour.”

Paul Begala spoke to advocates at the Families USA conference in January. He did not speak as a hard hitting political operative. Rather, he pointed out that the phrase which recurs most frequently in the Bible is “Be Not Afraid.” Whether Leon Fleisher at the White House or a disabled woman in a Mississippi town, we need to *Be Not Afraid* “to express ourselves honestly and without fear.”

The world is changing – don’t be afraid to see it in new ways. The world requires that we – whoever we are - step outside our own limitations. That requires that we listen, that we forge the links, that we build the bridges.

There will come a time when foundations will use their singular freedom to speak not **FOR** but **WITH** the people.

It is finally about democracy.

**If you do not believe in advocacy and if you don’t support it, you don’t believe in democracy.**

**If there was ever a time to believe in democracy, it is now.**

As we act on that belief, we need to do so in the right spirit.

The late Mollie Ivins had a spirited voice of wit and integrity. She wrote,

*So, keep fightin' for freedom and justice, beloveds, but don't you forget to have fun doin' it...Lord, let your laughter ring forth...rejoice in all the oddities that freedom can produce...*<sup>10</sup>

And as you go about doing the work of social justice, don't forget to tell the young people coming along, how much fun it is! Thank you.

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<sup>1</sup> Warren, C.J., *Trop v. Dulles*, Supreme Court of the United States, March 31, 1958, [www.law.cornell.edu](http://www.law.cornell.edu).

<sup>2</sup> George C. Halvorsan, *Health Care Reform Now! A Prescription for Change*. John Wiley and Sons, Inc. 2007, pp. 12, 19, 22.

<sup>3</sup> *Consumer Health Advocacy: A View from 16 States*, Community Catalyst, Boston, October 2006.

<sup>4</sup> Jim Payne, personal communication, January 15, 2008.

<sup>5</sup> John E. McDonough, *Experiencing Politics, A Legislator's Stories of Government and Health Care*. Berkeley, University of California Press, 2000, p. 20.

<sup>6</sup> Susan Sherry, personal communication.

<sup>7</sup> Gordon Whitman, "Beyond Advocacy: The History & Vision of the PICO Network," *Social Policy*, Winter 2006-2007, p. 52.

<sup>8</sup> Alain de Botton, *Status Anxiety*. New York, Vintage Books, 2004, p. 205.

<sup>9</sup> Leon Fleisher, "My White House Dilemma," *Washington Post*, February 9, 2008.

<sup>10</sup> Molly Ivins quoted in E.J. Dionne, "Molly Ivins's Joyful Outrage," *Washington Post*, February 2, 2007, A15.