

# FROM THE GROUND UP:

*Improving Community  
Health, Inspiring  
Community Action*

JUNE 2006

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KEYNOTE ADDRESSES  
FROM THE ANNUAL  
MEETING ON HEALTH  
PHILANTHROPY

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PHOENIX, AZ

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## FOREWORD

*On February 24-26, 2006 Grantmakers In Health (GIH) held its annual meeting, From the Ground Up: Improving Community Health, Inspiring Community Action, in Phoenix, Arizona. The meeting focused on how grantmakers are meeting the challenge of creating healthy and vibrant communities, with sessions that looked at how funders are engaging and fostering communities to improve access to health care and deliver the services and information that affect health, from needs assessment to evaluation, and at every step in between.*

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This compilation includes remarks from each plenary session and the Terrance Keenan Leadership Award luncheon. Our plenary speakers both framed the pitfalls and challenges facing funders engaged in this work and related personal experiences and hard won insights. Whether fighting infectious disease in Haiti and Africa, working with underserved communities in Baltimore or Cleveland, promoting diversity in the health care workforce, or representing a community grappling with social disenfranchisement and its own health epidemics, these plenary presenters provided inspiration and fresh ideas and challenged attendees to act on lessons learned from both successes and disappointments. We thank them for helping set the tone of a successful meeting and encouraging us to look thoughtfully and analytically at our own place in the communities where we work and live.

Our thanks go, as well, to our many Funding Partners whose annual support helps underwrite a portion of everything GIH does, including the Annual Meeting on Health Philanthropy. We are particularly indebted to those

Funding Partners that awarded GIH supplemental program grants, above and beyond their annual support, to help cover the substantial costs of this undertaking. Funders contributing to the annual meeting include: Archstone Foundation, BHHS Legacy Foundation; The California Endowment, The California Wellness Foundation, The Annie E. Casey Foundation, Consumer Health Foundation, Irvine Health Foundation, Robert Wood Johnson Foundation, Kansas Health Foundation, The Henry J. Kaiser Family Foundation, W.K. Kellogg Foundation, The David and Lucile Packard Foundation, Paso del Norte Health Foundation, The Virginia G. Piper Charitable Trust, Quantum Foundation, St. Luke's Health Initiatives, United Methodist Health Ministry Fund, and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

We would also like to thank those who helped to make the 2006 annual meeting such a success by designing and presenting breakout sessions during the meeting. This year's call

for sessions produced an all-time high number of submissions, representing the wealth of challenging topics facing health grantmakers. Our great appreciation goes to the following individuals who rose to the challenge of reviewing and evaluating the many session proposals we received: Patricia Baker, Connecticut Health Foundation; Bets Clever, Carlisle Area Health & Wellness Foundation; Juan Figueroa, Universal Health Care Foundation of Connecticut; Ralph Fuccillo, Harvard Pilgrim Health Care Foundation; Sandra Martínez, The California Wellness Foundation; Mary Vallier-Kaplan, Endowment for Health; and Anne Weiss, Robert Wood Johnson Foundation.

The Terrence Keenan Leadership Award selection committee also deserves special thanks for devoting considerable time to reviewing the nominations and discussing the merits of each nominee.

These committee members, drawn from GIH's Funding Partners, were Ruth Brousseau, The California Wellness Foundation; Judy Ford, American Legacy Foundation; Ellen Friedman, Tides Foundation; Jewel Garrison, Columbus Medical Association Foundation; Gary Nelson, Healthcare Georgia Foundation, Inc.; Ed Meehan, Dorothy Rider Pool Health Trust; and Betty Wilson, The Health Foundation of Greater Indianapolis, Inc.

For her work in editing the speeches in this report, GIH would also like to thank Anita Seline.

Producing this volume gave us a chance to revisit the thoughts expressed and challenges posed to meeting participants. We hope you will value the opportunity to reflect on these remarks again and that you will share them with others who were not able to attend.

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## WELCOME

### Richard Narcia

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Distinguished guests, board members, it is an extreme pleasure to be here with you. I would like to express my thanks to Grantmakers In Health for inviting me to be your opening speaker here at your annual meeting. I am very honored to be standing before such a distinguished audience.

My name is Richard Narcia, and for the past six years I have been in the leadership of the Gila River Indian Community. The first three years were as lieutenant governor, and I have just recently concluded my term as governor. On behalf of the Gila River Indian Community, I would like to welcome you and I hope your meetings will be productive and I am sure very useful. I applaud your efforts to help bring a positive focus on what is a formidable challenge: the well-being and health of all people.

I would like to give you a brief history and an overview of the Gila River Indian Community. For those of you who are not familiar with Gila River, our community consists of two tribes: the Pimas, or as we call ourselves, Akimel O’odham, which in our native language means the river people, and the Maricopas, or as they call themselves Pee Posh, a word which, in their language, means the people. We are the largest Indian tribe in the metropolitan Phoenix area. We number some 19,000-plus members.

The Gila River is located on 373,000 acres, or approximately 600-square miles here in south central Arizona. Our northern boundary is the southern boundary of metropolitan Phoenix. If you look to the north you will see where Phoenix ends and Gila River begins. Our neighbor to the south, the city of Tucson, is rapidly approaching our southern boundary, and we are told that, somewhere between 2015 and 2020, we will be completely surrounded by concrete and asphalt.

Our community, with the advent of gaming (we have three casinos), is maturing into a highly active governmental entity that is able to provide a wide range of public services, from health care and social service programs, to economic development planning, public infrastructure, and public safety. Today this represents nearly 1,600 employees with the community and an annual operating budget in excess of \$100 million. Contrast this picture with a picture of a decade ago where employees and budgets were one-tenth of what they are today.

As we move forward into the 21st century, we at Gila River face many challenges. Economic development is key to our survival. Gaming is only one variable that will enhance our economic prospects as we venture further into the world of revenue-

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*As we move forward into the 21st century, we at Gila River face many challenges.*

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generating projects. However, we must be careful, because gaming is not a panacea for Indian country. It is a tool that will assist our community to achieve the success necessary to meet the needs of our people. The Gila River Tribal Council has long recognized that while we have made significant progress in raising the quality of life on the reservation since the advent of gaming, there is still much to be done. Ten years of gaming cannot erase the hundreds of years of socioeconomic depression.

With this in mind, Gila River has moved forward with projects that will provide revenue aside from gaming, the ultimate goal being to move away from the economic dependency on gaming. The vision of our leaders and elders is to someday be totally self-sufficient. There is no denying that gaming has given the community the financial wherewithal to even contemplate large-scale development. It is very clear, however, that at some point, the revenue generated by gaming will dwindle. Various factors lead us to this conclusion, most significant being the regulations and restrictions placed on gaming by the state and the federal government. Therefore, the community has looked at innovative ways to spur economic development through diversification.

Construction of this 500-room resort managed for us by Sheraton is a good example of this diversification. Together with Starwood Hotels, which is the parent corporation of Sheraton, the community has created a five-star resort that will rival any

resort in Arizona and the world. We are very proud of this facility and what is happening here. This whole area has been slated for development. Things are happening here.

This resort has been operational since November of 2002, along with the Aji Spa. Another amenity that is part of the overall development is Whirlwind Golf Course just north of here. This is a true world-class, 36-hole course, managed by Troon Golf.

The development I have mentioned thus far is but a small part of the vision now being set forth. Other elements of the community economic plans include three industrial parks and a 500-acre business park that is now being developed. As you can imagine, it's a very exciting time for Gila River. We are now witnessing, with the major growth throughout the state of Arizona, and in particular, here within Maricopa County, Indian communities, including Gila River, are becoming more an interactive part of the valley's economic and political environment. Consequently, there is tremendous opportunity for Indian communities; however, as I mentioned earlier there are also challenges that must be overcome.

These challenges are not only limited to economic development. We believe that economic development will provide the ability to tackle the huge health problems we face here at Gila River.

I would like to tell you another story of my people — a story I hope will illustrate why the health of our people

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## SPEAKER PROFILE

**Richard Narcia** is former governor and a lifelong resident of the Gila River Indian Community. He was extensively involved in securing the community’s water rights through positions as director of the irrigation rehabilitation program and a member of the water negotiating team. Governor Narcia also has represented the community in construction contracting with the Indian Health Service. He currently serves on the board of The Morris K. Udall Foundation. The foundation, established by the U.S. Congress to honor Udall’s service in the U.S. House of Representatives, is an agency of the executive branch of the U.S. government, whose members are appointed by the President of the United States.

is such a priority, and why I believe the work that you all do is so important, not only for Native Americans, but for all Americans. The Akimel O’odham (Pimas) have always been and agricultural society and when the Pee Posh (Maricopas) joined us in the 1800s, they too depended on agriculture to survive.

History documents the advanced technology of our ancestors in building water systems that are still used today. In the more recent past, when Spanish conquistadors came to the Gila River Valley, they noted in their journals the lush fields of wheat and other vegetables grown by the Akimel O’odham. Later, in 1849, settlers traveling west through Gila River were in some instances saved by the Akimel O’odham. Produce grown was freely shared with these starving travelers. Life was good. Mother Earth blessed the people with health and an abundance of food for all to share.

Then in 1928 the river stopped flowing. Coolidge Dam was built

upstream of the reservation, creating the San Carlos Reservoir. Ironically, the justification for the legislation that authorized the dam specifically stated that it was to provide irrigation water for the Pima Indians. We were never to see this water, however. The federal government, as our trustee, negotiated an agreement that effectively took the water that would have come to the reservation and reallocated it to non-Indian irrigators. History also documents that our people were barred from the negotiations of this agreement.

When the water stopped, our people suffered severe hardships, among them, starvation. Once again our trustee, the federal government, came forth with an effort to help the situation by providing government surplus commodity food. Unknowingly, the introduction of these processed foods, which are high in starches, and the loss of a healthy lifestyle, caused great harm to the well-being of our people. We no longer worked in the fields or ate the natural foods that we grew. These

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*When the water stopped, our people suffered severe hardships, among them, starvation.*  
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events started our people down a path of illness that is devastating our people. We now have the unfortunate distinction of having the highest rate of adult onset or Type II diabetes of any ethnic group, per capita, in the world.

In trying to return to what we once had, our culture, our lifestyle, our health, one of the greatest accomplishments for myself personally and the people of the Gila River Indian Community, was the enactment of the Gila River Water Settlement by the U.S. Congress and signed into law by President Bush on December 10, 2004.

With the return of our water we now have another tool to fight this terrible disease. Diabetes has truly devastated my people. I have seen firsthand what a terrible disease can do and has done. Both my mother and father contracted the disease at an early age. I grew up watching them give each other insulin shots. We lost my mother as a direct result of this disease.

Both my sisters and I have diabetes. I now have to take pills and insulin for the rest of my life to control my sugar. It was a very sobering thought when I was told I have the disease, mainly because I have seen what diabetes does to people. Particularly, at the end of her life my mother was just a shell of the loving person we called "Mom." Both her legs had been amputated below her knees. She had lost the ability to taste food, and at the very end she was totally blind.

What I have told you is not an isolated scenario at Gila River.

Unfortunately, it is a common occurrence or experience in almost every family among my people. That is why I feel so adamant about finding a cure for diabetes and why I feel your organizations are so critical in assisting to reach that goal.

The community has instituted new awareness of diabetes in the hope of reducing the statistics now prevalent within our community. Our reservation schools have instituted an emphasis on healthy diets and physical fitness. The goal is to do early outreach through health education and living a healthy lifestyle. The community has established wellness centers to target the adult population as well as the youth. These centers are equipped with the latest in exercise equipment. They are also staffed with qualified people to assist our community members with suggestions on how to lead a better, healthy lifestyle. Physical activities, such as fun runs, are regularly scheduled.

Recognizing that prevention is one element in the fight to defeat the disease, the community is also addressing those already afflicted with diabetes. The community has built a new diabetes and education resource center to raise awareness of the disease and will provide preventive measures for the people of the Gila River. Last year saw the completion of two new dialysis facilities on the reservation. These are two state-of-the-art facilities and we are told that there are no other facilities in the United States like the ones that were built here.

As you can see, we have the dynamics that community efforts need to

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*Together we can build synergies  
that can raise the quality of life  
in our great nation.*  
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succeed. The survival and well-being of my people depends on how we meet this challenge. I believe that, with the help of organizations such as Grantmakers In Health, we can eliminate this terrible disease. I further believe that a partnership can be formed, not only with Gila River but with all ethnic groups, in order to curtail this growing epidemic. I believe the dynamics for success are at hand. I am very confident that together we can build synergies that

can raise the quality of life in our great nation.

The theme of this meeting is *From the Ground Up: Improving Community Health; Inspiring Community Action*. From my perspective, the Gila River Indian Community is moving forward as a community to meet the challenges with regard to health and taking aggressive action to achieve our goals.

Thank you.

## BUILDING COMMUNITY TO IMPROVE HEALTH

**Lauren LeRoy**

I want to welcome all of you to Phoenix and to Wild Horse Pass. We are visiting a region which is relatively new, sprawling in Western style, landlocked, warm and dry, and the fifth largest city in the country — more metropolitan than home on the range.

Some of those who have settled in Arizona came for health reasons. Others, like our hosts, the Gila River Indian Community, trace their roots back to 300 B.C. We have much to learn from this community, with its economic development successes and its investment in the health and well-being of its people. The people here also have a sense of community that does not stop at their own borders. The Pima Indians were recognized as Pathfinders for Health by the National Institute for Diabetes and Digestive and Kidney Diseases. Half of adult Pimas have diabetes. The disease has had a profound impact on the tribe. For more than 40 years, three-quarters of the Pima community has participated in a national longitudinal study on obesity and diabetes, not just for the benefit of themselves, but for the benefit of all of us.

So, as we spend the next few days together, we can take inspiration not just from the beauty and majesty of this place but from our hosts as well. The focus of this year's meeting is on

community: improving community health, inspiring community action.

I have to admit that I really struggled with the concept of community in thinking about what I would say. I decided that I would start with geography, figuring that most people associate community with a place. But then I was stuck again. For each of us, which place defines our community? Which should define it? How do we define what we are a part of, who affects us, and who we are responsible to?

Pretty quickly I found myself moving like a few clicks on a Google map from neighborhood, to nation, to the community of nations. But before I tell you some of my musings about community, I want to step back and briefly take stock of our community's health, broadly defined.

Starting first close to home, we are a growing population. We will reach 300 million later this year. By 2030 our numbers are expected to grow another 23 percent. Moreover, within 25 years there will be as many people over 65 as there are under 18, potentially redefining both work and care giving along with other aspects of our society.

We baby boomers, who are on the front line of caring for our parents

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*How do we define what we are a part of, who affects us, and who we are responsible to?*

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## SPEAKER PROFILE

**Lauren LeRoy** has served as president and chief executive officer of Grantmakers In Health since 1998. Previously, she was executive director of the Medicare Payment Advisory Commission (MedPAC), a nonpartisan congressional advisory body. Prior to MedPAC, she served as executive director of the Physician Payment Review Commission (PPRC). She came to PPRC from The Commonwealth Fund Commission on Elderly People Living Alone, where she served as associate director. Dr. LeRoy spent more than a decade at the Institute for Health Policy Studies, University of California at San Francisco, where she was assistant director and directed the institute's Washington office. She began her career as a health policy analyst in the U.S. Department of Health, Education, and Welfare. Dr. LeRoy is a fellow of the UCLA School of Public Policy and Social Research Senior Fellows Program and is a member of the national board of advisors of the Iris Alliance Fund; the Dean's Policy Advisory Council at the University of California, Berkeley School of Public Health; and the national advisory council of the California Health Benefits Review Program. She received a doctorate in social policy planning from the University of California at Berkeley.

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*Baby boomers, who are on the front line of caring for our parents and our children, are developing an intimate understanding of the needs and costs of an aging population.*  
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and our children, are developing an intimate understanding of the needs and costs of an aging population. Many of us may feel cautiously optimistic that we are going to make out fine without being a burden on our children or society. As a group, baby boomers' median income is about 35 percent higher than other Americans. But we should not be too sanguine about this generation's ability to fend for itself throughout retirement. Black baby boomers, for example, are no better off than their grandparents were in terms of income. They earn two-thirds of what white boomers earn. Potential cutbacks in pensions and health coverage, along with the rising cost of care, will put pressure on whatever assets boomers have accumulated during their working years.

We face continued demographic changes by race and ethnicity as well as by age. In 2000, whites made up 81 percent of the population, blacks 13 percent, Hispanics 13 percent, and Asians 4 percent. By 2040, those numbers will have shifted. Whites will make up less than three-quarters of the population, blacks will be 14 percent, Hispanics 22 percent, and Asians 7 percent.

The growing diversity of our population is a fact of life. Health disparities among racial and ethnic groups should not be. Gaps in both access and quality for minorities continue, although they have diminished for most groups. Hispanics, however, are the exception where disparities have actually widened during all these years

we have talked about eliminating them. Across the board, poor people suffer worse access and quality.

These facts are shocking but not surprising. With a national problem this profound, what is surprising is that 68 percent of Americans do not think minorities have worse problems than whites in getting quality health care. Obviously we have a long way to go.

A snapshot of the nation's health shows that life expectancy has hit a new high: 77.6 years. Deaths from heart disease, cancer, and stroke are down. But there are some ominous signs that we need to pay attention to. Baby boomers between the ages of 55 and 60 are in worse shape than those born a decade earlier when they were that

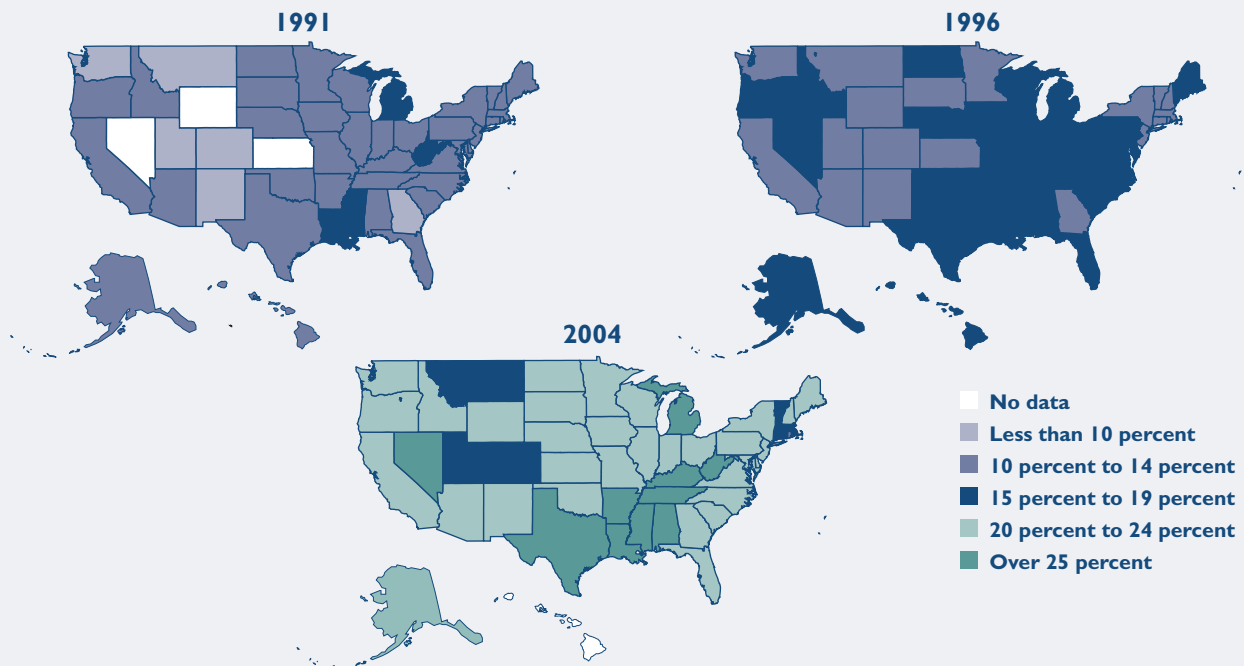
age. Half have high blood pressure and 40 percent are obese. The transition from adolescence to adulthood seems to be a turning point for many, away from exercise and towards smoking, drinking, and excessive eating.

We know that efforts to help people quit smoking or never to begin are a model for health promotion. But the temptation and the search for new markets are a constant threat to the success that we have seen.

I must admit that I am a sucker for watching the ball drop in Times Square on New Year's Eve. This year it was really worth staying up, just to hear Dick Clark's observation that, in years past, the most common New Year's resolution was to quit smoking, but

*In years past, the most common New Year's resolution was to quit smoking. This year, it was to lose weight.*

Figure 1. **Obesity Trends Among U.S. Adults, 1991 – 2004**  
(percentage of adults with body mass index of 50 or higher)



Source: Behavioral Risk Factor Surveillance System, CDC.

this year it was to lose weight. Sixty-five percent of adults in this country are overweight or obese.

I'm sure you've seen these maps before (Figure 1). They are stunning, as is the fact that since the 1970s, the prevalence of obesity has doubled for preschoolers and adolescents and tripled for kids aged 6 to 11. This obesity epidemic is a key contributor to the diabetes tidal wave that we are facing. Projections by the Centers for Disease Control and Prevention (CDC) estimate that one in three children born five years ago will become diabetic in his or her lifetime. For Latinos it is one in two.

Diabetes is also the culprit that could reverse the steady rise in life expectancy that we have seen over the past 200 years. Obesity is a risk factor in diabetes, but poverty is too. Less access to healthy food, opportunities for exercise, and health care create the conditions for poor health.

Promoting healthy behaviors is not easy. There are strong commercial interests working against it, and it takes self-discipline in the best of circumstances. We all know this, as we try to stay healthy ourselves, and healthy living often takes a back seat for many who are just trying to make ends meet.

There are, unfortunately, no quick fixes. I suppose we could try the French approach where the interest rate you pay on your mortgage is tied to your health risk. I have to say, however, that they have their own cultural blinders, since they do not ask about smoking in the health assessment.

We know that an increasing share of the country's disease burden is preventable, and the alternative to effective prevention is human suffering and a diversion of medical resources that is not likely sustainable. For example, in the four years from 1998 to 2002, bariatric surgeries grew 400 percent, with associated costs growing six-fold to almost \$1 billion. About 63 million adults were clinically eligible for weight-loss drugs in 2002.

Given that we do depend heavily on our health care system, how is it treating us? Health spending is a source of concern for individuals, businesses, and government. It increased by 7.9 percent in 2004, outpacing wage growth and inflation. How much it has risen on the national agenda was evident from the attention it got in the 2006 State of the Union address. The rate of increase in costs has slowed in recent years but the absolute amounts remain unaffordable to many. If we have not figured out how to stem expenditures for acute care, how are we going to tackle the growing costs of long-term care on the horizon? Alzheimer's disease alone is expected to afflict 16 million Americans by 2025.

In 1945, Harry Truman told the nation, "Millions of our citizens...do not now have protection or security against the economic effects of sickness. The time has now arrived for action..." These words capture so well the challenge we face today. We can celebrate the passage of Medicare and Medicaid, the expansion of employer-based coverage, and the enactment of SCHIP in the interim, but I would argue that we are losing ground.

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*One in three children born five years ago will become diabetic in his or her lifetime.*

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In January, Congress passed the fiscal year 2006 budget, taking more than \$11 billion in savings from Medicare and Medicaid. The Congressional Budget Office estimates that 100,000 Medicaid beneficiaries will lose coverage in the next 10 years because of their inability to pay allowed premiums. This comes at a time when states are just emerging from a period of fiscal crisis, and they still face budget shortfalls.

In 2004 we had a success story with SCHIP enrollment reaching nearly 4 million children. At the same time we need to remember that there are still more than 2 million children who are not enrolled in the program who we need to reach. And, we need to keep our eye on the ball because SCHIP is up for reauthorization next year.

The very rocky beginning to Medicare Part D masks the fact that it actually could provide new coverage for many people. We can certainly hope things will settle down quickly, but brace yourself for when people start reaching the infamous “donut hole.” While there continue to be calls for legislative fixes and people who are working hard on this, I think the prognosis is pretty bleak with a \$400 billion deficit and elections on the horizon.

Forty-six million people in this country are uninsured. Half of personal bankruptcies are due to unaffordable health care costs. Even with all the reflection on what this says about us as a nation, we have seen the numbers of uninsured swell as we discuss what a shame it is.

There are critics for just about every solution. That is part of the reason we

still have 46 million uninsured. Some raise issues and concerns about more government involvement. Critics of market solutions point out the inequities that would likely grow, hurting the same groups that are already losing ground.

With rising costs and no solutions in sight, employers are making hard choices. Starbucks spends as much on health coverage as it does on coffee beans. In circumstances such as these, we see a steady decline in the percentage of businesses offering coverage to their employees. In 2005, 60 percent of employers offered coverage, down from 69 percent in 2000.

Employer costs continue to rise and employees help pay for that through higher cost-sharing and lower wage increases. Average annual premiums for family coverage now consume more than the gross earnings of a full-time minimum wage worker.

Retirees face a similar scenario with benefit cutbacks, higher costs, and fewer employers offering coverage. This, coupled with pension freezes and overhauls, has many worried about retirement security.

State and local governments will now have to put future obligations for retiree health benefits on the books. This is an estimated \$1 trillion nationally. Many of these governments are in the difficult position of having to choose between tax increases, cuts in promised benefits, or bankruptcy.

For all the money that we are paying, what kind of service are we getting? Progress on quality improvement has

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*Even with all the reflection on what this says about us as a nation, we have seen the numbers of uninsured swell as we discuss what a shame it is.*

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been slow. We see just a 2.8 percent gain overall between 2003 and 2005, with no improvement or decreases in quality on many measures. The greatest progress has come from focused efforts to improve care. How we extend and replicate what we have learned throughout the country remains the challenge for us. We were encouraged about this last year when Don Berwick spoke to us, and again, we have a lot of work to do.

Since we last met, the nation and the world have faced unforgettable disasters. On 9/11 we were tested by man and fire. This time around it was nature and water. Both have brought into sharp focus the inadequacies of our public health system. We had a wake up call five years ago, but we are still groggy.

Recently, the Trust for America's Health (TFAH) reported that 60 percent of the states in this country achieved no better than 5 out of 10 possible indicators of health emergency preparedness. Only seven states and two cities were recognized by CDC as prepared to administer and distribute vaccines or antidotes in an emergency.

Experts consulted by TFAH gave the federal government a grade of D+ for its health and bioterrorism preparedness performance. That does not offer much comfort as we wonder how far off a flu pandemic might be. Even a midseverity outbreak could cause as many as a half million deaths and 2 million hospitalizations in this country alone. Will the lack of preparedness,

when we had time to plan, have people fending for themselves with not much more than Web sites such as [survivetheflu.com](http://survivetheflu.com) to help them out?

Some members of our community will fare better than others. That was made crystal clear by Hurricane Katrina. What we saw in New Orleans revealed a persistent link between race and poverty, discrimination and neglect. What I would argue is a lack of community. What sometimes seems like a well-kept secret is that New Orleans is not alone. In 2004, 36.5 million people lived in severe poverty. Nearly one-quarter of African Americans are poor.

Hurricane Katrina has captured our attention and concern, in part because it is close to home. But we cannot forget that we are part of a world community with vast inequities in wealth, opportunity, and circumstance. We were overwhelmed by the magnitude of the tsunami in 2004 which took 200,000 lives. Last October, nature shook us again with the Kashmir earthquake that killed 73,000 and left nearly 3 million people homeless.

But for most of us, our sense of connection with our global community quickly dissipates. We may be pleased when we are reminded that polio has been nearly eradicated through global immunization programs, but as a nation we barely seem to notice the staggering toll of diseases such as malaria and tuberculosis which inflict their greatest losses on the poor and developing countries.

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Our global community now has 40 million people with HIV/AIDS, with 3 million AIDS deaths in 2005. Globally, there are also 408 million malaria cases, 1 million malaria deaths, 15 million tuberculosis cases, and 2 million TB deaths. There are some high visibility efforts under way to reduce the numbers, such as the Global Fund to Fight AIDS, TB and Malaria; UNAIDS; the Rollback Malaria campaign; and projects funded by the Gates Foundation and its partners. Paul Farmer's work in some of the poorest areas of the world provides a model for both first-rate care and the right of every person to receive it.

There is a sad irony in the outpouring of generosity we see after disasters like the tsunami or Katrina compared to our apparent blindness to ongoing suffering. In philanthropy we have the luxury to both see and respond, whether at home or abroad. It is time we opened our eyes.

This brings me back to where I started: to define a clear conception of community that can both capture and guide our work.

What are the common threads across terms such as local community, faith community, academic community, retirement community, or communities of color? What is the difference between a true community and a convenient label? I grabbed Tony Proscio's wonderful monographs off my shelf to see whether he might have had his sights on our word. Sure enough, he had.

His tongue-in-cheek definition is: "A corral for keeping people together

in your own mind... a catchall term for any group of people with practically anything in common." Proscio warns that the vagueness of the word community is an invitation to mental sloppiness. We seem to tolerate its ambiguity and its indiscriminate application to just about every association among people.

Many foundations also seem to prefer the word community when what they actually mean is poor people or minorities. My question is, if we do not clearly articulate what community means, then how can we define what it means for a foundation to be a community partner?

In scanning the literature, I found one article from 1955 that had 94 definitions of community, and I can only imagine how many have been added in the last 50 years. As Princeton sociologist Suzanne Keller pointed out, however, there are some recurring themes associated with the use of the term, such as place, turf, territory, a collective framework of rules, governance, ideology, and values. When speaking of specific populations or groups with mutual interests that can transcend geographic boundaries, the term community also implies shared ideals and expectations or social ties and allegiances.

If we go back to the Latin, we see that the word community comes from a combination of two terms that create a union among people. "Com" is with or together; "unus" is the number one. Thus, individuality, diversity, and interdependence coexist in this one word.

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*There is a sad irony in the outpouring of generosity we see after disasters like the tsunami or Katrina compared to our apparent blindness to ongoing suffering.*

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All of us are members of many communities, some out of choice and some simply out of circumstance. Out of ignorance we may see homogeneity where it does not exist. In her book *Community: Pursuing the Dream, Living the Reality*, Keller points out, “Communities may display a unified front to the larger society but internally be sharply divided.” For example, in a report to The Annie E. Casey Foundation on family strengthening in Indian America, the researchers point out that diversity is the rule rather than the exception in growing up Native.

We also need to keep in mind that community is not synonymous with unanimity. Moreover, community seems to imply shared values; but even among people with strong connections, their values are not always in sync.

Do we really know how much or which values must be shared to hold people together? Diversity is often cited as a characteristic of successful communities, something that makes them stronger. But as Keller points out, “communities can create pressure for a separatist ideology that segregates us from them.”

We may also make incorrect assumptions about how strongly people identify with communities that we associate them with. Those assumptions can be tainted by racism, sexism, ageism, and the like. The value we place on diversity in our society, for all its benefits, can thus divide people by identifying them with their separate communities rather than connecting them to the larger society.

I want to make clear, however, that raising these issues and pointing out misconceptions does not diminish the power of community to determine people’s lives and their health. Communities are the setting where the factors that affect health and well-being come into play and where we will most likely see the success or failure of our efforts to try to improve conditions. They are the focal point for what Lester Breslow calls the third revolution in public health improvement which is characterized by community change to reinforce and support healthy behaviors. We have seen grassroots advocacy sow the seeds for broader social change. The personal attachment and direct experience that people share in their local communities can provide the foundation for more distant and abstract connections with the larger society. For these and other reasons, the local community is the context for most health grantmaking.

What concerns me, however, is that while many foundations, nonprofits, and people work tirelessly to improve conditions in local communities around the country and around the world, the sense of community in our broader society is in jeopardy. We are often too busy to notice the critical connection between these two things.

In his work, *Bowling Alone*, Robert Putnam documents the erosion of social connections, or what he calls social capital, across the country. He distinguishes between two types of social capital: bonding social capital or

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*If we do not clearly articulate what community means, then how can we define what it means for a foundation to be a community partner?*

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the ties among people who have much in common, and bridging social capital that eases connections across social divisions. He points out that the latter, this bridging social capital, is the hardest to create and perhaps the most important.

This country has always struggled with the tension between individualism and social responsibility. These days the pendulum often seems to swing away from community and towards the individual. The calls for individual retirement accounts and medical savings accounts, for example, reframe our assumptions about pooling risk, a fundamental principle underlying insurance protection. Hospitals and physicians are moving specialty services to affluent communities where they will not have to contend with the poor, the uninsured, or those on Medicaid. While suburban hospitals are finding ample money for expansion, inner-city hospitals are being put on the chopping block.

Plato and Aristotle would be absolutely shocked by the fact that we, as a society, pay so little attention to the erosion of community unless it affects us directly. They understood the concept of enlightened self-interest, that we have a stake in each other's lives and we pay a price for our indifference. How much of a price? The Institute of Medicine estimated the cost to society of the uninsured alone at between \$65 billion and \$130 billion a year, and the price is more than money. This is the background for foundations' work in communities. This is the challenge to all of you.

You have done some wonderful things in both addressing immediate needs and tackling the complex task of attacking the root causes of ill-health. In the past few months I have talked with some of your colleagues about what it means to be a community funder. What they shared with me was a pretty consistent philosophy rather than a number of project details. The philosophy behind guiding community funding is the belief that communities have assets, strengths, and resilience. Communities have knowledge that money can't buy. Issues, goals, and solutions should be community defined. Local people must be invested in the effort. Funders should listen more than talk, and show respect. They also emphasized the importance of funders being vigilant about the arrogance of privilege and guarding against disingenuous rhetoric about partnership.

Empowering communities does not imply that they can go it alone. Not all conditions that affect health can be changed by community actions. National progress will be slow if it occurs one community at a time.

Others outside of the community must do their part, whether it is bringing in needed assistance or demanding policy change. That is where our diminished sense of interdependence and social responsibility places everyone at risk.

As challenging as it is to tackle inequalities nationally, we cannot stop there, because the world is too small and the consequences too great.

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*We have a stake in each other's lives and we pay a price for our indifference.*

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We have to feel our connection with those around the globe, not just for the tangible ways that it may affect us such as a flu pandemic, but for what our actions say about our values and how they affect our leadership in the world.

From the time of Plato, major thinkers throughout history have posed questions about how communities are created and maintained, how the spirit of community is generated, and how human differences are bridged for the sake of the common good? I would add to these: How do we marshal the evidence of both our national and global interdependence and the consequences of bowling alone to propel transformative change? How do we come together to take action and to find the passion, the motivation, and the strategic wisdom that implies? These sound pretty far removed from health grantmaking, but they are at the core of what we do and they are critical to our effectiveness.

As I read through the philanthropic literature this past year, I found that discussions of effectiveness seemed to run in two tracks: one which focused on improved grantmaking and the other which focused on producing social change. So let us take a look at those for a moment.

Increased public scrutiny and expectations have quickened the pace of foundation efforts to prove themselves as accountable and effective organizations. Many have installed more rigorous operating procedures to

protect themselves from inappropriate business practices. They have also tried to bring greater transparency to their work, although there are critics who would argue that if funders' actions focus on one-way communications disseminated by the foundation rather than open dialogue with the community, then they are just staying in their comfort zone.

Some have felt pressure to cut administrative costs, a step that others consider to be short-sighted if it weakens a foundation's ability to monitor, learn, and be responsive to its grantees. Every year we debate whether performance measurement is possible or desirable in philanthropy.

I am reminded of an article about baseball in *The New York Times*. The reporter was describing what he called the equivalent of a theological dispute about whether baseball was more a game of statistics or intuition. The article was stimulated by the recent backlash to the book *Moneyball* which focused on the success of Oakland A's general manager Billy Beane's number-crunching approach to picking his players. Managers lined up in two camps: those who tend to stick to the numbers and those who trust their gut. The debate has been lively but the truth is they all do a combination of those two things.

There is another interesting insight from this example. Baseball has always been a game of statistics, much to the pleasure of fans, fantasy leagues, math teachers, and sports announcers. Wouldn't it be great if foundations

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*Empowering communities does not imply that they can go it alone. National progress will be slow if it occurs one community at a time.*

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could report their performance baseball-style, neatly arrayed on the equivalent of a baseball card?

Before we get too carried away with this analogy, however, let me point out that when managers began to apply statistical analysis in earnest to the management of the game, the stats that turned out to count were not necessarily the ones that people tended to focus on. As Albert Einstein observed, “not everything that can be counted counts, and not everything that counts can be counted.”

As we focus on these questions, remember also the second conception of effectiveness, what Peter Frumkin calls “mission effectiveness” or the larger role we hope our organizations will play as agents of social change. Making that kind of change requires community within philanthropy and with your grantees.

One of the most common expressions in philanthropy is “if you’ve seen one foundation, you’ve seen one foundation.” Grantmakers chuckle at that, but they actually take great pride in their individuality. Yet I do see some common themes that characterize

the field such as respect for diversity, desire to learn from colleagues, high expectations for professionalism, and commitment to improving people’s health. The question I have is how can we build on these to work together around shared issues and shared values to transform this field into a true community?

While we are at it, we might as well acknowledge foundations’ interdependence with those they fund. Building community with your grantees requires mutual respect, responsiveness, candor, and sharing. It takes getting comfortable with your power and prestige and using it to bring legitimacy to the community causes that you champion. At the same time, it requires recognition that having the money does not mean that you necessarily have all the answers. It calls for clear expectations about commitment on both sides, and real change requires staying the course and openness to learning.

Ultimately it calls for a kind of leadership that translates literally from the Navajo as “he who stands with us.” I know this is a tall order. But we all stand to gain if we truly share the work.

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## ACCOMPANIMENT: THE MISSING PIECE OF THE FUNDING PUZZLE

Paul Farmer

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It is a great honor to be here, to be invited to talk with people who are setting the trends and thinking hard about how to do philanthropy.

I am going to begin my remarks with Haiti but digress immediately back to an American city, the one I know best — Boston — to point out how some of the lessons learned in Haiti have been applied elsewhere. And then I will close by taking you to a place that has been riven by violence and by the very heavy burden of a preventable disease: Rwanda.

I feel emboldened to start grandly by introducing a word that is new to some people in the health community, although others will know it well, and that is the term “accompaniment.” This notion of accompaniment and some of the other lessons learned have been just that: lessons learned the hard way in settings where there are many obstacles to improving health. In each instance, in our experience, these obstacles can be overcome.

I am not so sure that I would have used the word “accompaniment” even five years ago in a speech such as this. The concept it embodies has been a very frustrating one for many of us since it is abused much more often than it is used effectively. But I think that I can clarify what we mean by sharing some exam-

ples as well as by referring to bigger issues that have already been mentioned by earlier speakers about community. These examples also can start to answer big questions — questions about social justice, what philanthropy means, and how we might invoke different models in thinking about our collective work.

I have thought a lot about what Dr. Martin Luther King, Jr. may have meant in saying that, “Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.” I think he was getting at something that resonates widely with all of us. The problem he refers to so astutely is not just about health and health inequalities but is about inequality of opportunity and access and about the direction in which the world is going. What I think Dr. King meant is that everyone here is going to be sick or has been sick. And everyone can imagine what it would be like to be sick but not have access to any kind of decent care, to say nothing about the kind of prevention that would make sickness involve less suffering and less early death. Dr. King said, I believe, something very profound: that thinking this way can bring a lot of people on board to support a broader movement for equity and to promote human rights.

Now I am going to turn briefly to the very specific, and this will be a sharp

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turn from what has been discussed already. (Of course, being a Harvard professor and a professional nerd, I am going to start with statistics because I want to talk about expert opinion in a loyal insider way. I will be very critical, as you can guess, about expert opinion and expertise as it is wielded today.)

The *British Medical Journal* published, in 2002, a graph that showed the plummeting life expectancies of Africans living in the Sub-Saharan countries with a high prevalence of HIV: South Africa, Botswana, Zimbabwe, and Zambia. When I first saw it, I thought it was a graph that I had seen before. I almost skipped right over it because I thought it was a graph of projections made a decade earlier by people such as Jonathan Mann at UNAIDS, for example, who predicted that HIV and related diseases, such as tuberculosis and malaria, would have a profound impact on life expectancy in many regions and especially in Sub-Saharan Africa.

But this was not a projection; it had actually happened. Amazingly, with all the frailties of demographics, epidemiology, and other quantitative methods, the predictions were stunningly accurate for the impact of this epidemic, or, rather, for the twin epidemics of HIV and tuberculosis, the latter of which is actually the major cause of death among people with HIV in Africa.

When we think about Hurricane Katrina and other problems that have afflicted this country, we refer to it as a “biosocial event”, because the real disaster is sociological and not really a natural biological one. HIV

and resurgent tuberculosis, however, have been big biosocial disasters. If this profound and abrupt a decline in life expectancy takes place, it does not take a degree in demography to imagine what this means for the fabric of society. (I will return to the question of AIDS orphans in closing, but let me just say now that there are an estimated 14 million children orphaned, one parent or both, by HIV just in Sub-Saharan Africa. Nothing of this sort has happened, really, in modern times. I am not sure it has ever happened.) This phenomenon should be more than just the blip on the grantmakers’ radar screen. In this country and elsewhere, it really is a significant and transregional issue. (Terms such as “transregional” and “translocal” are less appealing than terms such as “community” but they are better at describing epidemic disease.)

In contrast with the situation in Sub-Sahara Africa, there is now, in the United States, decreased death expectancy for people with HIV. Here we have our own health care system, which is ineffective, inefficient, and expensive. But even with that, our affluence and ability to get our hands on effective interventions still has a profound impact in decreasing bad outcomes. In other words, speaking more generally to grantmakers, in spite of all of the problems facing us, we can have an enormous impact on just about any major health problem that could be mentioned today.

How to explain the decreased death expectancy in the U.S.? Obviously, something happened in the mid-1990s, and that something was the develop-

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*HIV and resurgent tuberculosis have been big biosocial disasters.*

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## SPEAKER PROFILE

**Paul Farmer** is a founding director of Partners In Health, an international charity organization that provides direct health care services and conducts research and advocacy activities on behalf of those who are sick and living in poverty. His work is documented in Tracy Kidder's best-selling book, *Mountains Beyond Mountains*. Dr. Farmer's work draws primarily on active clinical practice. He is an attending physician in infectious diseases and chief of the division of social medicine and health inequalities at Brigham and Women's Hospital in Boston and medical director of the Clinique Bon Sauveur, a charity hospital in rural Haiti. Working with his colleagues, Dr. Farmer has pioneered novel, community-based treatment strategies for AIDS and tuberculosis in the countries of Haiti, Peru, and Russia. Dr. Farmer has successfully challenged policymakers and critics who claim that quality health care is impossible to deliver in resource-poor settings.

ment of effective suppressive therapy for AIDS. We call this combination chemotherapy, the word that gets used sometimes for antibiotics against tuberculosis and HIV disease, because you are using more than one drug. And in the case of tuberculosis, it is eventually curative, although it takes a long time. In the case of HIV, it is suppressive, not curative, but it is effective in managing this chronic illness.

Now I would like to invite you to imagine what it felt like to be moving between Harvard and Haiti at this time, in the mid-1990s. I had been doing that for more than a dozen years. Going back and forth between Haiti and Harvard has been really the most daunting and, in a way, inspiring learning experience, just as has been the shock of moving between Miami to Haiti in an hour and a half. To pick just one year for illustration, I chose 2003. I wanted to see how much

money Haiti had for public health and education in that year. The answer was that in 2003, in the face of a massive international aid shutoff to Haiti and to the elected government of Haiti, the budget for the entire country of between 8 and 9 million people was \$300 million. To compare, the city of Cambridge, Massachusetts, with about 120,000 people, had a budget that was higher than that. The teaching hospital where I work, just one hospital, had an estimated income of \$1.2 billion. These are just impossible inequalities.

In this era, about 1995, I was a fellow, doing my training in infectious disease at a Harvard teaching hospital where I still work. I was seeing lots of people with AIDS on both sides of that troubling trajectory between Boston and Haiti. In one day I found myself begging my patients in Boston to agree to take these antiretroviral medications and then spending my time a

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*In spite of all of the problems facing us, we can have an enormous impact on just about any major health problem that could be mentioned today.*

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few hours later in a place where I was being begged for access to the same medications.

I would submit that this experience a decade or so ago was not just anecdotal nor just my own. It was also the experience of others who were doing this work. We knew the medications were effective and we knew the burden of disease was growing rapidly in some places and shrinking in others. But it took us a long time, I thought — two or three years — to get these medications to Haiti, even though we were really trying hard. And we found ourselves completely alone. Here I am speaking to grantmakers: we could not find anyone willing to support a project to introduce this therapy to Haiti. It was a very difficult time.

Now fast forward to 2002, and think about the Global Fund (the Global Fund to Fight AIDS, Tuberculosis and Malaria), which was the first funding mechanism to take on these complex health problems. In 2002, this would represent 20 years I had spent in Haiti watching and waiting, since the very first case of AIDS in Haiti. And for the people, of course, who are living with these diseases, most of them did not last the 20 years. We had scrapped our way forward — begging, borrowing, though not stealing. I do not want to go into details, but we did just about everything to get these medicines. It was a very difficult row to hoe.

Then I got invited to give a plenary address to the 2002 global AIDS meeting in Barcelona. I thought, well, even though I've gone to these

meetings before, it would be irresponsible of me not to go this time because the battle is just now being engaged and maybe I can make an impact. And although 2002 may have been the year that the Global Fund was announced, the funding had not started flowing. At that point I do not think the President's Emergency Plan for AIDS Relief (PEPFAR) was even operational.

So I decided to go and to prepare my remarks carefully. I was going to talk about the importance of thinking outside the box, how to use these complex and expensive interventions in places such as Haiti and Rwanda, or wherever the burden of disease was heaviest. This does not sound like a very controversial thing now perhaps, but then it was. Some of you may have long enough memories to remember this.

In preparing my remarks I was using the Internet in, of all places, rural Haiti. I was looking at medical journals and just pulling things out of them. I found these two papers. (I will not tell you the authors' names because I do not want to get into a battle in this setting.) One said, and I quote, "Data on the cost-effectiveness of HIV prevention in Sub-Saharan Africa and on highly active antiretroviral therapy (HAART) indicate that prevention is at least 28 times more cost effective than HAART." The other said, "The most cost-effective interventions are for prevention of HIV/AIDS and treatment of tuberculosis, whereas HAART for adults, and home-based care

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organized from health facilities, are the least cost effective.”

Imagine slogging through the effort to get some of these medicines out there and then to read such things! There was this constant undertow of censorious comments about efforts, such as ours, given that the current religion or ideology was cost-effectiveness. I know you are subjected to it too because it is still the global religion of funding. But the confidence with which the claims in these articles are made is startling given their level of specificity. Obviously, you feel like a complete buffoon if you have spent all your time on the vastly less-effective intervention.

I was in Haiti then, so I asked a research assistant at Harvard to find me the references that were used to make such bold and confident claims because you could not see the references in the on-line version. In one of the two claims, the only data cited was a mathematical modeling exercise and some data from a *proposed* project in West Africa. In contrast, we had been doing this work for five years and we had real data.

But my big question here is not about AIDS or treating AIDS in resource-poor countries. Why would I importune you with these specifics? What are the metrics by which we can assess interventions? And what are the shortcomings of the current religion out there? Are they really ideologies?

Now I had learned the answers to many of these questions from

Haitians and I want to have the chance to give you one specific example that illustrates what it is we are working on and talking about in asking these questions. I live and work in a squatter settlement in the middle of central Haiti. And it looks, as you might imagine, very different now from 20 or 25 years ago. But it is a squatter settlement. People do not own the land, by and large. These peasant farmers — that is a term they use — were driven out of the valley by development of a hydroelectric dam that brought neither water nor electricity. It is a long and sad story. But, of course, living there and talking with people makes you very aware of what it actually means when you hear terms such as “sustainable development” given that the dam was one example of these development projects. It is similarly frustrating when you hear that certain approaches are not cost-effective or do not use “appropriate technology.” The Haitians have some words for these confident claims from experts and are suspicious of them as well.

So, we started this sassy project within our bigger health care program, and called it the HIV Equity Initiative, providing directly observed antiretroviral therapy and social support free of charge to more than 2,030 HIV-infected patients. The name perhaps was an unnecessary rhetorical flourish, but the Haitians really liked it. (When I say the Haitians, I mean our patients.)

I want to introduce you to a couple of our patients, with their blessing,

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Are they really ideologies?*

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since they have asked me to use their images and their names whenever possible. Most of you are involved in making the grants, but some of you are working in the very institutions, the frontline institutions, that meet people like the ones I am going to introduce you to.

Several years ago, I treated a young man who was wandering around urban Haiti sick with this consumptive disease. It turns out he had two diseases, and I am sure you can guess what they are. He got sicker and sicker, and eventually went home to central Haiti to die, ending up in a place called Los Cahobas, his home town. (By the way, whenever you privatize things and defund the private sector, notice how so-called free care from your mother or your aunt is gendered. It is another interesting story that is worth investigating, I believe.)

Just as an aside, speaking earlier of the Global Fund, we knew well before March 2003 that we would get money from the Global Fund to do this work, but then it did not show up. We had made promises to the community, to the people who we were serving, that we would open the public clinics in the area and introduce services like the ones in Cange to their communities. So we actually took out a loan from a commercial bank. We had to get one of our supporters, a Boston businessman, to back us up, to cosign the loan. That is how we started this project in August 2002, as promised, on schedule.

It made a difference to this particular patient because he arrived in Las Cahobas before the money started flowing from the grantmakers. Normally I would not go to this town, an hour-and-a-half away, to see a patient with AIDS and tuberculosis — an assessment by coworkers are more-than-able to do. But they asked me to come and see this patient, and I agreed, although I was not sure why I was necessary.

It turns out they wanted me to come and talk to him because this man, Joseph, had said he was going to die and his family had already purchased his coffin. I was asked by Haitian doctors and a student of mine to convince him that therapy was worth it and that it was not too late for him. (Of course, you can never be sure when someone is this sick, but his story turned out happily because as you can see from this photo, six months later, after therapy, this same man is alive and much healthier.)

There is more to this story, and now I want to go back to these broader themes of what does community mean? What does engagement mean? How do you measure the cost-effectiveness of that intervention for Joseph, for example? People in Haiti do not have much faith in public health because the public sector was defunded through a series of rapacious policies that were foisted by the donor community on poor countries. (More on that later if you would like.)

What reason would the villagers have to believe that someone could come

back from the brink? If you look at who would go into a prenatal clinic and ask to be tested for HIV ten years ago, before we introduced any of these interventions, it would be a very small fraction. Last year alone we did 52,000 voluntary testings with counseling, what are now called in the jargon “VCT”, which are a cornerstone of prevention. People such as Joseph helped make this happen just by surviving. But he did more.

I will return later to talk about the model of accompaniment that characterizes our medical care. Accompaniment here, for us, means that the patient does not have to get all the way to the clinic to get his care. He gets his care — and here I think is a good use of the word community — in his community, in his village. He has a community health worker whom we call an “accompagnateur.” She provides him accompaniment — not just giving him his pills but asking how he is feeling, finding out if he needs help with anything from child care to fees for education. Interestingly, in an interview that Joseph later had with another Haitian in my presence, he was asked a good question. The question was, “What do you want to do with your life now?” And he said, “I want to learn how to read.” That was his goal, to learn how to read. Now Joseph is going around and giving talks to other communities about AIDS prevention.

Earlier I mentioned the question of cost-effectiveness and confident claims about cost-effectiveness using the experience of someone I treated.

But let me be a little bit more hard bitten and less anecdotal. We go back to 2002 again, when it is held that one intervention is 28 times more effective than another. Here are the real data; this is not a mathematical modeling exercise. It costs about \$10,000 per patient per year to deliver one of those three-drug regimens. And already that year we were getting the same medicines for \$700 per patient per year. And the International Dispensary Association, which is the world’s largest nonprofit procurer of drugs, was already getting prices well below that. And then the price was lowered to just over \$400 per year. This is, again, not by accident. Some of you have heard about the Clinton Foundation’s engagement in this effort, which has been very helpful to us because they went and renegotiated the prices even lower. So it is now about \$150, or maybe less, per patient per year. This is a really profound change.

I use 2002 data because it was the very time during which the general wisdom was that you should not be providing this therapy in what are now called “resource-poor” settings. And then other critiques arrived: “You may be able to do this in Cange, Haiti but it is really not scalable. You cannot replicate it elsewhere.” We said, “Sure we can. What we need is for the grantmakers to support us.” This is what happened with the Global Fund grant.

Central Haiti is, as some of you know, very forbidding terrain. There are no roads, no telephones, and massive

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political upheaval. And yet during the worst years of the epidemic, the last few years, we have scaled up this same comprehensive project to improve primary health care and access across central Haiti.

I live in Cange, in the Central Plateau of Haiti, where there are only public facilities. Again, learning from our earlier mistakes in philanthropy, we spent ten years working very hard with our Haitian partners. We asked ourselves, after ten years, what have we done to strengthen public health, the public sector? Everybody said the public sector is no good. That is a long time to wait to ask that question. But again, just as with AIDS drugs, is that the beginning of a conversation or the end? You have to ask why. Why is the system no good? So we thought, how can we be unlike other nongovernmental organizations and grantmakers and contribute to rebuilding the public health system in Haiti? Our answer was to scale up our efforts with public institutions. So by the time we got to Rwanda, we knew what we were doing (the Haitian team particularly).

Now remember, this scale-up has taken place in the middle of some of the worst political turmoil Haiti has known. The reason that our patients never went without their medications is not because we were able to prevent our doctors and nurses from being kidnapped or our ambulances from being stolen by rebels. It is because we had made sure that this care would be delivered in the villages, in the community, by their neighbors. That

is “accompaniment.” It is accompaniment that made this project work under these circumstances.

Now what else does accompaniment mean? The experience of working in Haiti in the 1980s and 1990s without medicines was pretty much the same every time. People would come in and they would be withering away and they would say, “I can’t eat. My throat is too sore. I have diarrhea 10 times a day, I can hardly walk.”

Then you put them on proper therapy and they come back in the clinic, chatty as they can be. And sometimes I’m thinking, okay, we’ve got a long line here but they are saying, “Now I really need to get my kids in school and my house has a dirt floor,” and it goes on and on. The options, at that point, are to say “please leave,” or to listen to the patients. We listen to them when they talk about sending their kids to school or having clean water or having housing or learning how to read, as Joseph had answered. It was obvious that we had to get involved in this accompaniment in order to make these projects work.

But to go back to the human rights logic and Martin Luther King’s statement, is it not also good to say that we used the circumstance of AIDS to get at these broader questions of equity and of basic human rights? You know, human rights language is frowned on in public health circles, interestingly, because it used to be very popular. In the 19th century, efforts were largely focused on basic rights. The language may have been a bit different but

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people were given the right to clean water and the right to decent housing and the right to school. That is really strangely absent from the public health discourse today. (Not so absent, interestingly enough, as in a teaching hospital.) In the places where we need it most, discussion about human rights, community health and public health is missing.

Let me now go back to my home country. Some of you may know Carlos del Rio, who is an infectious disease doctor at Emory University. His team put together a comprehensive AIDS clinic right where it should be located in the city of Atlanta. When I say comprehensive, I mean it has a WIC office and a dental office. You can get chemotherapy. It is all right there.

So it is as good a job, in my opinion, as the medical profession can do without real accompaniment. And yet, if you look at the numbers, and it is a small cohort, only 13 percent of the patients enrolled on antiretroviral therapy have suppressed viral loads (a measure of how much virus there is in the blood) a year later. That figure in Haiti, with accompaniment and community health workers, is probably 90 percent. We are not even doing those tests anymore in Haiti because we know that the viral loads are suppressed. The tests are expensive to do, and we are not going to do them, not in Rwanda, either. That is not how we measure. One of the radical and novel metrics we use to measure our patients' response is to ask them how they are doing.

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*What if we could take the experience of accompaniment of our patients in Haiti and bring it to Boston?*

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So this experience in Haiti and working as a doctor in Boston, along with many others, of course, led us to say: what if we could take the experience of accompaniment of our patients in Haiti and bring it to Boston, bring it to the so-called inner city? (Now I made a mistake in my university of saying, "how about if we take a Haiti-level of care and try to bring the Harvard-level of care up to the Haiti-level of care?" My colleagues were irritated beyond belief, so I was asked to stop saying that.) But that is basically what we did. We took the same model of accompaniment, using community health workers, except that the enrollment criteria were much more stringent. In other words, we offered these services in the United States only to patients who had failed conventional therapy and had drug-resistant HIV. And they had to have low CD4 counts. These were really the sickest patients. These were the people who were ending up in the emergency room getting expensive high-tech care for primary health care problems.

So we took the model to Boston. And actually, guess what kind of problems we had starting this, oh dear grantmakers? We could not find funders at first. (Actually, the Blue Cross Blue Shield of Massachusetts Foundation came to our rescue, as did Harvard, the teaching hospital.) People said it is too expensive to have community health workers. In Haiti, it is cheap; you only have to pay them a tiny honorarium. But it costs too much to do this in the United States. But we were saying, no, it costs



too much to *not* do it. If you have someone bouncing in and out of a Harvard teaching hospital or Boston City Hospital with complications of advanced HIV disease who has never had sustained therapy, you are spending hundreds of thousands of dollars to deliver bad care. I mean, it is good when they are in the hospital and you are putting in a shunt because they have a parasitic infection in the brain (that only happens when people do not get care) and they get good neurosurgical care and good intensive care, and then they go out into the famous “community” for follow-up health care. Nurses and doctors cannot do home visits all the time. Yes, there is a distinguished tradition of nurses doing home visits and there used to be a distinguished tradition of doctors doing home visits, but that is no longer considered a sustainable model of care.

Think about diabetes. Think about seizure disorder. Think about major mental illness. For every chronic disease for which we have an intervention, a deliverable, how are we using that deliverable? The situation with infectious disease is acute because the microbes, whether viruses, bacteria, or microbacteria, develop resistance to the drugs if used improperly. So you really are forced to think about this more quickly in talking about infectious diseases. No matter what tools we develop to take on these chronic diseases, if we do not have a plan that allows us to reach so-called vulnerable populations or the community or whatever jargon is used next year, if we

do not have a good plan to use these tools wisely and equitably, we are going to have more bad medical care. And the cost is not purely economic.

We have encountered some forward-thinking funders and grantmakers. (Of course, in my position, whenever someone funds us, we say they are very forward-thinking, very progressive, very astute, and really represent the cutting edge of funding.) Our program in Boston is still, to this day, hard to fund, which is a shame, because yes, it is expensive. But it is just nowhere near as expensive as it is to provide this bad a level of intermittent medical care to Americans.

The same must be true in other affluent countries. Even those with good national health programs still do not have enough in the way of community-based care. It looks just like it does in Haiti, except that the community outreach workers have cars and not donkeys. Some of the community outreach workers from Boston came to Haiti and for the community health workers in Haiti, the *accompagnateurs*, the thing that most surprised them was the notion that a community health worker could have a cell phone or a car. Those in Peru, where we have also extended this model, have cell phones and now they are using hand-held Palm Pilots to enter data. Who knows where we are going to go in Rwanda, but we are going to try to strengthen the hand of community health workers because we know that is how we can provide better-quality services for the patients.

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*People said it is too expensive to have community health workers. But we were saying, no, it costs too much to not do it.*

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This model is also very important for prevention. In Boston, as in Haiti, we have been recruiting people—young people—living in these neighborhoods. As an aside, this group of, as they call themselves, kids, just wrote a grant proposal themselves and got \$2,000 for their work. Grant writing is a nasty business so I am very proud of them. This is a group of people who have been struggling with addiction and now they are leading the prevention and harm-reduction side of this project.

In closing, let me take you very briefly, to a continent that I think really merits all of our attention in this interconnected, global era in which we are living now. There are many children and many older people but there are few parents. This is Ground Zero of the AIDS epidemic. I'm going back to Rwanda but before that I am stopping in Western Kenya. I will tell you why.

Recently I was invited, at the behest of funders, to go to Kenya and sort through some problems they were having with another organization. This is a very interesting position, when you have always been on the whining end of things, to be able to go ahead and say, if you really want to fix this, you ought to do this, this, and this, and then to know that the funders back you. That is a very special kind of a power trip. Anyway, I hope for the right reasons, we were able to make some very substantive suggestions — all around the idea of accompaniment — to the people working in Western Kenya. And

they followed them. The results have been really exciting for us to see. So I am going back there on my way to Rwanda.

Less than a couple of years ago, we decided—and we knew not to do this until the time was right — that we could promote a comprehensive model to institute primary health care, basic economic, and social rights such as housing, primary school, and so forth. We did not want to begin working in Africa without being able to do that. So it took us two years to feel comfortable that we had the right combination of support for our comprehensive program. We had some funders of our own and support from the Clinton Foundation, and lots of what is called political will on the part of the Rwandan government and ministry of health. So finally we were going to work in Rwanda.

A year ago last November, the government in Rwanda told us that they were going to choose the sites where we were going to work. (We learned in Haiti that it is better for the government to choose the sites, to strengthen the public sector.) They took us to northern Rwanda, to a place called Ruhengeri, and brought us to a hospital. It's a very beautiful part of the world. There were lots of problems but it wasn't like Haiti. There was electricity and an x-ray machine and it was clean. It was really paradise compared to Haiti.

I made the mistake of saying to the minister of health, in front of the director of the national AIDS

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*I thought Haiti was bad, with its statistics of one doctor per every 20,000 people in rural areas. But 350,000 people without a doctor — and really without nurses either — was very, very daunting.*

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program, “Is this all you got? This is easy. We can do this, no problem.” The director of the national AIDS program is a Rwandan pediatrician, and she turned to the minister and said, “Throw Partners In Health into the most rotten part of Rwanda and they will flourish.” So they sent us to an area of around 350,000 people where there were zero doctors. Zero. That, I would say, is really grueling. I thought Haiti was bad, with its statistics of one doctor per every 20,000 people in rural areas. But 350,000 people without a doctor — and really without nurses either — was very, very daunting. But we felt that we knew what we were doing after our experience in Haiti. It is amazing what cleaning things up and painting them and putting tile on the floor and things like that will do to bolster morale. We put in a modern lab. And we put in place the critical tools (including labs and medications) that the providers of health care, whether community health workers or physicians, need to do their work.

We hear that there is a brain drain. Is that a surprise? Who would want to be an African doctor in a place where you do not have the diagnostic and therapeutics that you need to do a decent job? I know I would not.

We also had learned from Haiti that telecommunications was a problem. But as we had learned, if you do not have a telephone, put in high-speed Internet access instead, and so we did. (If someone ten years ago had said since you do not have roads and electricity in Haiti, why not use

high-speed Internet access instead, I would have thought that was silly. But it turns out to be just the way to go.) We can send, from Haiti to Rwanda, an X-ray, which is a lot of data, in a minute. And in fact, we do this all the time. The Rwandans do what we call a daily report, just like the Haitians, and we share all this information, whether we are in Siberia or Peru or Boston or Haiti or Rwanda. It has been a wonderful thing.

A lot of this began through funding to fight HIV/AIDS. But it really was never just about that. It was about these broader goals that I mentioned. We have been able to scale up in rural Rwanda much more quickly than anywhere else. In six months, we went from more than 100 patients receiving AIDS or tuberculosis treatment to more than 700 patients. This was accomplished only because we used the model of accompaniment. Accompaniment in Rwanda has meant almost the same thing as in Haiti. Say, for example, you are trying to prevent mother-to-child transmission of HIV. Mother-to-child transmission of HIV is readily prevented, which is why there’s no more pediatric HIV disease in the United States to speak of. A lot of people do not know that we have almost wiped out HIV disease among children in the U.S. Because if you give the right medicines to mothers, not just to prevent transmission but to take care of the women, then their children will not get HIV.

But to do that, there is a lot else that has to be done. For example, breast

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feeding is not a good idea if you are trying to prevent mother-to-child transmission. In the United States that has not been problematic for the most part, but imagine the situation in rural Rwanda or rural Haiti, where people do not have access to water, let alone infant formula.

So we knew from our experience in Haiti that we needed to get the water, the stoves, and the infant formula to the women in this program. But then we also knew we had to visit them at home and accompany them. And what we saw was just like in Haiti. Take the family in Rwanda in this photo — a woman, she is a widow with, I think, three or four children. And on the inside of her shack, on the floor are, of course, the materials that we have given her. A thermos we provided is stuck in the wall.

Is this the beginning of a conversation or the end of one? Are we going to say well, it is really too hard to do this in resource-poor settings such as Africa? Or are we going to say, what do we do next? The answer that we developed in Haiti with our Haitian partners was obvious: we improve housing. So we started this program in Haiti called the Program on Social and Economic Rights. Let me tell you, the grantmakers are not rushing to fund that either, which is a shame really because social and economic rights are the basis of accompaniment, whether in the United States or anywhere else. I do not think it is going to be popular in many circles, expert or public health circles. But it could be very popular in funding circles. Or at least it could be mandated to be of concern.

There is a difference between charity, development, and social justice. I don't knock charity much, although I think charity, compassion, pity, and empathy, are unstable concepts. But they're not bad concepts, and the world would be a lot less mean if there were more of those sentiments.

Development work has become such a huge machine now that it has its own internal critics, which it can well afford. We have tried to learn from development and its formal professionalized expertise. That expertise, though, contradicts itself every ten years. It says do structural adjustment. Oops, we were wrong, we killed lots of people, don't do it anymore. Or big is good, small is bad, and so on. It is better to take what you can of the good and not be dismissive of expertise that comes from development, but know that it's not going to be a guiding light for our work.

So what does that leave? It leaves for us this notion of social justice which is ahistorical. If you talk about alcoholism among Native Americans, do you really not want to talk about land appropriation and genocide? No population appreciates having their history erased. If you want to talk about crack addiction among African Americans in New York City, do you really not want to talk about racism, institutionalized racism? They hate it when we do that, to say nothing of those in Haiti and Guatemala and many other places hating it too.

So what are historically informed ways of doing work like yours, like

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*Growing social inequality is the basis of a lot of the epidemic disease we see. It's structural violence.*

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ours? That is, being honest about the social forces and processes that leave some people vulnerable, marginalized, oppressed, impoverished, and leave others well protected from any of those slings and arrows. And acknowledging that growing social inequality is the basis of a lot of the epidemic disease we see. It's structural violence—a term borrowed it from liberation theologians and a couple of other sources. It describes well, I think, what people are talking about when they have to fight every day.

In each of the places I mentioned — Haiti, Rwanda, Guatemala at the end of a civil war, Peru at the end of a civil war — we didn't go there because there was violence. But we did find ourselves developing expertise because of the violence. And one of the reasons that I think we're still there and we have such deep roots is because we talk the language of social justice which, by the way, we borrow from the people we serve.

Having nongovernmental organizations and charities and foundations do this work is good, but it's not the same as having these things — water, education, food — as a right. And who is the guarantor of the rights of the poor in health care and education? It is the public sector. And again, if the public sector is weak and inefficient, is that the beginning of a conversation or the end of one? Partners In Health is very committed to strengthening the public sector, not necessarily from the center outwards (beginning with a capital city or a national plan, although we do that

as well). But because we believe that the ultimate guarantor of basic rights in education, water, and health is the public sector, although much maligned even by nongovernmental organizations and foundations. Community-based organizations are fine but no one elected us; it is legislation and the public sector that are the guarantors of rights.

So my one little funding story to close is this. The group that did give us some money for this project, which is called in Rwanda, as in Haiti, the Program on Social and Economic Rights, is very interesting philanthropically. The funder is major brand of lipstick. When I went to a meeting to make this pitch to an AIDS funding initiative, all the proceeds from this particular kind of lipstick, which I think is called Viva Glam, goes to AIDS work. So I went to this meeting and they said, "would you like to see Estee Lauder's bathroom?" I thought the only polite thing to say was well of course and I did.

I hope that wherever they are they are proud, because this team in Rwanda built a house in three days. The bricks were made with a little machine that mixed mud and dirt. And then it has a coating of cement afterwards. In front of house stands the mother and her baby and her other children. Also present is the same woman, the pediatrician, who banished us to this area, the director of the national AIDS program, who is very pleased, I think, with what we have been able to start in Rwanda and what we hope to keep going for a very long time.

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*Having nongovernmental organizations and charities and foundations do this work is good, but it's not the same as having these things — water, education, food — as a right.*

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## REMARKS ON ACCEPTING THE 2006 TERRANCE KEENAN LEADERSHIP AWARD IN HEALTH PHILANTHROPY

**Robert E. Eckardt**

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A heartfelt thank you to the selection committee. This is really an honor I never expected to receive. Terry Keenan was one of the early staff members at the Robert Wood Johnson Foundation when it first became a national philanthropy. He was a consummate professional in everything he did and one of the best and most caring listeners I have ever met.

I had the opportunity to work with Terry in the early days of the Local Initiative Funding Partners Program. Every time you made a site visit with Terry, you would find him bringing up the rear. This was not for lack of interest, far from it. Instead, you would find that Terry had stopped to talk to people. He was engaged in conversations with everyone at the site visit, staff, patients, family members, local funders, the van driver, anyone he could talk to. He valued everyone he met and, in turn, I always valued the time I spent with him and how much I learned from him. So receiving this award named for Terry is a very special and a very personal honor for me.

It is also a privilege to receive an award from your peers and from Grantmakers In Health, an organization that has set a high standard in

our field over the years. I know that, under Lauren LeRoy's strong and effective leadership, that standard for GIH will continue to be met.

Over the years, I have benefited from many colleagues from whom I have learned so much. Although it is always dangerous to begin to name individuals, I will mention a few. Early in my career I had the opportunity to work under two great leaders in the foundation field: Homer Wadsworth and Steve Minter. Both men won the Council on Foundation's Distinguished Grantmaker Award during their tenure at the Cleveland Foundation.

I was especially close to Steve Minter, who was my program officer when I moved to Cleveland, then a colleague of mine at the foundation, and later my boss when he was promoted to director. I worked with him for more than two decades. I always felt he set the standard for community philanthropy.

Here, I would also note my fellow staff members of the foundation. Many of you have gotten to know Stacy Easterling over the past few years. She is emblematic of the exceptional people I have been privileged to work with and learn from.

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*Terry Keenan was a consummate professional in everything he did and one of the best and most caring listeners I have ever met.*

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Over the same time, I have also had the honor to work with a truly distinguished group of women and men who serve on the board of the foundation. Although serving on the board of a foundation is often seen as an honorific position, I know from firsthand experience the importance of strong and engaged board members, particularly in a field where metrics are difficult and the customers rarely complain.

One thing I have learned is that the foundation field in Cleveland differs from that in many other communities in its degree of cooperation. We may not always herd the cats successfully, but we have been successful in avoiding cat fights. I know of nowhere else in the country where you could pull together a \$30 million fund with more than 70 funders pooling together and sharing power to support regional economic and community development like we are doing in Cleveland.

Here I would particularly note my colleagues at the so-called conversion foundations. I know that colleagues from three such foundations in Cleveland are present today, the Mt. Sinai Health Care Foundation, the Sisters of Charity Foundation, and the Saint Luke's Foundation. As in other communities, these colleagues have brought a special energy and commitment to the field and have kept all of us fresh and energized. As a former board member of GIH, I certainly know they have that effect on this organization, as well.

I am extremely pleased that members of my family are able to be here, as well. When working in a community foundation you spend a lot of off hours on the job, whether it is the weekend board retreat of a grantee agency, the grantee's annual meeting, always in the evening it seems like, or the ubiquitous — at least in Cleveland — 7:30 breakfast meeting.

If you were ever fortunate enough to get the call from Lauren LeRoy informing you that you have won the Keenan Award, she will tell you that your selection means you get a chance to address your colleagues at the GIH annual meeting. What she will not tell you, but what you will soon discover, is how difficult this speech will be to write.

How do you reflect upon your work without sounding pedantic or preachy? Do you really have anything worth sharing? However, I take some solace in the fact that the theme of this conference, *From the Ground Up: Improving Community Health, Inspiring Community Action*, fits so well into what I wish to share with you.

What I want to speak about is the leadership role that foundations have. When many of us tell our friends what we do, we may cynically talk about foundations as piles of money surrounded by people who want some, with the staff playing a kind of mediating role. Although access to resources is a critical component of our role, just as important, I believe, is the leadership role we at foundations can play, but too often fail to seize.

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## SPEAKER PROFILE

**Robert E. Eckardt** is senior vice president for programs and evaluation at The Cleveland Foundation. Working with the Foundation's board of directors, he is responsible for providing overall direction and supervision for grants that total about \$60 million annually. He also has responsibility for managing activities related to program evaluation throughout the foundation. He also serves as a member of the foundation's management committee and is a corporate officer of the foundation.

Dr. Eckardt received his undergraduate degree from Grinnell College. He attended the University of Michigan where he received a master's degree in public health and a certificate of specialization in aging. He received his doctorate in public health, focusing on health policy through the Pew Doctoral Program at the University of Michigan.

Because of a unique combination of advantages we have, we are in a singular position to listen to our community, to inspire it, and to support it. Among these advantages is the ability to take the long-term view, to look beyond the interests of any single institution, to bridge between sectors, to amplify a voice that needs to be heard, and to allow others to take the credit for success while we take the blame for failure.

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I would like to present four examples. As some of you know, I have a strong personal interest in issues of long-term care. It is really at the interface of many of the challenges in the health care system, those we will be facing going forward, including an unprecedented demographic shift as societies around the world age, and our ability to treat, but not cure, many chronic diseases with the attendant increases in the burden of providing care over an extended period of time.

Yet despite the fact that, on any given day, more people are in nursing homes than in hospitals, and despite the fact that lifetime risk of nursing home placement is quite high and higher than most people estimate, few foundations have worked to address this. In contrast, we have worked extensively in this area, challenging the status quo around issues such as environmental design, staffing, and patient care. We have done it through forcing collaborations in a way that ensure that the benefits do not just flow to those residents of a select group of largely suburban philanthropic facilities.

For example, some 15 years ago the foundation led an effort to reduce or eliminate the use of restraints in Cleveland nursing homes. We identified barriers, most of which were attitudinal, on the part of administrators, and supported demonstration projects in both suburban philan-



thropic and in inner-city proprietary nursing homes to demonstrate that these barriers could be overcome.

We then supported implementation of the results, along with staff training for nursing assistants, those hands-on care providers. The result: every participating nursing home but one exceeded its restraint reduction goal, with several going completely restraint free. Long before it became a regulatory requirement, residents in Cleveland nursing homes were benefiting from new measures of autonomy, which led to them actually becoming safer than they were while they were restrained.

My second example deals with a specific area of medical education. Cleveland is privileged to have a very good medical school at Case Western Reserve University. Traditionally, however, this was a school that had defined its mission rather narrowly, that included neither a strong emphasis on primary care nor a commitment to enrolling more underrepresented minorities.

Every time Case approached us for support, we raised questions about this area. As the scenario repeated itself, the frustration grew. They asked us for support of their mission as defined, we raised questions about whether the mission was the right one for Cleveland. Not surprisingly, both sides were frustrated, until finally the logjam broke. They made a request to us to be helpful, rather than merely critical. This was a fair request.

This led to a multiyear commitment from Case and from us. Case broadened its educational offerings in primary care. It changed both recruitment practices and distribution of scholarship dollars. It began summer enrichment programs for talented minority undergraduates. It diversified its faculty. We supported these efforts.

There is a wonderful capstone to this story. Several years ago Case found itself profiled on the front page of *The New York Times* as one of six model schools, and the only one not known primarily as a primary care medical school, to be a leader in enrolling and graduating underrepresented minorities. Case deservedly received the credit, but all of us at the foundation took pride in the leadership role we played in creating this vision and making it a reality.

My next example also includes Case. For years Cleveland was the site of a cold war, my colleagues will remember, although sometimes it became quite hot, between its two leading medical centers, University Hospitals of Cleveland and the Cleveland Clinic. Case Western Reserve and its medical school were caught in the middle. What was really striking was that in Cleveland, which is really a big small town, these two medical giants were literally within a half-mile of each other and Case sat right between them.

This cold war went far beyond clinical competition. The animus was palpable. You know the old saying about academic politics being so

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vicious because so little is at stake. I do not know whether so little was at stake here, but it was vicious, with at least two presidents of Case facing no-confidence votes when they tried to bridge the divide.

Then one day the Cleveland Clinic made a major announcement. It would either start its own medical school or affiliate with Ohio State, a mere 145 miles away. It would shut out Case's medical school entirely.

We recognized this escalation was not helpful to Cleveland. We quickly spoke to a number of people in Cleveland, all of whom recommended we stay as far away from this as possible. I remember two reactions in particular. One was from the most powerful civic leader in Cleveland at that time. He said he felt impotent, a word I did not even know he knew, to solve this issue. The second, from a distinguished business leader, noted that this was the one topic that community leaders had taken off the table. They felt that they could discuss anything else and mediate any other issue except this one. It was simply too hot. As he told me, it separated friends and was best left untouched.

Good advice? Perhaps. But in any case, we chose to wade in because no one else could or would. Our first step was to issue a moratorium on all grants to both hospitals. This was fairly easy to do. Neither of the hospitals were a major recipient of support and we were small potatoes to both. However, we did it with a big splash. We publicly announced our

moratorium with a press conference and got tremendous media coverage. We indicated that we would hold our moratorium in place until our study commissioned on medical research and education had completed its work, an impressive sounding group we had yet to assemble.

But assemble it we did, under the leadership of Bill Anlyan, retired chancellor for health affairs at Duke, and they spent a year coming to Cleveland once a month and looking at the issues. They released their report in 1995.

Now I would love to tell you that this report led to immediate changes. It did not, however. As we went around and delivered it to the various parties, we were belittled as simplistic and out of our league.

But a funny thing happened. In the years that followed, as new leadership came to Cleveland, I kept getting calls asking for a copy of the report. No one knew what to call it, but they said, "we understand there is this report." We did not have anymore copies of the report, but luckily I had saved the master in my office, so we were photocopying it and sending it out to people. These new eyes read the report and new questions were asked. Today we have a rapprochement that we could never have anticipated.

My final example deals with AIDS. In the early days of the epidemic, then known as the gay cancer, three men came to see me and indicated they were forming a committee called the

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Health Issues Task Force to push the city of Cleveland to prepare for the epidemic, an epidemic with 44 cases in the state of Ohio at that time.

Intrigued, I called our city's health director and asked her what she was planning. She indicated a desire to do something, but that she had no discretionary money. Believing this was an important issue, we made a modest grant to the city to develop and implement its first public awareness campaign. With this move, we became the first non-coastal community foundation to make a grant related to AIDS.

Although the grant was important, more significant was that we indicated that the city needed to work with the Health Issues Task Force in developing the campaign's content. This forced a collaboration that otherwise never would have occurred.

But our role did not stop there. When it was time for the Health Issues Task Force to become our first AIDS service organization, it was very hard to identify board members in Cleveland, a town not noted for tolerance in matters of sexual orientation. I therefore had to quietly recruit the first board for the renamed AIDS Task Force.

Recognizing that the foundation's imprimatur would allow some people to serve on the board who otherwise would have chosen to say no, we made a number of confidential visits and asked people to assume a leadership role on what was a difficult and controversial issue in Cleveland.

Our work on AIDS nurtured a latent local response to the epidemic and became the example that catalyzed the Ford Foundation, not traditionally a health funder, to commit several million dollars to support efforts in other medium-sized non-coastal cities.

As I hope these four examples demonstrate, giving away money wisely, while never an easy part of our job, is really only part of our job.

I ended up working in health care due to a series of personal experiences in my teenage years. I lost my mother to metastatic breast cancer just after my 14th birthday and lost a best friend to leukemia within a year, while at the same time watching yet another friend's family struggle with an inherited neurologic disease that left three siblings blind and severely disabled. These experiences, whether consciously or unconsciously, dictated my career path.

Since that time, we have seen improvements in health care that would have made each of those lives and the lives of their families better. We should all recognize that, as we go about our work and encounter statistics that the statistics we see day in and day out consist of real people, people with their tears wiped off, hoping that we will make their lives better.

We all need to have a sense of urgency and to use all of the tools at our disposal in the work we do to improve the lives of others. I hope that is what this award symbolizes and I thank you all very much for it.

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*Giving away money wisely, while never an easy part of our job, is really only part of our job.*

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## CHANGEMAKING, NOT JUST GRANT-MAKING: THOUGHTS ON CREATING REAL AND SUSTAINABLE CHANGE IN COMMUNITIES

Ralph Smith

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*As our focus has evolved from child rescue to family strengthening, so has our approach to the enterprise as a whole. It is fair to say that we are in the process of redefining the business we are in. Many of us see grant-making as what we do. Our business however, is really about changemaking.*

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Much of what I have to say this morning is extracted from what I have learned during the decade plus I have spent at The Annie E. Casey Foundation. Casey's mission, simply put, is to improve the prospects and life chances for vulnerable children and families. And over the past two decades, the journey inspired by that mission has allowed us to learn much about what it takes to make a meaningful and durable difference. Ours has been a journey some may find instructive. Others might see it as a cautionary tale. And for others still, the truism holds: If you have seen one foundation, that's what you have seen, one foundation.

### From child rescue to family strengthening

Throughout Casey's journey — from New Futures to Rebuilding Communities to the Jobs Initiative and then to the design and development of Making Connections, our current flagship initiative — we have tried to make a difference, tried to produce results, and tried to remain open and appreciative of what we are learning.

True to the legacy of our founder, Jim Casey, the early decades of our

work focused on improving outcomes for children who were removed from their homes and families by the child welfare and juvenile justice authorities. As this work progressed, and as we looked upstream for ways to keep these children from falling into the deep end systems, we noticed another phenomenon: a large and growing number of children who are still at home, neither removed nor at imminent risk of being removed from their families, whose outcomes were just as bad as those children in the child welfare and juvenile justice systems. For many of us, these data crystallized a nagging concern: our work and that of others in this field was too tilted toward child rescue.

For many and good reasons, we had focused on the safety and well-being of the children. That was priority one. That focus, however, failed to accommodate an important reality. *Families are co-producers of good outcomes for their children.* This coproduction role is not easily replaced when families fail. A large number and growing number of children live with families under so much stress, and in such distress, that parents and caregivers are incapable of helping to produce good outcomes for their children. In fact,

some families actually are contributing to bad outcomes for their children.

This insight led us to move, quite intentionally but not easily, from child rescue to family strengthening. We began to focus on what makes families strong — connections to economic opportunity, positive social networks, effective services and systems. And we saw that the families who needed those connections the most almost always had the least. Family strengthening helped us to understand that, those of us who care about the future of children must care about the present circumstances and conditions of their families. And, further, if we care about families, then we have to care about the communities in which they live. Families matter. Place matters. In short, we had to do more, and we had to better.

## From grantmaking to changemaking

As our focus has evolved from child rescue to family strengthening, so has our approach to the enterprise as a whole. It is fair to say that we are in the process of redefining the business we are in. Many of us see grantmaking as what we do. Our business however, is really about changemaking. And we are learning that success in the changemaking business depends upon:

- choosing the right problems to solve,
- leading with powerful ideas,

- becoming relentless about results,
- seeding and cultivating a “common sense consensus,” and finally
- building durable community capacity.

Changemaking starts with choosing a problem that is seen and widely understood as pervasive, enduring, and urgent.

The sweep of history illuminates the three big drivers of change: authority, incentives, and ideas. What we know about authority is that the changes it inspires last only as long as the authority itself. As for incentive, those of us who are in foundations know all too well that change, like affection when purchased is really just leased. And that lease runs out as soon as that last check is in the mail.

With persuasive evidence that neither authority nor incentives are sufficiently powerful and durable drivers of change, change driven by powerful ideas seems a better bet. People do not die willingly for authority, and they try not to die at all but live for incentives. But people will work and struggle and give their all for a powerful idea. So if we want to be in the changemaking business, we have to find, lift up, articulate, and illuminate powerful ideas.

We must become relentless about results, pay attention to measurement, find good data, and build a results culture. Too many of us care about the futures and outcomes of disadvantaged children, and vulnerable

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## SPEAKER PROFILE

**Ralph Smith** is senior vice president of The Annie E. Casey Foundation, which he joined in 1994 after stints at the University of Pennsylvania School of Law and senior leadership positions in Philadelphia public schools. At the foundation he helped design the Neighborhood Transformation and Family Development initiative — a comprehensive effort to help communities improve outcomes for children by strengthening families and neighborhoods. Mr. Smith has spent the last decade working with a broad range of efforts to improve national and international philanthropy, including service on the board of directors of the Council on Foundations, the Aspen Institute Roundtable on Comprehensive Community Change, and the Venture Philanthropy Partners' board of advisors.

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*In a political environment that is increasingly polarized and partisan, we must become extraordinarily disciplined about keeping our eyes focused on policy, not be distracted by the politics, and try to articulate common sense solutions for children and families. Finding common ground and building bridges across the partisan, ideological, geographic divides is important and even urgent work.*

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families without really believing in their abilities and aspirations. I'll say more about that later, but in the final analysis, committing to results is the acid test of belief.

Although there is a relationship between politics and policy, they are not the same; in fact, they are different in fundamental ways. Much of politics is about finding that little difference, that bit of distinction, and exaggerating it into a major disagreement. Nobody has ever won an election saying, "You know, I barely disagree with my opponent." Instead, we find that difference and we scratch it and exacerbate it and exaggerate it until we make it into something that appears to be meaningful. Small differences are magnified into chasms.

On the other hand, the task of policy is to hear discordant voices, see divergent positions, and then search for the common ground. In a political environment that is increasingly polarized and partisan, we must

become extraordinarily disciplined about keeping our eyes focused on policy, not be distracted by the politics, and try to articulate common sense solutions for children and families. Finding common ground and building bridges across the partisan, ideological, and geographic divides is important and even urgent work.

What matters most? The three things that matter most are capacity, capacity, capacity. If we care about change, we must prioritize building durable capacity in the people, in the organizations, and in the institutions that do the work on the ground. By capacity, I mean the ability, among other things, to articulate a shared vision for change, to build strong partnerships across sectors, to cultivate and sustain leadership, to communicate effectively, and to use data to ensure accountability for results. By capacity, I mean that we nurture, sustain, and replenish leaders. The next successful effort I see without strong leadership

will also be the first. And yet, when it comes to leadership development, too many of us pretend as if serendipity is a strategy.

## What's your theory of change?

Once we have paid attention to choosing the problem, leading with ideas, being relentless about results, finding a common sense consensus, and building capacity, we can take on some of the other challenges of changemaking.

First, we need to move from “theory of change” as mantra to theory as a meaningful tool for accountability. Admittedly, for the boomer generation of philanthropoids, “theory of change” has taken the character of “what’s your sign?” The answer is not nearly as important as the conversation starter. Even so, we should take more seriously the benefits of insisting on an articulated logic model that is plausible, testable, and sufficient.

Let me focus for a moment on sufficient. In my view, it is the sufficient criterion that presents the biggest challenge to grantmaking. Sufficient requires some demonstrated nexus between strategies and results.

While David Lloyd George might have made the point more eloquently, Evel Knievel, one of my favorite philosophers, said it best, “You can’t cross the Grand Canyon in two small jumps.” He had a fundamental understanding of the notion of sufficiency.

Too much of the work we support proposes to cross the Grand Canyon in many small jumps. We need to really wonder aloud, wonder with each other, wonder with our grantees, and wonder in the context of our work, whether and how we demand more realistic outcomes, or demand more powerful strategies.

## Sustaining success, getting to scale

We also have to ask ourselves whether the same theory of change that produces results also will be sufficient to sustain those results and take them to scale.

For example, many of us make challenge grants. Sometimes we do this to stretch the dollars. On many occasions we require the match because we know that the broader the base of support, the more likely it is that success can be sustained. We understand that when sustainability is at stake, the source of the resources matters as much, if not more, than the amount.

## Respectful engagement of communities

The second set of issues has to do with engaging the community. For many in philanthropy, especially in foundations, this is a tender topic. There is an unavoidable tension between respecting the community and the stewardship obligations that attach to foundations. To the casual observer, it would appear that this tension is resolved by the simple proclamation

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that “the community knows best.” Sometimes this is an attempt to avoid bad behavior as represented by the pomposity, too arrogance and intrusiveness that too many assert as the perks of position. Sometimes it is cowardice. Sometimes it is abdication, pure and simple.

The truth is closer to heresy. “The community” is not monolithic and it does not always “know best.” And part of the challenge is that we lack the language to speak truth in the face of unresolved issues of race, class, gender, language, ethnicity and most of all, power. So we default to political correctness, and we mumble around race afraid that we might have to talk about it. How can we say that white people are not all-powerful, and that people of color are neither all virtuous nor all victims? We have no language to acknowledge and no metrics to account for embedded inequity and enshrined privilege. So we default to pc-speak, defer uncomfortable conversations, and risk paralysis when it matters most. Anyone who doubts that need only look at New Orleans today.

That is not to say that it is easy to work respectfully and collaboratively in communities and with low-income families and residents. Acute awareness of the imbalance of information that exists between those who study the issue, read the literature and those who live with the problems. Let me suggest this is because we do not have a good sense of how to create the knowledge we need to solve the problem. We pay for all this research,

so we do know a lot. We shouldn't be afraid to say that. We ought not to be apologetic about the fact that there is knowledge to be garnered from disciplined research. But we ought not to be similarly apologetic about the fact that there also is important knowledge to be garnered from reflective practice, and from the wisdom of lived experience.

The challenge we have is to braid knowledge from disciplined research, reflective practice, and lived experience into something more powerful than any one of them alone. If we do that, then we can legitimately figure out how to listen to the voices and the viewpoints of folks who are in community, give them a seat at the table and place in the fray without having to abdicate our stewardship obligation or default to political correctness.

### **The difference between caring and believing**

This brings us to the other major problem, the one I call the caring and believing conundrum. The “who is your hero?” question is a staple of every staged and televised debate. The answers generally are considerable more amusing than enlightening. But they are generally crafted with the audience in mind and to make a point. So is mine. My heroes are public schools teachers. Why? Because there are neighborhoods across this nation where doctors do not make house calls, where lawyers do not visit clients, where social workers go in pairs, where

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firefighters go only if accompanied by police, and police go only because they are armed. But teachers go into those same neighborhoods every day and not just because they have to. They go because they care. That's why teachers are my heroes.

Among these heroes, you will find perfect examples of what I call the caring-believing conundrum. Many teachers will go into these schools intent on creating a world where, for just a few hours a day, children can feel treated with regard, respect, and affection. And these are the teachers who become awfully distressed when they hear me say what I am about to say. Too many of these same teachers are dis-serving these children. How so? Too many of these teachers do not believe that anything they do will be powerful enough to affect the futures of those children. They think, and not without good reason, that the circumstances and conditions and the lives of those children outside of those classrooms, outside of those schools and playgrounds, are enough to overwhelm their best efforts. So they resolve that all they can do is provide this little oasis.

The fact is that, by seeking to provide that oasis, these well-intentioned teachers have turned public schools into hospices for the young. Hospice exists to provide a space where one comes to accept and even embrace the inevitable. When school becomes hospice and teachers provide palliative care, children die because their hopes and dreams are

denied the nourishment needed to envision a future.

Teachers are not alone in settling for palliative care as the best that can be hoped for when faced with overwhelming odds. We need to ask ourselves whether the organizations, the people, the institutions, our staff and ourselves — whether we care without really believing in the aspirations, abilities, and futures of people who have been left out and left behind. I suspect, if we are honest with ourselves, that that is going to be a more difficult question than we might be comfortable admitting. Yet, it is a question that we should ask ourselves every day. We ought to hold ourselves and hold each other to the standard of belief, not just the standard of compassion.

### Ending our silence on poverty

And if we do hold ourselves to that standard, we will inevitable come to the “P-word”: poverty. I say the P-word because, in recent years, poverty has become like sex and religion — not the subject of polite conversation.

Last summer, I visited Edinburgh just before and during the G-8 summit. I was amazed to see that “Make Poverty History” is a movement that's literally sweeping across that continent. In pubs and restaurants and on the talk shows, people were talking about the Millennium Development Goals and debating which of various approaches

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*Poverty has become like sex and religion — not the subject of polite conversation.*

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to aid, trade, and debt relief would be sufficient to reduce world poverty by 50 percent in the next decade.

This experience made all the more glaring the silence on those issues in this country. When poverty does emerge in conversation, we console ourselves with sympathetic murmurings and incomprehensible mumblings or whispers to the people we know and love and trust because they will not tell on us. Or we find ourselves in stunned, submissive silence, unwilling to appear soft-minded, sentimental and too idealistic to have opinions that matter.

Putting poverty back on the table forces us to ask ourselves, and each other, what we are about.

Imagine what would happen if philanthropy chose to think clearly, speak loudly, and act boldly on the challenges posed by poverty. Imagine what that would mean for this country, for this world.

Imagine what it would mean for our practice. That is the real challenge here — our practice.

If we did a tally sheet of the grants made by those foundations represented at this gathering, we would see that, together, we spend billions of dollars annually on solving health-related problems. Literally billions. These expenditures exceed the gross national product of half the countries in the world. Now suppose we were asked to offer a rough estimate of the effect this had on poverty. How many of us would be willing to stake

our paychecks or our careers, on an affirmative answer to that question?

I suspect that we would be enormously cautious in our response because we have managed to detach our work and our definitions of success from the poverty that is the root cause of the problems we seek to help solve. We have become fairly adept at recognizing and treating the symptoms while ignoring the disease.

As with public school teachers, there are many in philanthropy who are uncomfortable with that conclusion. They hasten to document the important and good work they do. That the work is both important and good. The challenge that we face, however, is neither between good and evil nor between good work and bad work. The real challenge is between good and better. And we ought to ask ourselves whether the good work we are doing is good enough, and whether we can do better.

## **Working together to do better**

Suppose this was a gathering of education funders. And suppose the President of the United States recently addressed the nation and declared that breaking the cycle of intergenerational poverty was an imperative to strengthening our nation, restoring our moral authority, and rescuing our economy. Suppose the President went on to say that breaking the cycle of intergenerational poverty would require the nation to start with education. To

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jumpstart the effort the President had proposed legislation that would go well beyond No Child Left Behind and mandate the nation to achieve, by 2020, the goals outlined in America 2000. Moreover, she had reached out to foundations and asked that philanthropic dollars match public dollars to reduce the achievement gap and produce better results.

### **Children achieving. Youth succeeding. Better late than never.**

How would education funders respond to the challenge? Probably recruit the health funders. Under the glare of public scrutiny and with targets and guidelines, they and the educators they support would quickly explain that education could not carry the burden of breaking the cycle of intergenerational poverty if so many children are chronically absent from the classroom because of asthma and other respiratory diseases and undetected and untreated hearing, vision and dental problems if cognitive development was compromised by lead poisoning and other environmental hazards.

Together the education funders and health funders would soon agree that the desired results could not be achieved if so many families continued to live in unsafe and unhealthy homes. So we would conspire to recruit the folks working on safe and affordable housing. This new coalition would quickly note that this effort to break the cycle of

intergenerational poverty by ensuring that children are healthy, school ready and well-housed is a fool's errand if the parents of those children do not have jobs with benefits to allow them to pay the rent, take care of their children and when disaster looms to get them out of harm's way. Here come the folks from workforce development, work supports, asset building, home ownership, economic justice, and environmental justice. Quite the coalition so far.

There are those who insist that the evidence is overwhelming that philanthropoids never went to kindergarten. Working with others and sharing are not within our skill sets. Yet, the scenario above invites to imagine foundations actually figuring out how to work together to solve real problems. And what's more, having to work across sectors and disciplines.

However difficult and fanciful it seems, that is precisely what philanthropy will have to do if poverty gets on the agenda. Confronting poverty is how our field can demonstrate that we are in the business of making change and not just grants, how we prove that we believe and not just care.

Several years ago, Alex Kotlowitz wrote *There Are No Children Here*. It chronicles the travails and triumphs of a family living in public housing in Chicago. The book was later made into a movie by Oprah Winfrey. At the end of that movie, an off-camera voice interviewed children who lived in that Chicago public housing development. If I recall correctly, the

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last interview was with a 12-year-old girl. She was asked what she wanted for her future. She paused, and then said “The future?” She paused again. And finally, she said, “I can’t imagine the future.”

We live in the richest country in the history of the world, and yet some of our children have an easier time planning their funeral than imagining their future. And almost all of these children are in that situation because their families are poor.

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*The challenge of our generation is to do what we can and what we must to become a nation where all children can imagine a future because it is one that nourishes their hopes, lifts up their aspirations, and fuels their dreams. This is our challenge — not just to do good. Good is not enough.*

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The challenge of our generation is to do what we can and what we must to become a nation where all children can imagine a future because it is one that nourishes their hopes, lifts up their aspirations, and fuels their dreams. This is our challenge — not just to do good. Good is not enough. Our challenge is to do better. Ours is important work. It is noble work. Let’s get on with it.

Thank you.

## DEVELOPING A DIVERSE HEALTH CARE WORKFORCE

**Louis W. Sullivan**

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It is a great pleasure and honor, as well as an opportunity, for me to be here with all of you. I want to share with you the activities of the Sullivan Alliance, work that has inspired me and, most importantly, I hope will challenge you. I am pleased to join all of you in focusing on improving community health and inspiring community action because effective solutions to community problems must involve members of the community.

While you are aware of the history of the health care challenges facing our nation, Grantmakers In Health continues to generate new thinking, new approaches, and new partnerships to address the health issues of our day. Just like Grantmakers In Health, I have been around a few years. There is great joy in seeing the results of our initiatives and in seeing progress in many of the challenges we have at hand.

I was born during the Depression, a black child in legally segregated Georgia. But my salvation was that I had wonderful parents, committed to education, who were inspiring and who had a strong moral compass. My father was an insurance salesman, which was not such a good business to be in during the Depression. I was born in Atlanta, but because

my father had difficulty selling life insurance, we soon moved to Blakely, a town in rural southwest Georgia, where my father became an undertaker and my mother was a school teacher. I grew up knowing the value of hard work, education, honesty, and integrity, because my parents firmly believed these were the touchstones to human achievement.

When we went to the family doctor, we would get in the car and drive 41 miles south to Bainbridge, to see Dr. Joseph Griffin, who was the only black physician in that part of southwest Georgia. He was my role model. He showed me that a black man could be a physician, a rare and almost unheard of concept for many African Americans in small towns in Georgia. When I was five, my mother asked me what I wanted to be when I grew up. Without hesitation, I said I want to be a doctor, like Dr. Griffin. Her response was, "You'll be a great doctor." So it was settled, and the rest is history.

In the several decades that have passed, many things have changed for the better in our country. But one thing has not changed. It is still far too difficult for the average young African-American boy or girl to view becoming a doctor as a realistic possibility, or, for that matter, to become a

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*It is still far too difficult for the average young African-American boy or girl to view becoming a doctor as a realistic possibility.*

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nurse or dentist or some other health professional.

The same applies to Hispanic Americans and Native Americans. Although more than 25 percent of our nation's population is African American, Hispanic American, or Native American, when we look at the health professions, we see that only 9 percent of nurses, 6 percent of physicians, and 5 percent of dentists come from one of these groups. These data are even more compelling when you realize that every year our nation's population is becoming more diverse. Demographers tell us that by the year 2050 there will no longer be a majority population in our country.

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My parents knew the value of being cared for by a doctor who understood our culture, our environment, and our health needs. They went to see Dr. Griffin because they knew he was not only a good doctor, but he also respected us.

In 2002, the Institute of Medicine (IOM) released its landmark report, *Unequal Treatment*, which documented what a lot of minority families already knew. There are still alarming disparities in health status, in access to health care, and in health outcomes for the nation's minorities, when compared to whites. These less favorable outcomes for minorities persist even after adjusting for differences in income, education, and health insurance status.

The IOM's report concluded that one of the reasons for these disparities

is the lack of a diverse workforce within the health professions. The report documented that minority health professionals are more likely than their white counterparts to care for minority patients, to practice in minority communities, and to care for the poor. Moreover, the report found cultural competence is strengthened through diversity in the health care workforce, which also promises to help reduce and eventually eliminate health disparities.

For most of my career, I have worked with others to remedy the lack of diversity in the health professions. As a young doctor just out of medical school at Boston University, I taught at Harvard University, then Seton Hall University, then back on the faculty at Boston University, caring for patients, teaching medical students, and conducting research. I also worked to see that more minorities had an opportunity in the health professions, as well as in academic medicine. At the time there were precious few who found their way to success beyond the barriers.

Then in 1975, I was offered the opportunity of a lifetime, to launch a new medical school at my undergraduate alma mater, Morehouse College, a medical school which would focus on recruiting and graduating more black and other minority doctors. There were more than a few of my friends in Boston who thought I had lost my mind, leaving a secure position as professor of medicine to establish an upstart medical school with an uncertain future. But then, as

## SPEAKER PROFILE

**Louis Sullivan**, former secretary of the U.S. Department of Health and Human Services (HHS), also chaired the prominent commission on health care work force diversity that bears his name. He spearheaded the creation of an alliance of professionals and institutions to help implement the recommendations coming out of that commission. Dr. Sullivan is currently chairman of that alliance, called the Sullivan Alliance to Transform America's Health Professions. Dr. Sullivan was the founding dean and first president of Morehouse School of Medicine, leading that institution from 1975 until his retirement in 2002, leaving briefly to take his appointment at HHS between 1989 and 1993. Dr. Sullivan continues to serve on the board of trustees, to teach, and to assist in national fundraising activities on behalf of the school. Dr. Sullivan was also the founding president of the Association of Minority Health Professions Schools and a former member of the Joint Committee on Health Policy of the Association of American Universities and the National Association of Land Grant Colleges and Universities.

now, I was convinced of the rightness of that mission and the importance of doing something to increase the number of minority physicians. We admitted our first class in 1978 as a two-year school in the basic medical sciences. In 1981, it became a four-year school and it was fully accredited in 1985 when we graduated our first four-year class.

One thing led to another, so that in 1989 I was honored to accept an appointment by President George H.W. Bush to serve as Secretary of the U.S. Department of Health and Human Services. Now, there are a number of accomplishments during the four years that I served of which I am very proud. But perhaps one of the most significant was the publication of *Healthy People 2000* in September 1990. This was a blueprint

for improving the health status of Americans. It contained specific national goals we hoped to reach by the year 2000, such as reducing tobacco use, alcohol misuse, infant mortality, kidney failure, diabetes, stroke, and heart disease.

The report also cited the glaring disparities in health status between majority Americans and minority Americans. We pledged to find ways to reduce health disparities and we made substantial progress in improving childhood immunizations, early prenatal care, reducing maternal and infant mortality, and other goals. But in other areas, such as adult obesity, we actually lost ground.

Then in 2000, I was pleased to participate in the release of *Healthy People 2010* with Surgeon General

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*One of the reasons for these disparities is the lack of a diverse workforce within the health professions.*

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David Satcher. The goals of *Healthy People 2010* once again focused on eliminating health disparities and increasing the quality and years of healthy life for all Americans.

Many began to recognize that one significant aspect of America's health disparities problem was the issue of diversity in the health professions. Of course, for many of us who had grown up in a segregated society, this came as no surprise.

A 1996 study reported in the *New England Journal of Medicine* found that low-income areas with the highest concentrations of blacks or Hispanics had fewer physicians than similar low-income areas that were predominantly non-Hispanic white. Moreover, black and Hispanic physicians were found to be more likely to practice in areas where the predominant population was minority.

Following publication of *Unequal Treatment* in 2002, the IOM formed a committee to address the issue of diversity in the health professions. It was chaired by Dr. Lonnie Bristow, the first African-American president of the American Medical Association. Then in 2004, the Institute of Medicine issued its report, *In the Nation's Compelling Interest: Ensuring Diversity in the Health Care Workforce*, which called on all stakeholders to come together to solve the problem of the lack of diversity in the health professions. The Institute of Medicine cited the June 2003 ruling by the U.S. Supreme Court in the University of Michigan affirmative

action case, *Grutter v. Bollinger*.

That ruling noted the compelling evidence that diversity helps break down stereotypes, improves classroom discussion, prepares students for the workforce and citizenship, and permits universities to cultivate a set of leaders with legitimacy in the eyes of our citizenry. The court reviewed evidence from an array of sources. Of particular note was research by Gurin, who studied 11,000 diverse students across the country and found that the benefits of a diverse college experience were observed across all racial lines, all ethnic groups, resulting in a better qualitative and quantitative outcome and, overall, better educated graduates.

Business benefits from a more diverse workforce because poor health outcomes for employees who are racial or ethnic minorities translate into loss of income, loss of productivity, lower tax revenues for our government, absenteeism, and increased health care costs. The bottom line is that the nation benefits from efforts to increase diversity in education. There is a need for leaders in our country of the highest caliber, leaders who are skillful and successful in interacting with a multicultural world, a world that is constantly changing.

In April 2003, I joined with a number of colleagues and, with the support of the W.K. Kellogg Foundation, we launched the Sullivan Commission, formed to examine the reasons for our nation's failure to achieve more racial and ethnic diversity in the health professions, as well as to develop

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recommendations and strategies to address this problem. The focus of the commission was on medicine, dentistry, and nursing, though we are aware that these findings apply to all of the health professions.

During the next two years, we held hearings in six cities across the country to examine this issue and to receive input from students, community leaders, business leaders, educators and others. In September 2004, the commission issued its report, *Missing Persons: Minorities in the Health Professions*. We put forth 37 recommendations for actions to address the root causes of underrepresentation of minorities in the health professions. The report was developed to attract broad support and to encourage academic and professional leaders to share the commission's vision for a health system that focuses on excellence, equal opportunity, and the delivery of high-quality care for our nation's entire population.

The commission's recommendations are based on three overarching principles. The first principle is, in order to increase diversity in the health professions, the culture of health profession schools must change to become more inviting and supportive. The second principle is that new and nontraditional paths to the health professions should be explored. And thirdly, commitments must be from the highest levels in our society, from leaders in government, leaders in the health professions, leaders in education, and the business community, in short, leadership from across our society.

Our report offered specific solutions for lowering the barriers in the educational pipeline and encouraging minorities to progress through that pipeline. The recommendations also noted the critical need to solve the problems that most minorities face in financing an education in the health professions and stressed the importance of creating a system of accountability so that the quality of care, institutional commitment, progress towards diversity, and benefits to the community could be measured and documented at our health profession schools.

After the release of the reports from the Institute of Medicine and the Sullivan Commission, the Sullivan Alliance was established in January 2005, with members of these former groups coming together. The goal was to transform the nation's health professions by working to implement the various recommendations of the IOM and the Sullivan Alliance. I am honored to serve as alliance chairman and we are very fortunate to have Dr. Lonnie Bristow as our co-chairman. The alliance formed a partnership with the Joint Center for Political and Economic Studies in Washington, which houses our operations. The plan is to catalyze actions and solutions across the nation, to bring about changes in health professions schools, health care delivery, health care institutions, educational institutions, foundations, corporations, individuals, and all levels of governments — federal, state, and local.

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*In order to increase diversity in the health professions, the culture of health profession schools must change to become more inviting and supportive. New and nontraditional paths to the health professions should be explored.*

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The alliance's overall goals are to facilitate improvements in the institutional climate or culture, to promote diversity at health professions educational institutions; to design inclusive admissions policies and practices; to implement innovative programming to identify, recruit, and graduate underrepresented minority students for the health professions; to promote diversity standards for health professions accrediting organizations; to engage our communities in efforts to diversify the health care workforce; and to advocate policies at local, state, and national levels to enhance diversity. The alliance has achieved significant success in building a base of partners and supporters of our work. Included in that success are the following.

In September 2004, the Virginia-Nebraska Alliance was formed, bringing together a consortium of two academic health centers in Richmond and in Omaha with all five historically black colleges in the state of Virginia and the J. Sargeant Reynolds Community College in Richmond. The goal of this alliance is to increase the success rate of students from these undergraduate institutions in Virginia in gaining admission to, and graduation from, a health professions program. In the summer of 2005, the Virginia-Nebraska Alliance placed its first eight students as research assistants at one of these academic health science centers. It also provided summer support for six faculty members from these colleges in the consortium to conduct

medical research at these academic health centers. The alliance has since grown to include the University of Virginia's School of Medicine and the University of Richmond.

A second accomplishment is in January 2005; the presidents of the American Medical Association, the National Medical Association, and the National Hispanic Medical Association announced that they had formed the Commission to End Health Care Disparities. The presidents of these national associations stated that the impetus for their coming together and forming this commission was the report from the Sullivan Commission.

Also last year, Dr. Bristow and I met with U.S. Secretary of Education Margaret Spellings to brief her on the alliance and its work and to solicit her input and support. Secretary Spellings indicated she was creating the Commission on Higher Education to evaluate the nation's higher education system and to make recommendations for improvements, including the issue of diversity. I have been honored to be a member of that commission.

In addition, the American Medical Association's Council on Ethical and Judicial Affairs issued a report stating that, in order to address the disparate treatment of patients, physicians are ethically obligated to treat all patients equally, providing all medical care in accordance with accepted standards of practice and patient's individual needs and preferences.

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*The alliance is exploring establishing new statewide alliances of minority and majority higher educational institutions.*

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Finally, there are a large number of requests from educational institutions, academic health centers, professional associations, and other organizations for members of the alliance to interact with their institutions to support actions or plans for implementing one or more of the recommendations put forth by the Sullivan Commission or the Institute of Medicine.

What are our plans for the future? In addition to building on the activities already undertaken, the alliance is exploring establishing new statewide alliances of minority and majority higher educational institutions similar to the Virginia-Nebraska Alliance, looking particularly at the nation's southeastern states and the southwestern states, where large numbers of black or Hispanic students reside.

We plan to advocate for more scholarships and low-interest loans from public and private sources. We hope to form an advisory task force of former U.S. secretaries of health and human services to guide our efforts. We expect to create and strengthen educational linkages between high schools, community colleges, baccalaureate institutions, and health professions schools to facilitate communication and joint programs. And finally, the alliance will hold workshops around the country to ascertain and share best practices in identifying, recruiting, and graduating more underrepresented minorities.

So, the alliance today solicits each of you and your organizations to

contribute your ideas, your suggestions, as well as your support to help us develop better and more effective plans and programs to reach more people in cities and states around our country. We also would like to hear about other initiatives that you might undertake to support this mission, such as your willingness to serve as neutral conveners in your cities or states with local leaders to develop strategies for increasing diversity among the health professionals of your community and your state. If we are to be successful, we need to enlist the ideas and the participation and support of many people and organizations.

The past 100 years in our country have seen remarkable improvements in biomedical research, public health, and health care. But, despite these achievements, we are still faced with the continuing challenge of the widening disparities in health status, access to health care, and health outcomes between white Americans on the one hand and the nation's minority populations on the other. So, our responsibility, yours and mine, is to seize this moment, address this challenge with solutions that improve the health of our citizens, especially those who have been left behind in spite of the marvelous advances in our nation's health system. Our society and our nation will be a better place if we succeed in these efforts. I cannot think of a more profound legacy than the gift of improved health for today's citizens and the generations yet to come.

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*Our society has come a long way from the day when my family had to travel 41 miles in southwest Georgia to see a black doctor. But as a nation, we still have a long way to go.*

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Our society has come a long way from the day when my family had to travel 41 miles in southwest Georgia to see a black doctor. But as a nation, we still have a long way to go. It is my hope that there will come a time in the not too distant future when shortages of health professionals and lack of diversity in the health professions, the existence of health disparities, all of these will be spoken of in the past

tense, a historical phenomenon of a bygone era. We have many miles to go before we reach that goal. But with inspired leadership and with sustained commitment, we can achieve it. I invite you to join us in this effort and I want to express my heartfelt appreciation once again for this opportunity to be with you to share these thoughts.

## DEVELOPING A DIVERSE HEALTH CARE WORKFORCE

Gary L. Yates

It is a pleasure to be with you this morning to talk about the grantmaking that The California Wellness Foundation does. The mission of the foundation is to improve the health of the people in California with a focus on the poor, the working poor, and the underserved in the state. To that end, we make about \$45 million in grants annually.

Several years ago, after having an extended strategic discussion led by Tom David, who was then the foundation's executive vice president, the board decided on a new paradigm of grantmaking that we call the Responsive Grantmaking Program. This program basically looks at unsolicited letters of intent and provides grants with an emphasis on core operating support. Eight health issues were prioritized for funding, one of which was diversity in the health professions.

The changing demographics evident nationally are even clearer in California. Today California has 33 million residents, well over 10 percent of the nation's population. There are three key demographic shifts that will take place between now and the year 2020 that echo the nation's demographic changes. By that year, California's population will rise from 33 million to 43 million, an increase

of 10 million people. The share of those that are 65 and older will have increased by 70 percent. With regard to ethnic diversity, California already is a nonmajority state with Caucasians comprising about 49 percent of the population and Latinos about one third of the population. That will shift by the year 2020 so that Caucasians will have dropped to about one third of the population and Latinos will be about 45 percent.

What does this mean? We are certainly going to need a much larger health care workforce in the state of California. The obvious has become inescapable if you stop for a minute and take a look. In addition, an ethnically diverse, culturally competent, language-proficient health care workforce will be needed if we are going to have the kind of access to and quality of health care that we all want. We are far behind at this point in time in moving in that direction.

If you look at California today, the data are striking about the deficiency in our health care workforce with regard to diversity. As I said, Latinos are one third of the population and yet they represent just 4 percent of the physicians and 4 percent of the nurses in the state. Other ethnic minorities have similar underrepresentation, so

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*As grantmakers, we can do three things well. The first of those is making grants.*

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we have a long way to go in the next 15 years to even begin to make a dent.

How can a foundation, even a foundation as large as The California Wellness Foundation, play a role to help move us in that direction? I actually think one of our great strengths in the foundation world is our individuality. I believe the folks doing the real work on the ground know how best to proceed with this work. The pioneering folks in the medical schools are people such as Ezra Davidson at Drew Medical School. They know what needs to be done. We need to support them.

I often say that, as grantmakers, we can do three things well. We may not do them well but there are at least three things that we have the potential to do well. The first of those is making grants. Make grants and do them well. That sounds so easy. For those of us that have worked in organized philanthropy, we realize that is not as easy as it sounds.

In the last four years, we have made about 100 grants for \$15 million in the area of health professions diversity. About 70 percent of those grants have gone for scholarships, pipeline programs, loan repayment, and retention programs. It is a lot of money and I am acutely aware of the fact that we received criticism for much of that. It is constructive criticism centering on the fact that this will not really make a difference in the systemic issue of increasing diversity in the health care workforce. Providing those scholarships may not

affect these numbers because it doesn't create systemic change. That may well be true. But I will tell you this, in just using the field of medicine for a moment, every year I receive letters from some of the young people who have received scholarships through the grants of The California Wellness Foundation to pursue a career in medicine. Every single one of them has a similar dream. They grew up in poor communities. Somehow early on in their lives, they decided they really wanted to be a doctor. And it was often somebody who was a role model who inspired them to reach their dream. They worked very hard in school, their academic credentials were strong, and they were able to apply and to be accepted at medical school. Every single one of them says in their letter that without that scholarship they would not be going to medical school, that they could not afford the debt burden of the loans that they would have to take — which by the way, averages hundreds of thousands of dollars. Almost to a person, they say that the reason they wanted to be a physician was to provide health care in the community they grew up in. And as long as we do that, if that is all we do at The California Wellness Foundation, then I feel we have made our contribution.

Now we are doing other things. The other 30 percent of the grants we make are for public policy work, developing the research base, the database, to determine the ethnic diversity numbers across all health professions. Our goal is to have a solid baseline

## SPEAKER PROFILE

**Gary Yates** is president and chief executive officer of The California Wellness Foundation and serves as a member of the foundation's board of directors. He is also assistant clinical professor of pediatrics at the University of Southern California School of Medicine, and is a licensed marriage and family therapist. Yates joined the foundation staff in 1992 after more than 20 years in health and social service organizations. Immediately prior to his association with The California Wellness Foundation, he was associate director of the division of adolescent medicine at Children's Hospital Los Angeles. His primary area of interest and expertise is adolescent health, about which he has written and spoken extensively. Mr. Yates previously served as chair of the board of Grantmakers In Health. Yates received his undergraduate degree in government from American University in Washington, DC and his master's degree in counseling psychology from the University of Northern Colorado.

of information and to disseminate that information to policymakers and opinion leaders in the state. We also look at promising practices or best practices for pipeline programs and retention programs in medical schools to find out what is really working to move this envelope along.

Then, finally, the foundation funds those organizations that are advocating for change to help them have the resources they need to push for the public policy changes that are fundamental to making progress. That is our grantmaking.

The second thing that I believe that we can do well is convene. There is something about foundations calling a meeting. People come. It may well have to do with the fact that we are sitting on the gold and people hope they will get a wheelbarrow and carry some out with them. But it does

not matter to me why they come. Over the years it has been clear to me that when we call a conference, when we call a meeting, we have large attendance, people come together. Over the last several years, we have had an annual conference for people in the field who have spent their lives working to increase diversity in the health care workforce in the state of California.

It was very interesting that at the first meeting we held, people talked about the fact that it was the first time they have ever been able to come together at a conference to talk about the diversity issue. In their fields of obstetrics/gynecology or pediatrics or whatever, there would be a small breakout of the folks working on the issue but never across the spectrum with community colleges, medical schools, and nursing schools coming into the same room. There is power

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in that. People get a sense that they are not in it alone and there is a lot more going on than they thought. The networking and sharing that goes on in those conferences is powerful.

There are ripple effects that come out of these meetings that we hear anecdotally. For example, Dr. Lonnie Bristow came and talked at the last conference about the work of the Sullivan Alliance, the Institute of Medicine report, and the Sullivan Commission report. Already, we have heard that two major institutions in California took information from there, and have put some of those recommendations into play. In the first year of having shifted their mission and their focus in the way that the reports recommend, there has been a dramatic increase in first-year medical students who are underrepresented ethnic minorities in the one school and at their dental school at the University of Southern California.

Additionally, we had State Senator Deborah Ortiz give the keynote address at one of the early conferences. She was chairwoman of the legislature's health and human services committee. A year later, she held two hearings about the specific issue of diversity in the health care workforce for her committee. Those are small steps, but they are important steps. It is the beginning of a movement in California to see real change.

Lastly, and sometimes I think more importantly than the grantmaking and the convening that we can do, is

that we can lend our voice and speak out about important issues that need to be talked about. We have done that in a couple of ways.

First, we have what we call the Champions Award, where three individuals who have worked in diversity in the health professions throughout their careers, many of them for decades, are provided an award of \$25,000, no strings attached. They can use the money to do what they want. We have a dinner to honor them before the annual conference. And then our communications department uses the award to spread the word about the need to increase diversity in the health care professions, with ethnic media, mainstream media, and policymakers throughout the state. It is a way of getting the issue seen and keeping it alive.

And then lastly the board recently approved a \$1 million grant for a public education campaign to raise the visibility of this issue throughout California. The campaign has two goals. The first is to inform policymakers, opinion leaders, and the general public about the need to increase diversity in the health care workforce as a key strategy for improving the health of the people of California. I will tell you that some of the members of my board, those who have worked in this area for a long time, think it is the key strategy for improving the health of the people of California, especially for those of us concerned about racial and ethnic health disparities.

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The second goal of the public education campaign is to inform ethnic minority youth about the opportunities that exist for careers in the health profession in the state of California. With the aging population, those opportunities do not just exist, they are going to expand.

What the grantee has been charged with is developing a comprehensive “one-stop shopping” Web site where any young person in the state is going to find out everything he or she wants to know and get all of their questions answered: what type of jobs are available in health care; how much they pay; where they are located; where can you get the certificates; where can you get the degrees; how can you get them paid for, and so forth. The test for the grantee (and the reason it is a one-year grant is so that, if they do not pass the test, we can look for somebody else) is that I, a technodinosaur, can go on that Web site and have my questions answered without becoming frustrated.

We get feedback about these ideas, and I want to say that one of the reasons I feel very good about the public education campaign is when we decided to do work around diversifying the health professions, we did not start thinking that we needed to do a public education campaign. We have listened carefully to the people who do the real work about this for the last four years. It is absolutely clear to us that this is something that is needed and wanted in the field. And therefore, it has a real chance of having some impact.

With regard to the Web site, there are a lot of barriers that keep young people, poor young people, ethnic minority young people in poor communities, from dreaming about and thinking about a career in the health professions. We cannot do everything to eliminate those barriers. But this can level the playing field somewhat, so that a young person in the poorest public school with no counselors who talk about getting to the next level will have the same access to the same information about going into a health care profession as a young person has in the best private school with the best counselors.

Again, I am a dinosaur with regard to technology. But my sons are not. Some of you know that I have five sons, which tells you about my mental health and who is really talking to you. So now you know whether to pay any further attention to what I have to say. My youngest just graduated with the same degree I had when I graduated from American University back in 1962, the all-powerful, get-you-a-job-anywhere political science degree.

He was on a golf scholarship and had never really thought there might have to be a job beyond golf when he left. I watched his panic three or four months before graduation, but then I watched him search for what he wanted to do. I have a few networks of my own and I talked to him about how I could hook him up. No thanks. He never opened the newspaper, never looked at the careers section on Sunday, but he was always on the Internet. In

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*We can lend our voice and speak out about important issues that need to be talked about.*

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talking to him, and in talking to other young people of his age, I learned that this is where they get most of their information. So we have a real chance here. What is he doing? He is working as a physical therapy assistant. That is what he decided he wanted to do for a while. By the way, that is the first step, a small step, of diversifying the health care workforce in the state of California, because my son is biracial.

This is a tough, tough issue in California because we do not have affirmative action, which was taken away in the mid-1990s. But I say this, we do not hope to move this agenda in the state of California rather, we intend that it will move forward. Within the next five to 10 years, it will be moved.

## THE POWER OF STORY CIRCLES

Theresa Ripley Holden and Donna Porterfield

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In our careers, we have had the privilege over many, many years of facilitating numerous community-based projects. What we have learned from the remarkable individuals and communities we have worked with is the overarching desire to make change. Change at individual, communal, and organizational levels — it is all necessary.

Given the theme of this conference and what we see as a deepening crisis facing our country, we must find strategies to make that change happen with large and diverse groups of individuals who then can effect change in their community, in the organizations in those communities, and then perhaps change in policies and change in governments. This is bottom up change. This is what we are all interested in. I know we are. We believe stories and storytelling can facilitate this kind of change.

What is a story? A story is a personal recollection of something that happened to you or someone you know. A story can have place, time, characters, narration, and dialogue. A story can be a simple event. It does not have to be a complete beginning, middle and end. A story is not an argument, a debate, or an expression of opinion. This does not mean that stories don't have arguments or ideas in them, but that these are for people

to glean for themselves. A story can stand on its own legs. It does not need its message to be explained at the end. It will be self-evident.

The experience we share with you today comes from many years of working in community-based organizations across the United States. Some of our experiences have been in the arts world and many of them have not. What we have learned and what we wish to share with you is how we have facilitated the telling of stories as a means to build consensus, to build coalitions, to build warm and open communities so that these communities can themselves tackle some of the hardest problems you can imagine.

A story circle is simply that. It is a circle of people, sans paper and pencil, who listen to each other tell stories. Story circles can be used to prompt dialogue and build coalition and consensus. Story circles can facilitate brainstorming of new ideas; they can facilitate project planning or strategic planning, cooperative or reaction research, orientation of new groups, group evaluation of a project, and organizational development. Story circles generate personal stories about a particular subject such as cancer, domestic violence, or racial tension from which community projects are crafted. Story circles create a safe place to discuss difficult subjects.

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*We know of the railroads and the dams of this country primarily from the historians and the corporate icons that had the vision and the desire to construct them. But we know little of the stories of the men and the women who built them. We are missing a huge part of the whole picture, therefore, a huge part of the truth.*

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## SPEAKER PROFILE

**Theresa Ripley Holden**, an artist, teacher, organizer, manager, producer, and consultant, is founder and director of Artist and Community Connection, a nonprofit organization that offers organizing, planning, facilitating, and producing services to nonprofit, community-based organizations. Ms. Holden also served as the managing director for Junebug Productions. Ms. Holden and her colleague, John O’Neal of Junebug Productions, were awarded the 2002 Leadership for a Changing World Award from the Ford Foundation for their work. Ms. Holden has planned and produced numerous community-based projects around U.S., including the Untold Stories Festival in Tempe, Arizona, and the Tamejavi Festival in Fresno, California. Ms. Holden has taught theater at the university level for 10 years. She has facilitated numerous organizational planning meetings and retreats for diverse nonprofit organizations. She currently serves on the board of directors of the Association of Performing Arts Presenters.

Story circles can be a tool for successful grassroots organizing. The term, grassroots, typically has come to mean work or efforts that represent or serve those with the least power in the society or community. The defining characteristic of grassroots work is to preserve, express, and serve the values, culture, traditions, and art of those often without privilege.

To understand grassroots organizing, it is helpful to remember that 98 percent of the people who have ever lived on this planet or who are alive today have been poor, have lived in poverty, and have been uneducated. Most did not have the luxury of writing their own history to tell us what it was like living their lives, lives in which they are often persecuted, exploited, or oppressed. We hear about the pyramid builders from the Pharaohs,

not from the people who built them. We know of the railroads and the dams of this country primarily from the historians and the corporate icons that had the vision and the desire to construct them. But we know little of the stories of the men and the women who built them. We are missing a huge part of the whole picture, therefore, a huge part of the truth.

As Curtis Mohammed, a community organizer in New Orleans, says of story circles and their use in organizing and building healthy, free societies, “we must excavate the wisdom of the people.” Stories are the way that excavation occurs. An African proverb illustrates the point this way: until the lion writes his own story, the tale of the hunt will always only glorify the hunter.

Our longtime colleague John O’Neal and the storytelling character from his plays, Junebug, says, “Now you see me, I’m a storyteller. I was called to be a storyteller. Now I say storyteller instead of liar because there’s a big difference between storyteller and a liar. A liar is somebody that’s trying to cover things over for their own personal good and their own private benefit. But a storyteller, that’s somebody trying to uncover things so that everybody can get something good out of it.”

The story circle methodology that we work with across the country enables this productive, deep grass-roots organizing and the subsequent individual and community change

to occur for two very simple reasons. First and foremost, the method of the story circle is equitable and respectful of all individuals present. It places the exact same value on each story, on each voice, and the method is as much about listening as it is about the telling. It is in listening that we learn, and therefore change. In fact, there is a theory that actually no story is ever told without the listener. It is in the listening that the meaning of the story begins to exist.

The second reason can be found in the power of stories themselves. This we have learned from the more than 40 projects and hundreds of workshops that we have conducted across the country which include the Color Line

## SPEAKER PROFILE

**Donna Porterfield** is managing director of Roadside Theater. She serves the ensemble in multiple roles, including playwright, dramaturge, and producer. She led a residency with the HOPE House, a women’s shelter in central Appalachia, in which she collaborated with survivors of physical and sexual abuse to write and direct an innovative play, *Voices from the Battlefield*, addressing domestic violence. A similar project with East Kentucky Health Services and Mountain Empire Older Citizens resulted in a play, *Life Circles*, created to promote cancer prevention in the mountains of east Kentucky and southwest Virginia. Performed by those with direct experience of the plays’ subjects, *Voices and Circles*, continue to be coproduced by Roadside and Appalachian community organizations. Ms. Porterfield is producer of Roadside’s ongoing 20-year collaboration with traditional Native American artists in the pueblo of Zuni, New Mexico; she coauthored the Roadside/Idiwanan An Chawe play, *Corn Mountain/Pine Mountain: Following the Seasons*, which toured nationally. She has served as consultant to the National Endowment for the Arts, Urban Bushwomen, Alternate ROOTS, Southern Arts Federation, Mid-Atlantic Arts Consortium, and various state arts commissions.

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*The method of the story circle is equitable and respectful of all individuals present.*

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Project in Cincinnati which dealt with racial tensions between police and the African-American community; the Environmental Justice Project in Louisiana with participants collecting stories about the toxicity and illnesses arising from their polluted neighborhoods and their water; the Montana Gay and Lesbian Story Project with stories that eventually helped change state laws; and the Project Home Story, a wonderful organization in Philadelphia, in which story circles shared between the homeless, the residents of shelters, service providers, and city officials helped to capture the history of this very successful effort and bring more funding its way.

The successful use of story circles can be found in the experience of the Roadside Theater. The Roadside Theater is one part of the Apple Shop, a derivative of the Appalachian Workshop located in the central Appalachian region in Whitesburg, Kentucky, a small town of 1,200 people. The theater has worked on several projects using stories from story circles and developing them into plays. For example, Roadside worked at Eastern Kentucky University to teach and to train people to do story circles. Our area has an abnormally high cancer rate so we focused on cancer awareness and prevention. We trained community people in doing story circles and they did story circles with cancer survivors and their families all over eastern Kentucky and southwestern Virginia. Several of the groups decided they wanted to make a public presentation out of them. So

about six years ago we wrote a play together and the groups performed this play. It is called "Life's Circle," and it toured to other groups' home communities. They still do the play about once a year.

Another project we did was a year-long project with a women's shelter that wanted to have the community see that domestic violence, which creates huge health problems in our area, is everybody's problem, not just the people who think it is their problem. So we did story circles with staff and clients of the women's shelter and ended up writing a play about domestic violence that was done as part of a day-long workshop. People saw the play and then we held story circles with everyone in the audience afterward to talk about what they had just seen.

The staff at the women's shelter was skeptical about this project in the beginning. They had genuine concerns that the women would not want to tell their stories, that they would be threatened by telling them, knowing that it might be heard by their abusers. But the women who did not want to tell their stories did not have to, and the women who did, who saw the value of it, relished the opportunity to get their stories out.

Then we read the first draft of the play, "Voices From the Battlefield." It did not sound that significant to us. These stories were just things we hear every day. We did not realize what we had created until we saw the first production and heard the audience's

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*It is in listening that we learn,  
and therefore change. It is in the  
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reaction in the story circles conducted after the performance.

We did this at a conference for the juvenile justice department, a state-wide conference of probation officers, judges, lawyers, social workers, health care workers — people who really hear these stories all the time and who become, understandably, very cynical about some of the things we are talking about. Working in our field, some said, there are many, many days when we think, what is the point? We work so hard and see our work undone in a moment when a woman turns around and goes back to an abuser. We know why it happens, that it is part of the cycle that takes a long time to change. But sometimes we can take it personally.

After hearing the stories in the play, people talked about how these stories opened their hearts to hear from these victims of abuse, how they planned to listen to stories with new ears, weeding out the trivial from the substantial.

On the other side, a survivor of domestic violence who was involved in both the writing and the performance of the play, said that she enjoyed the story circles the most. “They gave me more confidence in myself. They made me aware of my Appalachian culture. It helped me see that being from the Appalachian Mountains is not such a bad thing, like I used to think. With domestic violence, everything is mostly kept in the background. It was hard to believe that somebody would want to hear my story, to hear about

something that happened to me. It’s not just my story either, because there are so many people with the same story. It was like I could speak with one voice for many people.”

We have learned many lessons from these projects and the people involved with them, of the power of story circles. We have learned that stories encourage listening. When we listen, we learn. Stories build relationships among people by eliminating our connections. Stories are a way of collecting information. They identify and explore patterns. They build on previous knowledge before we move on to new information. Stories allow us to see possibilities we have not seen before. They redefine problems. They allow us to discover ways on our own to solve our own problems. They illuminate our similarities and our differences in a nonthreatening manner. They break down assumptions, stereotypes and generalities. They build a common memory among diverse people. They build common goals or consensus among diverse peoples. They give us strength from our memory base. They give us strength from a value base. They give us strength to move on.

The actual process of the story circle and what happens in it is something akin to the preparation of an excellent gumbo. Each ingredient is absolutely essential. But each ingredient is no more essential than the next ingredient. Each is added to that round pot in its own time and then, after all of the ingredients are added, not one

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*Stories allow us to see possibilities we have not seen before. They redefine problems. They allow us to discover ways on our own to solve our own problems.*

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ingredient left out, then the wholeness or — if you will — the truth of the gumbo comes alive.

The very same thing happens in a story circle. As the story circle proceeds, each story is placed or offered into the center, into what becomes a round holding pot for all of those stories, all of those images. Then the story circle is complete, when all the stories are told, there is a very different concoction in that pot. It is only in the combining or mixing of all those stories that a new truth emerges to become the new story for everyone. A story that is nutritious and whole, educational, and enlightening. One which can build consensus, can heal, and can make change. Naomi Newman from Traveling Jewish Theater put it this way: “the power of group storytelling lies in its ability to deeply know, heal, define, and validate.”

In the mid-1990s we participated, with several other artists and companies of artists, in a statewide project in Montana. In this project, the power of story became obvious and abundant. Several organizations from around the state and several arts companies met to discuss an idea that had to do with the need for those diverse communities to address the forces of change, many of them negative, on their community’s self-identity and self-esteem at the end of the 20th century. At the beginning, the project moved along much as any visiting artist residency does until the story circles were underway. At that point, it seemed that the source of the project

shifted. The stories’ power had set the tellers’ and the listeners’ lives into action. Change became a possibility. The project became each and every town’s own. It then became clear that this arts project could, in fact, lead to community transformation and it did.

The Montana Story Project was diverse in its themes and story projects, ranging from those of very small rural towns dealing with losing their young people as they left home and did not come back, to stories about homeless people in the larger cities. One of the most powerful, successful projects, the Gay and Lesbian Story Project, is still going on today, nine years later.

Arnie Malina, the director of a community-based sector in Helena which led the Gay and Lesbian Project said, “The story circles have been very successful and a good example of how stories can empower people. Men and women of every occupation gathered. Bureaucrats, teachers, care providers, lawyers, artists, they all participated as well as a wide range of ages, from young adults to senior citizens. A group was also blessed with some extraordinary gay people who were also disabled. People shared a lot because of this project. They laughed, they cried, they learned a lot. They gave strength and encouragement to each other. And they made plans.” This is a long way of saying that the goals of this project have been realized. The project helped to eventually change state laws about homosexuality.

Another project that comes to mind was in Cincinnati where we were

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*Transformation can occur when  
the source of change is internal.  
Stories can be such a source  
because they come from within  
and are owned first and foremost  
by the teller.*

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called in for teachers that were teaching welfare mothers who were required to get their GED if they were to stay on welfare. There was just huge racial tension in the group to the point that it was very difficult to teach. So we did story circles with the group. It did not solve all their problems. It did not mean there was no racial tension when we were finished. But the story circle made them listen to each other and realize that, while they might not like each other very much, they did share the same set of problems and that they would benefit from working with each other to solve those.

Another example of use of the story circle in the health field involved a class of newly immigrated Mexican women around the issues of sexuality and gender. Nervous about how to begin the class and not intrude on their culture and traditions, the leader started the class with a story circle, the theme of which was sexuality and gender roles. It worked perfectly. The stories that were shared around the circle were one myth after another, with each woman topping the last, adding their own rendition with much laughter and amazement. After that, they were all prepared to actually listen and learn from each other and their instructor about where, inside those myths and the stories, lay the truth and where they were really off. More importantly, after the first story circle, the class proceeded to basically teach itself. The class asked to use the story circle methodology for all of the remaining classes.

To see change, to find a way to foster change, most may know that transformation can only occur when the source of change is internal. Stories can be such a source of change because they come from within and are owned first and foremost by the teller. The wisdom, strategies, ideas that arise from the combined communal circle of stories is then owned by the whole circle, making both individual and community change possible.

This morning, before we gathered as this large group, we asked a few of your grantmaking colleagues to join with us and learn the story circle methodology. We are going to share with you the themes that came out of their story circles, and some of the uses that they now see that might be applicable in your field.

*Story circle participants respond:*

It took us about 25 minutes to go around in the circle. We were each given three minutes to talk about health and its relation to community and vice versa. We were a little puzzled on how we were going to start it out. Leo was smart enough to start, because then he could listen to everyone. I was the last one, so I had an opportunity to keep changing my story as I was listening to the others. It became a combination of both personal stories of our family members or people we know and love dearly, and also stories about our work. It became clear that as the stories progressed from one person to the next, people kept changing — it became more personal.

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*We acknowledged that, in the process of listening and storytelling, we actually built community.*

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We were actually each able to tell two sets of stories because we carefully regulated the time. What happened was there was a thread between the stories as the stories moved around the circle that created a deep connection between the members of the group.

Some of the themes that emerged as part of our circle were that caretakers come in all shapes and sizes, and they come when we do not expect them and in ways we have not imagined. We also identified as a theme the importance of intergenerational relationships, and families as the primary source of our stories. We acknowledged that in the process of listening and storytelling, we actually build community.

As we told our stories about the connection of health and community, we visualized threads coming from the stories and forming a tapestry from our story circle. A couple of other threads came from our story circle. One was the power of community support for health, whether it was for good, such as when family and friends surround a man in the hospital as he was struggling for his life, or for ill, such as how the traditions of a church can be so contrary to supporting a healthy lifestyle.

We also talked about the power of personal experience — how much more powerful it is for a person to tell a story than it is to listen to all the statistics and numbers that we have. We had one story, for instance, where a woman who had breast cancer told her story about the need for health insurance.

Then, also that personal experience and how powerful it is as a motivator, such as when the women were reunited with their children in a court case.

We identified the power of listening as a theme. We also acknowledged that community is made not only by what you give but by what you allow yourself to receive. So community is made through some kind of process of both vulnerability and empathy. There is an importance to helping people feel connected to one another, the importance of personal stories in developing connections with others.

Storytelling really gets people to listen to what you have to say. For example, we have seen presidential debates on TV at election time. While one candidate speaks, the other candidate often is not really listening to what the other candidate has to say. Instead he is trying to formulate his answer during that period of time. During this process of storytelling, you are forced to listen to what everybody has to say. Things may come up in mind that you may want to share. Through that process it also adds a human touch to the themes that you are trying to get across. So for example, we have all heard the phrase, a picture is worth a thousand words. Now with storytelling that is exactly what it does. It paints a picture for everybody to see.

We discussed and reflected on how this could be used in our work on health philanthropy. Many of us are already doing this, but it was reinforcement, to continue with our

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community dialogues, continue with our focus groups, continue to take time and make the space for people to come together and communicate in a genuine way about what the needs are in our community related to health.

There is power in storytelling and we should incorporate that into our communication to board members, encouraging our grantees to make sure they tell us a story. The data and the statistics are really important, but do not forget to tell us and provide feedback to us on good stories.

We talked about how we could use story circles to help our grantees learn from each other, to provide opportunities for grantees to come together, share their stories about working with a particular issue area or population and how they can learn from each other through this.

One of the things we found was that often the language that we use when we describe our work does not resonate with the community at large. They do not know what we are talking about. We can take the story and the power of that story to make a health care need that is pretty universal and translate it into an individual story

that will be compelling to get our messages across.

One potential application of the story circle would be to bring together some of the people in the population who are going to be affected by our funding into a story circle, for example, students in a school to tell us stories about how the particular issue we care about affects them, whether it is tobacco, mental health, or nutrition. Hearing their personal stories could be much more powerful at helping us to know what the points of intervention are than simply using our smarts and all-knowing selves to decide what is good for that population.

I think the story circle technique could be a very helpful process to try to get people in a less intimidating, open, and free discussion. As funders, we often convene community groups or a variety of people from the community and it is very difficult to get candid, frank conversation in a trusting environment. This is a really powerful tool for that. It forces people to stop, listen, and really hear where the other people are at, and it builds a sense of trust from which you can go further in dialogue.



# ABOUT GIH

With a mission to help grantmakers improve the nation's health, Grantmakers In Health (GIH) seeks to build the knowledge and skills of health funders, strengthen organizational effectiveness, and connect grantmakers with peers and potential partners. We help funders learn about contemporary health issues, the implications of changes in the health sector and health policy, and how grantmakers can make a difference. We generate and disseminate information through meetings, publications, and on-line; provide training and technical assistance; offer strategic advice on programmatic and operational issues; and conduct studies of the field. As the professional home for health grantmakers, GIH looks at health issues through a philanthropic lens and takes on operational issues in ways that are meaningful to those in the health field.

## Expertise on Health Issues

GIH's Resource Center on Health Philanthropy maintains descriptive data about foundations and corporate giving programs that fund in health and information on their grants and initiatives. Drawing on their expertise

in health and philanthropy, GIH staff advise grantmakers on key health issues and synthesizes lessons learned from their work. The Resource Center database, which contains information on thousands of grants and initiatives, is available on-line on a password-protected basis to GIH Funding Partners (health grantmaking organizations that provide annual financial support to the organization).

## Advice on Foundation Operations

GIH focuses on operational issues confronting both new and established foundations through the work of its Support Center for Health Foundations. The Support Center offers an annual two-day meeting, The Art & Science of Health Grantmaking, with introductory and advanced courses on board development, grantmaking, evaluation, communications, and finance and investments. It also provides sessions focusing on operational issues at the GIH annual meeting, individualized technical assistance, and a frequently asked questions (FAQ) feature on the GIH Web site.



## Connecting Health Funders

GIH creates opportunities to connect colleagues, experts, and practitioners to one another through its Annual Meeting on Health Philanthropy, the Fall Forum (which focuses on policy issues), and day-long Issue Dialogues, as well as several audioconference series for grantmakers working on issues such as access to care, obesity, public policy, racial and ethnic health disparities, and health care quality.

## Fostering Partnerships

Grantmakers recognize both the value of collaboration and the challenges of working effectively with colleagues. Although successful collaborations cannot be forced, GIH works to facilitate those relationships where we see mutual interest. We bring together national funders with those working at the state and local levels, link with other affinity groups within philanthropy, and connect grantmakers to organizations that can help further their goals.

To bridge the worlds of health philanthropy and health policy, we help grantmakers understand the

importance of public policy to their work and the roles they can play in informing and shaping policy. We also work to help policymakers become more aware of the contributions made by health philanthropy. When there is synergy, we work to strengthen collaborative relationships between philanthropy and government.

## Educating and Informing the Field

GIH publications inform funders through both in-depth reports and quick reads. Issue Briefs delve into a single health topic, providing the most recent data and sketching out roles funders can and do play. The GIH Bulletin, published 22 times each year, keeps funders up to date on new grants, studies, and people. GIH's Web site, [www.gih.org](http://www.gih.org), is a one-stop information resource for health grantmakers and those interested in the field. The site includes all of GIH's publications, the Resource Center database (available only to GIH Funding Partners), and the Support Center's FAQs. Key health issue pages provide grantmakers with quick access to new studies, GIH publications, information on audioconferences, and the work of their peers.

## DIVERSITY STATEMENT

GIH is committed to promoting diversity and cultural competency in its programming, personnel and employment practices, and governance. It views diversity as a fundamental element of social justice and integral to its mission of helping grantmakers improve the nation's health. Diverse voices and viewpoints deepen our understanding of differences in health outcomes and health care delivery, and

strengthen our ability to fashion just solutions. GIH uses the term, diversity, broadly to encompass differences in the attributes of both individuals (such as race, ethnicity, age, gender, sexual orientation, physical ability, religion, and socioeconomic status) and organizations (foundations and giving programs of differing sizes, missions, geographic locations, and approaches to grantmaking).

OVERFLOW TEXT!

In 1982 Dr. Eckardt assumed the position of program officer with The Cleveland Foundation. He was promoted to senior program officer in 1988 and in 1996 was given additional responsibility as manager of grant evaluation. In 2000 he was promoted to the position of vice president for programs and evaluation, and in 2005 to his current position. Dr. Eckardt has served as a board officer of several national philanthropic groups, including Grantmakers In Health, Grantmakers in Aging, Funders Concerned About AIDS, the Grantmakers Evaluation Network and the Health Policy Institute of Ohio and has consulted with foundations throughout the country. He is an active member of several professional organizations, such as American Public Health Association, American Society on Aging, and is an elected Fellow of the Gerontological Society of America.





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