GRANTMAKERS IN HEALTH

Navigating Risk and Control in Creating Public Will to Eliminate Racial and Ethnic Health Disparities

PATRICIA BAKER, *President and CEO, Connecticut Health Foundation*

Connecticut is one of the wealthiest states in the country, but there are two Connecticuts, and in many African-American and Latino neighborhoods, poverty is high and health is poor. One goal of the Connecticut Health Foundation's (CT Health) 10-year strategic plan is to improve racial and ethnic health outcomes in these low-income communities.

In 2006 CT Health's strategic planning committee met to take a hard look at several disparities initiatives – workforce diversity, cultural competency, and community-based health promotion – in which the foundation had invested. Had they made a difference? Were racial and ethnic health outcomes likely to improve in coming years? The hard answer, especially to the latter question, was "No."

True, the foundation had funded good programs. There were pearls in its portfolio; staff and board had learned from the experience, and individuals had benefited. Still, as worthy as these efforts had been, because they were limited in scope and reach or were simply limited in their effectiveness, they had not substantially advanced the foundation's goal of reducing racial and ethnic health disparities.

So what *would* achieve that goal? After much thought and discussion, the strategic planning committee realized that the foundation needed to be more systematic and take the step of initiating a high-risk process in which it did not control the agenda, goals, or objectives.

The committee's conversation frequently returned to CT Health's Policy Panel on Racial and Ethnic Health Disparity, a 12-member group of state leaders from the public, private, and nonprofit sectors created in December 2003. The panel's 2005 report opened the door with policymakers, and what CT Health had found behind that door was instructive. While some of the state's greatest champions of the cause embraced the panel's recommendations for developing sound policy, they spoke of difficulty pursuing them, since many in elective office and power saw any discussion of health disparities as one that could polarize the legislature rather than bring it together.

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If the champions were saying this, how much could CT Health really accomplish? It was a sobering thought that challenged the strategic planning committee's thinking regarding change – and the foundation's role as a change agent.

SHIFTING PUBLIC WILL

Committee members understood that without a shift in what was acceptable regarding health outcomes, racial and ethnic health disparities in Connecticut would persist and could grow even more disparate. They wanted racial and ethnic health disparities to be unacceptable, not only to CT Health and its grantees, but also to a critical mass of Connecticut residents and decisionmakers. They asked themselves, "If the results are to change, what conditions must exist and who has the power to affect change?" They knew that the shift required more than a neat program or a quick policy fix. The complexity of the issues demanded much more.

Ultimately, the bleary-eyed strategic planning committee concluded that sustainable, measurable change could occur only by shifting public attitudes and will, and by engaging a critical mass that demanded action.

It agreed that the effort should be led not by the foundation, but by the people who were most affected. The committee was willing to risk not being in control because of the importance of the moment. It reasoned that if the foundation did not seize the opportunity, Connecticut residents might not be willing to conduct a conversation about racial and ethnic health disparities until some time many years in the future.

DEFINING PUBLIC WILL

Once it took on the challenge of fostering public will to understand racial and ethnic health disparities and act to ameliorate them, the strategic planning committee was challenged with defining public will, defining success, and determining what to measure and where to start as a baseline. It defined public will as the expression of public sentiment or opinion through a set of efforts to educate, inform, or influence a particular segment of the public about racial and ethnic health disparities. The intent is having them support actions (or oppose actions that would have a detrimental effect on reducing disparities) at the programmatic, systemic, or policy level.

With the decision made to focus on building public will, CT Health now needed to outline a grantmaking strategy. It started with a baseline assessment, conducted by The Opportunity Agenda, that included a media content analysis, a telephone survey, focus groups, and legal research. The foundation also conducted one-on-one interviews and completed a social network map. The findings included the following:

➤ *Media Coverage*

The assessment analyzed news coverage of racial and ethnic health disparities from 2002-2007 in the *Hartford Courant*, *Connecticut Post*, *Boston Globe*, *The New York Times*, and *Associated Press*. The analysis revealed little coverage of the topic. When there was coverage:

- 62 percent of articles cited health care costs and access as the cause of racial and ethnic health disparities. Many saw it as lack of health insurance.
- Other media stories attributed the issue to patient behavior or, as we often hear, “Why won’t they take better care of themselves?”

When the media discussed solutions to health disparities:

- 64 percent cited health care as the source of the solution.
- 20 percent cited increased awareness.
- Only 15 percent cited systems change.

➤ *Telephone Survey*

The telephone survey contacted 785 Connecticut respondents over age 18, with an oversampling of African Americans and Latinos. The survey found that:

- 85 percent of respondents saw health care costs as the greatest problem.
- 70 percent believed that disparity resulted from the poor being in worse health, which they attributed to lack of access.
- 52 percent believed that racial and ethnic minorities have equal opportunity for quality health care.
- 90 percent believed that everyone has a right to health care.

The findings from the media and telephone surveys reflect the public perception of racial and ethnic health disparities that CT Health continues to battle: disparities are seen as a poor person’s problem. People of color even blame themselves for their health problems (I should eat better, take better care of myself, follow doctor’s orders, etc.).

➤ *Focus Groups*

The survey results identified specific groups to which efforts to build public will could be targeted, including Latino voters, ages 25-34; politically moderate/independent white women, ages 25-34; and politically progressive white men, ages 21-34. These results were affirmed by the focus groups. Key findings from the focus groups included:

- identification of lacking or inadequate health insurance as the most important Connecticut health issue;
- uncertainty about the definition of health disparities (when asked about health equity, focus groups associated it with health savings accounts);
- skepticism among white respondents about the existence of disparities and concern about undocumented immigrants overburdening the health care system – individuals they saw as "undeserving"; and
- agreement among participants that the Internet was the most important channel of information on health issues, while providers, family, and friends were seen as the most trusted information source.

➤ *Personal Interviews*

It is difficult to measure what individuals think and feel about racial and ethnic health disparities because how people feel about sensitive issues can be very different from what they articulate. Nonetheless, knowing that building public will boils down to fighting for the hearts and minds of the public, CT Health conducted numerous personal interviews. From them the foundation learned that a successful movement to build public will would have to:

- put a human face on the issue of disparities,
- tap into people's values, and
- deliver a unifying message with a clear agenda that could be acted on at both the local and state level.

➤ *Social Network Mapping*

CT Health's social network mapping showed that the state lacked a hub of influence or specific focus of power, such as a group of leaders who could move public opinion or organize strong constituencies to affect change.

➤ *From Prescriptive to Organic Solutions*

The overall message of the baseline assessment was that people in Connecticut did not understand racial and ethnic health disparities. This, coupled with the issue's complexity, showed the foundation that a multifactoral approach would be required – not a simple fix or simple "ask." For its initiative to be successful, CT Health knew it would have to support the development of clear messages that resonated with multiple populations, and that the approach would have to be inclusive, with multiple partners and constituencies.

To implement this strategy, CT Health recognized that it would have to move from the prescriptive (solutions from outside the group) to the organic (solutions from those most affected). Going beyond the comfort of discreet objectives (such as increasing the diversity of the health workforce) was unfamiliar territory, but the foundation was committed to shifting its approach in order to bring about systemic change.

Data collection is a key element of the public will initiative. Recent actions include:

- a grant to the Connecticut Department of Public Health to standardize over 27 databases, and include race and ethnicity in them, which will allow constituencies to track efforts;
- a foundation-initiated Community Health Data Scan for Connecticut that provides timely, accessible, accurate data (the scan has identified the metabolic syndrome as the emerging issue for everyone in the state, but clearly impacting African Americans, Latinos, and Native Americans at ever-growing rates);

- support for the NAACP to complete a report card on African-American health, which couples data with the public voice of those most affected; and
- seed funding for the Health Equity Index, which gives communities an in-depth assessment of their health, with a specific examination of equity.

In addition:

- CT Health's policy research on establishing Medicaid reimbursement for medical interpretation and funding of the medical interpretation coalition has provided a "win" and a glimpse of the possible.
- Investment in the documentary *The Deadliest Disease in America* gives a face to health disparities.
- Funding the Greater Hartford Interfaith Coalition for Equity and Justice strengthens the alignment of the faith community and the issue.

LEADERSHIP AND ORGANIZATION

Data collection is just one element of CT Health's initiative to build public will. The foundation recognizes that investments in communities to determine their destiny are the basis of an organic movement. Therefore, it is making major investments into leadership and organizing through support of a Health Leadership Fellows program and a leadership council.

When CT Health's fifth fellows class graduates in June 2010, a total of 100 midlevel professionals will have completed a 10-month program designed to improve and enhance their leadership skills and sharpen their focus on racial and ethnic health disparities. In effect, the state will have 100 new agents of change.

Meanwhile, the leadership council is just beginning with a 2009 grant to the Connecticut Conference of Churches that supports convening diverse opinion leaders from across the state and sectors, guiding them on ways to frame the issue and identifying an agenda for change.

Anger and frustration fuel passion, but to work consistently over time requires an aspiration, a dream, and belief of what is possible. Accordingly, the leadership council is charged with helping define the values that will rally critical numbers of people to achieve health justice. With support from the foundation, this frame and the agenda flowing from it will provide the blueprint for local communities to organize. The council will direct implementation of the agenda at the local level.

CT Health cannot predict what the rallying point for organizing will be. Nor can the foundation define the agenda, for it cannot be CT Health's agenda. Rather, the communities most affected will determine the agenda. The foundation, however, must participate, understanding that movement-building is a long-term investment. It is this movement that offers the promise of significant change.

A NEW VIEW OF COMMUNITY

As CT Health planned investments in local communities throughout Connecticut, the foundation had to acknowledge that the definition of community was shifting from hometowns and local geography to professional and social networks. This changing reality was reflected in both the findings of the foundation's social network mapping and in sentiments expressed in the individual interviews that were part of the baseline assessment.

Originally the foundation envisioned creating a central website to which grantees would steer readers and commenters. We now believe the most effective approach is to infiltrate media such as Facebook and Twitter. In a way, it is the basic tenet of organizing: go where the people are.

Using social media to increase awareness and action about health disparities will be challenging. This complex issue, unlike a political transaction, does not lend itself to a simple "ask." However, the foundation's hypothesis is that these communities represent an innovative, untapped, "can't-miss" – but high-risk – opportunity to foster change.

LETTING GO

With time, CT Health has learned that the Web functions as a true community, not just as a means of providing and obtaining basic information. It turns out that the questions to be addressed are similar to those in grassroots organizing:

- How will we get information and foster conversation about racial and ethnic health disparities?
- What are the issues to face and resolve when entertaining this virtual community?
- How do we plant the seeds to spark conversation, raise awareness, and move participants to action?

But there are important differences from community organizing as well, particularly because of the on-line medium's rapid-fire pace and atmosphere of anonymous free speech. With this aspect of the public will initiative, CT Health moved again into territory that required relinquishing control. Because the foundation would not be able to control on-line content, its reputation could suffer. Risks involved included:

- handling outrageous comments,
- ensuring that the conversation reflected the foundation's values, and
- deciding whether or not to engage if racist statements were posted.

The decision was made to accept the challenge. In the third quarter of 2009, CT Health awarded the Society for New Communications Research (SNCR) of San Jose, California, and its collaborating partner CRT/Tanaka, headquartered in Richmond, Virginia, a 15-month, $200,000 grant to create and implement a social media strategy to eliminate racial and ethnic health disparities in Connecticut.

SNCR is a global nonprofit research and education foundation and think tank. CRT/Tanaka is a public relations and marketing firm with extensive on-line, nonprofit, and health care expertise. The strategy will focus on inspiring participants to engage in on-line conversations related to health disparities elimination. We encourage other foundations to join us in developing this virtual community.

TAKING GREAT STRIDES

Since the strategic planning committee members first struggled with the concept of public will, CT Health and its partners have made significant strides. There are positive signs and opportunities for change. For example:

- The Connecticut NAACP, using a CT Health-funded report and working with others, has created a Connecticut Health Equity Commission.
- Health reform efforts – whether Connecticut's Health First Authority (created by the legislature in 2007 to study ways all state residents can access health care and health insurance coverage) or the present reform effort, SustiNet (passed into law in July 2009 to provide affordable health care coverage to 98 percent of Connecticut residents by 2014) – make reducing health disparities a primary objective.
- There is recognition of the need for medical interpretation to eliminate language barriers to effective health care and the responsibility of government and systems to provide this service.

The environment has changed and now many political leaders are willing to give public support to the debate regarding health disparities. This is an opportunity that cannot be lost. The public will effort must continue to build the critical mass of individuals who collectively declare health inequities unacceptable and who demand action. CT Health believes that over the next 10 years this public demand will lead to public actions, which will lead to health disparities reduction and ultimately improved health outcomes for populations of color.

Do we know the first action to be taken or indicator to be addressed? No. Neither can we blueprint this to outline the architecture or outcomes of the initiative. Yet the return – and the potential for real and lasting change – is too great not to pursue.

And the greatest return will be realized if we accept the risk of letting go.