PATHWAYS TO EVALUATION OF COMMUNITY-BASED PROGRAMS

Guidance from the CENTERED* Project's Blue Ribbon Advisory Panel

*Community-based
Evaluation
Networks
Targeting
Elimination of
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PREFACE

In 1998, President Clinton committed the nation to the elimination of racial and ethnic health disparities in six areas: infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection/AIDS, and childhood and adult immunizations. If this goal is to be achieved by the year 2010 it will require concerted and sustained efforts funded by federal, state, and local governments, to candidly address the underlying causes of racial/ethnic inequities, including the disproportionate occurrence of disease, in communities across America.

The United States Department of Health and Human Services is providing leadership in this initiative and a multi-pronged approach is being taken. Included are efforts to increase research into access to quality healthcare services, social determinants (including poverty and environmental factors) of health, and the effectiveness of community-based public health programs.

There are many community oriented health promotion programs that seek to improve health among racial and ethnic communities to reduce the chronic disparities in health within these communities. The purpose of the investigator-initiated Special Interest Project (SIP25PR, 1999; aka the CENTERED Project) was to create a forum for bringing together those with perspectives that are rarely brought to the table to consider how to evaluate community-based efforts to eliminate health disparities. The result was the formation of a twenty-five member core advisory panel comprised of community leaders, scholars and evaluation professionals from around the country to guide the work of the Project. The guidance of this national Blue Ribbon Panel was then complemented by periodic involvement of ad hoc advisors to enable additional perspectives. *Pathways* was produced early in the project to share those viewpoints represented within the project.

Given that the context in which community-based public health initiatives take place includes diverse cultural, social and political dynamics, it is clear that an individual's health is not only the result of personal actions and behavioral choices, but also the result of environmental/economic, genetic, and socio-cultural factors over which the person has little or no control. Moreover, the well documented historical patterns of racism and societal discrimination on the part of dominant cultures since the founding of the United States have created powerful impediments to the education, gainful employment, and acquisition of wealth by non-dominant persons. These socially-accepted impediments have created obstacles that limit potential and enhance the probability of disparate outcomes in many fields, including health. Attempts to eliminate racial and ethnic disparities in health must be sensitive to these contextual issues and concurrently address those factors that contribute to health disparities if whatever gains may be made as a result of the national initiative are to be sustainable.

Truly community-based approaches to disparities elimination empower communities to actively participate in identifying factors that contribute to the existence of those disparities. Participatory processes are the key to meaningful empowerment, but they must include a valuing of community interests if those interests are to be incorporated into process outputs and into policy revisions and assurance monitoring. *Pathways* documents early guidance from CENTERED's Blue Ribbon Panel advisory group, and provides the rationale for why tailored program planning and evaluation processes are essential. The valuing of participatory processes is also a central theme of the *CENTERED Evaluation Guide*, as is the need for communities to holistically address racial equity.

Community-based public health programs operate within their own social and political context. The success or failure of a given program depends on its ability to mobilize support from both inside and outside the community. Programs need to establish credibility and trust with local partners and intended beneficiaries, while at the same time satisfying the expectations of external funders. For community-based evaluation to work, the stakeholders and evaluators must work in true partnership.

> *Pathways to Evaluation of Community-based Programs* is intended to help community-based organizations (CBOs) that are running public health programs to find their own paths to the truth regarding the effectiveness of their programs. CBOs need feedback that fairly describes the results of their efforts; and, they need to know what is working and what is not.
>
> There are many ways to gather the information needed for assessing program effectiveness, but it is critical that active involvement of community stakeholders is assured at all stages of the program planning and evaluation. This enhances the likelihood that the evaluation will produce the fair and practical recommendations needed for improving program effectiveness and assuring that community interests are valued and continue to drive the program.

METHODS

The CENTERED Project is led by the South Carolina Department of Health and Environmental Control's Bureau of Epidemiology in collaboration with the University of South Carolina Arnold School of Public Health's Prevention Research Center. The project is funded by the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health. The Project was initiated in the fall of 1999 as an investigator initiated project that was proposed for 3-years extendable to 6-years, to develop evaluation support for community-based organizations targeting to elimination of racial and ethnic disparities in health. The three project goals were:

- To establish a national Blue Ribbon Panel to guide the work.

- To develop a framework for use in building evaluation capacity for community-based efforts targeting elimination of racial and ethnic disparities in health.
- To develop networks of support for the evaluation of such community-based efforts.

The national Blue Ribbon Panel (BRP) was developed by an open call for persons interested in serving on such a panel. The candidates had to have significant experience in the evaluation of community-based programs and be willing to commit themselves for the duration of the project. The BRP selection process involved a committee of experts convened to review and make recommendations regarding those candidates the committee felt to be most appropriate for the BRP. The committees' recommendations were then used as the basis for inviting BRP participation. Twenty persons were invited. Five seats on the BRP were reserved to enable the BRP to expand its membership as they deemed appropriate.

During the course of the Project the BRP grew to include twenty-five highly diverse and respected members drawn from across the nation. Each has designed or conducted evaluation of community-based programs related to one or more of the following priority health areas: HIV, diabetes, infant mortality, breast/cervical cancer screening, child/adult immunization, or cardiovascular disease. Panelists have practical experience from working in communities on community-based prevention programs, and have achieved varying degrees of national recognition for their expertise in evaluating community-based public health programs.

The guidance from the BRP has been augmented through inclusion of highly experienced community-based organization leaders, public health professionals, and academics as ad hoc consultants and advisors. To add local perspectives, leaders of local community-based organizations were invited to share their experiences and recommendations during the quarterly CENTERED meetings that were purposefully held in various regions of the nation.

During the first year, CENTERED convened the Blue Ribbon Panel four times in different venues: North Carolina, Florida, New Mexico and Washington state. The variety of meeting locations enabled investigators and panel members to come together with selected advisors, CDC officials, and local community-based organization leaders to consider how best to support evaluation of community-based efforts to eliminate racial and ethnic health disparities. After numerous discussions, consensus was reached that the initial goal of developing a "generic evaluation protocol" was not consistent with the intent to incorporate into an evaluation methodology the flexibility required to be sensitive to, and respectful of core community values which influence community approaches to problem identification and resolution. During the second and third years, CENTERED reconvened the BRP an additional 6 times in venues in Texas, Georgia, California, North Carolina, and Alabama. The final meeting was held in April 2003 at the Birmingham Civil Rights Institute in Birmingham, Alabama.

Valuation of the role of community cultural beliefs during all phases of efforts to address health disparities was agreed to be essential to the sustainable success of community-based public health interventions. Therefore, it was agreed that a more appropriate project output than a rigid evaluation protocol would be sought. Instead of a single, fixed format evaluation document, it

was felt that the project's output would be more useful if it consisted instead of a set of outputs which enable those who would evaluate community-based public health interventions to be sensitized to the importance of local cultural values, and to how these influence individual and collective thinking and decision making.

That local decisions and responses to similar problems have varied significantly is clear. The variability of responses has been the result of varying local values. This is seen in the variations in governance structures, and in the variance in societal responses to voting rights, women's rights, the right to carry a gun, the terms of marriage and divorce, and the freedom of, and limits upon, self-expression.

It was agreed that instead of a single approach to evaluation, the project would produce a guide that would be tailored to enable alternative, culturally appropriate "pathways to evaluation". The project has aspired to provide a framework for evaluation which respects and builds upon both the Center for Disease Control's *Framework for Program Evaluation in Public Health* (<u>MMWR</u> Supplement No. 48; September 17, 1999), and the Centers for the Advancement of Community Based Public Health's (Durham, NC) refined version of that document, *An Evaluation Framework for Community Health Programs* (July, 2000) – produced with supplemental funding from CDC for the CENTERED Project.

The CENTERED Project outputs provide examples of how community and cultural values influence community approaches to problem identification; how intervention strategies used to address those problems can vary between communities; and, how community definitions of acceptable outcomes can differ from traditional public health indicators. This appreciation is essential, as evaluation instruments and assessment tools must first be calibrated to local community and cultural values for their outputs to be meaningful and useful for guiding intervention refinements of local community-based interventions.

This tailored, non-traditional evaluation approach is the consensus product of the wonderfully diverse perspectives offered by the variety of project participant – investigators, BRP members, and the broad array of ad hoc consultants, advisors, and interested others. Their invaluable contributions, their willingness to join in this challenging endeavor, and their perseverance through the challenges brought on by the dramatic shifts in national priority that occurred following the change in national administration and the events of September 11th, 2001 were critical to this project. It is hoped that the CENTERED outputs are found to be practically useful, yet scientifically sound, and of assistance for enhancing the capacity of community-based organizations to fairly and credibly evaluate their efforts to eliminate racial and ethnic disparities in health.

Thank you, Marshall Kreuter, for your shared vision and support without which there would not have been a CENTERED Project.

Donald J. Goodwin, MS, DrPH
Principal Investigator, CENTERED Project

Contents

Chapter 1
Introductions

A Tale Of Two People

Two people were brought to the emergency room today. Each suffered from a heart attack. Here is what we know about them.

The first person:
- Has many other illnesses;
- Has no health insurance and no medication;
- Is unemployed;
- Has no money;
- Does not go to doctors;
- Is homeless;
- Is hungry;
- Is very stressed and distressed;
- Has always had poor nutrition;
- Lives in a hazardous place with polluted water, polluted air, and toxic wastes;
- Has little education;
- Does not speak the standard dialect;
- Experiences social rejection;
- Has a minimal support system.

The second person:
- Has no other illnesses;
- Has health insurance and access to medication;
- Is employed;
- Has money;
- Goes to doctors;
- Has a home;
- Is not hungry;
- Is not very stressed or distressed;
- Has good nutrition;
- Does not live in a hazardous place with polluted water, polluted air or toxic wastes;
- Is educated;
- Speaks the standard dialect;
- Does not experience social rejection;
- Has a good support system.

Is The Illness The Same For Both People?

What is the prognosis for these two people?

Does this illness exist in the same biological environments? Psychological environments? Physical environments? Social environments?

How do we measure the impacts of these environments on a person's health?

A Tale Of Two Communities

There are two communities in the town. Here are their situations.

The first community:
- Has suffered for generations from the racial and cultural prejudices of the dominant culture;
- Is still the target of racism: institutional, personalized, internalized, and cultural;
- Has poorer health in general;
- Has high poverty rates;
- Has high unemployment rates;
- Has fewer occupational opportunities;
- Experiences forced isolation;
- Has poor access to health care, jobs, or schooling;
- Has high rates of homelessness;
- Has high rates of poor nutrition and hunger;
- Experiences high rates of stressful events;
- Has cultural roots – values, philosophy, attitudes, behavior, spirituality – that are different from, and rejected by, mainstream white America.

The second community;
- Has not experienced abuse due to racial and cultural prejudices;
- Is not the target of racism;
- Has better health in general;
- Has low poverty rates;
- Has high employment rates;
- Has many occupational opportunities;
- Does not experience forced isolation;
- Has good access to health care, jobs and schools;
- Has low rates of homelessness;
- Has low rates of poor nutrition and hunger;
- Experiences low rates of stressful events;
- Has mainstream cultural roots.

Is Illness The Same For Both Communities?

What is the prognosis for these two communities? Does illness exist in the same biological environments? Psychological environments? Physical environments? Social environments?
How do we measure these environmental impacts and circumstances on a community's health?
Might the causal factors that affect health in these two communities act differently?

Two people, two communities, provide stark and simple contrasts. In reality, there are many people and many communities. There are many paths leading to health and illness for individuals and for communities. Treatments that work well for one person may not be necessary or sufficient for another. Programs that work well in one community may not work in another. How do we, as evaluators, capture the differences between these communities? Can we make any kinds of generalizations or are they really different kinds of entities? Maybe, we should be making comparisons among similar communities, for example, Native American communities compared with other Native American communities, and not with middle-class, white American communities. The dynamics, the environments, the pressures, the circumstances, the history, the culture itself, are different.

Community-based initiatives should be culturally sensitive and tailored to the true underlying issues that contribute to poor health outcomes for a given community. Evaluation should be community-based, too. The people and organizations that develop new approaches to promote health at the community level should also take the initiative in deciding how to evaluate those efforts. They have the clearest sense of what the program is designed to achieve and how success will occur. Evaluation should provide information that strengthens the program and improves its chances for success. Evaluation methods for culturally diverse programs should have three basic goals. The first is to do no harm. The second is to be helpful and constructive. The third is to remember the context.

The Eye Of The Elephant:

Cultural Perspectives On Evaluation And Communities

Pauline E. Brooks, PhD
California Endowment

Our current evaluation methods have a heavy European cultural influence. The evaluation models, the concepts and language, the research literature, the administrative rules and the tools all reflect a scientific, analytic Western approach. We have concepts; we have tools; we have assumptions; we have language; but these all rest on a particular kind of culture. The cultures that have generated these methods are not the cultures in which we are making evaluations of racial disparities. Our tools do not measure what we want to measure when it comes to changes in health disparities, because the meaning of the factors that contribute to health disparities differs among communities and cultures. There are alternatives for evaluating change. These alternatives are not better or worse than the present evaluation methods; they do not replace present methods: they are different. They emerge from the cultures of the people that the

programs serve.

Culturally relevant alternatives complement traditional evaluation paradigms, models, tools, concepts, language, and approaches, and expand them to include the worldview of the communities and their people.

THE BLIND MEN AND THE ELEPHANT

Not so long ago, a large gray elephant stood eating the lush greenery in the ancient walled garden of the Rajah's palace. He paused for a moment, and trumpeted loudly at the sight of six blind sages who were walking past in single file, each with his hand on the shoulder of the man before him.

"What made that sound?" cried the first sage.

The second replied, "I believe that is the sound of an elephant."

"What is an elephant?" asked the third.

"I am not exactly sure," said the fourth.

"I have never seen an elephant," said the fifth.

"Let us investigate," the sixth wise man boldly proclaimed.

The first blind man walked forward with fingers outstretched until he came to the side of the elephant. "How smooth and firm is this! An elephant is like a wall!"

The second wise man reached out and touched the trunk of the elephant. "How round it is, and so flexible in its movement. The elephant is just like a snake!" The third blind man walked directly into the elephant's tusk. "Ow! How sharp and pointed the elephant is! It is like a spear!" The fourth blind, wise man grasped the elephant's ear. He moved his hand along its surface, and jumped back as the elephant flapped its ear. " How wide and supple is the elephant! How cooling are its breezes! An elephant is like a fan!"

The fifth blind man went forward until he reached the elephant's knee. He reached around with his right arm. He reached around with his left arm. "How round and tall is the elephant. An elephant is like a tree!"

The sixth blind man strode up to the elephant's tail. He grasped it firmly and announced, "How thin and long the elephant is, very much like a rope." The sages fell to arguing among themselves. "The elephant is like a wall." "No, a snake!" "Not at all like a snake or wall – it is a tree!"

"Not a tree! An elephant is like a fan!" "It is a sharp spear!" "No, a rope!"

With billowing minds and bellowing mouths, To opinions these blind men held fast.
While the elephant stood, quite undefined, In his garden of ancient past.

Source: Adapted from: Lillian Quigley, *The Blind Men and the Elephant.,* New York: Charles Scribner, 1959, and Heather Forest, *Wisdom Tales from Around the World.* Little Rock: August House Publishers, 1996.

When we apply evaluation methods to community programs, we single out specific measures that will give us indications about the effectiveness of the program and its results. Our description of the program may be clear. The evaluation methods we choose may be scientific and appropriate. The measures may be accurate, valid and reliable. Even so, we may miss the meaning of the program, and its real impacts on the people it serves. We need the big picture of the community to evaluate the importance of the specific program. It is important for us to hear from the people themselves.

This means we must shift our approach to evaluation. We must seek multiple perspectives across multiple disciplines and coordinate the data from these multiple perspectives to get a better picture. We must get inside the "elephant" (community) and generate assumptions; develop and test hypotheses and theories; based on what the elephant sees, experiences, knows, feels, struggles with, and believes. To do justice to the communities and programs that we are evaluating, to really understand the health problems, we need to understand the environment and the perspective of the people of the community.

There are some fundamental flaws in the project paradigm that funds many community-based programs. Money is given to communities for a limited time period, to do some specific intervention, and show immediate results. This leads communities directly into a "trick bag," where the rules are designed by sponsors and evaluators. The trick bag has a lot of complexity in it. The trick bag asks community-based organizations (cbo's) to instantly implement services, to do evaluations, and to somehow at the end of three or four or five years, to have some type of scientific evidence that something has changed. Now, if in 300 years, people of the communities have not been able to do that, it isn't likely that they will succeed in two years or five years. It probably will not happen. Or, not happen in a way that evaluators and sponsors would accept as hard scientific knowledge. That's a trick bag. We are setting communities up, and we're setting the people up, for expectations that logically and realistically and historically probably cannot happen. Especially when these community-based organizations have other constraints. They design programs to fit the requests for proposals, and not to fit communities' needs.

How To Recognize And Get Inside The "Elephant"

As social scientists and evaluators, we need to begin to develop a whole new way of including the perspective from inside the "elephant" (community). We cannot solve the problems of racial disparities in health until we can take that perspective, because we are operating on limited information. Factors that characterize culturally isolated and racially segregated communities must be included in program evaluations. Racism, substance abuse, and environmental hazards each play a part in our communities, and must be considered as part of the "big picture". We need to explore non-linear and non-individualistic models. Our logic models tend to be linear. We think in linear ways: "this causes that". Community people rarely talk about health behavior in a linear fashion. It is a whole person and a whole community that is the appropriate model.

Issues should be studied in clusters as they occur, not examined in isolation. We need to be funded to listen, learn, and be guided by the culture of communities. The key is a process of informed observations. This means more than sitting as a passive observer. It requires a community guide who can accurately explain and interpret the information.

Fair comparisons need to be made among communities with similar racial and cultural characteristics. There are communities where health problems are less frequent. These communities can be compared with similar communities where there are very serious problems. We need to study health systems and follow people as they go through these systems. What happens as people of color go through institutions for care? What is the reality as one goes through the health system from beginning to end? Discrimination takes many forms, and has the potential to affect care at many points. If people get the message that they are not wanted from the person at the reception desk or the nurse, then they may not be compliant with treatment. The whole process needs to be considered. Evaluation efforts need to assess protective factors as well as hazard factors. An ecological perspective is important.

Programs should not have to make unrealistic promises for what can be accomplished with limited funding for limited time periods. Sponsors should plan to support community-based initiatives for a "fair trial period" – that is, for sufficient time for real change to occur. Few interventions have instant success.

The Culture Of Evaluation Science

Private, public, and philanthropic sources of funding for community-based health programs are influenced by a culture of science that adheres strongly to two principles: evidence and attribution.

Decisions about evaluation measurement and design, and consequently the support of particular intervention evaluation strategies, are driven by underlying assumptions about what constitutes "evidence" and what methods will allow observed effects to be "attributed" to the interventions in question.

Credible evidence is understood to be quantitative measures with proven degrees of validity and reliability, although acceptance is increasing for mixed method strategies that integrate qualitative and quantitative techniques.

Likewise, those who sponsor health programs expect to be able to attribute outcomes to a given intervention by controlling for sources of confounding. This remains the greatest methodological challenge facing community-based evaluators.

Marshall W. Kreuter, PhD

What Needs To Change?

A Conversation Of The CENTERED Project's Blue Ribbon Panel, August 2000

Pauline E. Brooks, PhD
The California Endowment
There is an underside to community-based initiatives. These communities have been pretty much throw-aways in this society. These were not communities that were loved and nurtured and cared for and valued. Community people know this, even if they never read a book. Given that history, why now?

The United States government, social scientists and professional evaluators, program people, we're not innocent in the creation of circumstances that communities experience. The data that we collect may be used for unintended purposes. There needs to be some protection for the community. Who will have access to the data? Agreements need to be made before researchers come in and collect information. Maybe we don't have to ask certain questions. For example, in work with immigrant populations, even if it is key to my hypothesis, I do not ask where people were born, since this information may be used against the people who are sharing the information.

The approach of trying to change one specific aspect or address one specific health problem does not really meet the communities' needs. For example, a program may be designed to address diabetes and evaluated to show some evidence that scientists will accept. That is wonderful, but what about all the rest of the health problems and the other problems that exist in our communities? Are you just trying to change one thing and leave everything else intact? That may sound good from a research perspective because we can control for things, but that does not sound good from a community perspective. How are existing health models and practices really not serving, actually actively under-serving, these populations? There are many other things that need to be examined.

Hank Balderrama, BSW, MS
Washington Dept of Social Services
We need to phrase things in the way that makes sense to people, that shows that not only are these factors harmful to people on a personal basis, but there are also some good social and economic reasons to do things differently. We can demonstrate that there are some human and financial benefits in giving people permission to do the right thing. I think that is a solid approach and one which is very difficult to argue with and very powerful, and which robs nobody of their dignity.

Joann Umilani Tsark, MPH
Papa Ola Lokahi
Change has to occur in a lot of places, but a main place is the establishments and institutions that fund interventions and then the evaluations of them. A lot of organizations that are funding work to address racial and ethnic disparities in health have a focus on specific diseases. Look at REACH. It is a disease, body part, condition-focused Initiative. The National Institutes of Health are certainly driven that way. Think about the groups that are trying to get money to do this kind of work. They have to write proposals. It is all this linear thinking, the traditional ways of thinking.

What are you going to try to do? What is your logic model? What is your intervention going to do? How are you going to measure it? How are you going to prove it? Communities are being given resources to reduce disparities, but they must fit into this traditional way of thinking about doing research. Before anything is really going to change, we have to change the way in which the whole thing is conceptualized and resources are given to fund these kinds of initiatives.

Paula M. Lantz, PhD
University of Michigan School of Public Health
Communities have to change, too. One of the lessons for communities is to not jump at every carrot that is out there. It is really hard, because communities want to respond to so many pressing problems. It is very tempting and there is a lot of need. The things that have succeeded in communities have been things that have been thought out. It takes time. Rarely do funders acknowledge the time it takes to bring about sustained change.

Doug Easterling, PhD
University of North Carolina at Greensboro
Evaluators need to change. The culture that defines "evaluators" has strong implications. The positivistic, empirical approach that science traditionally has brought to research, and that researchers have then brought to communities, has really impeded any kind of exploration or dynamic development of these contextual solutions. Everything that researchers do is to reduce it: reduce it down to individual logic chains; reduce it down to individual causal factors; reduce it down to individual outcomes. What communities need is to keep it big. Keep it at the level

where you get real solutions, and that means that evaluators have to accept their own limitations.

Quinton Baker
Community Health, Leadership and Development
I think a significant change has to take place with community-based organizations and the role that they play in terms of evaluation and in terms of the initiatives. Oftentimes, community-based organizations partnering with academic institutions or health agencies, allow those agencies to take the lead, allow them to set the tone for what is happening. This is particularly true with evaluation, because it is an area that we have shied away from or not wanted to be bothered with. So, I think one of the places that the impact has to happen is with community-based organizations. It is their ability to understand this idea of measuring their success in their community. And then, how they communicate that to CDC and other sources.

Deborah Jones-Saumty, PhD
American Indian Associates
One of the things that I try to do when I work with Indian Tribal communities is to encourage behavioral reciprocity. What that does is help the community feel that it is all right to move from being acted upon, to being an actor. That is very difficult for some communities, and some communities are not ready for that change. But the concept of behavioral reciprocity, I think, would apply to a number of communities of color, because many have been acted upon for generations. In some cases, if you simply give them permission to go from acted upon to being an actor, they can do it with no problem. Others will need much more guidance in terms of what it means to be an active participant in this change that we're talking about. So, I think we have to be ready to look at all levels of readiness for

8

change within those communities.

community's situation.

That's not in any of the tools that we typically see. We need tools that include

Belinda Reininger, DrPH
University of Texas-Houston
School of Public Health at Brownsville
I think what should change is that evaluation would actually be useful to communities. They would see evaluation information as important, not irrelevant and just something they had to do. I think that we, as programmers, evaluators, and communities would work in partnership over the long-term. We would stop seeing these three-year partnerships, or the partnerships to get a proposal funded. We would start seeing long-term networks. We would assess clusters of appropriate factors rather than individual factors; we would recognize and measure the impact of the contextual factors in our work. We, as evaluators and programmers, would recognize that our primary audience is the community and that we are accountable to the community first.

Quinton Baker
Community Health, Leadership and Development
The interesting thing to me is that, of the tools that I have looked at, all stick very much to a traditional model of evaluation. There is nothing out there that even introduces any of the concepts suggested here.

Jerry Del Gimarc, MA
South Carolina Turning Points
The typical funding sources want to see change and something concrete within a limited amount of time. That is not what we're talking about. We want to clarify what is community capacity, and how you would measure that. The other part is to look at really a whole different way of assessing the community's strengths and the

community history and community expectations, hope and sense of power and so forth. That is a whole different thing, because the assessment tools that you see are pretty standard for more organized programs. We want to understand clearly what the community sees as it's principle outcomes or statements of success, which might be different from the funder's. What do communities say is their success?

Bobby Milstein, MPH
Centers for Disease Control and Prevention (CDC)
I think one of the difficulties is that there is a chasm between what funders want and what communities see as successes. The community has not had the ability to articulate what they are doing and the successes, and have not had the power to influence what it is that funders are demanding to come out of communities. Until communities can really articulate their successes, and can really identify their issues, it will be difficult to bring about change.

Pauline E. Brooks, PhD
The California Endowment
Communities are doing a whole bunch more than anybody ever knows about. They have other kinds of capacities that we don't even recognize for functioning.

Doug Easterling, PhD
University of North Carolina at Greensboro
So, what you're saying is that there is almost an implicit social change model that

9

communities work under that has never been validated, never been documented. If communities were able to do it, you could almost hang a scientific term on that.

Hank Balderrama, BSW, MS
Washington Department of Social
Services
The academic community, the government community, the private funding community, the community-based organizations, they don't all talk the same, and they don't have the same values regarding efforts and how we document them. We need to have some way for those folks to communicate and understand.

Christine Lowery, PhD
University of Wisconsin
Communities are speaking. Women gathered on porches and family groups are talking about problems and issues of the community, but it is not taking place in the context of a community meeting. They are discussing things with family members and how they are involved with certain things. But, I think that there will be pathways.

There is a developmental progression in learning evaluation, which includes strengths of the community and strengths of individuals in the community and leadership in the community. You have pathways to evaluation. You start where the clients are, so that there are multiple starting points.

We could produce a guide such that somebody could recognize themselves in the examples that we've given, and say, "we're doing this," and we could integrate that into a model. Communities could already see that they are functioning. I think that would prove useful, so that you can see yourself. That's what I envision. It is an integrated analysis, a picture. It's visual, so that communities can see where they are and

where they can go, with one glance, and have some understanding.
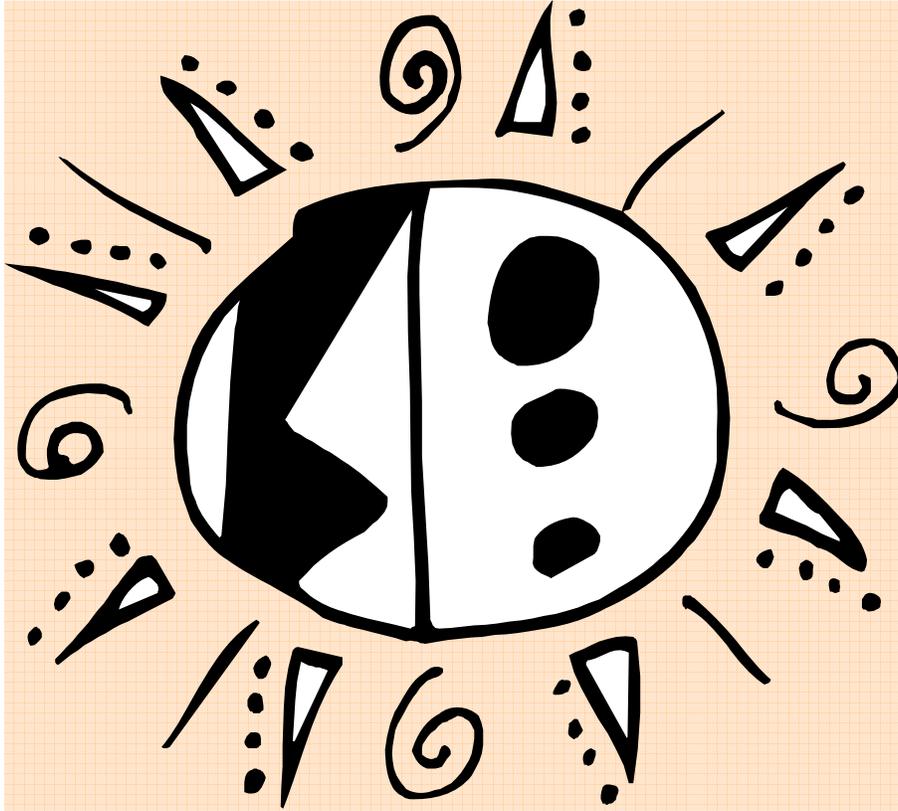
Chapter 2
Cultural Perspectives On
Health And Evaluation

How Do We Develop Cultural Perspectives On Health And Evaluation?

A Conversation of CENTERED Project's Blue Ribbon Panel, August 2000

Christine Lowery, PhD
University of Wisconsin

I'm a visual person and most members of my community are visual people. The Navajo rug tells a story through its color and its symbols. As a community, you would understand the story the rug tells: you would know where you are; you would have a visual picture of where you need to go. Then you can ask the questions.

This is where the conflict starts. It is very difficult to translate this concept into evaluation terms. I don't know how to say this in English, but if I could see it, I would know what it was. How do you translate that into action steps, because action steps don't even belong here? That is the cultural difficulty. I know what I can see, and I can recognize it when communities are making progress.

The picture in the rug is not a geographic location. There is something in there about the maker of the rug, it's telling about a time period, but all of that is embedded. If you don't have that understanding, you don't know what is going on. But if you can see

yourself as part of it, and this is where the community comes in, the spirituality of community is that each piece can contain your knowledge, and you are part of that story. And that is where the talk comes in. Each of you can see yourself in that picture or in that landscape. You bring your own version of that story, and you put it together. It's like laying a feast on the table.

Quinton Baker
Community Health, Leadership and Development

I think that to do it, you have to get out of our box of dealing with written words and linear thinking and you have to do story or music or something. You have to do something visually or orally, because most of the communities that we are talking about, communicate through oral or visual mains. They don't do a lot of writing for communicating their lives.

Ross F. Conner, PhD
University of California, Irvine

We've got to introduce the holistic perspective right off, by validating the community views, so the communities will be able to resonate. Then we can move to tools and all these other things. It's not taking that story and making it fit an academic model. Instead, it is making that story the center. The other evaluation things are brought in as needed.

Bobby Milstein, MPH
Centers for Disease Control and Prevention (CDC)

You can't convince other people to give resources to build community capacity, unless you can show where you are, and where you need to go. If it matters, you can measure it. The problem is, that until you formalize something culturally, you can't translate it to another culture. So, I believe that building a Navajo rug is great to clarify for the maker, what message they want to give, and to use the cultural symbols that are appropriate in their own culture, but when we approach cross-cultural communication, there is another challenge there. Here, we are talking about multiple forms of cross-culture communication fitting into a required formalism that has to turn into some kind of quantification and systematic tracking. If you can't link the investments to changes in disparities, at some point it is going to be like a house of cards, it is going to fall down.

Christine Lowery, PhD
University of Wisconsin

I think this is what we have to challenge in this, because we have an opportunity to challenge the required formalism. We're not saying, "do away with the formalism," we're just saying, "open it up."

Paula M. Lantz, PhD
University of Michigan School of Public Health

I want to throw something on the table that I think is an absolute of doing any kind of evaluation. Take any intervention, program, policy, or service, get a group of people who care about that, and ask them to think about, "what are the things that you want to know in an evaluation?" You can brainstorm and come up with dozens and dozens and dozens of things that potentially could be looked at. We could cover a whole wall with questions we might ask about one specific intervention in one community. So, something that we're going to have to grapple with, is the messy reality that different groups of people are going to be interested in different questions.

Now historically, the researchers and academics had been given the power to do the evaluations, and they had their own set of questions that they prioritized, and they've looked at, and that is what has emerged as being the knowledge that we want to produce about the evaluation. When you allow more people voice and power in determining those questions, you're going to get other things that rise and are of interest, as well. We have this big picture, this Navajo rug. We could construct this beautiful story about an intervention. When you let the researchers ask their traditional questions, they might just ask about two of the diamonds in the middle of the pattern. That is all they are going to focus on.

What you really want to do, is say, "How are we going to tell this holistic, whole story about it?" It is going to be really challenging to get there. Different people are going to have different questions, and no one is going to have the time, energy or resources to answer every question about it. How do you get all those voices in the mix at the beginning?

Don Goodwin, MS, DrPH
SC Department of Health and
Environmental Control
We need a way of communicating that is effective and appreciated by that community. It doesn't matter if it is a rug or a song or a dance or a painting, whatever it happens to be. You want to find that system and be open to non-traditional systems of delivery of care. The point of evaluation is whether your desired outcome is occurring, whatever that system happens to be.

I was in one village where the United Nations was doing an assessment. They went down a checklist. They were counting wells. They put out money for wells, they hadn't been back in a year, and they're going around checking the wells. They went out and checked outhouses, counted them, crediting the agency, "UNICEF paid for this." All you had to do was look at the demeanor of the people. There was total depression. And, I'm watching, and I finally took the people aside and said, "What is going on?" And they said, "We're moving. The government has ordered this community to move." So, all those wells, all those outhouses, they're going to be left behind. There is nothing that is going to be here. I went over and I talked to the leader of this UN mission. She was here for one day, looking at the village, and moving on to the next. When I asked her a question about where the village is going to be in three months, she finally asked the translator, "Where are you going to be?"
"Well, we're not going to be here."
"Now, just a minute. We've been counting and evaluating. What do you mean, you're not going to be here?"

Nobody had asked the people, "What are your priority needs?" The UN went in with its assumptions, these are the things you need: you need water - we build wells; you need outhouses; etc. Nobody asked about what was most relevant to them – the fact that they were being forced to leave their lands and were going to lose everything, the least of which were the UN's wells and outhouses. When the local military general was asked about this "move", he confirmed that it had been in the planning for a couple of years, but that no one from the UN had asked for his input on their work. The evaluation mission to that village was aborted.

Clearly, if you are an outsider, you must first learn to listen and ask questions, then work with the community to use your expertise to assist in addressing the priority needs as the community defines them.

Quinton Baker
Community Health, Leadership and
Development
You can be legitimized if you are from outside when you can use the tools that are in the community. Part of the cross-cultural thing is not changing the community to fit into a different culture, but being able to understand how they function in that culture. When the outside researcher or evaluator can use the tools of the community, then there is a legitimacy that automatically comes with that.

Bobby Milstein, MPH
Centers for Disease Control
and Prevention (CDC)
Evaluation is always going to be interactive. The minute that you have interaction among cultures, there are insiders and outsiders. We are going to have to deal with that issue of perspectives and interactions. That is fundamental. We have different languages or symbol systems. Somebody would represent this rug, and it would make a lot of sense internally in that culture, but it would need to be translated to others in a different symbol set. We are in a certain status, a place, a location, and we want to move to another location. Getting to a system of values is the hardest part of evaluation.

Johnnie Bell Bunch, BS, MS, RN
Hampton University School of Nursing
From a health perspective and as a health care provider, I would start at health. I wouldn't look at their disease and sickness because we are trying to move along the continuum from that illness to that wellness perspective. The goal is to promote healthy communities, so I would not introduce the concept of disease and sickness. I would start with the strengths. What is in that culture that allows some people to live long, healthy lives?

Christine Lowery, PhD
University of Wisconsin
So, the picture you want to draw, the rug you want to weave, is a healthy community, with healthy members of the community. They can do certain things; they do things certain ways. The valued male member in Native American society pays his village dues; he attends his village meetings; he participates in community work, and is called upon to do so; he supports his family. Those are all positive. And that is a measure of a healthy man.

Actually, it is a statement about who is a valued community member, because that is health. I am a community member and I contribute. This is how I contribute. This is how I behave. Physical health is just one segment of health and well-being. It doesn't matter as much in some communities, as what you contribute. For example, in my Native American culture, you could be on dialysis. You could go Monday, Wednesday and Friday, but the other days, you are participating in your community and you're considered a healthy person. Your contribution to the collective is what is considered the sign of health. You do everything you are supposed to do in village life, even though you go to dialysis three times a week.

Bobby Milstein, MPH
Centers for Disease Control and
Prevention (CDC)

Nobody sees the dialysis as a bad thing?

Christine Lowery, PhD
University of Wisconsin

That is part of the issue with diabetes: it is not seen as a bad thing, it is seen as something that has happened to you but you are still contributing, so it is not disease.

Bobby Milstein, MPH
Centers for Disease Control and
Prevention (CDC)

Except that you're going to die earlier than you should have, and the community is now denied your contributions after that. There are years of potential life that the community doesn't have.

Christine Lowery, PhD
University of Wisconsin

This is the difference in cultural thinking. You cannot think in those terms. A person does not come to be here for long: he is just here on earth for this length of time, and that is it. And when he goes, he goes. We're not into prolonging life. We live our life for today. These are the things that we have to do, these are the contributions I can give today. You have to shift the way you think of health and health prevention into that cultural context.

Quinton Baker, MPH
Community Health, Leadership and
Development

One thing that I have to deal with, in particular with diabetes, is the notion that, "God gave me this disease. If God wants to heal me, he will." All of this fuss that you're doing takes away from that relationship with God. And that is a very strong cultural piece in the African-American community.

You're going to have to take prevention and make it a part of God's plan. You can't say, "We have medicine and we have this and we can do that." Diabetes is rampant in the African-American community. It is so prevalent that people think it is a natural part of growing old. It's not as much of an issue within the confines of the culture as it is outside the culture. A lot of ministers don't talk about their illnesses because it denotes that they don't live right. Illness is something that happens because you're not doing something right.

There are a lot of cultural factors that we don't factor in when we take the biomedical model or the health promotion model and look at various cultures. We don't think about what is really at play there in the culture. You have to recognize and accept how the culture looks at health, illness, and well-being, and what are principle values within the culture. You have to look at it without the judgement piece - "This is bad."

Bobby Milstein, MPH
Centers for Disease Control and
Prevention (CDC)

But, you're not saying that diabetes is ever a good thing, are you?

Quinton Baker
Community Health, Leadership and
Development

It's not good or bad. The fact that both my parents were diabetic and that three of their children lived with the disease, is just an accepted thing. No one made any big fuss. When I was growing up, people had "sugar." It wasn't an issue, "Oh how dreadful, we've got to do something about this." It was, "Well, honey, my sugar is acting up a little today." You've got to understand that before you can even begin to think about how to reduce diabetes in that culture. You've got to understand the way that culture looks at diabetes.

Belinda Reininger, DrPH
University of Texas-Houston
School of Public Health at Brownsville

Part of what we want to send as a message is that evaluators better learn how to talk with their community within the community's cultural framework for any particular issue.

Christine Lowery, PhD
University of Wisconsin

If you don't listen, forget it. You shouldn't even go in talking.

Quinton Baker
Community Health, Leadership and Development

If you don't understand what Christine pointed out earlier about her culture and the way in which they look at life, death and health, what kind of indicators or measures are you going to use? What kinds of interventions are you going to be talking about? I think one of the clear messages we want to say to evaluators is, you can't come into a culture and impose a framework without really getting to the root of how the culture looks at the issues.
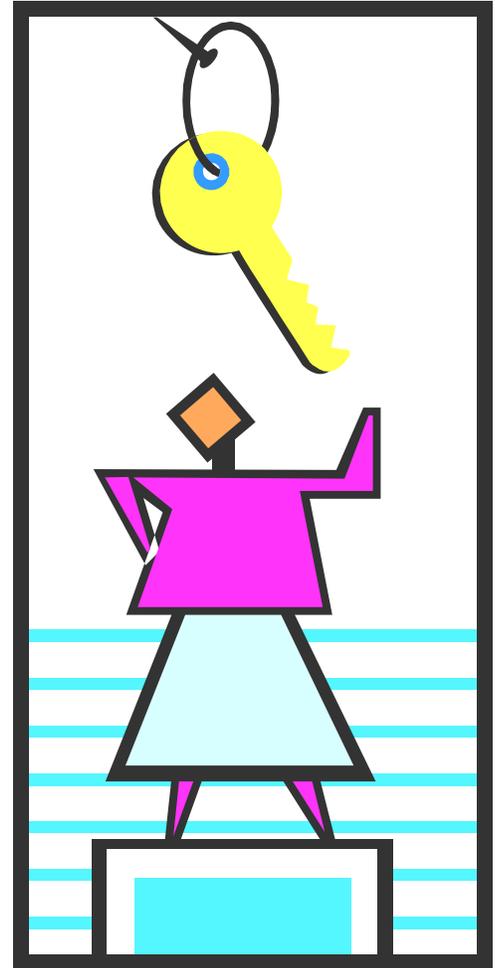
Cultural Perspectives On Health: Listen To The Stories

Pauline Brooks, PhD
California Endowment

Evaluation is operating in the space where two or more worlds meet: cultural, programmatic, financial, and scientific. The task is to find meaning for all involved.
What necessitates a trip to the doctor for treatment or prevention may vary culturally. If you come from another country, you may not see preventive or routine checkups as important, or may see treatments such as pills and surgery as negative. People may be reluctant to address or acknowledge illness; acknowledging it, naming it, may give the illness undesired strength.

Evaluation Challenges

Just counting the number of visits is not enough. The patient may not perceive the visit as helpful especially if there's miscommunication, even if both caregiver and patient are speaking the same language. A doctor visit doesn't indicate that a patient is on the way to getting better. With parallel treatments happening, one major challenge is knowing what it was that really helped the patient to get better---was it the doctor's treatment or the indigenous medicine or therapy? Or both? For some indigenous cultures, traditional medicines and therapies may be used but not talked about with people who are outside of the culture. How do we know what was actually done for prevention or treatment?

How do you evaluate treatment for an illness if there's a cultural stigma around talking about it, for example: mental health? What would indicate the success of a mental health program in such a community? How do we clearly demarcate where a community starts in order to measure how far a community has come? What happens when the distance between start and finish is not linear? How do we approach evaluation from a holistic perspective, respecting and understanding how cultures operate?

Even if the doctor explains treatment and all are speaking the same language, how do we know what the patient is really understanding or believing? Does the patient really believe and trust that the doctor is telling the whole truth? Does the patient really believe that health happens the way that the doctor is saying? What implications does this have for the patient in following the regimen exactly how the doctor has prescribed it? How do we capture what people actually do and their state of mind when they are doing it? These may be very different from what people tell us they did. How do you evaluate prayer as a medicine and the effects of prayer or spiritual healing, and the manipulation of positive and negative energy as prevention or treatment? Mixed into the above are history, the existence and manifestations of racism throughout the society and its institutions, socioeconomic status, acculturation, education, and habits and traditions. The challenge for evaluation becomes one of figuring out which, if any, of these factors significantly bear on the processes that result in racial and ethnic disparities in health.

> "Communities have natural ways of telling their stories about what health means, about what the journey is all about, and evaluators need to be more skilled in recognizing those stories."
>
> Doug Easterling, PhD
> University of North Carolina at Greensboro

From A Mexican American
Bad Air

During the time a woman is pregnant, there is a lot of care that takes place. There are times that midwives come to your house if you can't afford to go to the doctor's office. *Parteras* is what they are called. They can also be called during the delivery of the child. Generally we are taught that after we give birth there is a 40day *quarentara* which is a quarantine of specifically not being able to go outside, being "bedridden." Food is brought to the bed. Basically, all your household chores are done by someone else – taking care of the husband, feeding the family, washing the clothes. The theory is that the pores are open and the body can receive air causing hemorrhaging, headaches, inflammation, or muscle spasms. So, basically, the new mother is covered head to toe just to avoid possibly getting sick because that's supposed to be a very weak time that a woman is going through.

It's the fear of contaminating air and of how this air gets into, sucked into, your pores and causes your body to get inflammation, causing the body to sort of puff. At least my mom has told me this. Having been pregnant and not taking care of myself the way culturally I should of, my mom believes that's what happened to me and that's why I have not been able to lose some of the weight that I have gained. She says "*tienes aire, tienes aire*, you have air, you have air."

I am going to a holistic healer for massage therapy. He says that my arms have air pockets and other parts of my body, too. So, he says that I have to keep going back to release the air from my arms and other parts of my body. But, basically I need to have that pulled out, so that the energy releases and goes where it needs to go and blood starts to flow more. It is amazing because this is something my mom has told me, that my body after I had my son received a lot of air because I did not take care of myself.

A week after I had my son, I had to go out; I had business. It was cold, and I didn't have anything covering my head, didn't have anything covering my arms. I think I wore shorts to the Department of Motor Vehicles and I really didn't take care of myself. I cooked the week after that and that is something that you are not supposed to be doing. So my body has received cold air, as well as hot air. Because my pores were open, the air has come into my body and it gets locked into certain areas. The healer is Filipino. I'm not going to say that he is a doctor; he is a therapist. He is not a chiropractor, but he has his own business of a massaging, healing type of therapy. So I thought that was pretty fascinating. If it's true or not, I don't know what to say, but when you hear that two stories coincide, it starts to make you think that maybe mom is right. Maybe mom knows more than I want to give her credit for. And my mom is from Mexico, but she came to the States at a very early age, so she brought that along with her.

Question: Will you do something similar with your children?
I believe so; there are certain things that don't hurt to keep with you. The values.

Herbs

I know that herbs and teas are very, very common. How my mom used to use cactus, she would boil it and the water that came from that she would drink. She said that she felt better. Instead of taking the doctor's pill, she would drink that and that would make her feel better. Sometimes, she would make herself a "cactus salad" that also made her feel better. Eating lots of *apio*, which is celery, is a remedy that she used to use. For stomach pains, generally you do not go to the doctor. For a stomachache, you will drink some tea and also massage the stomach to heal some of the pain. *Yerba Buena* or *manzanilla*, which are chamomile or spearmint teas, are good for soothing the stomach. Herbs play a big part in the culture. When someone is very nervous, there is a plant called "*ruda*" which is supposed to help you calm your nerves. We always want to stay away from taking pills. If we can stay away from pills, we will do it.

Spells

My ex-mother-in-law told me a story of her mother-in-law, who before she died, began to spit mucus. She described it as moldy. Two weeks before she died they took her to a spiritual healer. He said that someone had cast a spell on her. The immediate family took her to the hospital for tests; the doctors concluded that there was nothing wrong with her. Although the doctors said this, she was not getting better. She was getting worse rapidly. If you are in extreme pain or you have a growth, those are certain circumstances that you may consider that someone has done something against you. It's something that is very common. Some people believe that witchcraft is very commonly practiced.

If someone cast a spell on you, it is seen that you are weak spiritually; maybe you don't have faith. If you believe in those things, then you are less prone to be affected.

If you do have a strong belief and say a person has a possession of yours, an undergarment or something, and they get a hold of that, it is believed that, they can do something to you by just having that possession. But usually it is because you are a weaker being.

Miscommunication

In my community, going to the doctor isn't always helpful. It all depends on how the doctor approaches the patient. Sometimes the patients themselves won't speak and they don't think the treatment is going to do any harm. But in some cases, for example, cancer patients who go through chemotherapy, they think it's bad against their body. It's going to affect them more than what the doctor chooses to tell them. There are times when it is seen as more than what it is, that it affects you more than what the doctor is willing to tell you. So there is a lot of skepticism in believing in what the doctors are really saying or that they are telling you the truth about the treatments that they are giving you.

Question: Why would there be that skepticism? Where do you think it comes from?
Because they don't feel better. I can just tell you an example. My mom goes to the doctors constantly and she feels like the doctor doesn't pay enough attention. She says, "The doctor is not listening to what I am saying because I am telling this hurts and he gives me another medication, but it makes me feel worse or something else hurts." I think this happens a lot, where the doctor doesn't listen to the patient. Instead of building confidence and being comfortable to tell the doctor what's really wrong with them, instead they are going to shut down even more. And if the patient doesn't know how to speak well or explain what's happening, it causes the miscommunications.

Question: Why would anybody go to a medical doctor?
They might go to a doctor for quick fixes. Possibly, they would go just to know that they have gone to different resources. They will fluctuate because they want to know, "Okay, am I really sick or is it because someone has done me some harm?" The quick fixes are sometimes just popping the pills and sometimes going to find out that something else is wrong with me. I'm not getting better from his medicine so I'll go to the *curanderas* to see if she can tell me something different. And that is what also causes people to go to Tijuana, because they would rather go to Mexico to get medicine instead of here. That sometimes causes them to get bad side effects and not to get better.

Getting Medicine

A lot depends on accessing medicine. Like going over the Mexico border to get over the counter medicine, where here you would need a prescription. When I was in Carlsbad, I had a sore throat. I was looking for this lozenge that you suck on and instantly your sore throat is fine. Rosalinda took me to a Mexican market and this woman had this tablet called *Ahin*, it's a very strong cure for a sore throat. You would have to have a prescription here.

So this lady pulls out this box and it was like doing a drug deal, but it is safe. I bought ten pills. I took them and my sore throat was gone right away. Even insulin syringes, you can just go to a market and get it. If you know where to go, you can get what you need.

Prayer

My mom told me that in her country the population believes a lot in saints. There is this one saint, a black saint. She said that a lot of people pray to this saint still today. In the villages and small towns where there is no access to health care, they might have one doctor but the means of getting to that doctor they might not have. They tend to pray and do what is called "*manda*," sort of like a promise to their saint that if he were to cure my son or my child from whatever illness the child might have, you will do good deeds. If it's a serious illness, they would promise to do a certain deed for the rest of days if that miracle were to happen. So I know that they would do that *manda* and they would burn incense around that child and they would hope that a miracle happens. Sometimes they wait until the child is almost close to death before seeking help from a doctor. They will set up sort of a shrine and pray and pray and hope for a miracle.

Evil Eye

My mother had a brother who died when he was child. The thought was that this woman had walked by him and put a curse on him. He was a beautiful blond baby, chubby, full of life – this woman looked at him and spit on him and then he got very sick and died quickly, right after that. They blamed that woman. I don't know if that woman was an outcast or just some crazy woman on the street, but she looked at him and spit on him and he got sick. Who knows, maybe from her saliva he contracted some illness, but that was never even brought up. The funny thing is that I was walking down the street this weekend, shopping with a friend and this elderly lady was walking towards me with her family and she looked at me and gave me this really dirty look. Even though I don't believe in this sort of thing, my girlfriend said, "Oh look she is giving you the evil eye." And I freaked – just because I've heard stories and so you tend to believe it.

From A Korean American

Dying At Home

I remember when my uncle passed away. When he was nearing his last few days, he would not go to the hospital. In his Buddhist culture, where you die is where your spirit will reside. It is important to decide while you are still alive. People want to live their last few days at home because where they die is where their spirit resides and so you want the person to pass away at home, not in the hospital.

Mental Health

In Korea if you have a mental problem, you don't seek help, and family members will be in denial. If it's really serious they will try to keep you away from society so that no one will ever discover it. To discover that someone in your family has mental illness, then it's in your blood and no one will marry you.

I think that's true for deformities too, even if you are perfectly functional. You have to spend the rest of your life away from people. It's not very acceptable. Retardation is like that also. Everything that is abnormal, it's not understood. The belief is that something is wrong with your blood. When you are about to marry someone, there are a lot of questions that are asked. It's like filling out a medical questionnaire.

Health And Happiness

If you raise a family of healthy children with healthy marriages and healthy grandchildren, you are considered healthy. If you have a happy family, then they are mentally stable. Your children are sort of an indication of how your family is.

Question: So if I was in the Korean culture and I had two children that were sickly, and my husband I really didn't get a long very well, would that mean that I was not healthy?
Yeah – I think people would question your blood, also something's not spiritually right, you are not raising your children right and if your relationship with your husband is not good, then your balance is not right.

Question: Would the definition of a healthy woman be different from a healthy man?
I think so. I think it would do with your ability to bear healthy children. Whatever happens to your child, illness, disease, sex, is usually blamed on the woman.

From A Taiwanese American

Medicine

In Taiwan, the little kids go to the doctor all the time. They have clinics. There are no appointments, you just walk in and the doctors have medicine right there. The healthcare system is so different there, usually neighborhood clinics. They do go to get shots, immunizations. People are aware of immunizations now. My pediatrician when I was growing up was just down the street. There was no institution where you had to make an appointment. He's just down the street. He knows every kid and we know where he lives.

From A Taiwanese And A Mainland Chinese American

Comparisons

Taiwanese: A lot of times I think the Chinese culture believes that with herbal medicines, as long as you have sort of a peaceful coexistence with this illness in your effort to manage it, then that's okay. A lot of times when you go to an acupuncturist it is about maintaining your condition; it isn't about curing your disease because sometimes you can't really cure

everybody. Even if you are recovering from heart disease it's mostly about the balance and condition of your body over all and how you use herbs to adjust that kind of balance. And that makes you able to work and function.

Mainland Chinese: But they do want to get a cure. Their cure is to also try traditional medicine, rather than go to Western medicine. Sometimes, when it involves surgery, they try everything possible rather than go through that. Unless it's absolutely a must, there is no cure and you are going to die, then they'll go under the knife.

Taiwanese: The other thing is that we still go to traditional medicine doctors if it's not something that is acute. If I have a really bad flu, then I go to a Western doctor, but if I have really bad cramps, my mom goes and seeks out this traditional medicine guy and then you get these herbs and you cook them and drink that. It was not urgent. We would never go to a Western doctor for anything like that.

From An African American

Stereotyping

Growing up in a middle class, multicultural, black household, I was raised to value education, opportunity, cultural events, nature, and I was taught by my maternal grandmother that everything I did reflected my family's name. I had always done well in school and had sometimes been too smart for the teachers. Due to the circumstances of my environment and education, I attended a New England boarding school for high school, dating didn't appear as a real option for me until college.

When I was 15 or 16 though, I will never forget my visit to a new physician. Despite the fact that I was only in for a soccer physical, the physician insisted on talking with me about birth control. I insisted that I wasn't sexually active, but she persisted with talk about condoms and the pill. She even mentioned birth control to my mother and began a conversation about "How all of these young girls lie about sex and most of them are doing it." She failed to understand the role that U.S. cultural silence around sex had on those who were sexually active. Most sexually active youth were unaware of options and consequences of their sexual activity, and had largely been failed by our medical and education systems. And she failed to remember that "most" of the adolescents she referred to in her paradigm, still left a few who were not sexually active. Based on appearances, one might have thought that this African-American, Southern woman would have been less likely to treat me based on a socio-cultural stereotype. Not only on this visit, but on two subsequent visits, this woman refused to believe me and pushed for me to have a pelvic exam. I did not have the exam and suggested that the doctor not treat all clients with a certain skin color that way. My mother and I filed a complaint with her, and found another physician: this time an Afro-Caribbean woman who remained my physician through college. Most of my school peers were white, Anglo-Saxon, protestant, upper-middle class to upper class, and unbelievably sexually active to me. I offered the few words of wisdom I gained about birth control to them, since I was sure their physicians never mentioned it.

As a woman of African descent living in the United States, the health care system has perceived me as a health problem waiting to happen. Without ever asking me about my diet, family history or customs, it has been presumed that I'm at risk for teenage pregnancy, substance abuse, high blood pressure, etc. I come from several generations of health providers and researchers. Most "black" foods haven't been a part of my family's diet. Two out of four of my grandparents hail from different countries. I have a cousin whose Thalessemia diagnosis was missed several times. Why? Race and color are poor proxies for culture, genes and or socioeconomic status more often than we think. Most of what culture influences is not visible to the naked eye: values, roles, diet, customs, traditions, spiritual and religious beliefs, history, education, exposure, acculturation, language, social and political identities, etc.

What Do The Stories Tell Us About Health And Evaluation?

A Conversation Of The CENTERED Project's Blue Ribbon Panel

Christine Lowery, PhD
University of Wisconsin at Milwaukee

There is no one, right way to do evaluation: there has to be many pathways. How do you help communities define the health landscape for themselves, in cultural ways? And then, how do you evaluate that, because the problem and the evaluation are so closely intertwined, that you can't do one without the other?

I will give you an example that I thought about yesterday. It is this whole idea about identifying culturally this issue of diabetes. If, in fact, we are going to do a cultural landscape of diabetes, one of the ways that you would do it in one of the villages on the Laguna reservation is by using genograms. Who, in clan groups, has diabetes? You would do it inter-generationally, so you would identify grandmothers who have died from diabetes. This is one pictorial way of demonstrating the impact of diabetes collectively on a clan group. You would draw that out, and you would talk about the implications of all of these deaths collectively, because our Tribal groups don't think in terms of individuals.

The concept of living a long life is a dominant cultural value. Our Indian value is living a good life, which is totally different. It has nothing to do with length. It is a good life. But, if you could see the impact of diabetes or heart disease on an entire clan group, then you can see collectively how much we are losing. Then that clan group becomes responsible for helping each other change individual behaviors. They do it in a collective way, inter-generationally, with grandmothers and grandchildren, because grandmothers want their grandchildren to be happy and healthy and have the opportunity for living a good life.

Communities can already do this. They may not have that missing tool which is a genogram. That is what I think we need to provide: to show communities the different tools that they can use to represent, in their own ways, what their pictures of health and disease look like. That helps them find the pathways to what they need to do to address these issues on their own, and evaluate their progress.

I think, from a cultural perspective, the types of tools that we want to use are those tools that really help communities see their own picture of their health and their lives and what they can do about it. Those would be the most useful tools.

Pauline E. Brooks, PhD
The California Endowment
Well, suppose I am sent out to your community to do an evaluation. What I understand is that an evaluator that comes out to your community needs to sit still and listen. They are going to need to be there for a while and be guided into that community, and then figure out what they could offer and what they couldn't offer. The evaluator is going to have to take the time to understand the community.

Ross Conner, PhD
University of California, Irvine
Participatory evaluation is really common now. All the evaluators are talking about it in their meeting this year. They think it's in their tool bag, but what they need is a whole different conceptualization: that this person who has diabetes is fine. That is very different. And the only way to tell that is through a story that shows how the culture gives meaning and defines what health and illness are. That is the insight that all of us got.

Bobby Milstein, MPH
Centers for Disease Control and Prevention (CDC)
I also got a lot out of the diabetes story. What I saw is that there is a very profound difference in how values identification has to happen in a project addressing multi-cultural disparities. Values identification is critical for engaging stakeholders; it is the aim of understanding local values. We need to expand the definition of what counts as data, to include the cultural landscape.

Belinda Reininger, DrPH
University of Texas-Houston
School of Public Health at
Brownsville
Something that struck me earlier is that everybody is talking about participatory evaluation. Well, certainly not everyone is doing participatory evaluation. As someone who has tried to do participatory evaluation, there are times that I get close, and other times that I'm pretty far from it, even though I'm saying it is participatory evaluation. Perhaps we can propose a descriptive continuum. I'm not trying to place value on that continuum, but certainly you can go through evaluation at a surface level of engaging community versus a very in-depth listening, community-driven way. We're trying to say evaluation needs to be at that deeper level.

Quinton Baker
Community Health, Leadership and Development
What I heard was that we need different indicators for marking what health is, different ways of determining how we judge what is healthy.

Christine Lowery, PhD
University of Wisconsin at Milwaukee
There really has to be some personal changes and understanding at that deeper level, on the part of evaluators. It is not just indicators. It is whole belief systems. It is whole lifestyles. It is the way life is conducted. It is the way one prepares to die. It is so contextual, that the evaluation framework, from my perspective, pales in comparison.

Quinton Baker
Community Health, Leadership and Development
We really have to help people understand that health, as it is defined by the dominant culture, is not necessarily

health in the sub-cultures. All of these community programs are going to be evaluated against the dominant culture's standard of what health is. The context of the community's story gives another perspective of what is healthy and what is good.

Jerry Dell Gimarc, MA
South Carolina Turning Points
We know that the current approach to funding, implementing and evaluating community programs isn't working. Unless we understand what is valued, and what is important to the community, all this stuff about exercise and diet, nattering away at people isn't going to make a difference. It hasn't been making any difference. What are the fundamental underlying values that are important for the community? What is going to bring about change that the community wants to see? Because what is imposed from outside is not going to do it.

Christine Lowery, PhD
University of Wisconsin at Milwaukee
Storytelling about illness shows how really complex our cultural differences are, because of where people think ailment comes from. I'm going to give you two examples having to do with the power of ants. That is the Power of ants, A-N-T-S. One of them goes back to my childhood, when my mother killed the queen ant in an ant pile underneath the clothesline in her village. She used a very powerful medicine and killed the ants.

For two years, she suffered with a sore that started as a pinpoint on her foot and then broadened to her whole foot. It was oozing for two years, and then she started having really severe earaches. My Laguna grandparents took their Hopi daughter-in-law to a medicine person, and said, "There is something wrong with her. She's been to the doctor off and on for two years. They don't know how to take care of this, and now her earaches are getting really bad." She walks in, and the first thing he asks her, because he is experienced here and he's old enough to be experienced with this kind of ailment is, "What did you do to the ants?" Because she had destroyed their home, they had moved into her foot. He applied a poultice and asked the ants to leave her body within four days. And in four days, it cleared up and went to a small piece, and the scab dropped off. But she had to do certain things to help with the ants, and the ants showed her. One morning, she was coming out of the outhouse and they were moving their colony from one anthill to another. She saw them move their queen and that was the sign that this was okay, that she did what she had to do, she was permitted to see it, and that stopped.

Now, there is an ant pile outside my grandfather's house. It wasn't the original ant pile. It was a pile of gravel into which the ants had moved. The contractor wants to use that gravel pile to throw into the house to raise the floors, and my mother is standing on the ant pile, and says, "No. These are very powerful. These ants have a lot of power. You won't use this gravel." We had to tell him, and he's a Laguna man, we had to tell him three times. I'm still afraid he's going to use the gravel, but we've done what we're supposed to do. We spread corn meal; my mother has spoken to them in the Hopi language, explaining to them why they have to

move. We've drawn the cornmeal trail to an area where they might be safer, but they haven't moved. We don't want him to use the gravel. He understands the power of the ants because he has seen people who have bothered ants go into a medicine man, and he said, "When they rub the feathers on them, gravel from ant hills actually falls off their body and you can see the living ants drop off." That's an even deeper cultural message about how we see we are connected to illness, and I don't know what CDC would do with these kinds of stories. But see, I'm a Native American who happens to be an academic. But my belief system is that I know the power of animals, and ants, and rocks, and wind, and water. I know all of that, and I don't mess with anything.

Bobby Milstein, MPH
Centers for Disease Control and
Prevention (CDC)
Just a question, what do you make out of that story relative to evaluation? What would we do with such a story? What lesson could be drawn from that story relative to the task of doing a better job of evaluating programs that are working on disease within that community?

Pauline E. Brooks, PhD
The California Endowment
For evaluation, the story may be the beginning place for the evaluator to understand something more about the community. It might be figuring out where things are not how they should be. It raises a whole other area that evaluators don't look at and that has to do with the power of spirituality or the power of thinking, and that also can assist in healing.

Ross F. Conner, PhD
University of California, Irvine
If you have the usual evaluator coming in to see your mother's infected foot, you focus on Western medical treatment only. You've got to really understand the large picture there before you can understand what might be possible causation for that infection, and what may be effective for treatment.

Paula M. Lantz, PhD
University of Michigan School of
Public Health
I have a little story related to that, too. Earlier this summer, I was in Anchorage working on an evaluation project for a program serving Alaska Native women. One thing we wanted to better understand was: What are the cultural beliefs that these women have around cancer? It was a cancer screening program. We were told, "You can go in and ask even the nurses and some of the community health aides about these cultural beliefs, but they're not going to want to tell you because they have the beliefs themselves and when you talk about them, you give them power. When you say these things out loud, you're going to give the cancer more power. There are things that people don't talk about. So, as an outside evaluator coming into a community, you can't just say, "Oh, we have to be culturally sensitive and collect information on some of the stuff." You're not going to get it.

Ross F. Conner, PhD
University of California, Irvine
I experienced something similar. A Korean woman named Wendy started a cancer-screening program in her community. She got some money, and started doing some mammograms for Korean women. Word got around that Wendy was spreading cancer among Korean women. This lady with her x-ray machine was viewed as a spreader of cancer among those women. Wendy stuck at it and now things have changed, but this is an example where the cultural beliefs were a barrier to effective screening.

Hank Balderrama, BSW, MS
Washington Department of Social and Health Services
I think an important issue is to legitimize the work that takes place in communities, because that work hasn't been done in the same framework. If you have somebody that is a folk healer, it doesn't matter which sub-culture it may be or which ethnic group, they have longer historic practices that work for their communities as part of that community's belief system. And that makes them no less legitimate in those communities than if you go to a hospital. But, if you go to one of those folks and somebody finds out about it, the person who is the folk healer may now have legal troubles, because the larger society doesn't recognize them as legitimate.

This was several years ago. There was an African-American professor who taught me about a situation where he was consultant to a young social worker in a hospital. The patient was an older African-American gentleman who had been there for a while, and the hospital staff couldn't figure out what was going on with him. So, the professor talked with the guy and it turned out that this guy was a kind of sick that the doctors in the hospital weren't going to be able to fix. He needed a root doctor. The social worker talked to the family and the patient and found this out. The next step was to find a root doctor, and then to bring the root doctor in, and the final step was to keep all of the medical staff away from there, so that the root doctor could do what the root doctor needed to do. The medical staff couldn't be there, overly skeptical, interfering in that process. Well, it worked, and within a couple of days, the guy was ready for discharge.

So, the lesson behind all of that is to understand what the man needed, coming from his frame of reference. I raised my hand after the professor had finished his case study, and I said, "How did you tell them to document that?" They were in the hospital, treating the patient and they needed to document what they were doing. The documentation of that intervention is no less legitimate than what the rest of the doctors there and the medical staff did, which wasn't working. Yet, just like the ant story, we hesitate to tell that in public because people won't understand. When we don't, it doesn't legitimize that which we do, so it's kind of "Damned if you do and damned if you don't."

Emma V. Sanchez, BA, BS, MPH
Harvard University
For me, the stories uncover the complexities that are involved in evaluation with diverse communities. I have a fear of legitimizing cultural forms that actually don't produce health and well-being. I don't think that all cultures are perfect and that all the cultural habits will be great. I think that is the risk that we might be taking.

Doug Easterling, PhD
University of North Carolina at Greensboro
One thing that the stories do is to expose that evaluator culture as culture. Each has biases and limitations. If the evaluation culture becomes one of many, as opposed to the one that gets superimposed on local culture, that brings up other problems. I see a lot of power in the stories, in terms of lessons for evaluators and funders. Most important is being sensitive and thinking differently about health and what health is.

Pauline E. Brooks, PhD
The California Endowment
I would be tempted, if I were working in Christine's culture, to get clarity on: "What are those boundaries where you feel that you do have power to influence your health?" Whether you have power to move those ants or not, and you're bringing something on yourself, as opposed to something that just comes into your life that you don't have control over, say diabetes. I think those boundaries are places where cultures can grow. Those are possible learning places, where different cultures can meet one another, where new ideas can be introduced. In our evaluation boundaries, we don't deal with spirituality. We talk about health. We don't deal with mental

health. We don't deal with things we can't see, touch, or measure. Those are boundaries that we have, a different kind of boundary, but one the mainstream society placed on ourselves.

Hank Balderrama
Washington Department of Social and Services
The thread in there is the need to individualize the evaluation in your community interventions according to the beliefs and the practices of the community, whether it is an African-American community in Detroit, or a Native American community in the Southwest. You still need to tailor what you do to those people, and you have to understand that within those groups there are going to be people who are very traditional in one aspect, and people who are much less traditional, and probably a whole lot more that are in the middle. So the object of all of this is the storyline, and the thread is individualizing your interventions and your evaluations.

Christine Lowery, PhD
University of Wisconsin at Milwaukee
I think these are illustrations. Stories are really for understanding. It is really to help you understand that there are other things that you have to consider. Stories start that thinking process, and they challenge your old ways of thinking, and that is their purpose.

Quinton Baker
Community Health, Leadership and Development
One of the crucial things the stories reinforce is the importance of knowing the culture. You need to spend time in the community. You have to be in that culture in order to have any intervention or evaluate the success of anything.

You can't do a cursory look. You can't make assumptions of what the culture is. If the stories do nothing else, they reinforce the need to clearly understand the community in which you are trying to evaluate.

Christine Lowery, PhD
University of Wisconsin at Milwaukee
I want to introduce another principle. This has to do with level of expertise and what experts are and what they are not. People shape things together and everybody brings a certain amount of knowledge. That is the idea behind the cbo, coalitions. From a Native perspective, there is this understanding of shared power and it really is the same concept of people coming together, but they bring their own body of knowledge

to the table. It is the integration of that knowledge that becomes the shared power.

I think that is one of the basic principles. This whole idea, that professional evaluators are the experts, needs to change. We have to acknowledge that we are shaping the evaluation through a shared power process because we don't know the answers. We should acknowledge the reality of the community, the resources they bring to the table, their knowledge of their own culture, and their world-view. We can bring this together with the world-view and the culture of the evaluator, through share power.

Health Disparities And The Impact Of Poverty, Race And Ethnicity

Terence L. Jones, PhD
University of New Mexico

While the United States economy is generating unprecedented wealth, not all-racial and ethnic groups are sharing in this economic growth and well-being. People of color are being left behind in terms of pay, benefits and even health, according to a recent survey by the Institute of Health Policy Studies at the University of California, San Francisco (1). In the long term, this type of inequality assures a continued and growing job and income gap, which is dangerous for the burgeoning United States economy.

The fact that low income children and families fare worse, in general, than their higher income counterparts is well documented (2). However,

> It is virtually impossible to have a frank discussion of inequality, nor devote an entire publication to evaluating community health programs, without confronting racism.

a growing number of academics and policy advocates point to an expanding body of evidence demonstrating how racial and social inequities plague the health, justice and other social systems in the United States.

Social inequality has historically been characterized both by income differences and group oppression (3). Stigmatization has been one important aspect of systemic oppression. It transcends income, and includes religion, language, and national origin. In America, racism has been instrumental in meting out-group oppression that coincides with the country's origins. The genocide and enslavement of Africans began with the *Maafa* or Middle Passage as it is typically known in United States history books: the decades of forced transport of Africans to America to then be sold into slavery. Subsequently, generations of African offspring born into chattel slavery and subjected to racial oppression, have, for all intents and purposes, kept these African Americans in limbo and unable to move significantly beyond the glass ceiling of the social pyramids' lowest echelon.

It is virtually impossible to have a frank discussion of inequality, nor devote an entire publication to evaluating community health programs, without confronting the continuing blight of racism head on. The elimination of health disparities is a major focus of current urban health initiatives such as the Centers for Disease Control and Prevention funded CENTERED Project. The rates of excess mortality among African Americans and other peoples of color has a sobering effect on public health practitioners, policy makers and concerned community members throughout large urban centers in the United States. Geronimus reported that only one of three 15-year-old males in Harlem and two of three similarly aged females could expect to live through middle age (4). This statistical information resonates a need for collaboration, both public and private, to improve health. Furthermore, Geronimus casts serious doubt on the impact of identification and modification of individual behaviors designed to increase life expectancies in disadvantaged communities (5). Instead, these seemingly omnipotent and ever increasing health disparities are cemented in basic social structure inequities, which are interwoven with the fabric of racism that continues to influence all aspects of life in America.

Other groups who have historically been affected by the stigma of inequality and racism include Native Americans who were slaughtered and forced onto reservations; Hispanics who had land taken and treaties ignored; and Asians who were placed in concentration camps. Incredibly, all of these same people, while being vilified and murdered in the workplace, helped fuel the United States' economic engine.

Institutional Racism. Simply put, it is "the use of institutional power to deny or grant people and groups of people rights, respect, representation, and resources based on their skin color. (Prejudice plus organized power. Rules, values, structures, practices, and processes, inculcated with generalized bias and prejudices that value and support one culture, race, or ethnicity over others)"(6).

While most urban health studies account for race, few analyze the impact of racism. The specter of institutional racism looms over all organizations in the United States, including the essentially humanitarian interests of the health care industry. "Health care" may be a misnomer, because the true focus of the system primarily involves the financing of medical care (7). Very little attention or investment has been directed toward the environmental, social, economic, or behavioral factors that affect health and well-being, or to the community-based strategies that are needed to address these factors (8). The rub occurs because government pays the vast majority of the United States' health expenditure each year. These are tax dollars generated by working people, so any suggestions of racial bias are highly disturbing.

Lancet reported in the January 2, 2000, issue that approximately 14% of the US population is African American, however, less than 3% of the physicians in the US are African American (9). The author reported that this discrepancy "is largely the result of centuries of institutionally enforced racial apartheid in one form or another." The mass media's role influences public perceptions of order and justice in society (10). Perpetrators of crime portrayed in the news represent "evil forces" which need to be controlled in order to maintain social order (11). If the perpetrators of crime on television are largely people of color, and the guardians of law usually white, then viewers may come to the conclusion that people of color are evil-doers and therefore deserve less.

The color of a patient and their doctor should not be an issue when one arrives at the doctor's office for an appointment. However, most people of color would likely agree that having a physician who understands your culture is very important and can make a difference in overall health outcome. There is a suggestion in this type of response that cultural sensitivity is important and that certain community residents sense a disconnect with the health care system. Research in Menlo Park, California, by the Kaiser Family Foundation, in October 1999 found 51% of African Americans felt they were treated fairly most or all of the time by health professionals as compared to 71% of whites (12).

Similarly in 1990, the American Medical Association's Council on Ethics and Judicial Affairs concluded that African Americans were less likely than whites to receive certain treatments (13). These differences in treatment prompted research reported in the February 25, 2000, issue of the *New England Journal of Medicine*. The survey of doctors showed videotapes of actors as patients presenting with chest pains. The patients were white and black, male or female. Blacks and women were less likely to be offered cardiac catherization than whites and men. For whatever reason, this finding was independent of other explanatory factors and is as close to a definition of institutional racism as doctors and health care providers may want to have noted (14). Unfortunately, these attributions do not cease with adult people of color. According to a report in the September 2000 issue of the *American Journal of Public Health*, African American and Hispanic babies are 70% less likely than Caucasian infants to receive complete well-child care. This disparity between minorities and European Americans is not diminished even by better socioeconomic conditions (15).

For public health to succeed, it must be re-crafted in a framework that locates organized and active communities at the center as initiators and managers of their own health. Political measures are necessary to narrow the abysmal gap in health disparities. Movements of organized labor, women, African Americans and others, separately and together, have won improvements through the strength of united action. (16)

There are only two states in America where the majority of the populations are people of color: Hawaii and New Mexico (17). In New Mexico, the 1990 Census Public Use Microdata Sample shows that poverty is more prevalent in the rural population than the urban portions of the state. The data show that more than 27% of the rural, as opposed to 18% of the urban, population reported living below the poverty threshold. Native Americans were the poorest racial group in the state, with a poverty rate of 47% (18). Nationally, in 1996, Native Americans had a poverty rate of 54%, African Americans 49%, Hispanics 61%, Asian Americans 29% and White Non-Hispanic 26%, according to the National Survey of America's Families.

Poverty And Health

The association between health and poverty (or, more broadly defined, socioeconomic position) is among the most robust findings of social epidemiology (19).
It is important to recognize that the factors, social and psychosocial, most closely associated with morbidity and mortality in the United States have an even more pronounced effect on those who are poverty stricken in society. Examples include material hardships; psychosocial conditions of acute and chronic stress or of overburdened or disrupted social supports; and toxic environmental exposures (20). As Link et al. pointed out, those of a lower socioeconomic position also have less ability than others to gain access to information, services, or technologies that could protect them from or ameliorate risks (21). Further, there appears to be a "dose-response" relationship: long-term poverty is more devastating to health than short poverty spells, both for children and adults. For impoverished African Americans, excess morbidity and mortality increase over the young and middle adult years, which suggests the cumulative health impact of persistent disadvantage (22,23).

As poverty radiates in downtown urban hubs, it has become the catalyst in the reaction with characteristics of the urban environment to produce a particularly lethal dose. Potential contributors to this dynamic include a lack of adequate housing in the urban arena. Increased housing prices have been a formidable problem for those already suffering, because their meager incomes have failed to keep pace. Remarkably, rather modest amounts of housing assistance have been shown to play a vital role in increasing one's employability. Equally important is whether housing developers will continue to have a keen interest in providing quality, affordable housing for those who are often underserved. More families have lost their Housing and Urban Development subsidized

housing, or risk losing it, because landlords are dropping out of the federal program known as "Section 8" to seek higher rents on the open market.

Neighborhood conditions invariably have some effect on access to education and jobs. Also contributing is the transition from a manufacturing-based economy to a service-oriented one (24). This restructuring resulted in extremely high rates of unemployment coupled with the loss of well paying, unionized jobs. These service sector jobs are characterized by little or no health or retirement benefits. Meanwhile, the urban poor have confronted new challenges in gaining access to medical care (25).

There appears to be a strong correlation between poverty and property deterioration. The two are part and parcel of the causes of early health problems and excess mortality in low-income communities. To begin to mitigate these ailments there is an obvious need for improved, affordable housing. Homeownership is the best way to accumulate wealth and build strong, vital neighborhoods. In addition, jobs are needed with wages that can sustain and assist a family to rise above the poverty threshold. Most importantly, communities and policymakers must understand the role of race in allowing deterioration of the nations' housing stock.

Discriminatory Public Policies

In order to comprehend the role of race and ethnicity in understanding poverty and urban health, one must look at the role of social relationships that have been institutionalized over time between the majority and "minority" populations (26). These relationships privilege the majority population and contribute to the poverty that is associated with race (27). The "minority" population, lacking power and privilege, includes an underclass that suffers disproportionately adverse health consequences. These symptoms occur in inner city neighborhoods that exist side by side with urban villages rich in social-connectedness and mutual cooperation. This coexistence belies the historical development of these cultures in the current urban environment.

The development of the current urban environment was influenced by race conscious policies. Prior to World War 2, there was a conduit established between the northern and southern United States. An exodus of African Americans headed north, initially in response to increased demand for labor to sustain the war effort. In northern urban destinations, European immigrant neighborhood groups, government officials, and developers worked to avoid integration of African Americans with established immigrant neighborhoods. This produced the outlines of today's urban black ghettoes (28). Highway construction and public housing projects isolated black neighborhoods from other areas, while other policies prevented blacks from moving to emerging suburbs. Following World War 2, African Americans were effectively frozen out of the suburbs by racial covenants, discriminatory mortgage practices, and racial steering. In contrast, whites were offered low-cost homes in the suburbs and low interest rates on government subsidized home mortgages, and benefited from publicly funded transportation projects that linked their suburban homes to employment and cultural centers.

Such housing and transportation policies promoted segregation and prevented many African Americans from escaping poverty, as urban centers lost jobs (first as industry moved to the suburbs and later because of macroeconomic restructuring away from industrialized jobs). They also precluded blacks from enjoying the accumulation of wealth associated with the vast appreciation of suburban housing values (29). Meanwhile, there has been little sustained investment, public or private, in central city areas. Race has been an explicit factor in this circumstance (30).

Stereotypes

Negative stereotypic judgements of African Americans affect the treatment decisions of health providers (31), and influence the hiring practices of potential employers (32). Thus, it is critical that public health programs understand the factors that shape public sentiment on race and determine how these factors might be influenced. Anti-black attitudes were described by Staples (33). He realized that he was perceived as frightening, particularly to Caucasians, merely because he was an African American. In particular, research on perceptions of and emotional reactions to crime suggests that Caucasian Americans are particularly likely to associate violent crime with people of color (and particularly African Americans) as opposed to Caucasians (34).

Clearly, the stereotyping of African Americans and crime has a long history and is a reflection of many variables. However, most individuals report that the media serve as their primary source of crime information (35). Entmann noted a greater frequency of African American criminal suspects than Caucasian criminal suspects, who were portrayed as "nameless" or unidentified in newscasts, a characteristic of news images that he feels may encourage stereotyping (36).

Consequently, future researchers must turn their attention to the effects of existing racial portrayals and to explore new ways of news reporting about crime that may help to combat destructive stereotyping of African Americans as "dangerous criminals."

Implications

To improve health and prevent disease, as illustrated in Healthy People 2010, the United States must do more to explain health disparities and research socioeconomic interventions (37). The nation's inability to achieve more than 15% of the goals identified in Healthy People 2000 (38) stems in part from the disproportionate burden of certain health problems in urban areas (36). Although rural areas also experience higher than average morbidity and mortality that demand attention, in the last 50 years, the excess mortality and morbidity experienced by the poor and people of color have become increasingly concentrated in cities (39).

The lack of a political agenda for improving social conditions in cities stems from several related phenomena including the shift of political power to suburban regions, where elected officials focused on policies that favored these areas at the expense of cities. At the same time, the national government lost power to the states and multinational

corporations. In addition, the public health community has failed to define a research agenda for urban health.

Policies that affect urban poverty influence fundamental causes of health inequality. Policies that are likely to erode income, housing or neighborhood conditions; fragment or impose new obligations on already overburdened networks; or proliferate demeaning and demoralizing stereotypes, affect the material and psychosocial conditions of life for the urban poor and thus their health (40).

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A Letter From The Community

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When we partnered with a community-based organization to apply for a Racial and Ethnic Approaches to Community Health (REACH) grant last year, we asked participants and residents to submit personal letters of support. We asked them to express in their own words how this grant funding would impact on their health status and life. Here is an excerpt from one of those letters written by a fifty-one year old Black woman who lives in a small, rural town located in Eastern Arkansas that has a majority Black population.

*I was hesitant about writing this letter, but the following passage from your request, "**The President has committed the nation to an ambitious goal by the year 2010 to eliminate disparities in health status experienced by racial and ethnic minority populations in key areas while continuing the progress we have achieved in improving the overall health of the American people,**" burned into my every thought and gave me the incentive to write this letter.*

I remember the day over twenty-five years ago when my mother was diagnosed with 'sugar.' She stated that she has many relatives and friends who have been diagnosed with diabetes: Two brothers, co-workers, neighbors, and a daughter. She shares the same belief as most of the people in her town: when people my age and older talk about their high blood pressure and 'sugar,' I think treatment; and when the younger staff is diagnosed, I think prevention and become gravely concerned.

As writing this letter continues to provoke thought, I can remember people talking about having to transport their loved ones to the doctors (some did not have transportation of their own, therefore, they had to access it). I can now recall people taking time off work, flexing their time, or missing work to access medical care. I now know that they did not understand all the aspects of these diseases.

*In everyday life, I am a wife, mother, sister, neighbor, community organizer, and advocate. Today, I am petitioning you to help us to help ourselves. There must be a process that will help us to eliminate some of the pain these diseases are causing the **Black Families** in my community. I am prayerful that it will not take **another twenty-seven years.***

Striving to make a positive difference,
Mrs. S.

Chapter 3

Dilemmas For Programs, Sponsors And Evaluators

Using Outcome Evaluation To Guide Grant-Making: Theory, Reality And Possibilities

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Raising The Bar For Evaluation

Over the past few years, the philanthropic sector has undergone a critical redefinition of grant making. Grants are seen less and less as *gifts* or *contributions* than they are as *investments*. This shift in terminology is not just semantic; foundations now have much higher expectations as to what nonprofit organizations will do with their grants. The sector is being counseled to pay deliberate attention to the *value to society* that is produced by a grant (Porter and Kramer, 1999; Prager, 1999) and even to step into the role of an *active* investor (i.e., a "venture capitalist") in order to push grantee organizations to their full potential (Letts, Ryan and Grossman, 1997).

The rants-as-investments paradigm immediately raises the issue of evaluation: foundations need to be able to measure what grantees accomplish with their grants in order to compute the return on their investment. Moreover, foundations operating under the new paradigm are much more impressed with *outcome* evaluation (i.e., an objective assessment of the actual effects of the funded program on the target population) than they are with *process* evaluation (i.e., an assessment of how the program was delivered by the staff and received by the clients).

This increasing emphasis on outcomes and results is reinforced by a number of other trends operating within the philanthropic and nonprofit sectors. For example, in the wake of some highly publicized cases where nonprofit executives paid themselves excessive salaries and exercised questionable spending practices, we have seen movement within Congress, foundations and the general public to require more accountability from the sector. In addition, many of the new foundations emerging over the past decade have been created out of the sale of hospitals and health systems (Milbank Memorial Fund, 1999). Such "conversion foundations" are often managed by health administrators, who are accustomed to making decisions that are based on concrete performance indicators.

Under this new results-based paradigm, funders are no longer mollified by *activity-based* progress reports that count how many meals were served, how many beds were filled, how many addicts were treated, or how many offenders showed up for group counseling.

Grantees now must gather data that accommodate bottom-line thinking, showing the concrete, tangible changes that resulted from the foundation's support.

The Sober Reality

Although foundations are becoming increasingly clear with their expectation for evaluation, the task facing grantees is often clouded and confused (Fine, Thayer and Coghlan, 1998; Walker and Grossman, 1999). Foundations will not elicit rigorous outcome evaluations from their grantees simply by asking for them. For many nonprofits, the requirement to conduct evaluation appears extraneous to the core mission and activities of the organization. Even those organizations that do recognize the value of evaluation often find it difficult to build this new function into their existing operations.   And those organizations that actually do evaluate their programs rarely obtain the type of data that would allow funders to compute the return on their investment or the ratio of benefits to costs.

The requirement to conduct outcome evaluation appears as a huge order for most nonprofit organizations (Billitteri, 1998). To support the transition from informal to rigorous evaluation, some funders have devoted resources to the cause of building evaluation capacity within the nonprofit sector.   United Way of America produced the guidebook, *Measuring Program Outcomes: A Practical Approach*, which is designed to assist local United Ways and their funded organizations in setting up useful evaluation systems.   Foundations such as W.K. Kellogg and Skillman have prepared their own manuals (*W.K. Kellogg Foundation Evaluation Handbook* and *A Guide to Evaluation for Skillman Foundation Grantees*), which cover topics ranging from logic models to working with research consultants.   More and more workshops and conferences are devoted to training the nonprofit and government sector in evaluation methods.   Foundation-supported websites such as Innonet (www.inetwork.org) provide users with

guidance and exercises that help even novices design an evaluation of their program, and then allow the user to upload those designs for on-line feedback.

 All of this exposure around evaluation has raised expectations and anxiety among program managers, without necessarily increasing the quantity or quality of the evaluation work that is actually performed. If a foundation is to employ outcome evaluation as a tool in its quest for organizational effectiveness, the practical limitations of this tool must be acknowledged and addressed.   The following issues have emerged as critical limitations as nonprofit organizations have ventured more deeply into outcome evaluation.

Outcome Evaluation Is Expensive

Many evaluation manuals and workshops begin with the reassuring axiom that evaluation is simply an extension of normal, adaptive behavior. For example, Posavac and Carey (1997) exhort that, "the practice of evaluating one's own efforts is as natural as breathing" (p.1).   These statements are intended to demystify the field of evaluation and to convince program managers that they can conduct evaluation even if they don't have formal training in statistics.   Although some forms of evaluation (particularly *formative* evaluation) can be built directly into an organization's operations with relatively little effort and cost, rigorous *outcome* evaluation rarely proves to be a natural, inexpensive or simple addition to a program. Measuring outcomes and impacts requires questionnaires, interviews, tracking clients

after they leave the program, data management and analysis: tasks that impose a real burden on staff and clients. In addition, few nonprofit organizations have the expertise on staff to design rigorous studies, identify valid instruments and carry out sophisticated statistical analyses. Workshops, training manuals and consultation can be effective in building basic evaluation competencies, but a good, solid outcome evaluation will invariably require the addition of new staff (or dedicated consultants) who bring extensive training in evaluation methods.

The Outcomes Of Social Programs Are Elusive

Few of the programs funded by foundations can be evaluated with the degree of precision that foundation board and staff would like. Particularly for board members who are accustomed to reviewing quarterly financial returns to evaluate the performance of their investment managers, the ambiguity surrounding the assessment of *programmatic* outcomes can be very disconcerting.

One problem related to elusiveness is that many foundation-funded programs have "soft" outcomes.

Indeed, nonprofit managers often contend that evaluators and their methods "miss" the positive effects of community-based programs ("I know my program works, regardless of what the evaluation shows.") Although many "soft" outcomes (e.g., self esteem, self sufficiency, community mobilization) can be measured reliably and validly, evaluators do face challenges in trying to fully capture the effects of programs that address complex issues such as substance abuse, violence, homelessness, discrimination and social injustice.

A parallel limitation in applying outcome evaluation to social programs is that many of these programs have *lagged* outcomes (occurring well into the future). Especially within the field of prevention, even the programs that are effective have benefits that do not occur until years after the intervention has been delivered. Take the case of David Olds' home-visitation program, which has attracted considerable attention from foundations and policy makers because of its demonstrated effectiveness in reducing the likelihood of violence among children of mothers who were visited by nurses during pregnancy and early childhood; the reductions in youth violence were observed 15 years after the intervention (Olds, et al., 1998). Significant expenses and complications are involved in following clients even a year after they exit a program.

Another methodological complication associated with outcome evaluation is that most of the programs funded by foundations operate in "noisy" systems. In other words, at the same time that a client is receiving some service from the grantee organization, that client is also experiencing a host of extraneous influences.[1] In some programs (particularly school-based programs), the clients undergo a whole host of developmental changes at the same time that they are being influenced by the intervention; any observed change in behavior or knowledge might be due to the intervention, but it might just as well be attributed to a *maturation* process. Likewise, *secular trends* (e.g., a changing economy, new technologies, a deteriorating neighborhood) also exert an influence on the clients of a program, over and above the impact of the intervention.

Because of these "background effects," the effectiveness of a program cannot be evaluated simply by assessing changes in client behavior or well-being; a true outcome evaluation requires that we identify the *unique contribution* of the program on the client. As every evaluation textbook makes excruciatingly clear, the challenge for program evaluators is to estimate what would have happened to the program's clients in the absence of the intervention. In theory, approaches such as random assignment, a "matched" comparison group and interrupted time-series designs offer solutions to this dilemma, but these strategies are exceedingly difficult to implement within most nonprofit settings, particularly given the level of resources typically available for evaluation.

Grantees Are Resistant To Outcome Evaluation

So far, we have been focusing on the *technical* limitations of relying on outcome evaluation as a tool for measuring the effectiveness of funded organizations. The *political, sociological* and *psychological* issues are just as critical. In particular, any attempt to introduce outcome evaluation into nonprofit organizations must contend with the pervasive sense of threat (and even dread) that accompanies the word "evaluation." Despite all its potential as a tool for learning, evaluation is traditionally viewed solely as a yardstick for measuring performance, with all the associated connotations of report cards, judgmentalness and punishment. Particularly when the evaluation is driven by the funder, and the funder emphasizes outcomes, the common response among grantees is fear and

avoidance.

Increasing The Relevance And Utility Of Evaluation Among Grantees

Even though outcome evaluation is expensive, complicated, threatening and inherently political, this does not necessarily mean that it is in appropriate; these qualities are true of most tools that facilitate change and growth. Evaluation has the power to bring a more deliberate, informed mode of decision making to foundations and the organizations they fund. However, for evaluation to achieve that potential, those who fund and practice evaluation need to be more strategic, thoughtful and sensitive in their approach to evaluation.

The following recommendations are intended to advance the state of evaluation within the philanthropic sector.

Set Clear, Reasonable Expectations For Measuring Outcomes

A good deal of the frustration associated with evaluation can be overcome through a more intentional definition of what the program is intending to accomplish, which in turn allows the measurement to be more focused. In particular, when foundation staff and boards are more clear and specific as to the intent of a grant or an initiative, the evaluation task becomes more straightforward. Evaluation methods can capture program-induced changes, but only if those desired changes are articulated beforehand.

On the other hand, even with a clear set of objectives, the evidence gathered by an evaluation may not be as definitive as the board and staff are hoping. A precise evaluation of outcomes requires significant funding, long-term follow-up, and random assignment of clients and/or grant

46

applicants: provisions that run against the grain of traditional foundation practice. It is important to recognize and appreciate the various costs involved in moving from an evaluation that yields *suggestive* evidence to an evaluation that yields *definitive* evidence. Once a decision is made as to the scope of the evaluation design, the foundation should accordingly adjust its expectations for outcome data.

Use Logic Models

The outcomes of strongest interest to foundations and funded organizations tend to be the "hard" effects that occur down the road: graduation from high school, staying in a job long run, maintaining healthy behaviors, improved social fabric throughout a community. The typical one-shot evaluation is inherently unable to detect these long-term outcomes. This issue of latency can be addressed to some extent by measuring shorter-term outcomes (e.g., increases in knowledge, new skills) that serve as proxies for the ultimate outcome of a social program (e.g., avoiding unhealthy behavior such as smoking or substance abuse).

Logic models connect the shorter term and longer term outcomes together in a chain of causality (Weiss, 1995). Logic models are very useful in establishing a common set of expectations as to how a program will unfold, if it is successful. By laying out the logic model at the beginning of the program, those stakeholders who are predisposed to assessing success in terms of a "bottom line" have a conceptual tool that allows a more reasonable scorecard for tracking the program's progress.

Involve Grantees As Partners In The Specification Of Desired Outcomes

Although foundations clearly have a right to define the expectations and objectives of their grants, the organizations receiving funding are not passive actors in this exchange. Indeed, nonprofits arguably have an even larger stake in establishing the criteria by which they will be held accountable by their funders and by themselves. These two perspectives must be brought together through open-ended funder-grantee negotiations, which in turn requires that both players share their own bottom lines, listen carefully to the other's perspective and then seek common ground. The process is complicated by the power differential that invariably enters into any conversation between funder and grantee, particularly when defining the terms and expectations of a grant. The degree to which the foundation and grantee succeed in establishing mutually agreed-upon outcomes depends largely on the strength and integrity of their relationship, which in turn rests on their mutual trust, respect and appreciation for one another's role.

Build Evaluation Capacity At The Same Time The Evaluation Is Carried Out

Foundations typically enter into the evaluation arena because of their desire to know the effects of their grants. At the same time that the foundation is meeting its own need to learn of the effects of its grants, it can serve its grantees by building their capacity to conduct evaluation.

Building the evaluation capacity of nonprofit organizations requires a concerted, long-term strategy on the part of funders, evaluators and the organizations themselves. One-shot workshops and introductory manuals can succeed in sensitizing an organization to the possibilities associated

with evaluating its activities, but these resources do not, by themselves, infuse deeper levels of skills and knowledge, build data systems, or transform organizational culture in a way that allows evaluation to take root. Thus, evaluation rarely succeeds in attaining its ultimate goal of improving the design and implementation of the program being evaluated.

Although much has been written about building evaluation capacity among community-based organizations (e.g., Fetterman, Kaftarian and Wandersman, 1996), there are two critical factors that come into play when a foundation works with a grantee. The first is fear. Nonprofit managers tend to be skeptical and suspicious of evaluation, particularly evaluation that is imposed by an external agent. To undo those connotations, a deliberate effort must be made to bring out intrinsically meaningful evaluation questions among the staff and board of grantee organizations. The intent is to transform evaluation into a tool for self-directed learning for the grantee.

A second major factor that comes into play in building the evaluation capacity of grantees is the potential disconnect between evaluation-related activities (e.g., data collection, analysis, interpretation, learning) and program-related activities (recruiting staff and clients, developing work plans, writing grants, gaining public exposure). To be successful in introducing evaluation into a nonprofit organization, the evaluators and data systems must accommodate the existing culture and constraints, at least at the beginning. At a bare minimum, this means that the foundation must make available resources that are sufficient to bring in the necessary staff, equipment and software. Further, the staff of the organization needs to have a strong say in how the system for evaluation will fit within the system for delivering services. This requires time, flexibility and sensitivity to different perspectives. Most of all, the staff must be assured that their own interests are being met in pursuing evaluation.

Increasing the Power of Evaluation within Philanthropy

Focusing evaluation on the outcomes of grantees leaves the foundation without a sense of how its own decisions are determining those outcomes. The return that a foundation achieves on its grants obviously depends on the success of its grantees. It is important to recognize how much that success depends on the foundation's approach to grant making, including the foundation's choice of funding areas, the duration and size of grants, the foundation's style of interacting with grantees, the requirements imposed on grantees, and the availability of technical support. Unless the foundation evaluates the effect that those decisions and activities have on the performance of grantees, no amount of grantee-level outcome evaluation will move the foundation to the point of realizing its own potential.

The paucity of foundation-focused evaluation severely limits the effectiveness of the philanthropic sector. No foundation can achieve its true potential without the deliberate data-collection, analysis and reflection that are the keys to good evaluation. Without objective data describing the results of its actions, a foundation is unable to learn from its mistakes and its successes. Foundations expect grantees to push themselves to increase relevancy, effectiveness, and wisdom; grantees should expect just as much from funders.

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Evaluation Dilemmas For Grantees

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Dilemmas regarding evaluation for community-based programs are numerous, with the core driving force being that evaluation must be done. Grassroots leaders and residents characterize funders as being unresponsive and non-inclusive. Communities are concerned with ownership: Who will control the data once it is collected? What resources will develop as a result of the evaluation? During my years of experience, the one consistent element that has been evidenced as a requirement to being successful in working with communities of color is relationship building. These communities must have a sense of commitment from funders before they are willing to be a collaborative partner.

First, community groups generally have not done evaluations; they have been evaluated. The unfortunate history has been that they have been evaluated with rigor only when someone in power decides that there is a "problem".

Most community-based groups do not feel that they have "permission" to learn from their errors or to shape or improve a program through iteration. They have to get it right, and get it right the first time or lose their money. In this sense, the normal request for proposal phrase, "Funding for subsequent years in the grant period is dependent on demonstration of adequate performance in the current year," is delightfully clear. We have the money and will unilaterally make the life and death decisions for your program.

Even when it is not a "gotcha game," evaluation too often remains almost entirely externally driven, with little internal value or utility to the community group. The basic process of evaluative assessment is useful in looking at some of these issues. First, doing a meaningful evaluation requires an agreement on objectives and expectations for the program and clarity in

the internal logic of the program's model. Talk to the stakeholders in most community-based initiatives and you almost always discover a range of expectations that is awe-inspiring. When the program involves collaboration among disparate organizations, agencies, and professionals in a community, ambiguity may be the enemy of continued agreement and collaboration.

Second, community organizations tend to see grant funds as core operating money, not as special project funding. Many community-based organizations do not have a regular appropriation for core program activities, but instead have to juggle a hodgepodge of grants and other funding so they can keep their doors open, staff paid, and their services going. Raising the issue of evaluation in this context is not a welcoming subject and in fact can be perceived as a threat to the continued operation and survival of the organization.

There are all kinds of real methodological issues that most community-based organizations don't have the technical evaluation and statistical skills to cope with.

If funders really want grassroots groups to be able to submit serious and substantive proposals, then they must give 90 or 120-day notice periods. A 30-day request for proposals that seeks a complex collaboration that brings together grassroots groups, statewide health stakeholders, academic medical centers, and local heath professions is not being realistic. Couple this short time period with an expectation for an effective evaluation model to be in place, and it is no wonder that many community-based organizations do not attempt to submit applications.

All of my colleagues supported the inclusion of community-based organizations in the initial phase of any project from planning to implementation to evaluation. This model encourages local participation and buy-in into the research process and facilitates the sharing of local knowledge. Therefore, evaluation will be seen less as a threat and more as a means of ensuring that programs and services are working as planned to effectively meet the needs of the target population. By reducing the occurrence of these dilemmas, the relationships between funding agencies and grantees can develop in healthier ways that benefit both sides.

A Community Dilemma: Community Autonomy Versus The Need For External Funding

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A health promotion effort was needed in a community located in Newport News, Virginia. Approximately 98% of the community residents were African American, with limited access to health care and health related services. The highest incidence and prevalence for diseases and illnesses for the city were concentrated in this community. The socioeconomic status of the

community was the lowest for the city, with the highest rates of children and families living below the poverty level.

Several public and private health and human services organizations formed an alliance to promote the health and well being of the children and youth in the community. The Alliance started to plan services for the community without approaching or involving the citizens who resided in the community. The community felt left out of the process, and expressed the opinion that they should determine what programs; services and resources should be brought into their community. The citizens of the community became upset and insisted on being involved in planning the services.

The major dilemma was this: the citizens did not have the resources to implement programs and services without the support of the Alliance. How could the citizens get support from the Alliance, without alienating the Alliance members?

The resolution was to plan collaboratively to establish a multidisciplinary center providing services to the residents. After three years of planning, in a process that included the city government, the Alliance and community residents, a multidisciplinary youth center was relocated from a school site to an old, renovated recreational center. The youth center formed its own board of directors, comprised mainly of citizens and administrators from schools in the community. The board created a slot for the principal of the school where the program was originally located. When that principal was reassigned, a heated discussion centered around whether the position was created for an individual or a representative from the school. The organizations and agencies continued to function as an Alliance and provided resources and services to the youth at the center. The board of the youth center divorced itself from the Alliance after about 5 years and developed contracts with individual Alliance organizations and agencies for programs and services. Today the center continues to provide a variety of educational, recreational and prevention programs. The Alliance continues to function with prevention programs," Youth Development-Developmental Assets" for the entire city. Recently the city formed an Office of Youth at the urging of the Alliance.

An Evaluator's Dilemma: How Can I Collect Comparable Evaluation Data Across Program Sites, When Some Sites Are Truly Unique?

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I have to admit, I finally met my match. As part of a larger evaluation of nine Healthy Community projects, I arrived in South El Paso expecting to lead a focus group meeting. When I walked through the door, I discovered:

- Thirteen 8-year-old boys on a soccer team, in uniforms and with soccer balls bouncing;
- Twelve teenage high school boys who were members of a break-dancing team;
- Two teenage girls who had just arrived on the scene, wearing their cheerleading uniforms;
- A set of adults involved in one community project;
- Another set of adults involved in a different project; and
- About a dozen staff members.

The kids spoke English; the adults spoke Spanish. The scene was utter confusion.
It was 5:30pm and prime dinnertime for the 8 year-olds, who had just been outside playing soccer--and there was no food anywhere.

I had come to gather data for an evaluation, expecting to use focus group discussions, a method well suited to the evaluation questions, the project and the community. Neither my experiences nor any of my training had prepared me to deal with such a large, diverse group--and diverse along so many dimensions. The adults were ready for a respectful discussion with this "doctor from California;" the staff were ready to talk about their programs; the kids were ready for dinner.

Well, first things first. We ordered food--quickly and lots of it: 15 pizzas and cokes. Then, I split the crowd into two groups, with the adults in one group and the kids, along with the majority of the staff, in another. A foundation officer along for the visit took the adult group and conducted a discussion in passable Spanish. I took the kids to a different room and tried to lead a discussion in English. Given the reactions I got, I might just as well have been speaking Chinese. It was pretty clear that the main focus of the teenage boys was those two cheerleaders. The teenage boys, when able to get their eyes away from the cheerleaders, acted like teenage boys everywhere: I was lucky to get one-word answers to any of my questions. Nothing even close to a discussion ever occurred. The two teenage girls were delighted to talk at length -- about anything. The 8-year olds...well, let's say that the phrases "have a discussion" and "8 year-olds" don't fit together at all.

These little guys were unbelievably well-behaved and polite, and they at least tried to respond. They talked more than the teenage boys, who, true to form, completely ignored the presence of these little guys.

I prayed for the pizza man to arrive. He finally did--and brought an instant, spontaneous end to the "discussion." The pizzas disappeared in a flash. The evening ended on a very positive note: the staff members stayed around after dinner, and we had an rich discussion, out of which came lots of data and many insights.

Dilemmas For Programs, Sponsors And Evaluators

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The Macro-Micro Dilemma.

Foundations and government agencies often fund multiple sites under a common initiative (e.g., REACH 2010). While acknowledging that the sites are all different, the funder still would like to evaluate the initiative using a common metric. This impetus typically leads to one of two distinct strategies, each of which creates a dilemma for the funded agencies:

1. *Establish a set of "common" outcomes to be measured across all sites.* For example, all programs funded under a hypertension-prevention initiative might need to measure their clients in terms of changes in diet, exercise and monitoring of blood pressure. Imposing these core measures on all sites will restrict the creativity of the funded projects, weeding out ideas that do not comport with the funders' implicit definition of what needs to be included in an "effective" project. This conformity in programming may have particularly detrimental consequences for programs that are attempting to improve health with individuals whose beliefs, attitudes and culture are at odds with "standard" models of behavior change. In other words, the required evaluation could force out the very strategies that might lead to the greatest improvements in health among a culturally diverse group, by building off deeply rooted (but "nonstandard") beliefs about health, relationships, balance and the meaning of life.

2. *Assess each site according to improvements in "capacity."* If the funder abstains from imposing a set of common evaluation measures (in order to leave open the question of what constitutes an "effective" program in any given community), the question arises as to how to evaluate the effectiveness of the initiative. Assuming that the funder wants to employ a common metric (as opposed to simply conducting distinct evaluations within each site), it is necessary to identify some outcome that should occur in common within each of the sites. Such an outcome is unlikely to pertain to the specific programs that the various sites implement, because those programs will have varying strategies, target populations and desired outcomes.

Rather, the common outcomes will likely relate to factors such as collaboration," "community capacity," or "program quality," factors that have relevance within all the funded sites, given the funder's strategy and philosophy.

This "light-handed" approach to evaluating community-driven initiatives avoids the problem of forcing programs into molds that may not fit the local culture, but it raises two new dilemmas. First, outcomes such as "community capacity" tend to be fuzzier, and thus harder to interpret than program-specific outcomes such as reductions in blood pressure or increases in the number of persons screened for diabetes. Especially with publicly-funded programs, an improvement in community capacity may not be tangible or compelling enough to elicit ongoing appropriations. The second dilemma that arises in pursuing this approach to evaluation is that the research question being answered is not necessarily interesting to the funded organizations. Learning that the initiative raised the capacity of the funded communities by an average of x points (assuming that capacity can be measured quantitatively) does little to support the needs of those funded communities. The people who develop and operate the programs are much more interested in how well their programs are achieving their own distinct objectives and what might be done to improve those programs. As a result they are best served by a different type of evaluation, one that addresses questions related to program effectiveness, not cross-site capacity building.

Ethical Dilemmas Of Evaluation

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Program evaluation and research involving human subjects raise complex ethical, legal, and social issues. For evaluators, there is a potential role conflict between their role as researcher and their role as consumer advocate. Evaluators should promote community control and participation as partners in the development, implementation and evaluation of programs to reduce racial and ethnic disparities in health. Program evaluators must have integrity and approach the evaluation task in an ethical manner.

Three principles should serve as guidelines for considering and making decisions regarding central ethical issues in evaluation research. These ethical principles include respect for all persons, beneficence, and justice.

The principle of respect for all individuals as persons is broader than simply assuring the autonomy and self-determination of the individual. The duty to maintain confidentiality and obtain informed consent from participants in the research is mandated by respect for persons (1). Respect for persons recognizes that individuals are members of a community and that their decisions may affect others in the community. It is important for evaluators to respect the person as an individual and as a community member, especially when evaluations involve value judgment about right and wrong actions, or good and bad behavior.

Informed consent to participate in evaluation research must be obtained in an honest, open and ethical manner. People who choose not to participate must be protected from negative consequences for their choice.

The principle of beneficence involves the intent to do good, to prevent injury or harm, and to promote good. Community-based professionals and participants in evaluation situations need to make thoughtful decisions to balance potential risks and benefits. These decisions may range from determining levels of interventions in a given situation or the numbers of consumers to be served in a community with limited resources.

Program evaluation decisions also require consideration of a principle of justice. Justice requires treating people fairly. The concept of "social justice" is based on doing good for the group (2,3). Systems of social justice may promote the equality of outcomes, not necessarily equality in process.

Tension may exist between people who most value social justice and people who most value autonomy for the individual, since attaining equal outcomes of goods and services necessitates forced distribution of goods and services (2). Justice requires that vulnerable people and communities not be exploited and that eligible people who may benefit from participation not be excluded without good cause. These issues become even more difficult in an evaluation context, especially when current scientific standards promote assessing the impact of an intervention by comparing a group who receives the intervention with a group who does not.

These conflicts should be resolved in partnership with individuals from the communities being served and the programs being evaluated. Racial, ethnic, and cultural differences in values may complicate situations in a multicultural mix of researchers and communities. Evaluators have a responsibility to inform themselves about the ethical, legal and policy standards that govern activities related to eliminating health disparities.

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Resolving The Dilemmas:
Expectations For Evaluation

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Expectations for evaluation need to be realistic. It is important to identify potential ethical dilemmas and to plan to resolve them in partnership with the sponsors, programs and communities. Here are some considerations for setting expectations for evaluation and resolving the dilemmas.

1. Provide Useful Answers To Questions Related To Program Success

For programs designed to eliminate or reduce racial and ethnic disparities in health, an appropriate and thorough evaluation uses credible evidence to test whether the disparities are actually being reduced. Because the elimination of disparities is such a long-term process, it is important that the evaluation of these programs build in shorter-term mileposts that track progress. These mileposts show the small steps that together result in the ultimate health-status outcome. The evaluation of a community-based program should produce clear benefits:

- Building community capacity and engaging communities;
- Improving programs;
- Facilitating the planning of new or improved prevention strategies;
- Influencing policy makers and funding sources;
- Sharing what works and what does not;
- Ensuring funding and sustainability; and
- Strengthening accountability.

2. Involve Multiple Community Sectors

Community-driven evaluation means that community members involved in or affected by the program are involved. As active partners with equal voices throughout the evaluation process.

3. Listening And Learning Throughout

Evaluation provides a process by which partners involved can listen and learn. An appropriate evaluation is one that is conducted by evaluators who are culturally competent with respect to the organization that is implementing the program and the clients being served. Moreover, the design of the evaluation should be informed by the various stakeholders of the program, and thus based in the reality of the local community. Funders also have a responsibility for cultural competence in their own expectations for evaluation. Expertise regarding appropriate evaluation should flow both ways, between the sponsor and the funded organizations.

4. Define Success And Specify The Evaluation Questions

An evaluation will be appropriate and relevant only if it measures progress toward the program designers' own definition of success, and only if it incorporates the assumptions and theories of

the program designers. Programs that are truly community-based will each have their own definition of success, depending on the identified health needs, the strategies chosen, the values of the program designers, and the intended results of the initiative.

The evaluation of a program needs to reflect the theory of change that the organization is employing to bring about the desired improvement in health status. The program should articulate the theory of change. This process will help community-based organizations assure that there is an adequate linkage between their activities and their proposed outcomes. Programs will have different definitions of success, none of which may correspond exactly to the definition promoted by the funding agency. Outside evaluators must be careful not to impose their own values as to what is necessary for the health of a community to be improved.

Evaluators may have to incorporate and measure ideas beyond what is required by the sponsor, to ensure that the community's questions are answered. Also, evaluators should be open to evaluating topics that are outside their realms of expertise. If the issue is important to the community, it becomes important for the evaluation.

5. Reasonable Expectations For Outcomes
Each program should have reasonable expectations for the results that are actually possible, given the scope of the program. The cultural context of the community should be considered in defining the intended outcomes.

6. Realistic Expectations For The Program's Effect In Reducing Racial And Ethnic disparities
In order to gain real understanding of whether or not a program has been successful in promoting the health of racial and ethnic minorities, the evaluation would need to model the effects of external factors such as racism and discrimination on health.

7. Understanding The Big Picture
The evaluation of a program needs to take explicit account of the contextual factors that influence the health of the program's target population. Because the context is dynamic in nature, changes in it may influence program outcomes. Thus, it is fundamental that those involved in evaluation have a thorough understanding of the macro-level factors such as welfare reform or universal health care, which may benefit or hinder the desired successes of the interventions. At the same time, evaluations must be sufficiently grounded within the local context to provide historically and culturally sensitive interpretations of whatever changes occur under the program. It may be more efficient or effective for a program to work on changing the contextual factors that limit the opportunities of a racial or ethnic group than it is to strive for traditional notions of health behavior.

8. Politics Of Evaluation
How can the politics of evaluation be dealt with? Stakeholders are partners central to the ongoing evaluation process, and their interactions are essential to the evaluation. This process is prone to multiple and --often political- challenges: 1) establishing a common frame of reference and a cross-disciplinary vocabulary for communication; 2) identifying individual participants' agendas, both organizationally and professionally, to meet program requirements and ensure group cohesion; 3) ensuring continuity of member participation. Stakeholder interactions are dynamic

and shaped by interrelated factors, including the larger societal context, geographic area, institutional environment, power dynamics, communication styles, and decision-making styles.

9. Mutual Accountability

Accountability is an essential component in program implementation and evaluation. Because stakeholders closest to the program must report to a particular institution about the evaluation results of the program intervention, it is important to establish mutual accountability mechanisms.

CURRENT PUBLIC HEALTH PARADIGM

Health choices are not governed solely by the individual, but also by environmental and community factors over
which individuals have little control.

> This is the rationale for community-based strategies for disease prevention
> and control.

Chapter 4

Principles For Community-Based Program Evaluation

Community Evaluation: Principles And Practices

A Presentation To The Blue Ribbon Panel, May 2000
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This article is an edited transcript of a presentation made to the CENTERED Project on May 4, 2000. For more complete presentation of these concepts, please see Goodman, R.M. (1998) "Principles and Tools for Evaluating Community-Based Prevention and Health Promotion Programs." Journal of Public Health Management and Practice, 4 (2), pp. 37-47. and Goodman, R.M. (2000) "Evaluation of Community-based Programs: An Alternative Perspective." In Schneiderman, N., et al. Integrating Behavioral and Social Sciences with Public Health, Washington, DC: American Psychological Association.

The literature on community-based evaluation presents important principles for working with communities. Social ecology is a basic concept that needs to be incorporated into community-based program evaluation. Cultivating community capacity is an important part of the evaluation process.

There has been an evolution of thinking about evaluation. Prior to the 1980's, most programs tended to be focused in organizational settings and not in communities. The dominant emphasis on community programs was implementing them through formal organizations. A shift started to occur in the 1980's, when the focus of programs moved from the implementing organizations to the communities. This change requires re-thinking evaluation models and strategies. The models of the early 1980's were based largely on clinical practice. A good example is the *PRECEDE Model* (Green, et al.) for evaluating health promotion initiatives. (1) Another prominent evaluation book, *How to Assess Program Implementation* by King, Morris and Fitzgibbon, emphasizes staff roles in doing evaluation processes. (2) The staff of the organizations that implement programs are not always from the community that the program serves. Evaluation methods that center on clinical practices and rely on program staff may miss important community dynamics that influence program results. Current perspectives on community evaluation are much more informed by social ecology thinking than the early evaluation models were. *Evaluation of Health Promotion, Health Education and Disease Prevention Programs* by Windsor, *et al.* is a very popular evaluation book in health promotion. (3) When Windsor describes process evaluation, a main emphasis is on

> Prior to the early 1980's, **formal organizations, and not communities**, often were the dominant emphasis of program implementation models, and management strategies were the primary vehicle used to foster effective program implementation

provider competency. Providers are typically professionals in organization. A second focus is on program adequacy, which typically has to do with resources, facilities, equipment, and level of staff effort in organizations. This is a very different way of thinking about evaluation than the social ecology approach to evaluating community programs. In the 1980's, several large-scale programs were implemented that began the shift to community-centered approaches to evaluation. There were a number of studies sponsored by the National Heart, Lung and Blood Institute of the National Institutes of Health: the Stanford Five Community Project, Minnesota Heart Health Project, and Pawtucket Heart Health Project. These projects signaled a shift toward the community emphasis. Implementing programs in communities required an expansion of evaluation models and strategies. The Minnesota Project started implementing activities that were based in the organizations of respective communities, but that also included community task forces, media, grocery vendors, and teachers: a basket of strategies rather than one singular intervention. When the programs were started at this population level in communities, the program designers realized that you could not evaluate these programs in the traditional way. Here were some of the earliest lessons in evaluation of community-level changes. The interventions were at the community level, and involved: risk factor screening, school programs, worksite physical activity, community task forces, media messages, speaker's bureaus, health practitioner programs, grocery labeling, community-wide contests, and menu labeling at restaurants. These activities could not be meaningfully evaluated at the individual level. Green and McAlister said evaluators now need "a distinct set of analytic

> **a shift in emphasis has occurred** in program implementation **from organizations to communities** that requires a rethinking of evaluation models and related strategies

and programmatic tools from those used with patients, clients, or customers." (4) That was one of the earlier lessons of this community program. Brian Flay of the National Cancer Institute said, "There are unique impediments in implementing community programs including reaching targets and the correct kind of attitude to get the desired effect." (5) David Altman, who has done a lot of work around tobacco prevention programs, said evaluators have to look at the "multiple causal mechanisms within complex community interventions." (6) So, when all these themes come together, evaluation must be thought about in a very different way.

In short, community programs are often difficult to evaluate because they have broad and multiple goals. They have to be purposefully flexible and responsive to changing local needs and conditions. It can take many years to produce results, so evaluations will have to be long-term; and they require multiple ways of thinking about data and analysis over the long-term. For all of these reasons, evaluators are presented with very significant challenges in developing an adequate approach to evaluation in communities.

> **... community or large-scale programs ... require a shift in perspective and the employment of ... set of analytic and programmatic tools [distinct] from those used with patients, clients, or customers**

So what's an evaluator supposed to do?

There are two fundamental themes that appear in the literature. First of all, we have to explode some of the old ways we think about evaluation, and eliminate the old concepts. They are not relevant to what we need to do. The classical experimental and quasi-experimental design is often inappropriate for community-based evaluation. The first principle: classic experimental, quasi-experimental designs may not be the most informative approaches to evaluation. Here is why. The classic way to do evaluation is this: there is the health program implemented in this community and there is no health program in another community. The evaluator takes the baseline measure and then sees what happens after the program. A baseline measure is made where you have no program and then a second measure is made, after the program in the other community. If your program worked, you should see a significant improvement from before to after. The strongest designs traditionally are those that use random assignment. The results are considered unequivocal: the evaluator can say that this program produces this result. Short of that "gold standard" of randomized experimental design, the next best thing is to use a quasi-experimental, matched comparisons design. The main point is that these designs are often not applicable to the community work.

Look at the basic concepts upon which these designs are based. First, there needs to be an association between the program and the outcome. The more intensive the program is; the more intensive the outcome should be. What that means is, that program and outcome need to be associated with one another. The basic flaw is that this kind of association is based on statistical principles. Often, you have to have sufficient numbers of community programs in place in order to find that kind of statistical association. Very frequently, evaluation is concerned with one program in one community. The numbers of communities studied must be large in order to have sufficient statistical power, and this can be quite costly. Community studies are expensive, complicated, and costly. So, the first principle of association often doesn't apply.

ASSESSMENTS OF COMMUNITY PROGRAMS ARE OFTEN DIFFICULT BECAUSE THEY:

- have broad and multiple goals
- are purposely flexible and responsive to changing local needs and conditions
- take many years to produce result
- require multiple data collection and analysis methods extended over long periods of time

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A second concept is that the program has to come before the outcome. If there is a change in outcome before the program is implemented, or if the intervention is not the same in each program, then the program did not cause the outcome. There is a certain fallacy of community programs that applies to this principle. Each community is unique in its own way. A basic principle of doing statistical work is that there must be fidelity in your intervention, which means that the intervention has to be the same in order to say that the intervention caused the result. It is a lot easier to do that clinically where you have a standard protocol applied in a standard way. When dealing with different communities, there will be levels of readiness to engage in the work, different community characteristics and different kinds of politics. Each community presents its own, unique challenge. There

are essentially different interventions in each community, not a single intervention. So, fidelity to the intervention and cause and effect are variable by community.

Another aspect of the classical experimental design is spurious association. That means some other factors outside of the study influence the causes or results. In community evaluation, other factors in the community are quite important. These factors might be considered spurious in some projects, but they are very important. Community programs are very complex. The evaluator must understand how each aspect of the program contributes. What appears to be spurious may in truth be quite essential.

The second guiding theme is that formative and process evaluation should be emphasized above the outcome measures, particularly during the initial development stages of the program. The second guiding principle is that, in the initial development stages, it is much more important to focus on process evaluation with measures tailored to the intervention. The emphasis on meaningful outcomes is certainly very important, because the reason for doing programs is that they have some kind of health benefit for communities. A lot of time, effort, and resources are spent to enlist community support in public health programs, but if they do not produce a result, we are wasting time, resources, and effort. That being said, outcomes cannot be assured without evaluating the processes that are calculated to produce them. This is particularly true in complex community programs.

Paul Berman of the Rand Corporation, in looking at education intervention, said: "No matter how data were analyzed, we could find no strong relationship between the type of innovation adopted and the outcomes. Indeed, it became apparent that the *same* technology, [the same intervention] was implemented in very different ways in different institutional settings with very different results. Moreover, factors associated with how the project was implemented explained a relatively high proportion of the variance in outcomes. In other words, in the instance of educational innovations, *implementation* typically dominates the *outcomes*." (7)

• A program requires a "fair trial point" before outcomes should be assessed
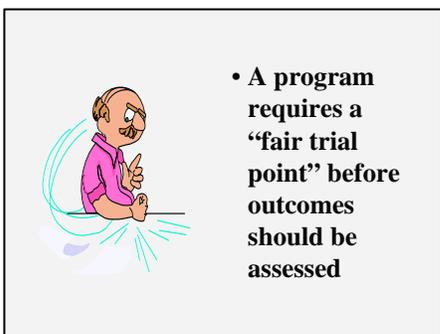
What does this mean? In scientific language, a Type I error in research is when the program effect is significant statistically, but the program was not. The conclusion reached is that the program was significant when it really was not. A Type II error is when the measured outcome is not significantly different, but the program really is doing something that is important. There is a "Type III error" that should be considered: that the program was not significant because it was never implemented in the first place. It is very important in complex community programs to ensure that the program occurs in the way it was designed to occur, so that outcome can be assessed. There needs to be a "fair trial point," in other words. The program implementation has to develop to a level of adequacy. In community programs, it takes time to achieve a level of adequacy: for the program intervention to really have an effect. The implementation of a program in multiple sites complicates the issue still further, when it comes to assessing outcomes.

Process evaluation of project formation and project implementation is very important to establish that the intervention has actually been put in place, and a fair trial point has been reached. This is critical because community interventions are complex, and require a fair trial point. There are often delays in the implementation of a community program, not always due to what the community did or did not do. If the outcomes are evaluated before the program is really implemented, then false conclusions may be drawn about the effectiveness of the intervention.

Here are five principles that appear in "Principles and Tools for Evaluating Community-Based Promotion Programs."

1. Program evaluation should include, and be focused on, logic models that were locally developed.
2. Evaluation instruments that are used for a community program must be content specific to the community.
3. Evaluation approaches should be guided by the questions that are asked, and they often require both qualitative and quantitative approaches.
4. Evaluations should be informed by social ecology and social system theory.
5. Community evaluations should involve local stakeholders.

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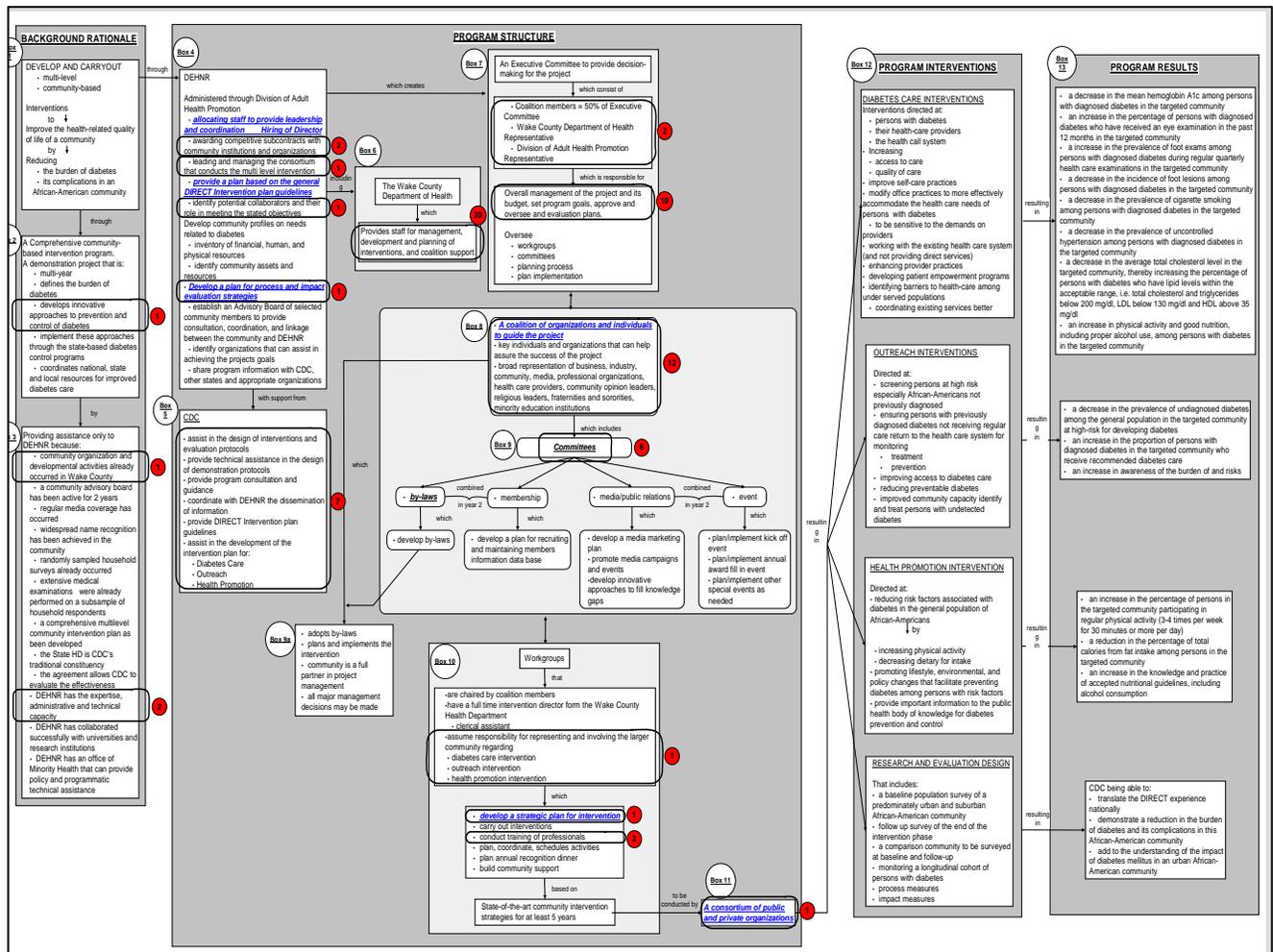
The above logic model is for a diabetes program in an African-American community in a Southern state. It is very complex [and we don't expect you to be able to read it]. Would we really expect a diabetes program to operate the same way, according to the same model, in a community with a Native American population? Would the program be the same with a Hispanic population? No. The intervention would be adapted to the needs of the specific community, and there are not going to be certain interventions to put into an experimental or quasi-experimental design. Therefore, evaluators need alternative evaluation strategies to say the program caused the effect. Logic models are logical statements that link near-term processes to outcome.

The following is a logic model designed for a community poll on issues with alcohol, tobacco, and drug prevention. Groups got together to do the needs assessment, then consolidated the work, developed a complex community plan to implement the study, and planned to evaluate outcomes. Participation influences outcomes. A logic model shows the

A MODEL FOR A COMMUNITY COALITION TO ADDRESS ALCOHOL, TOBACCO, AND OTHER DRUG ABUSE
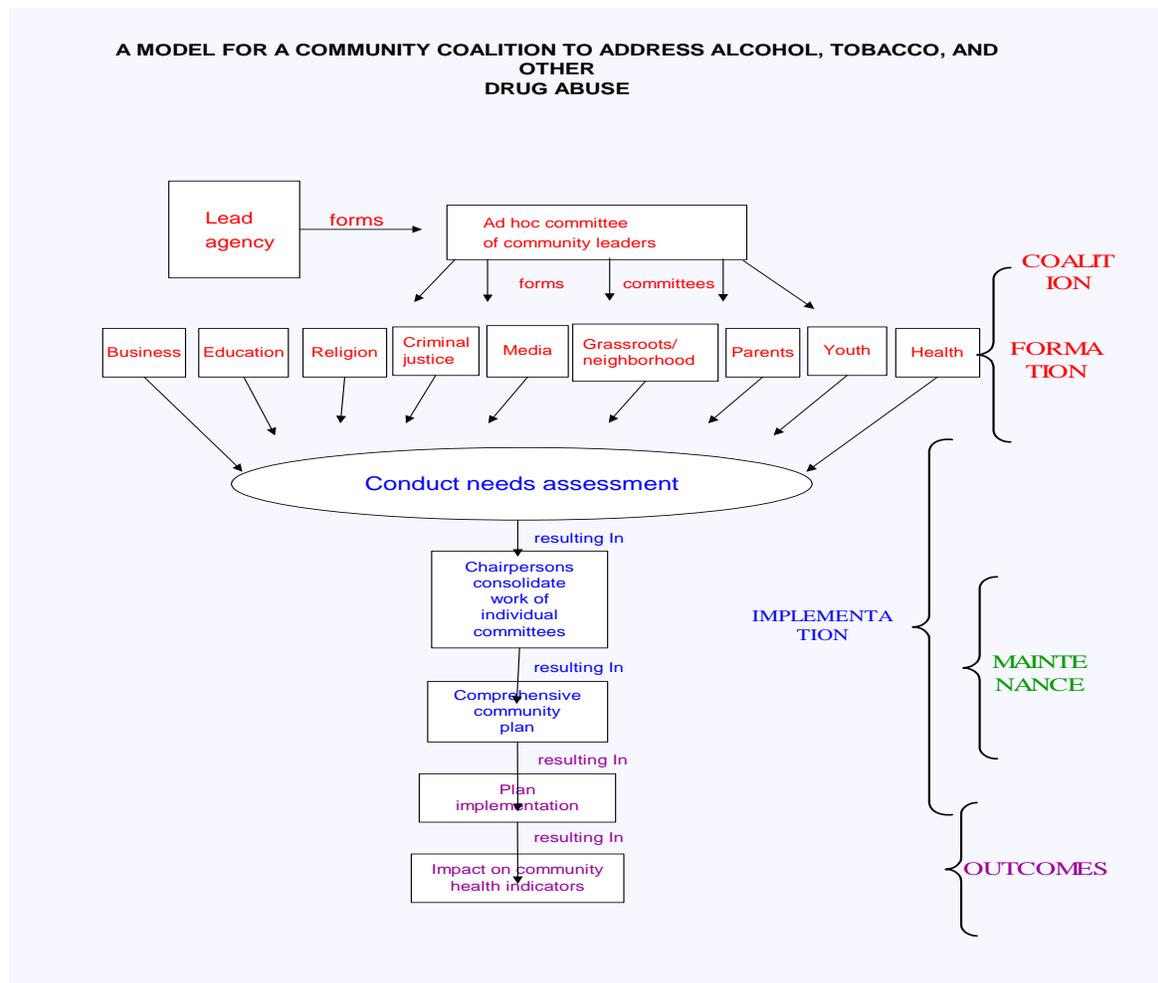
steps in the process and the roles of participants. This model was community-generated. The development process is the key: developing the model with the community; coming up with measures at each level; developing a cause-and-effect model; and developing indicators with the community. The level of adequacy is developed with the community: it

is what the community thinks is necessary. If the model is not working, the stage is set for dialogue with the community to problem-solve. Logic models are a valuable way of engaging communities in evaluation and, in planning the standards for considering program adequacy.

The evaluation instruments used to measure communities must be context-specific to the community. Locally developed instruments can increase focus, sensitivity, and decrease bias. An example: in a community in a Southeastern state there was a study of mental well-being in primary care clinics that provided prenatal care. One of the questions about well-being, taken from a national survey instrument, was: "When people talk to me, I generally don't understand them." Another question was, "When I talk to others, they generally don't understand me." These questions were used as an indicator of mental distress. Well, in the Southeastern state's program, the questions were posed to a Latino migrant population, and had an entirely different meaning in that context. It is very important to understand what the local context is when taking measurements.

Principle three is that evaluation approaches should be both qualitative and quantitative. Quantitative questions typically answer who, what, where, and how much. Qualitative questions typically focus on why something is working and how it is working. In evaluating single and complex community programs, "how" and "why" the intervention worked are often questions that the evaluator should discuss with the community. This dialogue should be the first consideration in developing a plan for evaluation.

The fourth principle is that social ecology and systems theory are important to think about when doing community evaluation. Most of the issues of concern today are really social issues. These are issues embedded in the social fabric, for example: AIDS, violence, and teen pregnancy. It is hard to separate these issues from discussions of racism and other economic disparities. Because these are social conditions, the interventions necessarily have to be complex and typically are on many different levels of social ecology. Behavior change is often wrapped up in social support systems that embrace people.

Community capacity to mobilize effectively is another aspect of social ecology. One important capacity is the ability for organizations and groups to cooperate with one another. Alliances are needed to affect politics and policies through media and lobbying. Advocacy is an important aspect of intervention in the community forum. Interventions should be connected so that they form synergies: one intervention links to others so that both do more to improve the community. When programs are layered and linked in a logical or intelligent way, these have a cause-and-synergistic effect.

The fifth principle is that evaluation should involve local stakeholders in a meaningful way. This means that the evaluator needs to be a facilitator of program development as well as evaluation. Evaluators become a program stakeholder, collaborator, and builder of capacity. Some of the skills that are important in this process are evaluation approaches. In participatory evaluation, the community helps define every step of the way. David Fetterman says that when the community becomes involved in self-reflection, self-

evaluation and self-awareness it becomes empowered. (14) Participatory evaluation is compatible with community development practices, participation and ownership.

What is community capacity? Most programs are functioning in an organization, and the evaluation framework is built around staff and resources of organizations. When programs shift to communities, the evaluation takes on a whole different flavor. What kinds of assets do communities bring to the table to work effectively? Community capacity includes the characteristics of the community that help to identify, mobilize and address social public health problems. Capacity also involves the cultivation and use of knowledge and skills as important community resources.

Some key elements for success include demographics, participation, leadership that is diverse, formal and informal leaders; skills in conflict resolution and negotiation of compromise; resources; ability to access and share resources; trust and reciprocity; and networks with a rich sense of community. The evaluator must understand the community and what has come before in the experience of the community. The central concept is that the community is empowered to be in charge of its destiny for betterment. There needs to be a strong set of community defined values around the projects that are being done. These are all aspects of community capacity.

In summary, community interventions that are population-based are significantly different than more traditional public health approaches. Experimental and quasi-experimental designs are not going to be the most salient ways of evaluating community programs. Without intensive emphasis on formative and process evaluation, including logic models, project functioning may not be maximized. The literature suggests that there are numerous practical tools for evaluating community programs, with both process and outcome evaluations. They require political will to institute them.

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Lessons From Evaluation
A Presentation To The CENTERED Project, July 2000

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Evaluation, if done well in the context of community empowerment work, can strengthen community building and really let you know what works collectively; but, if done poorly, it can blow the whole thing apart. The challenge is in trying to figure out what is effective in improving the public's health.   Seattle has diverse urban, rural, and suburban areas with all of the kind of income, ethnic differences that you would expect in a large geographical mass. It is a little larger than Delaware, and has about two million people. All of us who work in the Public Health Department have some notion of community that becomes very relevant in how you do any of your interventions and evaluations. This is our community and it is very obvious that it is made of different communities, even in just the city of Seattle. Thus, when you think about interventions and evaluating interventions to improve community health generically (or around some of the particular target problems that we're dealing with in chronic disease prevention) even the very notion of *community* is difficult.

In this county, King County, it is sometimes even more difficult than when I was in Boston, which was a fairly small, bounded area of 500,000 people.

What I want to focus on for the moment is evaluation and the context of health disparities. I think that for all of us who were trained in the science of what we are now calling Outcome Research and Evaluation, when you are looking at health disparities you are very much in the realm of the political and the social and the cultural and you've got to make those tools fit in that context. And that is very difficult, I think.

It's trying to strike the balance between what might be the most effective methodological approaches to try to measure an outcome, and what is going to be the best approach given the mission and the values of your intervention. Examples of that are rejecting randomization models because it goes counter to the ethos of the coalition. In some projects where we do randomize, we have been very careful with setting them up in a time-limited way and in diffusing the knowledge, if it is effective, to the population that's not getting the intervention. I know that confidentiality issues in design are really important, for very good reasons. Community members don't trust researchers, so making sure that the designs are really explicit and clear and how confidentiality issues are dealt with is really important. The other way is making sure there is continuous feedback of information about the results of whatever you are finding to the community where you are doing the study. In summary, sometimes it is not using just the state-of-the-art evaluation protocol, but the best fit between the state-of-the-art and the community.

I think the guidelines have to caution those who believe that all the truth lies in the literature in classic methods to be open to other community voices. Until very, very recently, the kinds of approaches that we had to draw on, the "science" of evaluation, were not necessarily imbedded in that kind of context and did not fit very well, or were not tested with the populations that we work with. Looking at evaluation in the context of health disparities, our goal is decreasing or eliminating health disparities based on race, ethnicity, language, income, and sexual orientation; that guides everything that we do. Assessing and monitoring outcomes is a complicated issue. However, I think the first thing to remember is that you are intervening in and having to evaluate a complex, political and cultural system.

If you are going to design interventions to eliminate health disparities, you need a framework for understanding what causes those disparities. You need to look at all of these areas: trust in the health care system, promotion of healthy behaviors, access to health care services, mental health, economic opportunity and equity, education, language, cultural factors, environment, stress, and social factors.

All of those things are relevant in both the design and evaluation of programs. It is sometimes difficult to fit our methods to these factors, since in looking at the disparity issues all of these things are operating at once. How do you capture what is most significant and not ignore or push to the margin things you can't measure? I think that is an important lesson. A lot of our methods lead us to push to the margin and not measure that which is most significant, because we've been trained in models where we work the other way. I think when you're thinking about eliminating or measuring the impact of

programs to deal with health disparities, you have to make sure you're not subservient to the models. It doesn't mean you don't deal with good science, but it means that you're dealing with the flexible interplay with good science, and the realities of what these factors look like in real live communities.

Evaluation guidelines have to be understandable, adaptable and practical. Understandable doesn't mean just translating research into other terms. It means understandable in the context of the lives of people that you're going to work with. Evaluation, when you get down to it, is really simply trying to figure out if something works, if it is effective, if it is making a difference. It is very important, at least in the work that we have done in our community-based evaluations, to come to a common understanding about the term and the use of evaluation. Again, it is not a simple function of taking the tenets of evaluation and translating them. It is working together to have a shared knowledge emerge. This is where you can't be a methodological tyrant, but you have to be flexible in your methods. You may want to trade off rigor to keep an evaluation model from being a powder keg in terms of your community building. Those are the kinds of things that I think adaptability means. As far as practical goes, it has to get done. You have to be very practical because you always, unless the world changes, are trying to squeeze the best evaluation into far fewer funds than they really require.

I cannot separate the community-building work and the coalition of the evaluation. And, one of the reasons we designed an evaluation that works under the coalition is that we couldn't afford to have some kind of artificial scientific split between the evaluators and the project. Some people like tables, some people like text. We just go down to whatever level anyone is, and engage them around the coalition to determine how to make the basic task of evaluation reasonable and understandable and demystified. We talk about the importance of evaluation almost as a marketing tool to help us show we've made a difference, not as a tool to show us where we've gone wrong.

One challenge for community-based evaluation is adaptability. One size evaluation doesn't fit all. I'm always suspicious of evaluation models that don't seem to vary, even depending upon what the evaluation problem is. This is where it takes really new, and almost cutting-edge work between the community and those people who are charged with working on the technical component of the evaluation to make sure that it fits for the problem that you're looking at in the communities.

I want to stress the importance of trying to provide a menu for evaluation, not a script: of a whole lot of things that you *might* do, and a lot of ways to talk about what *might* work or what *might not* work. The worst thing to do is approach this as: "This is received science. Here is how it has to look." Choices, flexibility, menus and not a script are vital. Again, we come back to practicality as in every evaluation, you've got to downsize it, you've got to fit it, you've got to deal with what are always marginal resources, and try to get the best measure of effectiveness that you can to make it a manageable size. Focus on useful data; we spend a lot of time in the coalitions that I work with on defining what is most useful to us as outcome data, based on our goals and based on trying to prove the effectiveness of services. These are the things that are meaningful to the coalition.

Therefore, evaluation is not some kind of research enterprise, but something that helps us advance our community-building enterprise.

Any kind of guideline for community-based organizations involved in the evaluation must be understandable, adaptable, practical, and community-driven. Local public health agencies play an important role, but I sometimes feel that it is maybe helping to set the table, providing some expertise, providing our own input as community members. However, even in the evaluation, it is not an over-determining role. It is a partnership role, supporting some of the emerging logic of what is going to make sense for an evaluation for a particular coalition. It takes a partnership to provide that technical support and to provide some advocacy.
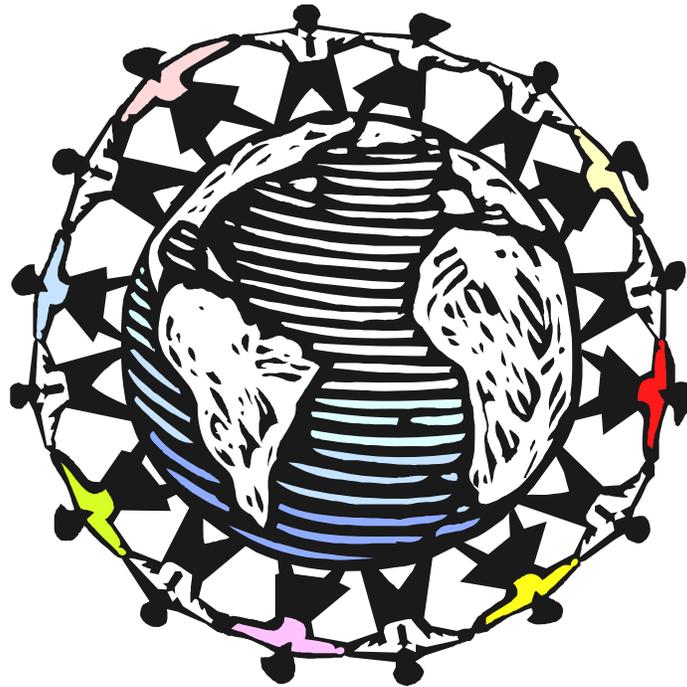
Ethical Principles For Evaluations

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Evaluation of interventions that attempt to reduce health disparities among racial and ethnic groups involves interacting with persons and communities who in the past have been marginalized and disenfranchised. The consequences of the evaluation results can impact the programs themselves and the persons they serve. Therefore, evaluators, program managers and staff have an obligation to pay attention to ethical questions.

Ethical issues will arise throughout the course of an evaluation activity. They may include how and why participant information is collected and used; deciding whether or not results are public information; and deciding who interacts with participants, when, where, and how the results are shared, just to name a few. Ethical issues may be generated by the evaluator, the program manager, or other stakeholders. Ethical guidelines serve as the basis for the thoughtful reflection and sound judgment needed to address these issues.

The principles listed below are guidelines that program managers can expect evaluators to follow when carrying out an evaluation. The list was developed by reviewing and compiling codes of ethic guidelines from a number of disciplines that included: epidemiology, psychology, sociology, behavioral research, and evaluation. It is neither exhaustive nor exclusive; it is intended to help guide decision-making.

- **Community Involvement**—First and foremost, the community's interests, expectations, priorities, and commitment should be determined before the evaluation takes place. The community should be consulted and involved directly, throughout the entire evaluation process and to the degree to which they would like to participate.

- **Competence**—The evaluator: should be knowledgeable in the historical, geographical, cultural, social, political, and economic background of the program; should also possess the education, abilities, skills and experience appropriate to complete the tasks; should be able to design a

tailored-made evaluation plan; should be able to interpret the findings and make recommendations base on those findings. The evaluator should practice within the limits of his or her professional training and competence.

- **Role**—The roles of the evaluator, community, program staff, and other stakeholders should be stated explicitly to avoid confusion about who is expected to do what.

- **Honesty**—This requires a good-faith intent to tell the truth as best one knows it and to avoid communicating in a way that is likely to mislead or deceive.

- **Openness Of Communication**—The evaluator should be forthcoming with results and respond to the community's concerns, suggestions, and questions in a timely manner.

- **Reliability**— The evaluator should make all reasonable efforts to fulfill commitments.

- **Respect**—The evaluator should show regard for the worth and dignity of a community. Respect does not allow violence, humiliation, manipulation, intimidation, coercion, and exploitation.

- **Accountability**—The evaluator should be responsible for providing the community with clear, accurate, and fair information to help guide their decision-making concerning the evaluation process, modifying interventions, allocation of funds, developing policies, etc. Results should be shared in a timely and understandable manner. She or he should be responsible for the completion of the evaluation as agreed upon by the community.

- **Confidentiality And Anonymity**—The evaluator should assure the community that all information collected is held in strict confidence. Released information about the community or participants should be in aggregate form only so that no single individual can be identified.

- **Sharing Results**—The evaluator should share all evaluation results with the community prior to public release. The community should have the opportunity to give feedback and make changes before results are shared with the public and other stakeholders.

- **Protection Of Program Staff And Community**—The evaluator should interact fairly and sensitively with program staff and the community and should avoid causing harm.

- **Fidelity**—The evaluator should comply and adhere to the agreement and fulfill his or her duties and obligations set forth by the community.

- **Fairness**—The evaluator should not make preconceived opinions or judgments about the community, but should make decisions about the evaluation in partnership with the community without favoritism, prejudice, and self-interest. The evaluator should correct mistakes, promptly and voluntarily; and, behave in a manner that is legally right and proper.

- **Integrity**—The evaluator should accurately represent herself or himself and her or his level of knowledge and skill; and, should conduct herself or himself in a manner that is appropriate and sensitive to cultural, social, and political environments of the community.

In Conclusion, these principles should form the ethical basis for conducting evaluation of programs to reduce health disparities. Program managers and staff should be familiar with these principles and develop explicit agreements with evaluators that address these ethical considerations.

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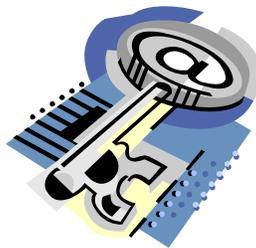
Principles For Evaluating Interventions TO Reduce Racial And Ethnic Disparities In Health

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There are some basic principles and essential elements for evaluating interventions to reduce racial and ethnic disparities in health. It is important to state that there is no single, right way for conducting this type of work. Just as interventions and programs need to be tailored to their communities, so do the evaluations of these interventions.
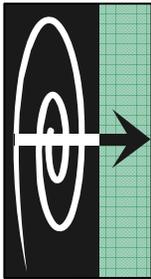
Engage The Community In The Process
Community members should be able to be engaged in intervention, implementation, and evaluation activities with minimal training.

Define Success On The Community's Terms
Intervention success needs to be defined in culturally relevant terms, with input from community members. Researchers or outside "experts" should not be deciding what evidence will be used to say whether or not an intervention was successful. Communities need to have input regarding what are fair and useful measures of success.

Respect The Community
Evaluation efforts need to understand and respect the complexities and unique circumstances of communities.

Address Racism
Community's perspectives on where racism exists and how it affects community members should be explicitly considered in evaluations of efforts to reduce racial and ethnic disparities in health.

Community Participation Is Essential
An overarching principle is that evaluation efforts of interventions aiming to reduce racial and ethnic disparities in health should be *community-based* and *participatory.*

This approach recognizes the knowledge, expertise and capacity that exists in all communities, and emphasizes a collaborative and mutually beneficial relationship between health professionals, researchers and community members.

Rather than being research that is carried out "on" people, community-based participatory research is carried out with and by local people.

76
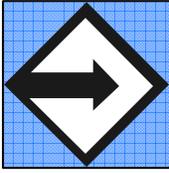
Community Members Have Control

The main difference between participatory research and more traditional research is that community members have a voice and actually have control regarding what intervention is going to be implemented in their community and how that intervention is going to be evaluated. In this evaluation model, community members play a key and active role in defining community problems, crafting interventions, and evaluating the responses.

Relevant Evaluations

There are many benefits and advantages to using a community-based, participatory approach to evaluation research. This approach increases the chance that the research actually will be relevant and useful to the community, that it improves the quality of the research findings by tapping into local knowledge, experience and expertise, and that it gives communities that have traditionally been marginalized and without voice more power and control in the research process.

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Putting Principles Into Action

To engage in community-based, participatory evaluation research, community representatives and researchers need to discuss and agree upon guiding principles for how they are going to work together. This takes a great deal of time and effort, but it is a necessary part of the process by which community members are represented and their voices are heard regarding the interventions being implemented and evaluated in their communities.
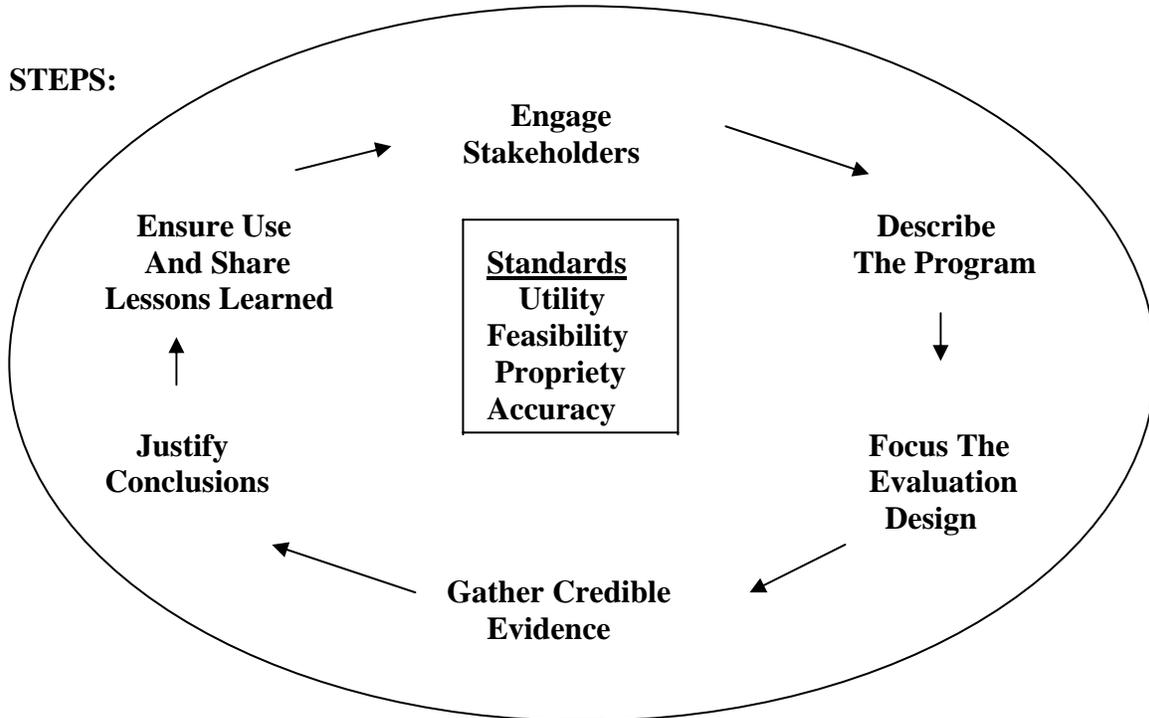
The CENTERED Project's Principles For The Evaluation Of Community-Based Programs

1. CBPH program evaluations need to be tailored to reflect and respect the complexities and unique circumstances of the target community.

2. Good relationships must be established between community partners and CBPH program evaluators before any evaluation planning or work actually begins.

3. CBPH partners should be culturally competent relevant to the target community.

4. The target community should help to define indicators of success in culturally relevant terms.

5. The target community should help to determine the measurement and scaling of evaluation indicators, so the evaluation findings are practically useful and easily understood by all CBPH partners.

6. CBOs should assess, respect and build into each evaluation the community perceptions regarding sources of racism and the impacts racism may have on health disparities within their community.

7. CBOs should assess whether the evaluation process has helped to increase its own (and the community's) capacity to plan and conduct evaluations in the future.

8. CBOs should involve community partners in all stages of the evaluation process, including planning, implementation, data analysis, and reporting of findings.

CDC's Framework For Evaluation

Source: CDC Evaluation Working Group. Framework for Program Evaluation in Public Health. *MMWR* Supplement No. 48; September 17, 1999.

STEPS:

Engage
Stakeholders

Ensure Use
And Share
Lessons Learned

Standards
Utility
Feasibility
Propriety
Accuracy

Describe
The Program

Justify
Conclusions

Focus The
Evaluation
Design

Gather Credible
Evidence

REFERENCE CARD:

STEPS IN EVALUATION	PRACTICE STANDARDS FOR EFFECTIVE EVALUATION
• Engage Stakeholders Those involved, those affected, primary intended users	
• Describe The program Need, expected effects, activities, resources, stage, context, logic model	**• Utility** Serve the information needs of intended users
• Focus The Evaluation Design Purpose, users, uses, questions, methods, agreements	**• Feasibility** Be realistic, prudent, diplomatic, and frugal
• Gather Credible Evidence Indicators, sources, quality, quantity, logistics	**• Propriety** Behave legally, ethically, and with due regard for the welfare of those involved and those affected
• Justify Conclusions Standards, analysis/synthesis, interpretation, judgment, recommendations	**• Accuracy** Reveal and convey technically accurate information
• Ensure Use And Share Lessons Learned Design, preparation, feedback, follow-up, dissemination	Source: CDC. Framework for Program Evaluation in Public Health. *MMWR* Supplement No. 48; September 17, 1999.

OVERVIEW

Purpose

Effective program evaluation is a systematic way to improve and account for actions by involving procedures that are useful, feasible, ethical, and accurate. The framework in a practical, non-prescriptive tool, designed to summarize and organize essential elements of program evaluation. The framework comprises steps in program evaluation and standards for effective program evaluation. Adhering to these steps and standards will allow an understanding of each program's context and will improve how program evaluations are conceived and conducted. The specific purposes of the framework are to

• Summarize and organize the essential elements of program evaluation
• Provide a common frame of reference for conducting effective program evaluations
• Clarify steps in program evaluation
• Review standards for effective program evaluation; and
• Address misconceptions about the purposes and methods of program evaluation

Steps In Evaluation Practice

The framework emphasizes six connected steps that together can be a starting point to tailor an evaluation for a particular effort, at a particular point in time. Because the steps are all interdependent, they might be encountered in a nonlinear sequence; however, an order exists for fulfilling each -- earlier steps provide the foundation for subsequent progress. Thus, decisions regarding how to execute a step are iterative and should not be finalized until previous steps have been thoroughly addressed.

Standards For Effective Evaluation

A set of 30 standards -- organized into groups of utility, feasibility, propriety, and accuracy – is also included. These standards help answer the question, "Will this evaluation be effective?" The standards are adopted from the Joint Committee on Educational Evaluation (1994); they are an approved standard by the American National Standards Institute (ANSI) and have been endorsed by the American Evaluation Association and 14 other professional organizations.

Applying The Framework

Professionals can no longer question whether to evaluate their programs; instead, the appropriate questions are, "What is the best way to evaluate?" " What is being learned from evaluation?" and "How will lessons learned from evaluations be used to make program efforts more effective and accountable?" The framework helps answer these questions by guiding its users in selecting evaluation strategies that are useful, feasible, ethical, and accurate. When applying the framework, the challenge is to devise an optimal -- as opposed to an ideal -- strategy. An optimal strategy is one that accomplishes each step in the framework in a way that accommodates the program context and meets or exceeds all relevant standards.

Integrating Evaluation In Routine Program Practice

Evaluation can be closely tied to routine practice when the emphasis is on practical, ongoing evaluation that involves all staff and stakeholders, not just evaluation experts.

Informal evaluations are done routinely by individuals, who ask questions and consider feedback as part of their daily professional responsibilities. Such informal evaluation processes are adequate when the stakes involved are low. When the stakes of a situation increase, however, then it becomes important to use evaluation procedures that are formal, visible, and justifiable.

ADDRESSING COMMON CONCERNS

Common concerns regarding program evaluation are clarified by using this framework. For instance, many evaluations are not undertaken because they are perceived as having to be costly. The expense of an evaluation, however, is relative; it depends upon the question being asked and the level of certainty desired for the answer. A simple, low-cost evaluation can deliver valuable results.

Rather than discounting evaluations as time-consuming and tangential to program operations, the framework encourages conducting evaluations that are timed strategically to provide necessary feedback. This makes it possible to integrate evaluation closely with program practice.

Another concern centers on the perceived technical demands of designing and conducting an evaluation. Although circumstances exist where controlled environments and elaborate analytic techniques are needed, most program evaluations do not require such methods. Instead, the practical approach endorsed by this framework focuses on questions that will improve the program by using context-sensitive methods and analytic techniques that summarize accurately the meaning of qualitative and quantitative information.

Finally, the prospect of evaluation can trouble many program staff because they perceive evaluation methods as punitive, exclusionary, and adversarial. The framework encourages an evaluation approach that is designed to be helpful and engages interested stakeholders in a process that welcomes their participation.

FOR FURTHER INFORMATION: CDC Evaluation Working Group
http:/www.cdc.gov/eval

Guidelines For Selecting An Evaluator

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It is going to take a special kind of evaluation lead by an evaluator with specific skills to assess and document improvements caused by projects designed to eliminate racial and ethnic health disparities. The following information is provided as a guide for organizations that are interested in selecting the best evaluator for a project that will be implemented in a community setting. This information is based on two studies (1,2), other documentation of evaluation approaches (3) and my personal experiences with evaluation.

Choosing the right evaluator can complement the team approach to the project and help ensure success. Having the right evaluator can ensure that the project staff and participants are involved in setting evaluation questions, designing evaluation instruments, collecting data and receiving useful information about project activities. On the other hand, selecting the wrong evaluator can mean the collection of useless information, disruption of project activities, and the lack of feedback to project personnel and participants.

But who is the "right evaluator?" Aren't all evaluators the same? Actually, no… Evaluators are not trained similarly and all do not have experiences that relate to conducting evaluations in community settings or to the elimination of health disparities.

Some specific tips for hiring an evaluator or an evaluation team are provided below. Projects should hire evaluators for community-based projects who:

- Take a team approach to decision-making and work tasks;
- View the work to be done as a partnership;
- Select evaluation questions using an empowerment evaluation approach;
- Have past experiences with community-based evaluation that is both process and outcome focused;
- Know how to create useful evaluation products (obtain examples of reports and presentations);
- Translate their work so that it is easily understood and used by staff and participants;
- Have grant writing skills to assist in furthering the initiative;
- Have strong communication skills;
- Are personable, approachable and open to new ideas;
- Strong ability to work with staff and community personably and professionally;
- Be culturally competent with the community that is the priority for this project;
- Have strong data collection and management experience from past community-based projects;
- Collect and analyze qualitative and quantitative data;
- Have good organization skills.

In summary, the evaluator selected should have solid community-based research skills, and more importantly be committed to the community and social change. If possible, it can be useful to hire an evaluation team comprising members who collectively cover the above-listed characteristics.

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Chapter 5
An Agenda
For Change
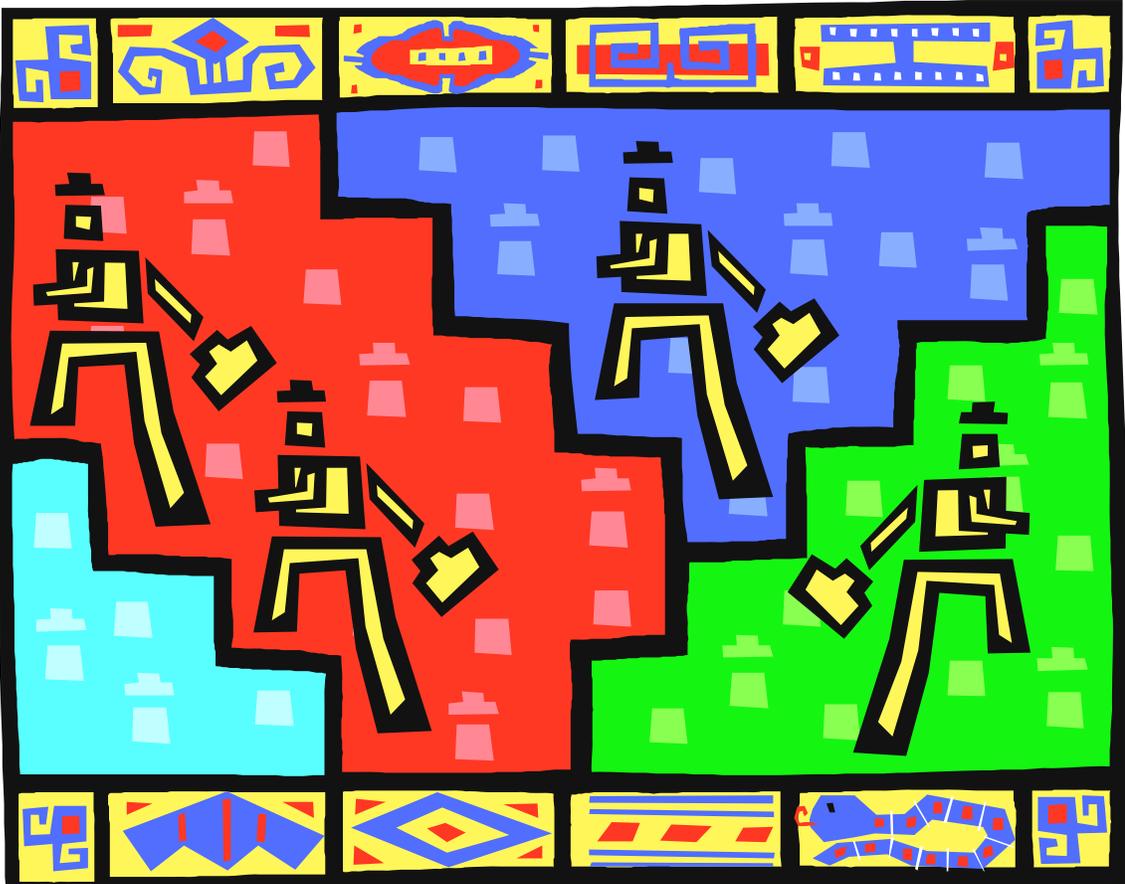
Building Community Capabilities And Empowerment

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The World Health Organization's *Health for All* goal is recognized as the global strategy to improve community participation in improving health, with the recognition of their capabilities and empowerment. The enabling goals established are to:

- Increase years of healthy life;
- Promote healthy behaviors;
- Protect health;
- Assure access to quality health care;
- Strengthen community prevention; and
- Eliminate health disparities.

Many health problems still persist which hinder social and economic development and must therefore be urgently addressed to further equity in the attainment of health and well being (1).

If the desired outcome of health promotion is equity, its main objective should be to implement participatory strategies towards this goal. It is not possible to develop a convivial and healthy environment without the participation of individuals and communities (2). Building community capacity and empowering communities to improve living conditions are complex and difficult social and political processes. It is not possible to implement them in a vacuum or out of focus; people need incentives to participate. The best incentive is to provide individuals with opportunities to resolve situations that affect their daily lives.

To work with communities, it is very important to realize that evaluation results are not the only inputs into such decisions.

Decisions are affected also by budgetary considerations, political considerations, and staffing considerations, among others. The goal of the evaluation should be to produce maximally useful data and to present that data in such a way that they can readily be put to use. The most important part of an evaluation process is to involve the community and make it useful for the important decisions that it has to take and identify an involve important stakeholders.

Mobilizing communities means channeling resources: people, goods and services, time, money. The community organization process seeks to stimulate community energies, interests, and resources in a collective response. This organization process is a critical aspect of health action and is a kind of "glue" that maintains citizen interest, nourishes participation in programs, and encourages support for long-term maintenance of successful intervention efforts (3).

Community involvement is based on the principle of participation, which states that's large-scale behavioral change requires the people heavily affected by a problem to be involved in defining the problem, planning and instituting steps to resolve the problem, and establishing structures to ensure that the desired change is maintained. (4). The process requires listening to people and having respectful attitudes towards their rights and values (2).

The principle of *ownership* is closely related to the principle of participation. Ownership means that local people must have a sense of responsibility for and control over programs promoting change, so that they will continue to support them after the initial organizing effort (5).

It is important not to make any kind of analysis about human behavior without first taking in to consideration the human point of view (6). All human behavior responds to a series of needs and the search for their satisfaction.

The concept of *empowerment* refers to the transfer of powers. Is defined in general terms as people's ability to acquire knowledge and to have control over personal, social, economic, and political forces that affect individuals in such way as to allow for improved conditions and quality of life. In the field of the promotion of health care, empowerment is considered as a community intervention strategy (7).

Additionally, empowerment is the process whereby individuals, communities and organizations acquire control or dominion over their lives. For analytical and practical purposes, it may be classified in three different levels: *at the individual, organizational and community level*. The reason for this new focus is based on the interaction that exists between each level: the individual is not isolated from the community, which in turn is linked with organizations. The development of one level can affect the others directly or indirectly (6).

Two other components must be considered when we talk about empowerment: *capacity* and *equity*. Capacity is the ability that an individual or a community has to solve its problems. Equity reflects the concept of fairness or equality in the distribution of existing resources. The possession of power rests upon the individual that initiates a change with or without the consent of these toward whom change is directed. Individuals and communities can accept the responsibility of behaving for the good of others. Decision-making processes and social changes are easier to achieve with the development of a sense of community. This sense of community offers a sense of power to its members.

On the other hand, the lack of equity represents a big problem when we want to empower the community. The persistence of inequities in health indicates the desperate need to encourage strategies of building community capacity. Community empowerment starts when people listen to each other, engage in participatory and liberating dialogue, identify their commonalties, and construct new strategies for change (8). It is very important to define barriers, problems and solutions to illustrate the real

possibilities of community empowerment.

The following are special considerations that we have to consider when we decide to work with communities and improve their capabilities (9):

- The process of actively involving the community or group is as important as the interventions implemented.
- Community analysis of health conditions and readiness for actions should be done in collaboration with the community and local institutions.
- It is important to guard against the assumptions that all members of a community or group are homogeneous and that one message or one channel of delivery will appeal to the entire group.
- Readiness of the community to work on a particular health issue may depend on the organizer's ability to integrate other community issues into the overall project design.
- In multiracial and ethnic communities more than one group can be involved in and can collaborate on a community-wide project.

The process of empowering communities is dynamic and ever changing. We have to define how we want to empower the community and how we are going to measure this empowerment. It is recognized that communities need help in this process, but how an evaluator can help must be discussed.

Notes:

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Overcoming Obstacles To Evaluation

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Obstacle	Strategy For Overcoming The Obstacle
Perception that evaluation is punitive.	Use evaluation as a tool for improvement—a learning checkpoint. Make program evaluation a participatory process with community and/or coalition members fully involved.
Evaluation focuses on the wrong measures.	Expand the "menu" of indicators to include community's priority indicators (both positive and negative). Identify and incorporate community-defined issues into the evaluation.
Evaluation is for academics and it's intimidating.	Build education and training of community partners into the RFP process. Provide opportunities for interested community members to become active in the evaluation process to help build community evaluation capacity. Offer evaluation training and make evaluation tools and reports "user friendly".
Communities are reluctant to share negative findings from evaluations.	The community should be involved in analyzing and interpreting findings during the draft results stage and seek consensus on the findings and recommendations. The recommendations should be constructive, practically useful, and implementable.

A participatory process for evaluation is important. Evaluation should be included from the start of a project, beginning with the program's planning phase. A participatory model should encourage and promote:

- Community-defined evaluation processes and indicators;
- Building of trust between the community, coalition members and persons responsible for conducting the evaluation;
- Airing of any negative perceptions about evaluation and increased awareness of evaluation as a valuable tool to communities and community programs;
- A broader spectrum of indicators that will more accurately account for community processes and practices that contribute to the success of programs;
- Clarification of roles—community coalition members as well as academics;
- Clarification of how the evaluation results will be used and disseminated;
- Evaluations that are tailored to be culturally relevant to the community;
- Accountability of the evaluators to the community;
- Periodic evaluations to enable tracking of indicators of success over time; and
- Capacity building through training and education about how to conduct and fully benefit from the program evaluation process.

Improving Funding Relationships

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It is no secret that relationships between funding and grantee organizations are sometimes marked by lack of trust and mutual understanding. Divergent expectations and lack of clear communication can hamper the achievement of that goal. Below are several recommendations to help address these dilemmas and improve funding relationships that some private foundations are putting into practice:

1. Some level of collaboration or at least a trusting relationship must exist between the funding source and community-based group before major commitments are made. This gives all the entities involved a level of shared understanding about expectations and objectives.

2. Community-based organizations need an opportunity to build their capacity and relationships during an extended planning period of six to nine months. Groups are resourceful, but most don't have a strong network of health and evaluation professionals. Some funders work with community-based group during this stage of their development, and invest in training to bring potential applicants to a point where they can be competitive for grant approval. This model has very positive implications for strengthening community-based organization capacity and building trust.

3. Transparency should be built into the funder's program reviews and decisions about renewal of funding. The evaluation data should be useful and useable for the program operator as well as the funder. There should be a focus on jointly learning from the data and continuously improving the program rather than making a pass or fail decision at renewal time.

4. Funders should recognize the appropriate scale of programs to be operated by community-based organizations. By definition, if an organization is going to be rooted in and focused on a community then its expertise and unique capacity is limited to that community. Community-based organizations bring unique strengths to assist in eliminating disparities only within their own "ecologies". When program requirements force them to expand the geographic scope of their services, they may lose their unique advantage and may overload their management and staff capacity.

5. Funders should recognize that transaction costs, the cost of managing grants for community-based organizations, are higher than for institutional grants. These increased costs are primarily in the staff time it takes to build and maintain a relationship with grantees. It may also require staff with different kinds of competencies as well as sensitivity to community perspectives and cultural differences.

The Benefits Of Change

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To achieve our vision of community-based evaluation, it will take work and require changes on the part of everyone involved: communities, sponsors and evaluators. There will be many benefits from these changes. Here are some thoughts about what needs to change in evaluation, and the potential benefits for improving programs to reduce health disparities.

Building Communities' Capabilities And Empowerment

Better community-based evaluation will require some changes in the ways many communities go about doing business. The changes that many communities will need to make include:

- Clearer specification of program goals and objectives;
- More thinking about the idea or "model" that underlies a program and about its components;
- More time spent with the evaluators to educate them about the program and to discuss the program with them;
- More involvement providing input in creating the evaluation plan and measures;
- More involvement reacting to learnings from the evaluation;
- Investment of some resources in evaluation activities.

The benefits of better community-based evaluation for communities include:

- A clearer idea about what the program intends to accomplish;
- A clearer idea about what program components are critical for success;
- Information about what works and what is in need of change;
- The development of some capacity within the program for evaluation work;
- The development of staff with some evaluation skills.

Building Sponsors' Capabilities To Better Support Community Programs

Better evaluation will require some changes in the ways sponsors go about doing business. The changes that sponsors will need to make include:
- Better understanding of the realities of program development and implementation;
- More flexibility in the definition of outputs, outcomes and impacts, tailored to each program;

- Additional resources devoted to evaluation.

The benefits of better community-based evaluation for sponsors include:
- Better specification of and documentation of goals, objectives and activities;
- Better identification of outputs, outcomes and impacts;
- Better identification of program strengths and weaknesses;
- Better understanding of evaluation among program staff and clients for future projects.

Building Evaluators' Capabilities

Better evaluation will require changes in the ways some evaluators go about doing business. The changes that some evaluators will need to make include:

- More flexibility in defining goals, objectives, inputs, outputs, outcomes and impacts;
- More flexibility in selecting evaluation designs that capture all the important components of a program;
- More use of mixed-method designs to capture all the important aspects of a program's outcomes and impacts;
- More attention to unexpected outcomes;
- More time devoted to evaluation training among program staff and, possibly, clients;
- More time spent with programs to form, develop and nurture the partnership.

The benefits of better community-based evaluation for evaluators include:
- More sensitive designs and measures;
- Better rapport with program clients and staff;
- Greater likelihood of use of findings;
- Greater pool of diverse community-based people who can conduct some basic evaluation activities or who become interested in receiving better training in evaluation (thereby resulting in a more ethnically-diverse population of evaluators);
- Stronger findings that truly reflect the outcomes of a program;
- Stronger contributions to the future development of theory, policy and practice.
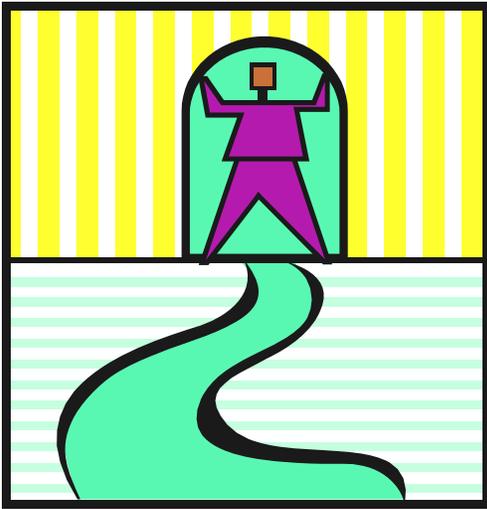
Finding The Pathway To Evaluation

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Building Sponsors' Capabilities

Sponsors who fund interventions and their evaluations, need a better understanding of the pitfalls of traditional evaluation approaches in assessing efforts to reduce racial and ethnic disparities in health. Many messages need to be communicated to government, foundations and other types of funders. This includes:

- The dangers in funding the evaluation efforts of researchers or experts who are outside of the intervention community and who have not demonstrated they have worked with community members to identify issues, interventions and evaluation strategies. Evaluation proposals that do not demonstrate community participation and involvement in intervention design and evaluation plans should not be funded.

- The need to build enough time and resources into the evaluation process to allow for a true participatory approach.

- The need to fund efforts to build evaluation capacity within communities and to build the infrastructure for community research partnerships.

- The need to balance the evaluation interests and priorities of the community receiving the intervention with the interests and priorities of other stakeholders (including the sponsor).

- The fact that a wide variety of data collection methods will likely be needed in this type of work. The evidence regarding the strengths and limitations of particular interventions will often come in both quantitative and qualitative forms.

- The need to better craft requests for proposals to the realities of doing this kind of work. Requests for proposals need to emphasize the importance of considering both the cultural context and the effects of racism within the culture context in the

- evaluation efforts. Requests for proposals also need to reflect an understanding of the human, financial and time resources involved in evaluating community-based interventions to reduce disparities in health.

- The need to have the "right" people (i.e. those who understand different pathways to evaluation and are not biased against non-traditional approaches) review and score proposals.
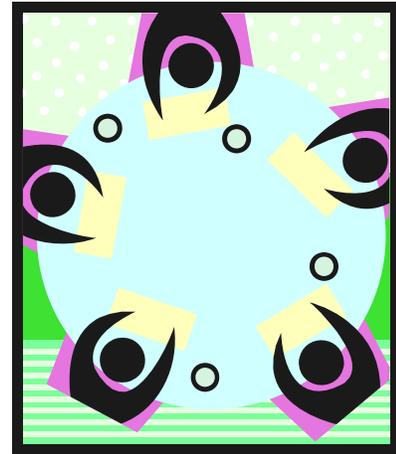
These messages need to be communicated to sponsors directly from community representatives and also from the professional researchers and evaluators. Some possible ways in which communication about these issues could occur are as follows:

- Community members with good and bad experiences with evaluation need to share their stories with sponsors.

- A video in which community members discuss good and bad experiences with evaluation, accompanied by a concrete set of recommendations for funders or sponsoring agencies, could be produced and distributed.

- Community members with experience in evaluating efforts to reduce racial and ethnic disparities in health need to identify themselves to sponsoring agencies and volunteer to serve as consultants and as proposal reviewers.

- Discussions of different pathways to evaluation need to make their way into the peer-reviewed literature. Traditional orientations toward evaluation need to be countered with stories and analyses of cases in which traditional approaches did not work well and when alternative approaches found success. Non-academic or non-researcher partners in evaluation efforts, including grass roots community members, need to participate in these articles.

Building Evaluators' Capabilities

Evaluation training at the graduate level needs to incorporate a better understanding of the limitations of traditional evaluation approaches, and alternative pathways to evaluation. Presentations and round table discussions of these issues (which involve community members with good and bad evaluation experiences) and their implications or evaluation curricula should take place at professional meetings and conferences. This will give those people who teach evaluation the opportunity to engage in dialogue about alternative approaches.

- Model curricula for teaching public health evaluation approaches at the graduate and undergraduate level could be developed and disseminated.

- People who have finished their formal schooling also need opportunities for re-training or re-tooling in the area of evaluation.

- Training programs within government agencies should include instruction and discussion of non-traditional, participatory approaches to evaluating health disparity interventions.

- Community members need to communicate with professional evaluators about what works and does not work in evaluations of community efforts to reduce health disparities. This needs to occur through venues that reach this professional group. Although it may be difficult to achieve, the voice of community members regarding the need for new approaches to evaluation needs to reach evaluators.

- Both positive and negative case stories regarding evaluations in the area of racial and ethnic disparities in health need to be shared often and widely. Evaluators who have made mistakes need to be willing to acknowledge their mistakes and what can be learned from them.

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