



Health Care Reform, "Racialized Urban Ghettos," and Community Based Participatory Research

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Presented at the 16th Annual Summer Public Health Research Institute and Videoconference on Minority Health, June 8, 2010, University of North Carolina at Chapel Hill

The Lens Through Which I View Health Disparities and the New Health Care Reform Bill

- ▶ 40 years of professional experience as a community health anthropologist
- ▶ Important lessons learned while a faculty member at UNC's School of Public Health, 1976–1987.
- ▶ Persons of influence on the development of my thinking about community health.

Two of the Many Lessons Learned while a Faculty Member at UNC

- The most important role of a public health professional is to identify and try to respond to the health care needs of those at greatest risk of disease and ill health, the most underserved in terms of health care and other services, those in greatest need of health care services, and often the hardest to reach when services are available.
- One of the most important roles of the health educator is to be a "facilitator" or "broker" between those in the greatest need of health care resources, and those who might be able to respond to such needs.

A Few of the Sources of These Lessons Learned While at UNC

- ▶ Guy B. Stuart
- ▶ Howard Barnhill
- ▶ Leonard Dawson
- ▶ Margaret Pollard
- ▶ Polly Lambert
- ▶ John Hatch

Other Lessons Learned While at UNC...

- ▶ The importance of broad health policies as among the tools necessary to address such complexities and thus in turn successfully bring about changes in health conditions.
- ▶ That policies remain simply tools unless there are action plans that use these tools.
- ▶ Most community health problems are very complex, and thus there is need for multiple tools and action plans to effectively address most community health problems.

A Federal Policy Tool to Address US Health Disparities

- ▶ In 2000, Congress established the National Center on Minority Health and Health Disparities (NCMHD) to lead, coordinate, support and assess the NIH effort to eliminate health disparities.
- ▶ Based on the recognition that while "Americans enjoyed improved health and longer lives during the latter part of the 20th century.....African Americans, Hispanics, Native Americans, and Asian/Pacific Islanders continued to experience striking health disparities, including shorter life expectancy and higher rates of diabetes, cancer, heart disease, stroke, substance abuse, and infant mortality and low birth weight".

Yet Health Disparities Are More than Simply Macro-Structural Statistical Differences

- ▶ The problem of health disparities goes beyond the macro-structural differences cited between ethnic, class, and gender categories.
- ▶ It is, however, within these demographic categories that we also find the largest proportions of those at greatest risk, the most underserved, those in greatest need of health care services, and often those that are the hardest to reach.

Health Disparities Reflect Not Simply Individual or Group Differences

The problem of health disparities also pertain to:

- ▶ whole communities, or population groups within communities that are underserved, or have a lack of access to health and other services;
- ▶ communities and population groups that are experiencing economic and political marginality in relationship to mainstream society;
- ▶ population groups or individuals who experience health and general literacy issues;
- ▶ population groups or individuals who have attitudes of distrust of the mainstream health care system based in past individual or group of racial, ethnic or gender prejudice, discrimination, or abuse.

Health Disparities and "Racialized Urban Ghettos" (RUGs)*

- ▶ Over the last 20 years, my small research unit at the University of Maryland, the Cultural Systems Analysis Group (CuSAG), has carried out more than a dozen ethnographic and qualitative research studies in economically distressed and underserved communities in the Baltimore-Washington Urban Corridor (the BWUC).
- ▶ These studies have focused on a number of health and social issues including HIV/AIDS, drug trafficking, and the impact of mass incarceration and re-entry on individuals, communities & families.
- ▶ We refer to these communities as RUGs.

Characteristics of Racialized Urban Ghettos (RUGs)

- ▶ **Predominantly populated by African Americans (90% and above).**
- ▶ **The role of race and racism (policies, attitudes, and practices) in the evolution and persistence of these communities.**
- ▶ **High population density.**
- ▶ **Low male to female population ratios in the 15-45 age group.**
- ▶ **High rates of single female-headed households.**

Characteristics of Racialized Urban Ghettos (Cont)

- ▶ Inadequate employment opportunities.
- ▶ Since the early 1970s, continuing increases in unemployment, underemployment, and decline in employment opportunities.
- ▶ Since the early 1970s, the exodus of higher SES residents resulting in lower tax base.
- ▶ High rates of concentrated and extreme poverty.
- ▶ Difficulties in trying to take advantage of employment opportunities in nearby Suburbs and Edge Cities.

Characteristics of Racialized Urban Ghettos (Cont)

- ▶ Highest mortality rates from all leading killer diseases from prenatal to older years.
- ▶ Continual environmental deterioration since the late 1960s.
- ▶ High levels of social and cultural isolation.
- ▶ Recent in migration of other ethnic groups and increased competition for resources.
- ▶ Gentrification processes with displacement of long term low-income residents.
- ▶ Continual increases in the rates of violent crime, drug abuse & trafficking, and incarceration between 1985 and 1995 (a period, that I refer to as the "Crack Decade," and increasing rates of prison to community re-entry.

“Unhealthy” Communities and Multi-Sectorial Accountability. . .

- ▶ Citing many of the RUG features outlined above, I had participants in a community stakeholders focus group refer to their communities as “unhealthy.”
- ▶ They also strongly called for a multi-sectorial accountability in addressing the ills of their communities.
- ▶ They called for accountability from: *parents, schools, neighborhoods* and *community*, and *universities* and colleges, *service agencies, political leaders*, and *inter-sectorial approaches* to community accountability.

Multiple Tools Needed for Success in Reducing Health Disparities

- ▶ While the USPHS’s adoption of a goal to reduce health disparities is an important tool in the quest, multiple tools are needed to succeed in achieving this goal at a national level.
- ▶ Multiple policy tools are also needed because of the complexity of issues related to the socio-cultural determinants of health status, of health disparities, and health seeking behavior, particularly among those at greatest risk, the most underserved, and the most in need.

CBPR as Another Important Policy Tool for Reducing Health Disparities

- ▶ *Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.*

CBPR as Another Important Policy Tool for Reducing Health Disparities (Cont.)

- In 2001, the Agency for Healthcare Research and Quality (AHRQ), in collaboration with several Federal agencies and the W.K. Kellogg Foundation, convened a 2-day conference
- ▶ to promote and support the use of CBPR;
 - ▶ to develop strategies to advance CBPR; and
 - ▶ to explore the use of CBPR as a resource for policymakers to help guide their program development.

CBPR Not Simply A Policy Tool, But Also An Action Plan Because Of Following:

- ▶ CBPR leads to *co-learning and reciprocal transfer of expertise* by all research partners
- ▶ CBPR emphasizes *shared decision making power*, and *mutual ownership* of the processes and products of the research enterprise.
- ▶ CBPR *creates bridges between scientists and communities*, through the use of shared knowledge and valuable experiences.

CBPR Not Simply A Policy Tool, But Also An Action Plan (cont.)

- ▶ *CBPR collaboration lends itself to the development of culturally appropriate measurement instruments*, thus making projects more effective and efficient.
- ▶ *CBPR establishes a mutual trust* that enhances both the quantity and the quality of data collected.
- ▶ CBPR leads to an ultimate benefit of *a deeper understanding of a community’s unique circumstances*, and *a more accurate framework for testing and adapting best practices* to the community’s needs.

Relevance of HCR for RUGs & Other Underserved Communities

- › Expand coverage to 32 million Americans who are currently uninsured;
- › The uninsured and self-employed would be able to purchase insurance through state-based exchanges with *subsidies available to individuals and families with income between the 133 percent and 400 percent of poverty level.*
- › Funding available to states to establish exchanges *within one year of enactment* and until January 1, 2015.
- › Separate exchanges would be created for small businesses to purchase coverage (but not effective until 2014).

Health Care Reform– Another Policy Tool in Need of Action Plans

- › As stated earlier, while federal bills are important tools to overcoming health disparities, such tools are not effective without strong action plans.
- › Such action plans are most significant for reaching those in greatest needs, at greatest risk, the most underserved, and the hardest to reach, such as the residents of RUGs.
- › Because I believe that CBPR is our best strategy yet for reaching such populations, who are also at the heart of the health disparities issues, then I believe that further *enhancing CBPR approaches is where we might start such actions.*

Towards Enhanced Approaches to CBPR

- › There are CBPR and other community action efforts that are now in place at Universities all over the country.
- › I was recently reminded, however, that there are some disappointments with the outcomes of many CBPR efforts, that they were deemed as not achieving the results in which had been hoped for when these initiative were first initiated.
- › Whatever difficulties that CBPR efforts are having, however, I do not think that it is a reason to give up on this approach as one of central strategies that we must undertake if we are indeed going to achieve the goals of health care reform and the elimination of health disparities.

Towards Enhanced Approaches to CBPR (Cont.)

- › Similar to every other new societal wide policy initiative, we should not expect CBPR to neatly achieve its desired goals right out of the gate, but that we need the ongoing development of the concept, including the inclusion of new approaches.
- › It is one such new approach that I have been developing over the years, and that we have initiated as the focus of a new CuSAG 5 year strategic plan titled: *Towards A Consortium /Center of Applied Ethnographic and Community Health Sciences (the CAECHS)*

Background of The Cultural Ecology of Health and Change (the CEHC)

- › The first activity of CuSAG's new 5 year Strategic Plan is to continue developing the community action system that has evolved over the past 30 years, beginning while I was at UNC, and continuing over the past 20 years at UMD.
- › The name of this system is the *Cultural Ecology of Health and Change* (the CEHC).
- › Most of CuSAG's work over its 20 years of existence has been informed by the CEHC.

The Development of the CEHC as a CBPR Framework.

- › Such public health paradigms as the Belief Model, PRECEDE PROCEED, and Social Ecology from Public Health contributed to the evolution of the CEHC.
- › However, methods and theories from ethnography and anthropology are most pronounced in helping to better understand and assess the elusive issues of *socio-cultural complexity*, as well as the *socio-cultural contexts, dynamics, and meaning systems* that influence all human behavior, including health risk and health seeking behavior.,
- › The CEHC also consists of four community action subsystems, which address important action research components in which researchers and academicians can play important roles within a CBPR format: *community and cultural assessment research*, and the *planning, implementation, and evaluation* of community based planned change initiatives.

The Four CEHC Conceptual and Methodological Subsystems*

- **Project Design and Implementation Planning (The PDIP).** The PDIP is primarily a *service system* and consists of methodologies for assisting organizations in the *design* of community based initiatives.
- **Ethnographically Informed Community & Cultural Assessment Research Systems (the EICCARS)** is a multi-method *research system* that analyses: (1) conditions, needs, challenges and risks within a community as they relate to a specific health or social problem; and (2) the organizational and other assets within the community that attempt, or can be utilized to effectively address such conditions, needs, etc.

The Four CEHC Conceptual and Methodological Subsystems (Cont.)

- **Project Implementation Programs (the PIPs).** The PIPs is also primarily a *service system* with several programs including: research and evaluation, resources development, community organizing and participation, staff monitoring, developing community and culturally appropriate materials, developing and implementing community and culturally appropriate intervention projects, and the "energizing" of community cultural systems.
- **Ethnographic Assessment and Evaluation Systems (the EAES).** The EAES provides a multi-method *assessment* of project or organizational *goals, objectives, strategies, implementation processes, outcomes, and impacts* through four evaluation programs, *formative, process, outcome, and impact evaluation.*

The Urban Health and Human Ecology Project (the UHHEP)*

- › The second program in CuSAG's five year Strategic Plan is the Urban Health and Human Ecology Project (the UHHEP).
- › The UHHEP builds on the EICCARS and its multi-method ethnographic data collecting system.
- › Over the past several years I have offered a course using these methods to collect data in neighborhoods in the DC Metropolitan Area.
- › A couple of years ago, I begun organizing these data into comprehensive neighborhood data bases* that on two important contextual areas in urban community health: (1) needs, challenges, and risks for various illness and social issues found in urban environments; and (2) community resources or assets identified as attempting to address these conditions.
- › This UHHEP was initiated the Urban Health and Human Ecology Project as a way of providing some integrated structure for further developing these databases, and to facilitate their use in informing future research and action.

A Proposed *University to Community Health Outreach Network*: Background

- › The third program of CuSAG's 5 year Strategic Plan Designed to further our commitment to a CBPR approach is the establishment of a *University to Community Health Outreach Network* (the UC-HON).
- › The Idea for UC-HON grew out of contentious 2006 Focus Group Discussions with RUG community stakeholders involved in CuSAG's current research on prison to community re-entry in DC.
- › A question to me the moderator: "*Are you here to help us, harm us, or do nothing!!!*"

Background of Proposed *University to Community Health Outreach Network* (Cont.)

- › From these same discussion, descriptions of their own communities as being unhealthy, and calls for a inter-sectorial accountability in addressing these community issues, as mentioned earlier.
- › In response to community calls for more university based accountability, in 2008 CuSAG organized a meeting of colleagues at UMCP who were involved in research or social action regarding incarceration and re-entry issues.
- › In May of 2009, CuSAG organized a workshop at the UMCP on the impact of incarceration and re-entry issues to which researchers, policy makers, organizational representatives, and community activists were invited.

First Proposed Annual UC-Hon Conference/Workshop -January, 2011

- › 3 day Conference/Workshop being planned for January, 2011.
- › This summer invitations are being sent to regional researchers, policy makers, etc to become members of the UC-HON, and join in the planning, implementation, and co-sponsoring the event.
- › Event to be used to expand UC-HON membership
- › Being conceived as annual event wherein 2011 will focus on mass incarceration and re-entry as urgent public health problems, while subsequent conferences to focus on other health topics as recommended by UC-HON members.

Tentative Schedule of 2011 UC-Hon Conference/Workshop

- The first two days will focus on reports and panel discussions focusing on range of issues related to the health and social impact of mass incarceration and re-entry on the individual experiencing these phenomena, their families, their communities, and the wider society.
- The third day will be committed to formally establishing the UC-HON, with presentations on the capabilities that academic UC-HON members – including CuSAG, have to offer CBOs and public agencies who are working on re-entry issues.

CuSAG's Offerings at Planned 2011 UC-HON Conference/Workshop

- The EICCARS. CuSAG will make a presentation at the Conference/Workshop on EICCARS methodologies, as well as offer technical assistance in the training and use of methods.
- UHHEP. CuSAG will also make presentations regarding the UHHEP data bases, and offer workshop attendees who are representatives of local agencies and organizations from those communities, co-ownership of those data bases.
- The EAES. CuSAG will also make presentations at the Conference/Workshop on its evaluation programs, with the workshop focusing primarily on its formative evaluation program related to the development of a project design/logic model that will enhance the success of project implementation/process evaluation and monitoring, and outcome and impact evaluation.

The Importance of Involving UMD's New School of Public Health in the UC-HON

- › The plans for developing the UC-HON is way overly ambitious and probably unrealistic for such a small unfunded research unit (CuSAG) in a small Anthropology Department as we have at the University of Maryland.
- › Thus it is for this reason that one of our goals this summer is to build on my relationships with a number of programs in the University of Maryland's relatively new School of Public Health (established in 2006).
- › While the SPH does not consider everything that it does as being CBPR, the community action initiatives that it has put in place during its 4 years of existence is in the spirit of CBPR, and is quite impressive.

UMD's School of Public Health Community Action Initiatives

- › The City of Seat Pleasant (MD)-UMD Health Partnership (Now in its 10th year).
- › The CDC-funded UMD Prevention Research Center.
- › A New *Center for Health Equity*.
- › The *Madieu Williams' Center for Global Health Initiatives* (Prince Georges County and Sierra Leone, West Africa).
- › A new American Cancer Society's \$1.8M funded project to "Encourage Cancer Awareness through Churches."

UMD's School of Public Health Community Action Initiatives (Cont.)

- › The Herschel S. Horowitz Center for Health Literacy.
- › The *Cultural Competency in Health Care Initiative*.
- › A new Health Care Reform Initiative to Fight HIV/AIDS in Prince George's County.

My Involvement with UMD's Community Action Initiatives

- › Affiliate Professor with the Department of Public and Community Health.
- › 3 years served (2004-2007) as a member of the Seat Pleasant-UMD Health Partnership's Board.
- › Presently a member of the Schools Prevention Research Center's Faculty Advisory Committee.
- › A Co-Investigator on its Encourage Cancer Awareness through Churches Project.
- › As we move forward with hope for further collaboration, from Anthropology, to become more involved with the activities of three of the Schools other Centers: the Centers for Health Literacy, Cultural Competency in Health Care, and Global Health Initiatives.

Excited About Possibility of Working with Center for Health Equity

- › Recently UMD's School of Public Health successfully recruited Dr. Stephen Thomas, and his entire team (Dr. Sandra Quinn, Dr. James Butler, Dr. Craig Fryer, and Dr. Mary Garza) from Univ. of Pittsburgh to the new Center for Health Equity.
- › I have known Drs. Thomas and Quinn, and followed their work for more than twenty years, and know their approach to community health to be similar to my own.
- › Thus I am very optimistic over the possibility of our future collaboration, and that my goals for the UC-HON as a CBPR model, and our shared goals of contributing to the reduction of health disparities (with HCR as impetus) will be achieved.

Conclusions

- › This presentation is not a long info-commercial for the work going on at UMD and CuSAG.
- › I use this as an opportunity to share my optimism about our work, about Health Care Reform, and about what I would like to contribute to the efforts to reduce health disparities.
- › Perhaps by sharing my goals for the UC-HON the DC area, it might give those of you who live and work in other locations, some ideas about how you might approach university-community partnerships in addressing health disparities in your area.