

# Ending Racial and Ethnic Disparities in Health Outcomes: From Community-Based Research to Community Action

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### Introduction

Americans increasingly distrust their physicians and the healthcare system in general.<sup>1</sup> Recent attention to medical errors<sup>2</sup> and overall quality issues<sup>3</sup> in health care through the publication of reports by the Institute of Medicine and scores of other researchers has provided solid research evidence to support this growing mistrust. In addition, data on variations in treatment decisions<sup>4</sup> remind us how little of medical practice is solidly evidence-based. Increasingly aggressive treatment goals for hypertension<sup>5</sup> and cholesterol<sup>6</sup> suggest that increasing numbers of formerly “healthy” adults now must face the possibility of a life of medication. The debate over managed care has put the financial side of medical practice firmly in the face of the American public. Finally, for people of color a multitude of reports on racial and ethnic disparities in health outcomes adds further concern about the quality of the health care they receive.

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<sup>1</sup> Armstrong K, Rose A, Peters N, et al. Distrust of the health care system and self-reported health in the United States. *J Gen Intern Med.* 2006;21(4):292-7.

<sup>2</sup> Kohn LT, Corrigan JM, Donaldson MS. *To Err is Human: Building a Safer Health System.* Committee on Quality of Health Care in American, Institute of Medicine. National Academies Press. Washington, DC. 2000.

<sup>3</sup> Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century. Committee on Quality of Health Care in America. Institute of Medicine. National Academies Press. Washington, D.C. 2000; McGlynn EA, Asch SM, Adams J, et al. The Quality of Health Care Delivered to Adults in the United States. *N Eng J Med.* 2003;348:2635-2645.

<sup>4</sup> Wennberg, JE, Fisher ES, Baker L, Sharp SM, Bronner KK. Evaluating the Efficiency of California Providers in Caring for Patients with Chronic Illness. *Health Affairs.* 2005 Nov16 [Epub]:W526-W543; Weinstein JN, Bronner KK, Shower Morgan T, Wennberg JE. Trends: Trends and Geographic Variation in Manor Surgery for Degenerative Diseases of the Hip, Knee, and Spine. *Health Affairs.* 2004 Aug 4 [Epub];VAR81-9.

<sup>5</sup> The Seventh Report of the Joint National Committee on the Prevention, Detection, Evaluation and Treatment of High Blood Pressure. U.S. Department of Health and Human Services, National Heart, Lung, and Blood Institute, National High Blood Pressure Education Program. December 2003. NIH Publication No. 03-5233. <http://www.nhlbi.nih.gov/guidelines/hypertension/jcintro.htm>. Accessed June 28, 2006.

<sup>6</sup> Grundy SM, Cleeman JI, Bairey CN, et al. Implications of Recent Clinical Trials for the National Cholesterol Education Program Adult Treatment Panel III Guidelines. *Circulation.* 2004;44(3)720-32.

This presentation focuses on the efforts of Bronx REACH, a long-term research and community intervention program to engage a community of 280,000 people in the Southwest Bronx in defining the root causes of health disparities in their community and in partnering with community organizations to actualize changes in law and regulation needed to address the outcomes of this research. It is this engagement and the facilitation of positive, tangible actions that build trust in the research process. The community might rightfully ask – and does “What benefit is it for us to research yet another example of disparities in health outcomes for people of color? Enough is known already. We need to understand why these disparities happen and work to change them.”

### **The Institute for Urban Family Health and the Bronx Health REACH Coalition**

The Institute for Urban Family Health is a non-profit provider of community health services, health professional education and health services research. Even after 20 years of developing 23 community health access sites in the Bronx and Manhattan (13 community health centers and 10 homeless health care outreach sites), the Institute’s work has not resulted in an elimination of the disparities in health outcomes between the communities we serve and the more affluent communities elsewhere in the Bronx and Manhattan. Serious racial, ethnic and insurance coverage disparities remain and are associated with significant reductions in health outcomes. With a grant from the Centers for Disease Control and Prevention (CDC) Bronx REACH established a consortium of health agencies, community organizations and faith organizations to address this issue.

### **The Bronx REACH Consortium**

The CDC Reach 2010 initiative required that any prospective grantee be already engaged with a community organization or coalition of organizations. A requirement of funding was being able to demonstrate a historical connection to the community. Though many grants require plans for involving the community, this CDC program clearly went a step beyond in requiring proof of an existing collaboration.

We have learned through Bronx REACH that relationships between researchers and the community cannot be simply project based. Trust develops through an ongoing partnership with the community and community partnerships cannot be produced on demand like hiring a statistician to help with data or engaging a laboratory to run sophisticated tests on blood samples.

The Bronx REACH coalition built on work that the Institute had done for the prior 15 years in building health centers and homeless healthcare sites in the community. The Institute’s model of development as an organization of health care professionals was to partner with established community based organizations for every center or grant program it developed. Thus, when the opportunity arose to apply for funding from CDC to engage the issue of health disparities, a solid foundation for this work has already been built.

### **The Research and Evaluation Program**

The CDC Reach 2010 Initiative required a sophisticated research and evaluation plan, reviewed by an approved Institutional Review Board (IRB). The CDC also required an

action plan to be developed after the first year of funding which would address the issues identified through the research. Bronx REACH was committed from the start to using community residents in every possible role from research activities to executing the interventions we established. Roles filled by community residents included a door-to-door community survey of diabetes care, a grocer survey of all the major supermarkets and storefront bodegas in four zip codes and the dissemination of a basic course on diabetes to community residents. In each case coalition partners helped to identify suitable candidates for the work and assisted in overseeing the completion of the tasks assigned. All residents engaged in this work were paid through program funds.

In addition to hiring community residents, approximately one-third of all program funding was subcontracted out to community-based organizations to engage in research and program evaluations as well as manage one or more interventions. Such subcontracts included an after school nutrition program (the MARC After School Program), a fitness program (through the Women's Housing and Economic Development Program), the community advocates program (through the Highbridge Community Life Center and the Mt. Hope Housing Corporation), a faith-based initiative (coordinated by pastors from the cosmopolitan Church of the Lord Jesus, the Walker Memorial Baptist Church and Church Alive) and an educational program for seniors (through Neighborhood Self-Help for Older Persons Project – SHOPP).

Bronx REACH was assisted from the beginning in developing its research and evaluation program by the Center for Health and Public Service Research (CHPSR) at New York University. CHPSR assisted in the development of logic-models, provided oversight for the focus group leaders and organized the analysis of focus group findings. CHPSR also organized the community survey of diabetes care, the grocer survey and many other aspects of the program evaluation. Approximately 20% of all program funds were applied to this subcontract.

### **Literature Review and Focus Groups**

Bronx REACH started by performing an extensive literature review on health disparities, especially with regard to diabetes and cardiovascular disease, the focus of our funding. The literature revealed that in almost all studies on racial disparities in health whites consistently do better in health outcomes than people of color. Little of this information had appeared in the lay press or in television or radio news broadcasts. Whatever was known about health disparities remained largely in the domain of the health care community.

The Bronx REACH consortium presented the results of individual research findings to focus groups comprised of community residents of color and asked them to interpret the results in the context of their personal and family life experiences. Ten videotaped focus groups were conducted with community residents. Eight were conducted in English and two in Spanish. The focus groups were facilitated by two members of the community who were trained by experts for this study.

The groups were asked to help us (health care providers and researchers) understand from the vantage point of their personal and family health care experiences, why they thought

these disparities existed and how the healthcare system actually produced worse care for people of color than for whites. We asked them to comment on the actual research results of selected studies that we had translated into plain language at a simplified reading level.

### **Focus Group Findings**

Focus group recordings or transcripts can be analyzed in a variety of ways. Here again we chose to use the leaders of our coalition organizations to assist in the analysis of the focus group video tapes to identify the dominant themes. Turning to community leaders for this assured us that the statements made by focus group participants were being properly understood.

A number of issues were identified as important through the focus group process, however, one major theme emerged as the most important identified factor in understanding health disparities. That theme was *trust*. Distrust in the health care system was a nearly universal experience for people of color in the Bronx.

The Consortium partners asserted that the legacy of Tuskegee is lived everyday in New York City and that racial and economic prejudices combine to impede access to quality health care for people of color in New York City. While only some of the community residents knew about the Tuskegee study none failed to produce a personal story where they believed they or their family failed to be availed of the best the New York City health care system had to offer.

### **Mistrust as a Causative Factor for Health Disparity**

Many themes related to *trust* emerged from the focus groups. REACH coalition members often use these issues to illustrate the inequities in health care that exist:

- payments to providers for Medicare for the elderly and chronically ill are substantially higher than for Medicaid, which primarily covers the poor indicating lesser concern of government for the quality of health care for the poor;
- academic medical centers that operate faculty practices and clinics side-by-side in the same facilities and sort patients by insurance are engage in discriminatory practices;
- people of color in New York City are 2 ½ times more likely to be uninsured or publicly insured than whites;
- the life expectancy of African-American males in the US is a mere 66 years, yet they pay into the Medicare Trust Fund with every pay check they earn and they benefit, if at all, for 8 years less than their white counterparts
- municipal hospitals in New York City are often located side-by-side with private hospitals and patients are sorted by insurance (and thus by race) into public facilities;
- language barriers still exist in spite of legislation requiring the availability of translation services – especially for the Latino and Asian-American immigrants and a large new influx of African immigrants into the Bronx.

### **From Study to Action**

As issues related to the causes of health disparities started to become clarified through dozens of coalition meetings and a growing coalition membership, Bronx REACH engaged community partners in defining an approach to addressing health disparities. A 7- point regulatory/legislative agenda was developed and is currently being promoted to address a range of issues. This agenda supplements the ongoing educational interventions taking place daily through program staff. The 7-point plan includes advocating for:

- universal health insurance
- an end to the segregation that still exists in health care facilities more than 40 years after the Civil Rights Act
- making cultural competence training mandatory for health professionals and the enforcement of mandates for translation in health facilities and offices
- accountability for bad debt and charity care funds paid to hospitals
- increasing diversity in New York's health professions schools
- increasing resources for public health education through community organizations and social marketing, and
- an end to the environmental racism that continues to pollute our poorest communities and those already burdened by poor health.

A true partnership has developed between community residents, their political and faith-based leaders and the Institute's program leadership to effectuate the changes needed in the healthcare system. Two major events –attracting upwards of 500 people have taken place in the community, educating residents about diabetes, heart disease as well as actions they can take to improve their chances of getting good health care if they are ill. In March of 2004, eleven busloads of community residents and a dozen REACH staff demonstrated on the steps of the State Capitol and then had 92 meetings with New York State Assemblypersons and Senators concerning the REACH legislative and regulatory agenda. Support for the event was raised by coalition members and REACH staff took time off from work to engage in this natural progression of their activities to address health disparities in the Bronx.

### **Summary and Implications for the NIH**

**1.** Government must address the many issues which create and sustain disparities in health care and health outcomes for people of color. If people do not trust that they have access to the same excellent care that their white, insured counterparts have, they will not trust these same people to come into their communities and engage in research there.

**2.** Community-based research must be built on pre-existing, sustained relationships between academicians and community organizations. These relationships must not only include exposure of academicians to community leaders but their willingness to engage with community residents in educational activities as well. Researchers must

spend time educating the communities they work with so the communities understand the importance of the research they are doing and how it may affect them.

3. Trust can be enhanced by an early commitment to training community residents as research assistants, surveyors, data entry workers and lay educators.
4. Evaluation and discussion of early research findings should be shared freely with the community
5. Funding for projects must be long-term and secure assuming adequate progress is made. Projects that come and go in a year or two will always be seen as opportunistic.
6. Researchers should be required to demonstrate a long-range commitment and strategy for helping the community address any issues which are revealed through the research.
7. A very sharp look must be taken at the concepts of non-coercive agreements to participate in clinical trials. Uninsured patients often use clinical trials as a way to obtain medical care that they could not otherwise afford. An offer for community residents to participate in such a trial as a condition for obtaining treatment is commonplace in the research community and breeds mistrust in the research enterprise and the entire medical care system.
8. Demonstration programs for community based research should be considered where community based coalitions apply for research funding and serve as the grantee and contractor with a required linkage back to the research department of an academic institution. In this model, the community would take the lead and the researchers would support inquiries that the community finds important.

### **Summary**

Building trust in the research enterprise requires building trust in the health care system. While this is evolving, NIH can move in a positive direction by (1) engaging communities in the interpretation of and defining the actions around research, (2) linking academics, health services researchers and health care delivery professionals with communities and (3) developing lasting partnerships with the community by committing to work together with communities to address specific problems with health care that are revealed through research.

NIH must move from funding research within communities to fostering lasting and trusted partnerships with the community. This should be accomplished through a commitment that researchers will not only do research on the community's problem and with the community's help, but will maintain a relationship with the community over time to help correct the problems that have been identified.