## From the Field

# Making Health Equality A Reality: The Bronx Takes Action

A coalition of health professionals and community and faith-based organizations uses its knowledge to drive change.

### by Neil Calman

**ABSTRACT:** In response to growing evidence of racial and ethnic disparities in health, Bronx Health REACH, a coalition of health care providers and community and faith-based organizations, is engaged in an effort to identify and eliminate the root causes of health disparities in their Bronx neighborhood. The group has gained a community perspective on health disparities that it has developed into a seven-point advocacy agenda: universal health insurance, an end to segregation in health facilities based on insurance status, accountability for state uncompensated care funds, culturally competent care for all, greater health workforce diversity, an expansion of public health education, and environmental justice.

'n the southwest bronx, where I practice family medicine, women are Ltwenty times more likely to die from diabetes than women living on the Upper East Side of Manhattan, two subway stops away. Neighborhood residents are twice as likely as nonresidents to have diabetes or hypertension and to die of heart disease. Although there are fewer new HIV diagnoses per capita in this neighborhood than in the Chelsea and Clinton neighborhoods in Manhattan, the mortality rate from HIV/AIDS in the South Bronx is almost twice as high. Examples of inferior health status in the Southwest Bronx are too numerous to list here, although one demographic statistic is particularly relevant: This community is more than 95 percent black and Hispanic, and poor.

My patients are not surprised by these horrifying statistics. With rare exception, they are able to relate one example after another of their lack of access to the care they need and deserve. I am not surprised, either, as I try to obtain the diagnostic tests, specialty consultations, and medications they need. Being poor or a person of color or uninsured—or worse, a combination of these—dooms my patients to sicker lives, unnecessary disability from chronic illness, and premature death.

Disparities between the health status of U.S. racial and ethnic minorities and that of non-Hispanic whites are widespread. The racial disparities that have been documented nationwide (and which are recounted in the papers in this volume) are all too apparent here in the South Bronx. In the words of Joe Albert Bush, pastor of the Walker Memorial Baptist Church, "Racism is alive in America. It's alive in education. It's alive in housing. It's alive in health care."

Although the determinants of health disparities are complex and varied, we do not need to unravel every last piece of this puzzle to begin to take action. The research commu-

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nity, health officials, and policymakers must begin to act now to pass legislation and regulations to address what is already known. In the Bronx, we also have begun to take action on what we know.

#### **REACH's Bronx Beginnings**

A coalition of community partners, Bronx Health REACH, has initiated both long-term community-based research and interventions to address the high rates of diabetes and cardiovascular disease in the South Bronx and the underlying factors in the community that lead to disparities in almost every other health outcome measure as well. Nearly forty community groups representing the 280,000 residents of four ZIP codes in the South Bronx, including social service agencies, health care providers, housing development corporations, an afterschool program, and faith-based institutions, have joined to address these health disparities. The coalition's efforts, which began in 2001, are supported by a multiyear grant from the Centers for Disease Control and Prevention's (CDC's) Racial and Ethnic Approaches to Community Health (REACH) Program, with additional support from the New York State Department of Health's Office of Minority Health and several local funders.

The guiding principle of Bronx Health REACH is to educate the community about health disparities and to engage in efforts that link community leaders and activists, legislators, and providers in addressing their root causes. Bronx Health REACH's initial task was to conduct an extensive literature review on health disparities, which revealed that in almost all studies, and particularly for diabetes and cardiovascular disease, whites had better health outcomes than people of color. The results of this research were presented to ten community focus groups in lay language (both English and Spanish). The focus groups were intended to provide the coalition with a basic understanding of the community's perspective on why these disparities exist. Community leaders were then asked to review transcripts and videotapes of the focus groups to ensure that the interpretation of the participants'

statements reflected both community and academic perspectives.

The main themes identified through the focus groups have informed the subsequent work of Bronx Health REACH. Focus-group participants consistently expressed feeling undervalued and disrespected in their encounters with the health care system:

Ghetto care means long waiting times—feeling like an abandoned dog.

Participants expressed strong opinions about what constitutes "good care," and it is not what most of them felt they routinely received. They complained bitterly about the lack of communication between their doctors and themselves:

I didn't feel like I was being told anything. I don't think any doctor should just give you some pills and not explain why you are taking them, or what they're supposed to do.

A major underlying theme that emerged from these discussions is a deep-seated and widespread distrust and fear of the health care system and an understanding of the racial prejudices involved in clinical decisions:

For a black man and a white man with the same symptoms, they send the black man home and put the white guy in the hospital for observation

The participants expressed the belief that self-advocacy is important to obtaining necessary, appropriate health care, but many found it difficult to carry out. Some did not understand how to advocate for the best care because they did not know what care they needed. Others stated that as people of color, advocating for themselves or family members often threatened white providers and ran the risk of getting them worse care than they might have received otherwise. People felt that they were under tremendous stress in their day-to-day lives, and they linked this directly to poor health and shorter lifespans.

Ironically, the public's growing exposure through the media to the vast body of research on health disparities reinforces minority communities' distrust of the health care system.

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Continuing research on disparities absent efforts to address the problems that are uncovered only furthers this distrust and impedes the development of functional provider patient relationships.

At a recent meeting of the National Institutes of Health (NIH) on Community Participatory Research, I argued that it is impossible for the public to differentiate between the clinical research enterprise and the larger health care system and that as long as academic medical centers (AMCs) provide limited access to the poor and uninsured, people of color will not trust those institutions to enroll them in clinical trials. I recommended that the NIH require institutions, as a condition for obtaining clinical research funding, to develop links to established community-based organizations and to involve community leaders in organizing participation in clinical trials. I suggested that both the NIH and its funded researchers act as resources for community health education and commit themselves to assisting communities in implementing solutions to problems identified through their research.

#### The Agenda

Establishing trust through collaboration and coalition building is essential to the continuing success of research and the development of strategies to address disparities. In the case of Bronx Health REACH, for example, the community has been the driver of most program activities. The coalition first identified a variety of factors contributing to health disparities among residents, some of which are examined in this volume of Health Affairs. The coalition then sought to channel this raised awareness into the development of a sevenpoint regulatory and legislative agenda for change. This agenda has been presented to New York State health officials and legislators. Bronx Health REACH is actively advocating for the realization of this agenda.

■ Universal health insurance. Because people of color are less likely to have health insurance and, therefore, have less access to timely health care, Bronx Health REACH is

advocating for comprehensive, universal health insurance. A recent study of New York's State Children's Health Insurance Program (SCHIP) found that the proportion of children in the study group with unmet health needs decreased from 31 percent to 19 percent after enrollment in SCHIP, and several indicators of health care quality improved.<sup>3</sup> Programs such as SCHIP are important steps toward universal insurance. We must be vigilant in ensuring that the design and administration of these insurance programs maximizes the beneficial effect of improved access on the elimination of health disparities.<sup>4</sup>

Although no one questions the positive affects that Medicare and Medicaid have had on health care access, it is important to recognize that racial disparities in access to ambulatory care have resulted from these very programs. Medicare has a national methodology for establishing fees that has largely given the elderly excellent access to the nation's finest health care. Medicaid, for the poor, depends upon states to set rates—rates that are almost always far below the standards set by Medicare. In many states these rates are grossly inadequate for recipients to get access to health care in a private physician's office, and Medicaid enrollees are thus relegated to institutional care in clinic settings. In Manhattan, for example, Medicare pays two to four times the rate for a private physician outpatient visit than Medicaid does.5 Coverage alone, without a guarantee of adequate reimbursement for providers, does not ensure access.

In addition, there must be increased outreach and a simplified enrollment process for existing government health insurance programs so that all eligible people can participate. Long and complicated application forms, confusion about eligibility, and being made to answer personal questions are among the top reasons for not enrolling cited by Medicaideligible survey respondents.<sup>6</sup>

■ Nonsegregated health care. Universal health insurance will not end racial and ethnic disparities by itself. There is ample evidence that even when there are no differences in health insurance, income level, stage of illness,

and other confounding factors, people of color receive worse care.<sup>7</sup>

As our focus-group participants are painfully aware, separate systems of care exist for those who are uninsured or publicly insured and those who are privately insured. Maintaining separate facilities that provide differential care based on insurance coverage is a violation of New York State-mandated Medicaid, Child Health Plus, and Family Health Plan contracts and the Patient Bill of Rights, which the New York State Department of Health requires to be posted in every state-licensed health care facility and handed to every patient upon admission. Nonetheless, many AMCs still operate faculty practices and clinics side by side and sort patients by insurance. Since insurance status is so closely linked to race in New York, this creates a de facto sorting of patients by race as well.

To understand more about barriers to care, Bronx Health REACH conducted a survey of four specialty services of particular importance to people with diabetes at three hospitals that are key providers of specialty care in the South Bronx. At one of the three hospitals, surveyors were told that fee-for-service Medicaid was accepted at all of the hospital clinics but not at any of the four specialty faculty practices. At another hospital, this was the case for two of four specialty services. In these separate facilities, uninsured or publicly insured people were found to be far more likely to receive care from residents, whereas privately insured patients received care directly from attending physicians.8 In addition, all private faculty practices had evening and weekend office hours or telephone coverage for emergencies, or both, while at seven of eleven clinics surveyed, patients calling after office hours were referred to the emergency room by a telephone recording. In short, Department of Health regulations mandating equal care regardless of payer are being violated everywhere we looked.

There is no financial rationale for this discrimination in care. Inpatient payment rates for Medicaid-insured patients are now higher than most of the discounted rates hospitals ne-

gotiate with commercial insurers. For example, one of our affiliated hospital systems provided data from an internal report that showed an average adjusted revenue of \$14,127 per case for Medicare and Medicaid patients, compared with an average of \$8,922 for privately insured patients with a nearly identical case-mix intensity and length-of-stay.

With people of color more likely to be uninsured or publicly insured, policies that segregate care based on insurance result in racial and ethnic discrimination. Our coalition is demanding that compliance with existing government health plan contracts be enforced and that regulations established in the Patient Bill of Rights be enforced to ensure equal care for all patients.

State received \$847 million in 2003 in public funds to cover the costs of bad debt and charity care. Despite payments to single institutions of as much as \$60 million, hospitals receiving these funds are not required to inform underinsured or uninsured patients of the availability of charity care funds, lack mechanisms to apply funds to individual patient accounts or inform patients that the cost of their care has been covered by these funds, and do not have to demonstrate the provision of specific amounts of charity care to receive funds.

Because people of color are disproportionately underinsured and uninsured, they are more likely to incur large medical debt or, worse, put off needed visits to a health care provider. Bronx Health REACH seeks the creation of mechanisms that will bring greater accountability to the uncompensated care funds to ensure that these funds are used to provide care to those most in need, and that people in need can access these funds directly to support their care. Model legislation has been passed by the Nassau and Suffolk County legislatures requiring hospitals to inform patients of their ability to obtain charity care as a condition of doing business with those counties. Such legislation should be modeled at the state and national levels.

■ Culturally competent care. Commu-

nities also need access to high-quality care that is responsive to the cultural and linguistic diversity of their populations. Language barriers and cultural differences in approaches to health care have been identified as factors in health disparities.<sup>10</sup> The 2000 census identified nearly twelve million Americans as "linguistically isolated," all of whom need access to the health care system.11 In the Bronx, more than half of the population speaks a language other than English at home. For example, I recently had a patient with severe psoriasis, who spoke only Spanish. When I tried to enroll her in a clinical trial at a prestigious Manhattan medical center, I was told that the facility had neither consent forms in Spanish nor an interpreter available to obtain the patient's informed consent. With my intervention, she was eventually enrolled. However, once her condition improved, she was discharged from the trial and, because of inadequate insurance, was no longer able to obtain the treatment she needed from that institution. Such experiences reinforce the perception among people of color that the health care system is not designed to provide access to all people equally.

Language barriers have been described as "the low-hanging fruit" in strategies to address health disparities because of the potential for translation services to overcome this obstacle.<sup>12</sup> Bronx Health REACH advocates the enforcement of mandates requiring the availability of qualified translators.

Despite the important role that culture and language play in health education, clinical encounters, and overall health outcomes, most health professionals are not trained to address their patients' cultural and linguistic diversity. Compromised communication and its negative impact on the patient-provider relationship affect diagnoses, treatment compliance, and, ultimately, health outcomes. Cultural competence training should be made mandatory for health professionals, but it must be noted that cultural competence cannot be taught in institutions that are not themselves culturally competent. When health care institutions teach cultural competence in the classroom and then send students and residents to train on so-called teaching patients—uninsured and Medicaid-insured patients—in their clinics, they undermine their own efforts by effectively teaching that private-pay patients "deserve" better care.

■ More diversity in the health care workforce. Studies have found that patients are more satisfied with their care when there is racial and ethnic concordance between patients and physicians.13 The persistent underrepresentation of racial and ethnic minorities in the health professions minimizes opportunities for concordant encounters in an increasingly diverse population. The most recent data show that underrepresented minorities, including blacks, American Indians, Alaskan and Hawaiian natives, Mexican Americans/Chicanos, and Puerto Ricans, represent just 11 percent of medical graduates. 14 This compares to a U.S. population that contains more than 25 percent underrepresented minorities, with several of these groups expected to double as a proportion of the population over the next several decades.15

The failure of high-profile efforts by the Association of American Medical Colleges (AAMC) to increase the number of minority medical school graduates nationwide to 3,000 by the year 2000 makes it clear that new strategies are required.16 Federal and state governments have largely ignored the potential of their influence over medical schools through public funding and the accreditation process. Medical schools, especially those in large urban areas, are often "academic islands," with minimal community connections and little or no stated commitment to promoting medical careers and admit students from the neighborhoods in which they sit. Stronger pipeline programs are needed in places like New York City, which houses six medical schools and dozens of other health professions education programs. These pipeline programs must start with helping primary and secondary school students, as more than half of New York City's African American and Hispanic students do not graduate from high school.17

The "community benefits principle"—that the large amount of public funds provided to

medical schools entitles the community to certain public benefits—is an approach that should be considered.<sup>18</sup> Health professions schools and health care institutions must make commitments to diversity and cultural competence to change the status quo and must implement specific strategies, such as more flexible education pathways and pipeline programs, increased financial aid to minority students, and the adoption of more comprehensive admissions policies that do not place excessive weight on standardized tests.<sup>19</sup>

Also, the lack of racial and ethnic diversity among the leadership of health care institutions, medical schools, and public health departments can contribute to programs and policies that are ill suited to meeting the needs of minority populations, and these must also be addressed. Bronx Health REACH is seeking support for programs that recruit minorities into the health professions and encourage the recruitment of institutional leadership from underrepresented minority groups.

■ Increased public health education. Health education can make important contributions to preventing and treating disease, yet it is greatly underfunded. Public health education has resulted in widespread changes of behavior in areas such as drunken driving, seatbelt use, improved nutrition, and reduced smoking and can be credited with saving millions of lives. Campaigns that have involved the entertainment media have been extremely effective at reaching large audiences. For example, after the Designated Driver Campaign included this concept in popular television shows, nine in ten U.S. adults and nearly all young adults were aware of the designated driver concept and rated it favorably.<sup>21</sup>

Current education efforts to raise awareness of factors that contribute to health conditions for which some of the largest health disparities exist, such as heart disease and diabetes, must compete for attention with pervasive advertising for fast foods that are high in fat and sugar content. The U.S. Department of Agriculture's \$333 million budget for nutrition education, evaluation, and demonstrations is dwarfed by the corporate power and advertis-

ing budgets of fast-food chains; five of the top U.S. fast-food chains alone had combined advertising budgets of nearly \$1.5 billion in 2001.<sup>22</sup>

Direct-to-consumer pharmaceutical advertising promotes medications to treat conditions that might have been amenable to prevention through more effective public health education. One participant in our focus groups noted that he had seen advertisements for drugs related to diabetes but didn't pay attention because he was unaware of the symptoms of diabetes and did not know that he had it until he was diagnosed.

For health education to work, it must be culturally relevant, easily understood, and widely disseminated. Increased public funding must be made available for the development of effective public health education programs through mass media at a level that can compete with the unhealthy advertising to which the public is exposed. For example, I am confident that a recent full-page advertisement in the New York Times pointing out one hospital's poor record on treating Hispanic patients raised more awareness of disparities in health care than the unresolved complaint I filed more than two years ago with the Office of Civil Rights in the U.S. Department of Health and Human Services on behalf of a Hispanic patient of mine who received discriminatory treatment at that same hospital.

■ Environmental justice. Where residential segregation of minority communities persists, the physical and socioeconomic environment can also contribute to health disparities.<sup>23</sup> The South Bronx bears a disproportionate environmental burden that exacts a heavy toll on residents. This community houses eighteen waste transfer stations and other waste facilities, a New York City Department of Environmental Protection sewage treatment plant processing all of the Bronx's sewage (some of which is discharged into local waters), and the New York Organic Fertilizer Company, which processes at least half of New York City's "treated" sludge.24 There are scores of brownfields, and more than 403,000 vehicles, including tens of thousands of trucks, use local highways daily. The South Bronx has the third highest asthma rate in New York City, with Hunts Point children suffering twelve times the national average. The lowest birthweights in the country are also found in the South Bronx.<sup>25</sup>

Bronx Health REACH is promoting the increased recognition of the impact of environmental stressors on minority communities through the documentation of adverse health effects from pollutants, such as the health tracking system proposed by the Pew Environmental Health Commission. <sup>26</sup> The coalition seeks to raise awareness of environmental issues and to mobilize the community to take action against further neighborhood development that would adversely affect health. The government must enact community health impact laws that end the disproportionate burden that environmental factors place on the health of minority communities.

#### **REACH's Advocacy Efforts**

Advocacy efforts for these agenda items have been enlivened by widespread community participation. In March 2004 eleven busloads of residents of the South Bronx and Bronx Health REACH staff demonstrated on the steps of the New York State Capitol and held ninety-two meetings with members of the State Assembly and Senate concerning its legislative and regulatory agenda. The coalition hopes that omnibus health disparities legislation to be introduced in the New York State legislature's 2005 session will greatly advance progress toward the coalition's goals.

Community-based programs in at least twenty other states receive CDC REACH funding to address health disparities. In addition, a growing number of other state and local coalitions are focusing on disparities, with some able to demonstrate specific health-related achievements.<sup>27</sup> As evidenced by the array of topics discussed in this volume, disparities in health care and health outcomes are complex, but Bronx Health REACH is not alone in acting on its belief that they can be overcome.

In our bronx Health REACH brochure, Martin Luther King Jr. is quoted as saying, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane." With an ever-expanding body of evidence that racial and ethnic health disparities are pervasive in our health care system, the nation and its richly varied communities must now chart a course for addressing this grievous inequity.

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