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A Community Mobilizes to End Medical Apartheid

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Abstract

Problem: People of color suffer worse health outcomes than their White counterparts due, in part, to limited access to high-quality specialty care.

Purpose: This article describes the events that led to the Bronx Health REACH coalition's decision to file a civil rights complaint with the New York State Office of the Attorney General alleging that three academic medical centers in New York City discriminated on the basis of payer status and race in violation of Title VI of the Civil Rights Act of 1964, the Hill-Burton Act, New York State regulations, and New York City Human Rights Law.

Key Points: Although the problem has not yet been resolved, the related community mobilization efforts have raised public

awareness about the impact of disparate care, strengthened the coalition's commitment to achieve health equality, and garnered support among many city and state legislators.

Conclusion: Community groups and professionals with relevant expertise can tackle complex systemic problems, but they must be prepared for a long and difficult fight.

Keywords

Community empowerment, community partnerships, community engagement, community organizing, health equality, health equity, health disparity, health policy, racial disparities, civil rights

On virtually every health indicator measured in the United States, people of color suffer worse health outcomes than their White counterparts.¹ Much has been written to explain why this is so,² yet very little of this literature focuses on the institutional policies and practices that contribute to and exacerbate racial disparities in health care. In New York City, academic medical centers offer two standards of care—a clinic system for the publicly insured and uninsured, and a faculty practice system for those with private insurance.³ Given that Blacks and Latinos in New York are more than twice as likely as whites to be publicly insured or uninsured,⁴ it is people of color who are most often found in the clinics, whereas Whites are more likely to receive care from private physicians in the hospitals' faculty practices.

The Bronx Health REACH Coalition has highlighted this problem since 2002, through public meetings, symposia, articles, press conferences, meetings with hospital leaders, state officials, and legislators, and finally, a formal civil rights complaint filed with the New York State Office of the Attorney General, which resulted in no remedial action. With few exceptions, the problem of segregated systems of care remains largely unchanged, so the coalition is now working to introduce legislation in New York State to address this disparity.

This paper examines two important processes: The evolution of our community's commitment to achieve equal access to health care, and the development of statewide policy designed to eliminate disparities. We describe the actions we have taken to date, what we have learned, and where we

will go from here, discussing the impact of unequal care and highlighting the strong collaboration of multiple segments of our community—including faith leaders, community based organizations, health care providers, and public interest lawyers—to resolve a persistent barrier to providing equal care for all.

BACKGROUND

Bronx Health REACH began in 1999, targeting a four Zip code area in the southwest Bronx—located in the poorest urban congressional district in the country,⁵ ranking 62nd out of 62 counties in New York state in health outcomes.⁶ The population includes roughly 275,000 individuals made up primarily of African Americans, Caribbean Americans, and Latinos. From the outset, the coalition employed a community-based participatory research approach based on shared decision making.

We were also committed to working with both the African American and Latino communities, something we later learned was markedly different from comparable REACH efforts that tended to be more homogeneous in their racial and ethnic composition. And in contrast with many similar efforts, there was a nearly 10-year history of collaboration between the Institute for Family Health, the lead organization, and the community partners, which had resulted in the construction of three neighborhood health centers, and fostered the mutual respect the partners had for one another's experience and expertise.

By 2000, the Bronx Health REACH Coalition had 10 member organizations and an expressly articulated mission to “eliminate racial and ethnic disparities in health outcomes by creating a movement . . . to increase awareness of racial, ethnic, gender and other disparities in how health care is delivered . . . and serve as a national model of community empowerment.”

Over the years, our coalition has grown to over 70 organizations, and sponsors a wide range of health promotion activities focused on nutrition and fitness education, as well as efforts geared toward diabetes prevention and management. We also offer workshops designed to help community members understand the health care system and the impact of disparities in access and treatment. Our efforts are based on a socio-ecological model, focusing on individual, organizational, and community change, often emphasizing policy changes.

Perhaps the coalition's greatest policy success was our role in the community advocacy that led to the substitution of low-fat milk for whole milk throughout the entire New York City Public School System.⁷⁻⁹

MEDICAL APARTHEID

The greatest challenge to the coalition, by far, has been realizing its goal of eliminating discrimination in the health care system in New York. As community members frequently state, REACH has taught them so much about caring for themselves and their communities, but when they get very sick, they still require specialty care. How can they ensure that they will get the best care available? It was clear that the racial and ethnic disparities in health outcomes that we were witnessing would not be eliminated until the health care system became more equitable in its treatment of people of color. In short, the group recognized that a system based on inequalities in treatment is certain to produce inequalities in outcomes.

Our efforts to address these systemic concerns began with a Call to Action, held at the Walker Memorial Baptist Church in the Bronx, in 2001 (Table 1). Nearly 700 community members filled the ample sanctuary, with clergy from approximately 14 local churches in attendance. The audience heard story after story of how the health care system failed to serve its community and the consequences that were suffered as a result. Two senior clergy members, both coalition leaders, urged the crowd to make a long term commitment to the struggle for equal rights in health care, calling it “the next step in the civil rights movement.”

To better understand this issue, in 2003, the coalition sponsored a Health Care and Civil Rights Symposium at the New York Academy of Medicine attended by coalition members, health care providers, pastors, and civil rights and public health attorneys. The lawyers in the group provided us with the history of the legal system's failure to address equal access to care. Participants agreed that the legal system alone could not win this battle, and that the community coalition was our strongest asset. We were urged to continue educating the community and to use its power to press for change, and we were warned to prepare for a long haul.

Convinced that our elected officials needed to be brought on board, the coalition brought 500 Bronx residents to Albany

in March 2004 to educate legislators about our Statewide Advocacy Agenda to address disparities in health, which we called Inequality by Design.¹⁰ We visited 92 legislators to explain the agenda, which included an end to segregated care, a more diverse health care workforce, insurance coverage for all, culturally competent care, public health education, greater accountability for the use of uncompensated care funds, and an end to environmental racism.

Subsequently, the coalition decided to focus on the issue we thought most glaring, and the one least likely to get addressed by any other organization—the two-tiered system of care in the city’s academic medical centers resulting in unequal treatment. To test our assumptions, we performed the first of two telephone surveys, calling hospitals and asking to be referred to a specialist about a particular condition. In

virtually every call, the first question that the caller was asked was about insurance status. We found that where the caller was referred was directly related to their response regarding insurance. People who received Medicaid or who were uninsured were almost always sent to outpatient clinics, whereas those with private insurance were steered to the faculty practices. In New York City, where Blacks and Latinos are more than twice as likely as Whites to be publicly insured or uninsured, separating patients based on insurance effectively segregates based on race.⁴ Segregation of care is not unique to New York City. The literature has repeatedly documented that resident physicians see a disproportionate number of patients from racial and ethnic minorities groups, and a disproportionate number of patients with either public or no insurance.^{11–13}

Although the New York State Department of Health

Table 1. Bronx Health REACH Health Equality Advocacy Timeline

Year	Action Step
1999	Bronx Health REACH Coalition established.
2000	Out of the Shadows ²⁹ is published, an essay by the Institute for Family Health’s president binging attention to the impact of health disparities on patients and providers.
2001	Community Call to Action attended by 700 community residents, leaders, elected officials, and health care providers.
2003	Civil Rights Symposia to discuss the elimination of separate and unequal systems of care.
2004	500 Bronx residents go to Albany to speak to legislators about the need to eliminate health disparities.
2004	Conducted first specialty care survey of NYC private teaching hospitals.
2005	Separate and Unequal: Medical Apartheid in NYC ²¹ is published.
2008	Conducted second specialty care survey of NYC private teaching hospitals. Civil rights complaint filed with the NYC Attorney General’s office against three NYC private teaching hospitals. Over 150 coalition members and supporters attend press conference.
2009	CNN’s AC 360 with Dr. Sanjay Gupta features the complaint filed with the NYS Attorney General. Health disparities workshops series developed to increase knowledge on the impact of the two-tiered system of care. A Health Disparity Workgroup is formed to spread the word about disparities through public information sessions and conversations.
2010	Bronx Health REACH leaders participate on a health disparities panel at the Black, Puerto Rican, Hispanic and Asian Caucus Weekend in Albany. Over 140 people attend Make Health Equality a Reality, a Bronx Health REACH community town hall meeting. Health Disparity Workgroup visits to elected officials. Legislation to eliminate practice of discrimination based on health insurance is introduced in the NYS Assembly (A10988) and Senate (S7807). City council member drafts resolution to support state legislation.
2011	Coalition identifies new Assembly member and seeks new Senator to sponsor re-introduction of legislation.

maintains guidelines for medical residents as specialty care providers¹⁴ explicitly requiring continuity of care, availability for emergency consultations during nonclinic hours, and the creation and timely transmission of consultation reports, we found that these practices are not employed in the outpatient clinics.

Studies indicate that the use of residents in primary care does not negatively affect care,^{11,12} but we found no documentation regarding residents' roles in outpatient specialty care settings. However, there is substantial documentation linking continuity of care to increased preventive care,^{15,16} earlier identification of chronic illness,¹⁷ reduced hospitalization,^{18,19} and greater patient satisfaction,²⁰ and we know that it is virtually impossible for specialty residents, who generally rotate monthly throughout their training, to provide such care.

The coalition's monograph, "Separate and Unequal, Medical Apartheid in NYC,"²¹ showed that many of the disparate health outcomes affecting communities of color are associated with institutional policies and practices that limited access to high-quality care for the publicly insured and uninsured (Table 2). It also demonstrated how the current system of segregation by insurance status results in de facto racial segregation.

The release of the monograph led to years of meetings with hospital officials, two consecutive Commissioners of the New York State Department of Health, and the health care and civil rights divisions of the New York State Office of the Attorney General. No one denied that what we had written was true, but most claimed that an integrated model of care was not possible. Hospital representatives were particularly defensive,

citing business reasons why providing care in a single setting was not possible, adding that it would negatively impact their ability to attract top specialists and private patients.

The coalition retained a lawyer, who refuted each of the concerns that the hospitals raised about billing practices in the integrated settings, confirming our sense that this was certainly a legally resolvable issue, lacking only the will of the institutions to resolve it. The feasibility of a fully integrated care model was documented in a January 2006 letter to the State's Health Commissioner.^{22p.44-46} Nevertheless, two years later, there was no sign of change. Exposing the problem for key decision makers was clearly not enough. To achieve change, the system would have to be pressed.

DOCUMENTING THE PROBLEM

At the same time, the coalition was pursuing solutions with the hospitals and health department, one of the coalition members, a nonprofit civil rights legal organization, the New York Lawyers for the Public Interest (NYLPI), suggested working with state administrative agencies to compel them to enforce civil rights laws. In 2007, attorneys from the Civil Rights Bureau of the New York State Office of the Attorney General reached out to both Bronx Health REACH and NYLPI to discuss the issues presented in *Medical Apartheid*. We described the phone surveys we had conducted, and offered to document our findings. The AG staff encouraged us to think about filing a formal civil rights complaint with respect to specific institutions, which they could use to open an investigation and, we hoped, compel the hospitals to change their practices.

Table 2. Separate and Unequal Care ^a		
	Faculty Practice	Clinic
Who Gets Seen There	Privately insured patients	Uninsured and Medicaid patients
Providers	Board-certified physicians	Residents and fellows
Continuity of Care	Each patient has their own private doctor	Patients see doctors in training who rotate
Coordination of Care	Good written reports and communication	No reports; limited coordination and communication
Night/Weekend Coverage	Doctors are on call for their practice; have answering services	Patients told to go the emergency room; usually do not have doctor on call
Hospital Care	Doctors take care of their own patients	Another group of doctors or resident takes over who don't know the patient

^a Based on a chart that appeared in Calman N, Golub M, Ruddock C, Le L, Hauser D. Action Committee of Bronx Health REACH Coalition.³

In contemplation of submitting a complaint, we decided to repeat the phone survey—to document our belief that nothing had changed since our original survey. This time, we worked with researchers from New York University to develop a more refined survey tool and protocol. We conducted two telephone surveys. The first was about specialty services at five major hospitals located in the Bronx and northern Manhattan. Two hundred telephone calls were conducted and recorded over the course of 2 months, with eight different staff members and interns making calls, relying on a standard script to ask about the specialty services available for a relative. With each call, they altered the script to say that a relative had either fee-for-service Medicaid, Medicaid Managed Care, Medicare, no insurance, or a private insurance plan.

The other component was a semistructured telephone interview with hospital practice administrators at both faculty practices and clinics to compare the characteristics of the two systems. A Bronx Health REACH staff member called the hospital’s executive office stating they were an Institute for Family Health employee looking for information on specialty services to use for the purpose of making patient referrals. Questions included the type of insurance accepted in each setting, providers (board-certified faculty physicians vs. residents), days and hours of operation, referral services, and coordination of care.

In short, our findings confirmed our beliefs. Surveyors found that patients with private insurance were referred to faculty practices, where their insurance is accepted, whereas patients with Medicaid were referred to the hospital’s clinic system.

THE COMPLAINT

In June 2008, NYLPI filed a civil rights complaint with the New York State Office of the Attorney General on behalf of Bronx Health REACH alleging that three of the most prestigious academic medical centers in New York City discriminated on the basis of payer status and race (Table 3).²² The complaint was delivered with 72 organizational and 4,200 individual signatures. It was announced at a press conference held on the steps of the Bronx Borough Hall, attended by 150 community members on a day when the thermostat hit 105°.

The three hospitals named in the complaint were Montefiore Medical Center in the Bronx, and Mt. Sinai Medical Center and New York-Presbyterian Hospital in Manhattan. Although coalition members do not believe these to be the only hospitals where this type of segregation takes place, we chose these three because they were the places our coalition members used most frequently, and where our surveys showed the most profound discrimination.

The complaint documented two major concerns. First, it was alleged that the three hospitals we identified were discriminating against recipients of public health insurance programs like Medicaid, in violation of the federal Hill-Burton Act,²³ a law that was passed in 1946 and provided millions of dollars to hospitals across the country to modernize and upgrade their facilities. As a condition of receiving Hill-Burton funding, hospitals agreed to a perpetual obligation to treat patients with public insurance such as Medicaid without discrimination. Similarly, the New York State Patients’ Bill of Rights prohibits its hospitals licensed by the state from discriminating based

Table 3. Legal Framework for Attorney General Complaint

Laws or Regulations	Impact
Federal Title VI of the Civil Rights Act of 1964	No person shall be excluded from participation or be denied benefits in any program receiving Federal financial assistance on the grounds of race, color, or national origin.
Federal Hill-Burton Act	Medical facilities that received funding through the Hill-Burton program must take steps to ensure that the services of their facility are available to recipients of governmental programs such as Medicaid without discrimination because they are beneficiaries of such programs. Facilities also may not discriminate on the basis of race.
New York State Patient Bill of Rights	Prohibits hospitals licensed by the state from engaging in discrimination based on source of payment and race or national origin.
New York City Human Rights Law	Prohibits places of public accommodation from disparate impact discrimination—that is, conduct that may seem neutral as to race or national origin, but still disproportionately affects certain groups.

on “source of payment.”²⁴ All of the hospitals named in our complaint were recipients of Hill-Burton monies and licensed by the state, and, we argued, were not meeting their obligation to treat patients with Medicaid without discrimination.

In addition, the complaint alleged that the three hospitals were engaging in race discrimination in violation of the Civil Rights Act of 1964,²⁵ which prohibits recipients of federal financial assistance from engaging in any conduct that even unintentionally results in discrimination based on race or national origin. A similar local law, the New York City Human Rights Law, prohibits the same actions in places of “public accommodation.”²⁶ We argued that the hospitals named in our complaint were places of public accommodation that received billions of dollars in federal financial assistance, and that their practice of steering patients into separate and unequal care settings based on payer type disproportionately impacted people of color because of their overrepresentation among the publicly insured and uninsured.

In researching our claims, we learned that health systems in other parts of the country have struggled with these same issues. For example, a whistleblower lawsuit filed in Texas in August 2010 alleged that a “two-tier system of management” existed based on payer status within the University of Texas Southwestern Medical Center in Dallas, to the detriment of publicly insured and uninsured patients.²⁷ We also spoke to colleagues at highly respected institutions across the country and within particular departments at New York City medical centers where the leadership promoted integrated care delivery. As a senior administrator at a Seattle area hospital told us in an interview (July 2, 2010), “When you have the vision that you will eventually eliminate pediatric disease, it’s not about the economics or holding on to status or prestige; it’s about the care.” Conversations such as these convinced us that alternative models exist.

COMMUNITY MOBILIZATION

The filing of the complaint marked a critical step in the effort to mobilize public opinion and engage elected officials in the fight for health equality. The message was clear: Receiving equitable care at academic medical institutions is a legal right. However, many coalition members acknowledged that they did not always know when the care they received differed from what was available to others.

As a result, the coalition organized disparity workshops focused on increasing community members’ understanding of health disparities and the impact of the two-tiered system of care. Participants were trained to offer presentations at community forums, faith-based organizations, and legal, medical, and academic institutions. They also formed a Health Disparity Workgroup to continue this educational work on an ongoing basis and to develop organizing strategies to address the problem.

Over the following year, the coalition worked to keep the complaint in the public eye. In summer 2009, CNN aired a story about Bronx Health REACH and our complaint on *Anderson Cooper360*, a nightly news show. The piece featured a Bronx resident who saw doctor after doctor who failed to recognize that a serious infection in his finger and his extreme weight loss was caused by his undiagnosed diabetes. Medical reporter Sanjay Gupta used the story to highlight the issue of segregated care in New York City private academic medical centers. CNN reported that the attorney general’s office refused to provide any information about the status of the case. The hospitals’ spokesperson said it was unfair to blame hospitals for the gap in health outcome between Blacks and Whites, and pointed out that the outpatient clinics offer care for the poor “where it otherwise would not exist.”²⁸

In spring 2010, the coalition hosted a town hall meeting that was attended by more than 150 Bronx residents interested in learning more about discrimination in health services. Community members shared personal stories about their interactions with providers who brought biases and stereotypes into the examination room, as well as the systemic discrimination that they had experienced. Panelists presented different solutions to the issues, including the importance of training the next generation of health care providers to be more aware of disparities, and the need to develop legal and legislative solutions to achieve high-quality health care for all. All shared their frustration that the complaint had not resulted in further action from the attorney general’s office.

HEALTH EQUALITY LEGISLATION

In response to the lack of action by the attorney general, the coalition worked with a local state assemblyman and senator to introduce legislation—The Health Equality Bill—with a goal of making separate and unequal care a violation of public

health law. The legislation, which was introduced in the 2010 session, contains a key provision that requires academic medical centers to provide outpatient specialty care in an integrated setting staffed by both attending physicians and residents. These integrated practices are required to treat all patients, regardless of insurance type or source of payment. The bill's objective is to ensure that academic medical centers, which receive millions of dollars each year from the New York State Department of Health to care for the poor, use these funds for that purpose in a nondiscriminatory manner.

The bill also includes two other important provisions. The first states that the hospital must publicize its financial assistance policies on its website and its patient referral line so that patients who call to schedule an appointment know that insurance status is not a barrier to receiving care. The other provision requires hospitals to ensure that all medical providers employed by the hospitals are credentialed by local Medicaid managed care plans.

The bill was not considered in the 2010 session, and the coalition is currently working with several local legislators committed to re-introducing the bill in 2011. We have also received a commitment from city council members to introduce a resolution to support the state legislation when it is introduced.

In the coming months, the coalition plans to continue to train community members to lead disparity workshops and optimize our use of both traditional and social media to promote our concerns. We will continue meeting with legislators to co-sponsor and gain support for the health equity bill. We are asking legislators to contact the office of the new attorney general to inquire about the status of the complaint. Finally, we are exploring the question of whether a federal forum for addressing our concerns now exists in the new federal administration.

DISCUSSION

The goals of our 10-year campaign for health equality have been to educate the community about the impact of racial and ethnic health disparities, to engage the community in a movement to end health disparities, and to achieve policy changes in New York City that ensure equal access to care.

More than 70 organizations now belong to the coalition. Thousands of community members have learned to

describe health disparities and their impact on individual and community health. People from various sectors of the community—community based organizations, faith-based organizations, health care providers, advocates, lawyers, and policy makers—have developed a shared language and a shared vision for change. Residents have developed the skills and the confidence to navigate the health care system for themselves and their family members. And a 10-year movement has been born and sustained. The community has remained steadfast, determined, and focused on the goal of eliminating the separate and unequal specialty care system in academic medical centers in New York City.

Along the way, we have learned many things. First, although our complaint to the office of the attorney general has strong legal basis, the will to enforce the law is missing. The coalition must develop that will, through education, media, and partnering with strong allies. Systemic change requires an ongoing, multifaceted effort—one that reflects stakeholders from multiple perspectives with a shared goal. It is important to develop partners from many arenas, and to speak out with a clear message.

Second, health care is a charged issue involving very powerful institutions. Systemic change must balance many competing interests, including various forces that would prefer to maintain the status quo. Health care is particularly complex—involving long-standing traditions in graduate medical education and reimbursement systems, as well as state health care codes and regulations, and a deeply rooted socioeconomic dynamic that determines who benefits from the current system. To succeed in this venture, we must engage experts in both health care policy and the law to assist us.

Third, we realized that political leverage is necessary to change complex institutional behavior. We needed to understand the political processes that impact the work we are doing, and engage political allies in the fight for health equality to achieve lasting policy change.

Fourth, we must celebrate interim successes and critical milestones. This is a very long fight and events such as press conferences and rallies are important to mobilize, energize, and rededicate the group. Media attention can be particularly powerful in this regard; our coalition members felt emboldened by the national attention garnered through the CNN piece. The celebrity spotlight validated our work, and the tape

itself has been a valuable tool, spurring lively discussions at community meetings.

Fifth, we must continue to provide resources to this effort. We are grateful to the CDC and other funders who understand that community mobilization for health is a long-term process. It is critical to build coalitions that can sustain the work by integrating it into the mission of member organizations. Our group has remained together for longer than 10 years, and has lost very few members. Members who have moved away have started sister programs in their new communities. Longevity is an important key to systemic change.

Finally, we must remain true to our mission. Bronx Health REACH is fortunate to have a coalition of individuals who believe that health equality is truly the next step in civil rights. Our work represents a moral commitment that builds on per-

sonal histories—from the Civil Rights Movement to battles to restore blighted and neglected communities—and will proceed until we reach our goals.

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