



A Participatory Action Research Pilot Study of Urban Health Disparities Using Rapid Assessment Response and Evaluation

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Healthy People 2010 made it a priority to eliminate health disparities. We used a rapid assessment response and evaluation (RARE) to launch a program of participatory action research focused on health disparities in an urban, disadvantaged Black community serviced by a major south Florida health center.

We formed partnerships with community members, identified local health disparities, and guided interventions targeting health disparities. We describe the RARE structure used to triangulate data sources and guide intervention plans as well as findings and conclusions drawn from scientific literature and epidemiological, historic, planning, clinical, and ethnographic data.

Disenfranchisement and socioeconomic deprivation emerged as the principal determinants of local health disparities and the most appropriate targets for intervention. (*Am J Public Health*. 2008;98:28–38. doi:10.2105/AJPH.2006.091363)

HEALTHY PEOPLE 2010

established “eliminating health disparities”¹ as a public health priority, proposing that social

determinants such as poverty, violence, and poor housing may negatively affect health outcomes. Health gradients have been demonstrated for income,² education,³ and socioeconomic deprivation⁴; these, however, do not fully explain racial disparities.^{5–10} For hundreds of years, Blacks were systematically denied full citizenship rights in the United States.¹¹ Since the end of legalized segregation, they continue to be marginalized in our society,^{12–31} with unequal access to education,²² jobs,^{23–24} and housing^{25–26} and through myriad forms of racism.^{26–28}

Miami’s historically Black neighborhood of Overtown has one of the highest rates of poverty²⁹ and mortality from chronic disease in the county (G. Zhang, PhD, Miami–Dade County Health Department, written communication, 2006).²⁹ Miami’s early Black residents (mostly immigrants from the Bahamas and other parts of the West Indies, as well as parts of the southern United States) were restricted to living in “Colored Town,”^{30(p62)} later called “Overtown”^{30(p151)} because it was just “over” the

downtown district. During its prosperous heyday (1930s through the 1950s), visiting Black entertainers, not allowed to stay overnight in Miami Beach after their performances, stayed in Overtown. Overtown came to be known as “Little Broadway”^{30(p142)} and grew into a commercial, professional, and cultural center, home to physicians and other leaders of the Black community. In the mid-1960s, business and political leaders of the City of Miami routed the Interstate 95–395 intersection through the center of Overtown (M. Dluhy, P. Cattán, K. Revell, J. Strube, and S. Wong, unpublished report, 1998).^{30,31} Thousands of Overtown residents were evicted, leaving public housing and multifamily zoning where single-family dwellings had once existed.^{30,32}

Today, Overtown is an English-speaking, predominantly Black, distressed urban enclave surrounded by Hispanic communities and the downtown business and hospital districts, with contentious redevelopment and gentrification projects surrounding and rapidly encroaching into the community.³³

Two state senators sponsored legislation funding construction of 2 clinics in central Miami–Dade County—the Jefferson Reaves, Sr Health Center (JRSHC) and the Peñalver Clinic—“to bring affordable health care to their respective communities” (B. Loyd, administrator, JRSHC, written communication, April 10, 2007). A partnership between the Miami–Dade County Health Department, a state agency, and the county-operated Jackson Health System allowed the JRSHC to open in 1998 as a county-operated primary care center with the mission of serving Overtown.³⁴ A community clinic operated by the Family Medicine Department of the University of Miami Miller School of Medicine merged its staff into the JRSHC, which then became the primary training site for the Jackson Memorial Hospital family medicine residency program administered by the university.

Two JRSHC interventions targeted health disparities. Beginning in September 2004, a Health Resources and Services Administration (HRSA) Title VII³⁵ primary care training



grant funded a multifaceted research project to develop a curriculum for cultural competence (i.e., the ability to function effectively in cross-cultural settings), develop tools for the evaluation of cultural competence, and incorporate service-learning projects based on principles of community-oriented primary care.³⁶ Concurrently, a gift from the United Health Foundation targeted improved disease management, multidisciplinary care, and careful attention to the processes of care.³⁷

This study was initially conceived as a multimethod community health needs assessment for the HRSA project. Because there was another project targeting disparities starting concurrently, and given our local expertise, we elected to implement a rapid assessment^{38–40} targeting health disparities.

Rapid assessment procedures include (1) formation of a multidisciplinary research team including a member indigenous to the cultural group of interest, (2) development of materials to train indigenous team members, (3) use of several data collection methods to verify information through triangulation, (4) iterative data collection and analysis to facilitate continuous adjustment, and (5) completion of the project quickly, usually in four to six weeks.^{38(p375)}

METHODS

Initially, we wanted to answer these questions: (1) What is the context of health disparities in our community? (2) Who

composes the JRS HC community? (3) Given the context, what interventions are most likely to be effective in reducing health disparities? (4) What and who are the most appropriate available resources, informants, or data for us to seek, within our timeframe, to answer these questions? The investigation targeted the clinic, the community, and the interface between the two. We studied the social determinants of health in a distressed urban context; the health care-seeking behaviors of community members; the attitudes and practices of health system staff; and the interactions among community members, primary care center staff and systems, and public policies and systems.

We began with the Department of Health and Human Services Rapid Assessment Response and Evaluation (RARE) manual.⁴⁰ Wherever “HIV” was mentioned in the manual, we substituted “health disparities.” We focused on the JRS HC and the catchment area defined in the United Health Foundation project, which aims to develop a “center of excellence” in the delivery of primary care for patients with chronic diseases at the JRS HC.

We used participatory action research, which is an approach to research that aims at promoting change; that occurs through a cyclic process of planning, data collection, and analysis that is then repeated with refined data collection and analysis strategies; and in which members of the group being studied participate as partners in all

phases of the research, including design, data collection, analysis, and dissemination.

We recruited a field team that included ethnographers, cultural guides (i.e., representatives of the cultural group being studied who assist the ethnographer in gaining access to participants and in understanding the cultural context; we required our cultural guides to be community residents, JRS HC patients, and prominent community activists), and a multidisciplinary team of family physicians, psychologists, and advanced practice nurses who worked at the clinic. During 3 days of training (see the box on the next page), the field team developed the initial interview guides (available as a supplement to the online version of this article at <http://www.ajph.org>) and data sampling strategies. The plan for obtaining key information was revised as new information emerged.

Investigators identified relevant historic, epidemiological, and planning data (Miami-Dade Empowerment Trust, unpublished data, 2001)^{29,41–58} by Internet search (see the box on page 31). They asked key informants to provide or suggest data sources and participated in updates of needs assessments concurrently conducted by countywide health and social service agencies.^{29,42} We made or borrowed geographic information system (GIS) maps of census,²¹ epidemiological,⁵⁴ and planning data.^{32,55}

We obtained billing data on all visits to any Jackson Health System location for all patients

($n=26\,202$) seen at least once at the JRS HC from January 1, 1998, through September 30, 2004 (698 726 visits). We performed GIS mapping of home addresses,⁵⁹ determined the demographic characteristics of patients and the frequency of diagnoses and of visits to the various locations, and stratified the overall sample by diagnosis, ethnicity, and age subgroup. We first selected random charts for psychosocial chart review and then purposefully selected representative charts for review from among diagnoses of chronic conditions identified through billing data. We borrowed published chart audit tools or developed them on the basis of national standards of care (American Board of Family Practice, unpublished data, 2003).^{60–68}

The field team, including cultural guides, met weekly for 2 months to report on data gathered the preceding week, assess the field findings, discuss emergent themes and analysis, and plan data collection strategies for the subsequent week. With guidance from the cultural guides, the field team recruited participants to 3 meetings of a community advisory committee.

Cultural guides accompanied ethnographers in the clinic and into the community. Other research team members conducted interviews and chart audits in the clinic, and analysis of administrative and epidemiological data continued throughout the study. The principal investigator followed the recommendations of key informants to identify



The Training of a Field Team for the Jefferson Reaves, Sr Health Center (JRSHC) Community Rapid Assessment Response and Evaluation (RARE) in Miami, Fla, 2004

Day 1 of training, November 4, 2004

- Reviewed RARE methods
- Reviewed study focus on health disparities, access to care, the JRSHC system, and cultural factors
- Discussed community involvement in the field team (cultural guides) and advisory committee
- Discussed the triangulation of observations by cultural guides, experienced ethnographers, and students, providing both “nuance” and “fresh eyes”
- Reviewed plan to begin with mapping and observation, then interviews, then focus groups and surveys
- Reviewed mixed methods with triangulation of ethnographic data with epidemiology and administrative data linked to chart audits
- Discussed the purpose of ethnographic investigation: “to define the extent of the cultural complex”
- Discussed lessons learned in prior rapid assessments
- Discussed inductive approach to identify emergent concepts (i.e. issues that arise through study, rather than those defined in advance)
- Conducted field note exercise: team made field notes of food gathering behavior at local food court and discussed the fact that field notes should be descriptive and not interpretive. Examples of proper note-taking were described

Day 2 of training, November 5, 2004

- Interview training: techniques meant to elicit discursive answers, recognizing and dealing with obstacles during the interview process.
- Developed interview guide for community members and patients (available as a supplement to the online version of this article at <http://www.ajph.org>)
- Homework to develop interview guide for staff
- “Ethnographic expedition” exercise

Day 3 of training, November 11, 2004

- Trainees worked together to revise the questionnaires
- The team engaged in a lengthy debate over the use of “cultural bias” and “poor” in the questionnaire because of the possibility of multiple perceptions of the terms and the unforeseen consequences
- Focus group training: elicit discursive answers, understand group consensus, ensure all voices are heard
- Focus group exercise to explain the paramount role of the moderator; when to intervene, how to address the group, etc. (topic was health disparities)
- Discussed multiple topics that can arise in a live focus group, such as definition of health disparities in a language that can be understood by all and the role of slavery and race, environment, government, immigration, and community cohesiveness in health disparities
- Discussed human participant protection and research ethics
- Team identified potential community advisory board members to contact

Themes that emerged during the 3 days of field team training:

- Three requirements for cultural guides: (1) community activist, (2) patient of the clinic, and (3) resident of our catchment area
- The clinic catchment was initially defined as “Overtown,” “Melrose,” and “Lemon City” on the basis of catchment defined in center of excellence project
- We could only find cultural guides meeting all criteria for the community of Overtown
- During initial mapping after training it became clear that Melrose and Lemon City were out-of-date-names; other clinics served those neighborhoods; Jackson Memorial Hospital defined the catchment differently; the actual catchment varied greatly from either definition; no staff at the clinic had a clear understanding of the catchment; and no policies made effective use of the defined catchment
- Hypothesis emerged in team discussions that racism was a major underlying cause of health disparities
- Cultural guides raised the issue of the history of segregation: people want a doctor that “looks like them”
- Cultural guides and ethnographers described the long history of mistreatment of Overtown and the profiteers of disenfranchisement
- Cultural guide described receiving culturally inappropriate nutrition counseling
- Cultural guide described many people on the streets of Overtown with overt mental illness
- Cultural guides and ethnographers discussed the public nature of drug trade in Overtown and a locally recognized cycle where young people begin with low-level street drug sales, then become drug users, and finally become addicted, with subsequent cycling in and out of prison, hospital, and streets



Jefferson Reaves, Sr Health Center (JRSHC) Rapid Assessment Response and Evaluation (RARE): Summary of Data

Mapping and observations (620 hours in the field)

- Overtown, Melrose (Little Havana, Allapattah), and Lemon City (Little Haiti)
- Observation in the clinic of patients and staff, following selected individuals over time
- Multidisciplinary multicultural panel observation of videotaped doctor–patient encounters

Interviews (approximately 200 informal interviews and 42 formal interviews)

- Clients and staff at all levels at JRSHC
- Community members in 3 communities, later focusing on Overtown
- Key informants at community-based organizations: public service lawyer, minister, homeless and ex-offender advocates, health and social services agency community-based organization leaders, community development advocates, public school teachers and principals
- Staff at other primary care centers and a federally qualified community health center
- Physicians to the level of associate dean at University of Miami and Jackson Memorial Hospital
- City and health system administrators

Focus groups (group interviews)

- Cultural competence (family medicine resident physicians)
- Self-medication and alternative medications (Overtown residents)
- Segregation, incarceration, health disparities (ex-offender advocates and medical anthropologist)

Intercept surveys (33)

- JRSHC staff surveys that indicated lack of comfort with HIV care: 6
- Community members surveyed about knowledge about HIV who correctly identified HIV risk factors but demonstrated doubt about the effectiveness of treatment: 20
- Specialty clinic staff surveyed who indicated their perception of communication with primary care centers was fair to poor: 7

Key epidemiological and planning data

- US Census
- Healthy Start Needs Assessment
- Alliance for Human Services Comprehensive Health and Human Services Master Plan
- Health Council Comprehensive Health Plan for Miami–Dade County
- Mayor’s Healthcare Access Taskforce
- Comprehensive Assessment for Tracking Community Health (Health Department/Health Council/ others)
- Florida Health Insurance Study
- Florida Department of Education Web site for school demographics and ratings
- Florida Department of Health: Florida CHARTS (for disease rates and disparity rates)
- Miami-Dade E-maps Online Geographic Information Systems (land-use and other mappings)
- Overtown Area Economic Programming
- Southeast Overtown Park West Community Redevelopment Agency
- Miami-Dade Taskforce on Urban Economic Revitalization: Urban Summit Findings and Recommendations
- Overtown Charette Report
- Miami Dade HIV/AIDS Partnership Needs Assessment
- Health Department (Specific Data Request)

Chart Audits

- Pilot audit of 25 charts focusing on psychosocial and behavioral context and systems of care
- Review of 5–20 charts for each of 6 different health disparity conditions until reviewers reached “saturation” in understanding of the strengths and limitations of the documented quality of care

Clinic Administrative Data

- Demographics, utilization, diagnoses
- Geographic information system mapping, frequencies, rankings
- Purposeful selection of charts to audit

additional key informants in the health and social services sectors. Several field team members read all field notes and transcriptions. The principal investigator, guided by the interim analysis during weekly field team meetings and 3 community advisory committee meetings, and assisted by keyword searches, used an editing technique to prepare summaries and case studies abstracted from the various data sources (see the box on page 30). Field team members reviewed these and provided feedback. PowerPoint (Microsoft Corp, Redmond, Wash) presentations, interim data, and GIS maps were presented to the community advisory committee, who provided interpretation and guidance (see the box on page 32).

The final community advisory committee meeting was held in a town hall format to maximize community input. The iterative process allowed the team to propose a variety of hypotheses about health disparities and triangulate these against available data (Table 1). The principal investigator then drafted a report for policymakers out of team consensus of the findings and recommendations (available as a supplement to the online version of this article at <http://www.ajph.org>). We distributed this 148-page document to stakeholders and policymakers at all levels and requested comment. We then took turns drafting and revising manuscript sections with selected results displayed to highlight the linkage between methods, data, and analysis.



Jefferson Reaves, Sr Health Center (JRSHC) Rapid Assessment Response and Evaluation (RARE) Community Advisory Committee (CAC) Activities and Feedback

First CAC, December 1, 2004, at JRSHC

- Membership of the CAC was suggested by community guides, ethnographers knowledgeable about the community, and physicians working in the health system
- There was a significant presence of community-based organization representatives
- Research team members presented initial findings, including Miami's geographic patterns of health disparities, and the widespread JRSHC catchment
- The following questions were asked by CAC members:
 - Are patients accessing acute and preventive care?
 - How do you deal with population diversity and immigration?
 - How do you address self-medication?
 - Where do patients come from and why?
- The following recommendations were made by CAC members:
 - Collaborate with federal agencies, other primary care centers, and other systems
 - Translate the project into real results for the community
 - Work with the schools and address distressed context
 - Consider changing nature of community (discussion following this suggestion revealed strongly conflicting views over redevelopment and gentrification)

Second CAC, December 15, 2004, at JRSHC

- Although some community-based organization personnel, a city official, and community members did attend, the conversation was dominated by health system personnel
- Discussion included interim findings on cultural disconnect between clinic and community, communication problems, and the complexities of access and finance
- A challenge to the validity of qualitative findings was raised by a health system administrator

Final CAC, January 12, 2005, at the Culmer Neighborhood Center

- Held at neighborhood center
- Recruitment by cultural guides resulted in the best representation by community members
- Key findings and recommendations of study were presented by the principal investigator
- Many questions raised and distress was expressed by community members about access, eligibility, waits, and costs
- Extensive discussion ensued about waits in emergency departments by community members
- Concerns raised by community members about school health and managed Medicaid access barriers
- Community members urged a focus on basic needs, community outreach, and charged us to move toward action

miles away, often passing by multiple public and private health facilities that lay between their homes and the JRSHC.⁵⁹ The demographic characteristics of the clinic's clientele more closely resemble those of the county than those of the Overtown community.

Patterns of Health Disparities

The population of Miami is 69.3% White, 20.1% Black, 1.4% Asian, 0.2% American Indian, and 9% "other"⁵⁴; ethnically, 60% of the total population is Hispanic and 4.2% Haitian. The Black population includes African Americans (i.e., Blacks born in the United States), English-speaking Caribbean Blacks, Haitians, and Hispanics of many nationalities. Multiple state data sources have indicated that, in many health categories, the Black population has poorer health than the non-Black population.^{29,47,54} Strikingly, the most significant indicators of poor health and low socioeconomic status were found in a group of distressed, predominantly Black communities stretching from Overtown to the Broward County border in a corridor along Interstate 95 in north Miami-Dade County,^{21,29,52,54} a pattern that is a concern to local health and social service leaders.

Social Determinants of Health and Barriers to Quality Care

The oft-noted importance of social determinants of health was reinforced by the dramatic

RESULTS AND INTERPRETATION

Defining the Jefferson Reaves, Sr Health Center Community

Staff interviews revealed neither clear understanding of the intended catchment area nor catchment-related policies or procedures. Staff expressed concerns that the clinic was not reaching Overtown residents.

JRSHC patients commonly reported having been referred from the Jackson Health System, other public agencies or community-based organizations, or by word of mouth. As a Jackson Health System facility, the clinic accepts any resident of the county who chooses to attend. Once opened, the JRSHC drew referrals from a variety of sources. The clinic serves a

primarily indigent population with negligible private insurance coverage. According to the billing data obtained from the Jackson Health System, approximately 10% of the patients seen at the JRSHC in 2004 came from Overtown. Another 15% of patients came from the adjacent neighborhoods of Wynwood, Allapattah, and Little Havana. The rest came from as far as 30



TABLE 1—Major Field Hypotheses and Emergent Themes From Jefferson Reaves, Sr Health Center (JRSHC) Community Rapid Assessment Response and Evaluation (RARE): Miami, Fla, November 2004–January 2005

Field Hypothesis	Outcome of Subsequent Field Work and Emergent Themes
Racism and cultural bias are at the root of health disparities.	Complaints of cultural bias were widespread among the major ethnic groups in an extremely diverse Miami community. Given a prominent definition of racism as racial discrimination enforced through power, the hypothesis was reframed in terms of intergenerational disenfranchisement of the local Black population.
Disenfranchisement leads to health disparities.	A variety of emergent themes combined to suggest and support this theory, including: Historic context of segregation. ^{13,30–32} Historic context of major initiatives affecting the community that have no direct benefit to Overtown, but that serve the needs of the broader county population. ^{30,31,33,71,72,81,82} Description by community-based organization leaders of Overtown as “Scorched Earth.” Lack of ownership and civic engagement among Overtown residents. Intergenerational poverty. Job and housing insecurity, and ongoing displacement because of gentrification. Social, economic, cultural, and linguistic isolation of community residents. Prevalence of fatalism and suspicion reported in the community. The public nature of the drug trade in Overtown and a locally recognized cycle where young people begin with low-level street drug sales, then become drug users, and finally become addicted, with subsequent cycling in and out of prison, hospital, and streets. Prevalence of drug abuse, mental illness, disability, and incarceration. Disparate impact of access barriers on community residents. Disempowerment impacts Overtown residents in multiple interrelated and reinforcing ways (social, ^{8,10,13,15,27,52} historic, ^{11,13,30,31} political, ^{14,31,44,70,71,75} geographic, ^{13,15,17,18,20} environmental, ^{9,15,31,32,70,71} educational, ^{22,52,56} economic ^{2,23,25,44,52}), which compounds or multiplies the effect. ^{15,52,57}
Linguistic isolation leads to health disparities.	In Miami’s Hispanic-dominant context, Overtown residents who do not speak Spanish have become linguistically isolated, with some avoiding the clinic because of the perception it is a “Hispanic clinic.” Monolingual Creole and Spanish speakers also face linguistic isolation in some situations, especially the former. Health statistics for Miami’s Haitian population frequently best approximate the data for the Black population. Hispanics have better health outcomes.
Overtown residents have a tradition of using emergency department rather than primary care and waiting until they are extremely sick before seeking care.	Hypothesis confirmed and a variety of contributing factors were identified, including access barriers at the primary care centers and social, cultural, and linguistic isolation. Access to urgent and after-hours care is limited, reinforcing the pattern of deferred preventive care, waiting until conditions are in an advanced state before seeking care, and reliance on the emergency department. Variations on “Black people don’t get sick” were heard in a variety of settings. Yet, on further examination, this reflected a tradition of deferred preventive care. Nonetheless, many who had access to some type of health care—through private insurance, the Veterans Administration, or Jackson Memorial Hospital—greatly valued it.
Barriers to health care access and inefficiency create health disparities.	The inefficiencies and quality-of-care issues reported by the staff of public primary care centers and found through chart review highlight a variety of areas for improvement (available as a supplement to the online version of this article at http://www.ajph.org). These barriers were perceived to be widespread, and their contribution to health disparities is best seen in the light of systematic power and resource differentials and disenfranchisement.
Poor access to and quality of chronic disease care result in health disparities.	Interviews and observations in the clinic revealed that access barriers effectively divert many who do not have the self-efficacy to meet the rigorous documentation requirements and the patience to endure extensive waits. The most common diagnoses in the administrative data reflect chronic disease care with a paucity of acute care diagnoses, and few well-child visits, confirming the perceptions of staff that the clinic serves primarily those with chronic diseases, rather than serving as a true primary care center for the community. Need for improvement in health promotion, patient collaboration, and mental health care was a prominent finding of chart review.
HIV is prevalent in Overtown but is not commonly seen at JRSHC.	In intercept surveys, staff expressed a lack of confidence to care for HIV patients, and chart review revealed that most HIV care is referred out.
Discomfort with HIV care is because of complex medication regimens.	Chart review found medication regimens to be appropriate, but prevention guidelines were followed inconsistently.



convergence, as revealed by GIS mapping, of poor health^{29,54} and low socioeconomic status²¹ in the same predominantly Black communities, and by the distinctly different built environment³² and ethnographic context seen when Overtown was compared with neighboring communities.

Black professionals interviewed for our study described harmful personal experiences with racist encounters in housing, education, health care, and the workplace, which at times resulted in great stress and other negative consequences.^{8–19,22–27} These professionals described a subtle “institutionalized” form of racism that was different from the “overt” form of racism that was common from the 1940s through the 1960s. In focus groups held by the Healthy Start Coalition in low-income neighborhoods throughout Miami, discrimination and poor service was a nearly universal complaint, regardless of the race/ethnicity or the community of the participants.⁶⁹ Prior assessments produced similar findings (Alliance for Human Services, unpublished report, 2001).^{44,47} Given (1) the context of serious interethnic rivalries and the universal experience of discrimination and (2) the culturally dominant White Hispanic immigrant population in Miami, the hypothesis that racism is a cause of health disparities was reframed to one in which disparities emerge from the impact of racial, cultural, and geographic^{12,13} disenfranchisement,¹⁴ with resulting socioeconomic deprivation,⁴ social isolation,^{13,15} and stress^{9,15} (Table 1).

The effects of disenfranchisement on the residents of Overtown are myriad and interrelated. Discrimination and access barriers disparately affect those with less agency.⁷⁰ Poverty, disempowerment, and the experience of discrimination result in social isolation. The built environment is unhealthy because local disenfranchisement results in an external locus of control (M. Dluhy, P. Cattan, K. Revell, J. Strube, and S. Wong, unpublished report, 1998).^{31,71,72,73} In this context, the “franchise” is not only the right to vote but also includes other fundamental rights and privileges that empowered citizens use to further their lives.⁷³

Overtown initially served the purpose of segregating Black residents of Miami.³⁰ As integration laws were passed, most Overtown residents were evicted to make way for highway construction (M. Dluhy, P. Cattan, K. Revell, J. Strube, and S. Wong, unpublished report, 1998),^{30,31} a situation common to many Black urban centers in the United States.³¹ Currently, there is minimal corporate presence in Overtown; only 11% of residents own their home, and most live in poverty. Given its lack of political and financial capital, Overtown is described by key informants as the “place of least resistance” for citizens and services shunned by other communities. Proposals for a toxic waste dump in Overtown and interstate ramps adjacent to the local high school emerged recently.^{70–72} Chronically homeless, unemployed, mentally ill, and drug-addicted people often

wind up in Overtown, cycling between the streets and the public drug trade and nearby prisons, hospitals, and shelters. Our field team consistently encountered homeless people, people recently released from prison, and mentally ill former patients.

One emergent finding was the striking sense of marginalization and isolation many “Townners” feel from the surrounding communities and from the daytime-only inhabitants. Many Overtown business clients and churchgoers are former Overtown residents returning to avail themselves of services, reflecting a class dichotomy between those who left and those who remain. The disconnection between Overtown residents, the business community, government, and even those providing services in the community was repeatedly raised by community members and observed through our field work. One community-based organization leader reported that Miami organizations often refer to Overtown as “Scorched Earth.” In informal conversations with our field team, as well as formal interviews, residents of Overtown complained that those receiving funding for services in Overtown have provided services to outsiders or “daytime residents.”

Financial stress, barriers to employment, housing insecurity and displacement because of gentrification and the shrinking supply of affordable housing, and the need for any health intervention to focus on basic needs were concerns repeatedly expressed by our cultural guides, community advisory committee members,

Overtown residents, and key informants in the social service sector.

The Health System and the Community

One prominent field hypothesis (Table 1) was that Overtown residents tend to wait until they are extremely sick before seeking medical care and then use the nearby Jackson Memorial Hospital emergency room through established custom.

Many Overtown residents did in fact report that they were in the habit of going to Jackson Memorial Hospital for health problems and that they tended to wait until problems became acute before trying to get medical care. As one resident said,

I don't see how you can say how the kids dying [high infant mortality]. . . . We seen generations grow up, little kids come from dis [sic] here, I don't know about too many of them dying, going to jail maybe yeah, but dying no, we don't have that too much. . . . Everybody got their paperwork . . . but you know, we don't get sick like that. . . . When we do, we go to the old places where our parents use to take us. Jackson Memorial or wherever we got to go.

Nevertheless, the explanation for their not using the JRS HC entailed additional, and perhaps more important, considerations. We made the following field hypotheses: (1) procedures to verify health system eligibility result in barriers that defeat attempts to obtain ambulatory care; (2) because the JRS HC accepts referrals from elsewhere in the Jackson Health System, the clinic's busy appointment calendar is often crowded with overflow



patients from other zones of Miami–Dade County; (3) because the vast majority of these patients are Hispanic, people in Overtown come to perceive the JRSCH as a Hispanic clinic. All 3 of these hypotheses were confirmed during the field investigation through observation as well as informal and in-depth interviews with community residents, clinic patients, and clinical staff (Table 1).

Established JRSCH clients were generally satisfied, but those interviewed in Overtown often did not avail themselves of medical care at all. Many reported being unaware of the existence of the JRSCH or having negative impressions of it. Although former Overtown residents are among the JRSCH staff, there are social and class barriers between the clinic staff and indigent residents of Overtown. Our observations confirmed that Spanish is the principal language in the waiting rooms and of many of the registration staff. According to one Overtown resident, “It really ain’t like no American hospital, you get over there and everybody’s talking Spanish and you really can’t understand what’s going on.”

Community residents said they were certain to be seen if they went to the emergency room—a result of laws guaranteeing access⁷⁴—but complained of extensive waits (see the box on page 32). In addition, physicians and nurses reported referring patients to the emergency room for minor acute care and as a circumvention because of difficulty in obtaining timely specialty consultations and diagnostic

procedures. As one JRSCH physician explained, “Often when we reach a consulting service to expedite a patient’s appointment, we are told to send the patient to the ER [emergency room] to be admitted to expedite the consult.”

People in the community, key informants, and existing-needs assessments repeatedly cited the problem of poor public sector customer service and barriers to accessing care in Miami.^{42,44,50,57} We observed individuals go through extended periods without care, enduring multiple failed attempts to meet documentation requirements for registration. Patients, community advisory committee members, many health care staff, and prior needs assessments^{49,57} found the requirements and documentation burdensome, intrusive, or confusing. Fraud was cited by health system administrators as justification for the documentation requirements. Inefficient systems, inadequate staffing, and a lack of financial incentives to improve access all reinforce access barriers. As one Overtown resident said, “Everywhere you go, you first have to be violated [i.e., verification made that use of the clinic was not in violation of clinic rules].”

This lady . . . told me that I need to bring . . . all these credentials. . . . I told her, I am indigent, I am broke, I am poor, I don’t have anything, if it wasn’t for my brother, I would be sleeping on the streets . . . and she told me to bring my brother’s last four consecutive check stubs. . . . I sat out on that bench from a quarter to 12 to a quarter to 4 . . . and still didn’t get seen. (Client in JRSCH waiting room)

You could not really get the services . . . because there were rules in effect and the folks that were enforcing the rules . . . felt that they were doing you a favor . . . may not have liked you because you were of a different race or were poor. . . . If you are not treated with respect, if you have a long wait for whatever reason, you are not going to feel comfortable going to ask for the help, and therefore, you may not go, to even get the help if the help was available. (Leader in the social service system)

“Fragmentation” is a concern repeatedly cited by health and social service providers.^{42,49,57} Service delivery, health information, resources, and access rules are fragmented among various payers, locations, and paper and electronic formats, with pervasive incompatibility and inefficiency problems. Access to health information and knowledge of available resources varied widely. Some physicians described expending enormous individual energy to identify and connect patients to resources. Past health, mental health, and psychosocial information was often difficult to find or unavailable in patients’ medical records. Community members expressed confusion about access rules and complained about being reassigned to new managed health plans or providers against their will. Communication within the health system is poor, both for patients calling into the system and for health care professionals attempting to communicate with one another. One JRSCH nurse said, “The patients complain that they try and try, but there is no one there to pick up the

phone. I know myself that if I try to call, I cannot get through.”

According to staff interviewed by the field team, poor communication often results in extensive waits for patients and inefficient care. Key informants confirmed that for the indigent, there are significant waits throughout much of the public health care system in Miami.

Time after time, key informants spoke about the difference in the quality of and access to care available to those with employer-based health coverage and to those who were uninsured and with limited means. Frustration with barriers and inefficiencies and a sense of being unable to offer the highest-quality care to all patients are endemic to providers of health care for the indigent. As a physician at another primary care center said,

You prescribe medications, and the patient can’t afford them. You write a referral for a specialist, it sits in the clinic for 3 months and then it takes another 4 months for the appointment to be made. I have no idea when my patients are hospitalized or what recommendations are being made. It is a nightmare.

DISCUSSION

Disenfranchisement⁴⁴ and socioeconomic deprivation⁴ have been identified as fundamental causes of disease since Virchow, sent to investigate an outbreak of typhus in 1849, called for “political reform and local democratic self-government [and] . . . education, with its daughters, liberty and prosperity.”^{75(p523)}

Overtown is strategically located next to a major urban



health center, school of medicine, and sites of future biomedical research infrastructure. It is these institutions' responsibility, as well as in their enlightened self-interest, to partner with residents and community organizations to advocate for and impel change to improve this community's health status. Participatory research⁷⁶ and participatory urban planning^{15,77} promote equity and agency⁷³ to redress the disenfranchisement of residents in communities like Overtown.

We identified a set of targets for health system intervention (available as a supplement to the online version of this article at <http://www.ajph.org>). Resulting initiatives include a "Mental Healthcare Improvement Project" at the JRSHC based on the chronic care model,⁷⁸ a participatory primary health promotion program based at Overtown's Booker T. Washington High School, the "Overtown Cookbook,"^{79,80} and collaboration with the Booker T. Washington program and the community-based organization PowerU to foster healthy community policies in the face of highway reconstruction.^{81,82} ■

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Contributors

D. R. Brown conceptualized and supervised the study and led the writing. A. Hernández helped conceptualize the study, performed geographic information system mapping of epidemiological data, and contributed significantly to all aspects of the study. G. Saint-Jean helped design the administrative data sampling and analysis strategies, performed the quantitative analysis, and assisted with writing and critically revising the article. S. Evans, I. Tafari, C. Gómez-Estefan and F. Regalado were on the field team and contributed significantly to all aspects of the study. L. G. Brewster contributed analysis and critical revision of the article in response to the critique of the reviewers. M. J. Celestin coordinated the field team and contributed significantly to all aspects of the study. S. Akal contributed to the analysis, writing, and critical revision of the article. B. Nierenberg contributed to the data collection, analysis, writing, and critical revision of the article. E. D. Kauschinger contributed to the data collection, analysis, writing, and critical revision of the article. R. Schwartz helped conceptualize the study and contributed to the analysis, writing, and critical revision of the article. J. B. Page conceptualized the use of Rapid Assessment Response and Evaluation methods, led the field team as lead ethnographer and analyst, and participated in the drafting and critical revision of the essay.

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Human Participant Protection

This study was approved by the University of Miami's institutional review board.

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