SEPARATE AND UNEQUAL IS ILLEGAL:

a discussion guide for community- and faith-based organizations on discrimination in the health care system

INTRODUCTION

In the CNN news story you just watched, several Bronx residents who were on Medicaid or had no insurance experienced long delays in getting doctors' appointments, were shuffled between doctors, and got little face-to-face time once they actually saw a doctor—often with very troubling results. Some were even asked to participate in clinical experiments or trials without full disclosure of possible side effects.

Purpose of this discussion guide

The purpose of this discussion guide is to promote a conversation within communityand faith-based organizations about health disparities and how you can advocate for yourself and others to make sure you get the health care you deserve.

The objectives of the guide are to:

- Facilitate discussion on what health disparities are and why they exist.
- Learn how a health disparity affects you as a patient.
- Know your legal rights to make sure you get the care you deserve when at the doctor's office or hospital.
- Spread the word and advocate for better medical care, regardless of health insurance status or race.

We hope that these materials will be useful to you and your community as you think about how to foster productive conversations about the often difficult issue of health disparities and health care discrimination.





BACKGROUND

What are health disparities?

As the health of all Americans improves, the gap between the health of whites and minorities still remains. Health disparities exist for many reasons. One reason, documented in the CNN news story, is when patients with the same medical condition are treated differently by a hospital based on factors such as their race or insurance status. For example, the patients interviewed by CNN were steered to a hospital-based clinic for treatment because they were on Medicaid or were uninsured. If they had private insurance, they would have been seen in a "faculty practice," which is essentially a private doctor's office within the hospital.

Question: Do you believe this kind of steering happening in the hospital where you and your family receive care? Do you think this kind of steering happens because Medicaid is a bad insurance, or because hospitals' systems are structured to treat Medicaid patients differently?

Significantly more blacks and Latinos are on Medicaid or are uninsured in New York City than whites. As a result, when hospitals decide where to treat patients based on the type of insurance they have, they are also separating patients based on their race. Black and Latino patients tend to be seen in the hospital clinics, while white patients are treated in the faculty practices. Hospital waiting rooms may no longer have "Whites Only" signs on their doors, but racial segregation is nevertheless achieved when hospitals treat patients differently based on the type of insurance they have, or if they have no insurance at all.

Why do health disparities matter?

Differences in the quality of care a patient has access to impacts her health outcomes.

- Patients receive care from less experienced doctors if they are seen in a hospital-based clinic. Hospital clinics are often staffed by residents and student doctors, who are new to the field and less experienced. Doctors in faculty practices are experts in their fields, and have years of medical experience.
- Patients seen in a clinic have to wait longer for an appointment, and get less face-to-face time with the doctor once they are seen. Hospital clinics are often busier than faculty practices, and so patients referred to clinics may have to wait longer for appointments than patients referred to a faculty practice and tend to have less face-to-face time with their doctor than a patient referred to a faculty practice. This can lead to delays in terms of when patients are diagnosed or impact whether they are diagnosed at all.
- Patient care is disrupted when patients are seen by a different clinic doctor each time. Patients who are seen in a hospital clinic often do not get to see the same doctor each time they have an appointment. This makes it harder to build a

relationship with the medical provider and make sure that s/he fully understands the patient's medical history and current needs.

The result is **separate and unequal** care based on health insurance status and race. Over time, patients who receive worse care are likely to have higher rates of preventable conditions such as diabetes, obesity, heart disease, etc. **This means that low-income patients of color live sicker and die younger than affluent white patients**.

Question: Do you agree that differences in care such as those described above exist in hospital-based clinics? How, if at all, do you think this impacts the well-being of you and your community?

Separate and unequal is illegal

A medical provider that segregates patients based on whether they have private insurance or Medicaid or are uninsured are in violation of federal civil rights law as well as state and local laws. Hospitals, medical offices, and private doctors are bound by the following laws:

- Federal civil rights laws prohibit policies and practices that have a discriminatory effect on people because of their race or ethnicity.
- Federal and state law prohibits hospitals from treating patients differently based on if they have public health insurance such as Medicaid.

If a medical provider violates these laws, government agencies such as the state Attorney General have the power to investigate and pursue solutions. And solutions are available. Some of the country's most well-respected health care institutions, such as the Mayo Clinic in Rochester, Minnesota, do not separate their patients based on the type of insurance they have. Also, some departments within New York City hospitals have voluntarily integrated their practices because the leadership in those departments felt it was wrong to segregate patients. These integrated practices provide top quality of care to all of their patients without compromising their bottom line or their training of residents and medical students. Simply put, integrated health care delivery means that all patients are treated to the same high quality health care in the same place, at the same time.

DISCUSSION

Reminder: The purpose of the conversation is not to point fingers or blame any particular medical facility or doctor.

I. Survey participants' reactions

Here are some questions to get the conversation going:

- What were your reactions to the stories you just heard?
- Do you think the patients profiled in the story received inadequate care?
- Is your reaction to the story influenced by your own race, ethnicity, or socioeconomic background, or that of your family?
- Are the experiences of the patients in the news story familiar to you? If no, then why do you think these particular patients received the kind of treatment they did?
- What were your reactions to the characterization of the health care system as racist?
- Are there other reasons the patients profiled in the story may have received inadequate care besides their lack of insurance or Medicaid status?

II. What are some of the effects of health disparities?

Ask participants to list some of the effects of health disparities. Point out both immediate consequences that can result from health care disparities, as well as long-term consequences. Examples of immediate repercussions are: less access to preventative health care, higher rates of illness or conditions going undetected, lower rates of access to elective procedures, etc. Examples of long-term consequences are: lower life expectancy for blacks than for whites, higher rates of obesity, diabetes, and heart disease, etc.

Statistics from the federal government's Office of Minority Health about the effects of health disparities:

- Compared to whites, people of color and people whose first language is not English often receive lower quality or no health care. As a result, as a group they have less health and die younger than whites.
- African Americans, Latinos, Asians, and Native Americans have higher rates of diabetes, heart disease, and obesity than whites.
- Though the health of all Americans has improved over time, a gap between the health of minorities and whites still exists:
 - A black baby born today on average will live six years less than a white baby born today.
 - Latinas are four times as likely to die from AIDS as white women.
 - Latinos are almost twice as likely to die from diabetes as white males.

 Almost two times as many African American men have diabetes as white men.

Source: Office of Minority Health, African American Profile, and Hispanic/Latino Profile, www.omhrc.gov.

III. Why do health disparities exist?

Think of potential factors of health disparities broadly, including environmental and social causes, and consider whether disparities exist because of reasons beyond differential medical treatment and health care. What about income? Or access to healthy food, exercise, and other factors that affect a person's health?

Point out to participants some causes of health disparities that they didn't identify:

- Race and ethnicity
- Income
- Language
- Education
- Insurance status
- Access to healthy food

- Access to parks and walking spaces
- Access to quality health care
- Intentional or unintentional discrimination
- Housing
- Poverty

Are health disparities the result of intentional discrimination by individual providers? Have members of the group seen a nurse, doctor, or resident clearly treat a patient differently based on her race, income, or insurance? Have *they* been treated differently based on race, income, or insurance?

Even if health disparities are not the result of intentional discrimination against patients of color or low-income patients, the effect of policies and practices that separate patients based on insurance may be the same. Structural discrimination—the legitimization of a discriminatory practice over time—occurs in hospitals through practices like when a medical provider adopts a policy or practice that segregates patients based on insurance status. While the decision to treat patients differently based on their health insurance may be motivated by a legitimate concern, such as reducing overall costs, the result is racial segregation of white patients and patients of color.

IV. What can you do to make sure you get the care you deserve?

Ask participants for suggestions of how to advocate for themselves and their loved ones within the health care system.

- What should you do if the only appointment you can get is three months away and you need to see the doctor immediately?
- What can you do if your first language is Spanish, but your doctor only speaks English?
- Can you ask to see a specific doctor, or insist that you are referred to a doctor in the faculty practice instead of the hospital clinic?
- What are some ways you make sure your doctor addresses your concerns and answers your questions?

After participants have made suggestions, discuss other ways you can advocate for good health care.

A preliminary list of ideas includes:

- Know your rights! Familiarize yourself with the New York Patients' Bill of Rights.
- Prepare for a doctor's visit by making a list of things you want to talk to your doctor about, especially your symptoms.
- Bring a family member or friend to support you.
- If you are more comfortable communicating in a language other than English, ask for an interpreter.
- Be honest with your doctor, and tell her or him about any medications you are taking, your diet, exercise, and any other lifestyle choices. Remember that anything you tell your doctor will remain confidential.
- Don't be afraid to ask for more information about your illness, diagnosis, and prescribed treatment.
- Write down instructions about what the doctor told you to do to get better.
- Write down the names of staff you've interacted with on your visit.
- If you feel you have been mistreated, you can ask for the administrator on duty or a staff supervisor, or file a complaint in person or in writing with the hospital or the Department of Health.

V. How can you advocate for change so that all patients get good health care? Ask participants for suggestions of ways to raise awareness and end disparities in health care in the community.

Some possible suggestions include:

- Conduct Know Your Rights workshops to increase awareness about your rights as a patient, especially if you have Medicaid or are uninsured. Remember that workshops can be conducted in schools, community centers, places of worship, the subway, on the street outside of a hospital, etc.
- Talk to your friends, neighbors, and family members to see whether they have experienced disparities or different treatment based on their insurance status. Write down and collect those stories to create a log of how often, when, and who faces health disparities. Share that log widely.
- Write a letter to your local newspaper.
- Write to a hospital or medical office that is providing different treatment for patients based on their insurance status. Let them know that their policy or practice is violating the law.
- Contact local officials and tell them about the health care disparities you've seen in your community. Let them know that hospitals and medical providers who discriminate based on source of payment are violating the law.
- Let people know that they don't have to settle for bad medical care just because they have Medicaid or are uninsured.

Questions? Concerns? Want more information? Contact: Bronx Health REACH (212-633-0800) or the Health Justice Program at NYLPI (212-244-4664).