

# ALLEGHENY COUNTY HEALTH

in

# BLACK AND WHITE

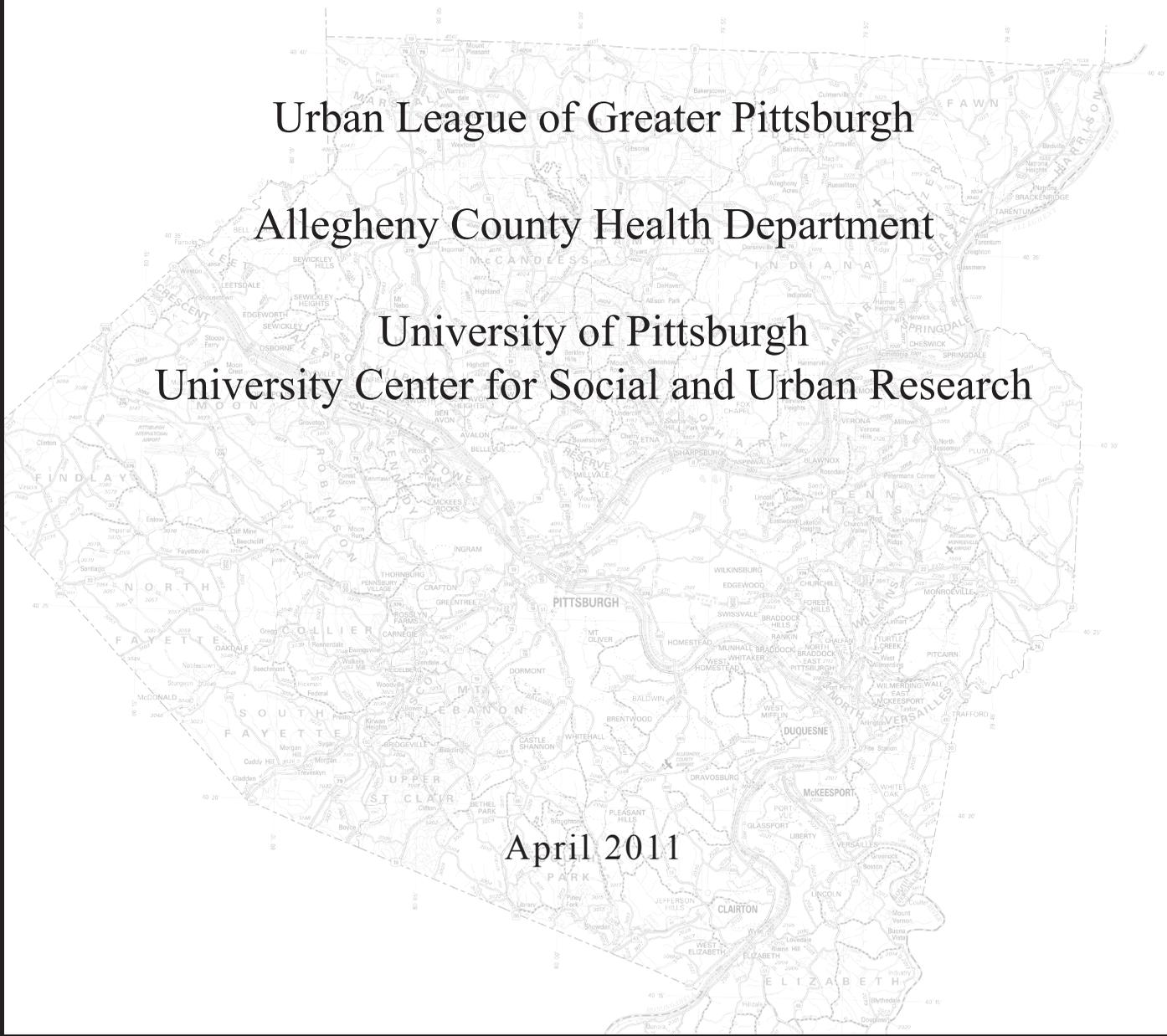
Urban League of Greater Pittsburgh

Allegheny County Health Department

University of Pittsburgh

University Center for Social and Urban Research

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## INTRODUCTION

The Urban League of Greater Pittsburgh, in partnership with the University Center for Social and Urban Research at the University of Pittsburgh and the Allegheny County Health Department, is pleased to publish this second volume of what has come to be known as Pittsburgh's "Black Papers"—a series of reports documenting the public health status of African Americans in Allegheny County, Pennsylvania.

The social and historical context for the Black Papers—which have been described as “a landmark in public health in Pittsburgh”—was set forth in the introduction to volume one,<sup>1</sup> which was published in September 2002:

*“The Black Papers represent a starting point from which we can improve the health status of African Americans in Pittsburgh and Allegheny County. [They] provide a solid foundation of valid and reliable data about the gap in health status between our black and white citizens. . . .”*

More than eight years have lapsed since the publication of our first comprehensive report on the quality of health of the region's African Americans. Despite the passage of time and the labors of many, the evidence reveals that significant gaps remain in the overall health status of African Americans, who according to U.S. Census figures constitute roughly 12.9 percent of Allegheny County's population.

Volume two of the Black Papers—*Allegheny County Health in Black and White*—is a 21<sup>st</sup> century call to action. This benchmark report lays out, in black and white, the vast differences that exist in the incidence, prevalence, and treatment of diseases such as cancer, diabetes, and HIV/AIDS, among others. It also provides an opportunity for all of us, working together as one community, to eliminate the disparities that persist and to improve the quality of both health and life for the entire community of Allegheny County residents.

On behalf of the Urban League of Greater Pittsburgh, I wish to extend my gratitude to everyone who made this publication possible. To the authors of the Black Papers for their body of outstanding work: (listed alphabetically) Laura Bettencourt, Erin Dalton, Renée R. Hanson, Pat McGlone, Deborah McMahan, Collette N. Ncube, Goutham Rao, Lyn B. Robertson, Anthony G. Robins, Terri L. Rosen, Miriam C. Seidel, Margaret Smith Washington, Jeannette E. South-Paul, Emily Sturman, Latoya Warren, Michael A. Yonas, and Janice C. Zgibor; to Drs. Thomas E. Starzl, Jeannette E. South-Paul, and Kenneth S. Thompson, each of whom contributed to the manuscript's preliminary matter; to the talented and dedicated group of editors, including Ralph Bangs, Diane Hernon Chavis, Anthony Robins, and Ken Thompson; and to the project staff members Monique Constance-Huggins and Allison Robinson—this publication would not have been possible without all of your many efforts.

We also are extremely grateful to the University of Pittsburgh's University Center for Social and Urban Research, which provided much of the leadership and the funding for this project, and to the University of Pittsburgh Office of Public Affairs for the design and printing of this publication.

Esther L. Bush  
President and CEO  
The Urban League of Greater Pittsburgh

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## Endnotes

<sup>i</sup> Volume one, entitled *Black Papers on African American Health in Allegheny County*, contains three papers. The first describes the overall health status of the county's African American population. The second focuses on sexually transmitted diseases within the same community, while the third targets health problems among the county's African American women ages 35-64.

## FOREWARD

This is a particularly important time to review the health of African Americans in Allegheny County. While all of the attention in recent years has resulted in thoroughly defining the problem, we have not succeeded in addressing the health care deficits of Black citizens. The current climate of change in America now provides us with a good opportunity to implement solutions. This book promises more than just another description of the problem. It also is intended to offer concrete action steps toward solutions.

Organ transplantation provides a historical lesson that may be useful today. Early in the development of kidney transplantation, we established that when all six of the human leukocyte antigens were matched between donor and recipient, statistically better results were obtained. It also was anticipated that a less perfectly matched kidney (let's say five of six or four of eight antigens) would do better than one with matches of only one or two antigens. In fact, we did not find any real difference in outcomes except with the six-antigen match. This came as a surprise to many, especially those in the field of tissue typing. Many years passed before our findings were accepted.

After legislation was passed in 1973 that funded the care of end stage renal diseases, the transplant community, in conjunction with the various stakeholders, was assigned the task of constructing regulations to govern the allocation of the increasingly scarce resource of transplantable kidneys. Due mainly to controversy regarding the value of incomplete matches, this goal proved to be elusive.

In the final days leading up to the deadline for publishing the regulations, the lack of consensus resulted in the wholesale adoption of the allocation system that we already were using in Pittsburgh, which gave heavy weight only for perfect (six antigen) matches. In essence, our plan distributed the less-well-matched donor kidneys to candidates who had been waiting the longest. While accepting our scheme, the final regulation left open the possibility of substituting alternative rules at a regional level. These regional variations subverted the Pittsburgh plan and made nearly meaningless the time spent waiting on the list.

What, you may ask, does this have to do with the health problems of African Americans? As it turned out, African Americans were more likely than other population groups to have intermediate level tissue matches. Consequently, the allocation policy that evolved in most regions systematically deprived African Americans of their appropriate rank on the kidney waiting list and their fair share of the precious kidneys. The average wait time for Blacks on the list was getting longer and longer compared to other ethnically-defined patients.

The firestorm that resulted from exposure of this unintended injustice was slow in developing. The community of transplant professionals eventually reverted to our original rules that gave special consideration only for the perfect match. Time spent waiting was restored as the major factor for kidney allocation, but this required more than 15 years. Eventually, conversation

turned to questions like, “How could this have been allowed to happen?” or involved efforts to defend what now was recognized to be indefensible.

Recent publications have shown disparity in many other kinds of treatments for minorities that can best be explained by economics. The evolution of health care in the direction of a business enterprise has dispossessed—and will continue to dispossess—many. A mountain of costs, careers, and complexity in today’s fiscal-approval interface between health providers and insurers has been created in the name of “health maintenance,” “outcomes based,” “cost consciousness,” or “risk avoidance.” This can be seen by many people as a way to exclude some segments of the population.

While this focus is not limited to lower socioeconomic populations, the preoccupation with payment and increased profits will certainly disadvantage the poor. Should affirmative treatment programs be created? Or would it not be better to solve the problem for everyone who needs increasingly costly treatment? I do not know the answer, but I do know that there are powerful forces asking, what is the most effective and direct path to help people? Perhaps some of the solutions to these problems and questions are contained in this book.

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## Urban League of Greater Pittsburgh

### MISSION STATEMENT

The mission of the Urban League Movement is to enable African Americans to secure economic self-reliance, parity and power, and civil rights.

### OUR MOVEMENT

Established in 1910, the Urban League is the nation's oldest and largest community-based movement devoted to empowering African Americans to enter the economic and social mainstream. Today, the National Urban League, headquartered in New York, spearheads the non-partisan efforts of its local affiliates. There are over 100 local affiliates of the National Urban League located in 35 states and the District of Columbia which provide services to more than 2 million people nationwide through direct services, programs, advocacy and research.

### OUR STRATEGY

The Urban League employs the following 5-point strategy, tailored to local needs, in order to implement the mission of our movement.

1. **Education and Youth Empowerment:** Ensuring that all of our children are well educated and prepared for economic self-reliance in the 21<sup>st</sup> century.
2. **Economic Empowerment:** Empowering all people in attaining economic self-sufficiency through job training, good jobs, homeownership, entrepreneurship, and wealth accumulation.
3. **Health and Quality of Life Empowerment:** Working to build health and safe communities to eliminate health disparities through prevention, healthy eating, and fitness, as well as ensuring complete access to affordable healthcare for all people.
4. **Civic Engagement and Leadership Empowerment:** Empowering all people to take an active role in determining the direction, quality of life, public policy and leadership in their communities by full participation as citizens and voters, as well as through active community service and leadership development.
5. **Civil Rights and Racial Justice Empowerment:** Promoting and ensuring our civil rights by actively working to eradicate all barriers to equal participation in all aspects of American society, whether political, economic, social, educational, or cultural.

## **VISION STATEMENT**

We believe it is imperative that appropriate resources of the Greater Pittsburgh Community be marshaled to ensure equal social, political, and economic justice for all Americans. To that end, the Urban League of Greater Pittsburgh will provide bold leadership and innovative programs, services, and policies, which will contribute to the strength of the Greater Pittsburgh region by ensuring that African Americans achieve their full potential. With the active engagement of community partners, the Urban League will serve as a premier advocate for economic opportunity and justice that lead to significant improvement in the equality of our lives.

**We would like to acknowledge all who supported the writing of these papers.**

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## EXECUTIVE SUMMARY

Since 2002 when the *Black Papers on African American Health in Allegheny County (Black Papers)* was first published, significant disparities in health between African American and Caucasian American citizens have persisted. Recognition of the specifics of those health disparities in Allegheny County, Pennsylvania, has spurred studies to better explain why there are disparities and to pilot programs to eliminate them. This follow-up book to the *Black Papers* expands the scope of conditions described and attempts to understand where progress has been made and where the disparities have persisted or even widened. The National Institutes for Health defines health disparities as “differences in the incidence, prevalence, mortality and burden of disease and other adverse health conditions that exist among specific population groups in the United States.”<sup>i</sup>

In 2007, George Kaplan described health status as having much more to do with how we live—with the social and economic conditions that shape our lives—than with the medical care we receive or with what public health authorities do to control contagious disease.<sup>ii</sup> Furthermore, David Williams, professor of African and African American Studies, Public Health, and Sociology at Harvard University, has said, “race does matter” when looking at health disparities. The income disparities between races, exposure to social and economic adversity over the life course, and experiences of discrimination and institutional racism can affect the health of minority groups in multiple ways. Although some Americans believe racism is a thing of the past, racial disparities do exist and have been persistent over time, as can be seen when viewing disparities between 1950 and 1998.<sup>iii</sup> Both the influence of living conditions and socioeconomics as well as aspects of health and health care services are explored in this update to the “Black Papers.”

The African American population in Pennsylvania grew by 12.4 percent between 1990 and 2000 to reach more than 1.2 million. By 2007, the Black population numbered 1,328,630, which is 8.5 percent higher than the 2000 figure. The average annual change remained constant at 1.2 percent in the 1990s through the 2000s. The overall result is a net growth of 21.9 percent between 1990 and 2007.<sup>iv</sup> In 2006, in this time of population growth, the age-adjusted rate for total deaths in Pennsylvania was almost 30 percent higher for African Americans (1,083.1) compared to whites (837.8). The mortality rate for HIV/AIDS among African American residents (15.8) was more than 10 times higher than the rate for whites (1.5). The homicide rate was more than 14 times higher for African American residents compared to whites. More so, the homicide rate with firearms for African American residents (29.2) was 20 times higher than the rate for whites (1.4). The death rate for viral disease among African American residents (19.5) was more than six times higher than the rate for whites (3.2). The death rate for prostate cancer among African Americans (61.9) was more than twice the rate of whites (25.0).<sup>v</sup>

This book focuses on many of the conditions in which dramatic disparities in outcomes are seen among racial/ethnic groups. In Chapter 1, Anthony Robins describes the evidence that African Americans have a lower life expectancy at birth than any racial group in either gender. African Americans have higher overall rates of death than white Americans and a higher

prevalence of preventable diseases. Overall, African Americans are less likely to have health insurance—and less likely to access health care services—than white Americans in the United States. When they do access health care, they are more likely to receive inadequate care compared with white Americans. In addition, African Americans experience higher levels of poverty, unemployment, incarceration, and discrimination than their white counterparts, and the scope and depth of the health crisis are more dramatic. Robins notes that health challenges faced by African Americans are complex and multilayered and are superimposed upon a core of misunderstandings and lack of recognition of cultural influences that impact responses to these issues.

Renée Hanson's chapter on child and adolescent health disparities in Allegheny County emphasizes that the health issues facing our population begin as early as during infancy. From birth, African American children in the United States and Allegheny County fare worse than their white counterparts. According to 2005 data, in Allegheny County, the percentage of African American babies with low birth rate roughly doubles that of white babies. Furthermore, African American infants were more likely to die and lead in infancy death rates between 2003 and 2005 than were white infants. In addition to the racial disparities in infant birth rate and mortality, there is evidence of grave disparities in teenage pregnancies as well. In terms of adolescent pregnancy, African American and Hispanic adolescent females overwhelmingly continued to have high pregnancy rates compared to white adolescent females in the state of Pennsylvania.

Siedel, Bettencourt, and Zgibor discuss the impact of diabetes mellitus on African Americans in Allegheny County. Projections for diabetes indicate that approximately 29 million people will be affected by the disease by the year 2050 [5]. The largest increase in prevalence is expected to occur in African American males +363% (2000-2050) and females +217% (2000-2050). Overall, the estimated risk of developing diabetes in those individuals born in 2000 is roughly one in three. The lifetime risk is even higher among minority populations where non-Hispanic Blacks and Hispanics have a two in five chance of developing diabetes if current trends continue [6]. This increased diabetes prevalence is beginning to present itself at a much earlier age than it has in past generations. Furthermore, once seen only in adults, type 2 diabetes has been rising steadily in youth, especially minority youth, mirroring the increase in obesity and inactivity seen in children and adolescents.

Goutham Rao focuses on the growing obesity epidemic. Obesity in Allegheny County largely mirrors national trends. In 2002, 69 percent of African American adults (men and women combined) were either overweight or obese, compared with 58 percent of whites. That same year, 70 percent of African American adults in Pennsylvania, and 69.8 percent of African American adults nationwide, were either overweight or obese. Differences between Allegheny County, the state as a whole, and the country were not significant. In 2006, 67.8 percent of African American adults in Pennsylvania and 71.8 percent of African American adults nationwide were either overweight or obese.

Lyn Robertson's chapter on cancer notes that all Americans are not at equal risk for cancer and disparities exist among subpopulations, contributing to poor outcomes in certain groups. These differences have been shown to independently affect outcomes in mortality

patterns. The sociodemographic factors of education, race, and socioeconomic status (SES) have been shown to directly impact the mortality rates of a population. Minorities have higher mortality rates for multiple reasons, most notably because of adverse social conditions such as lack of access to health care, disparities in educational attainment, and poverty (Woolf, 2007). Irrespective of race, individuals from a lower SES experience a higher prevalence and mortality from cancer than individuals from a higher SES (Siminoff, 2005). Cancer is the second leading cause of death in Pennsylvania. Progress has been made in reducing the numbers of individuals who die from cancer yearly; however, in Pennsylvania, the mortality rate is higher than for the nation as a whole. In addition, there is a marked disparity between the death rates for African Americans and whites in the state. As the number of cancer survivors increases, resuming normal routines remains a significant challenge for a growing number of cancer survivors and their families in Pennsylvania. The 2003 cancer incidence rate for African Americans was 7.1 percent higher than the rate for whites. The Pennsylvania cancer incidence rates for African Americans were approximately 5 percent higher than the rates recorded by the National Cancer Institute's SEER Program.

McGlone and McMahon discuss the impact of HIV/AIDS in Allegheny County. African Americans are again disproportionately represented among people living with HIV/AIDS. From 2000 to 2005, Black non-Hispanics ranged from 44 percent to 46 percent of people living with AIDS in Allegheny County despite representing only 12 percent of the population. Whites in the county accounted for 49 percent of all AIDS cases compared to their share (75.6 percent) of Allegheny County's population.<sup>1</sup> The Southwestern Pennsylvania AIDS Planning Coalition (SWPAPC) issues updates and reviews epidemiological data for the region, along with HIV/AIDS needs and service utilization for the southwestern PA region.<sup>1</sup> The SWPAPC Coalition Regional Services and Strategic Plan (CRSSP) 2007/2009 cites the regional trends of (1) an increase in female AIDS cases from 12 percent (1980-1990) to 21 percent (2000-2005); (2) an increase in Black (non-Hispanic) AIDS cases from 33 percent to 48 percent in the same time period; and (3) injection drug use (IDU) as a transmission mode remaining the same at 17 percent. In the same time period, heterosexual transmission increased from 6 percent to 24 percent. The majority of females living with HIV/AIDS are African American women living in Allegheny County, and heterosexual transmission is the primary transmission mode.

Dalton et al. discuss community violence as a major public health concern in the United States and within many urban, impoverished communities of color. An essential element to effectively addressing and preventing community violence is the use of strategic intervention and prevention activities in the local area. Their chapter illustrates the characteristics of community violence in Allegheny County, Pennsylvania, and specifically examines the racial disparity of this public health epidemic. Although homicides and drive-by shootings tend to receive the most media coverage, they occur far less frequently than aggravated assaults with firearms. Pittsburgh's murder rate (4.8 per 100,000 in 2005) is lower than the national average and that of many benchmark cities like Detroit, St. Louis, Baltimore, and Richmond. However, examination of violence trends among different demographic groups shows that, in particular, Pittsburgh's young Black men are at acute risk of homicide victimization. The homicide rate for this group was 284.2 per 100,000—60 times the citywide average and more than 50 times the national average.

When reflecting on the substantial burden of disease seen in African Americans, South-Paul et al. emphasize that primary care remains the foundation of health for every citizen, but remains of utmost importance to the most vulnerable citizens in the nation— children, the disabled, racial/ethnic/social minorities, the poor, and the medically uninsured. They discuss the role of publically funded clinics as a major component of primary care in the United States. The so-called federally-qualified health centers (FQHCs) are designed to have one of five areas of focus—community health centers, migrant health centers, homeless health centers, school-based clinics, or public housing health centers. They are nonprofit, community-directed clinical entities designed to provide care by serving communities that otherwise confront financial, geographic, language, cultural, and/or other barriers (National Association of Community Health Centers, PA Health Center Fact Sheet, 2007). FQHCs are located in high-need areas, identified as having elevated poverty, higher than average infant mortality, and where few physicians practice. FQHCs serve a critical role in providing clinical services to a substantial percentage of African American and other vulnerable populations in Allegheny County.

Margaret Smith Washington focuses on doctor-patient communication, emphasizing that patients must assume responsibility for self-managing their diagnosis based on sound medical advice and not on observations of others with similar diagnoses. She recommends a series of action steps that include making a commitment to learn about their illness, using their physicians as resources in the learning process, and recognizing the importance of communicating their fears and frustrations in a manner that seeks a clearer understanding.

The overall theme of this follow-up book to the *Black Papers*, therefore, is that significant health disparities continue to exist for African Americans in Allegheny County. There are scattered county, state, and federal programs that focus on individual disparities, but the gaps in health between minority and majority populations have not narrowed and, in many cases, have widened. These papers are a call for community and governmental action and for strategic planning and resource allocation to address this growing problem!

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## Endnotes

<sup>i</sup> [www.achd.net/biostats/pubs/Gabe/disparities.html](http://www.achd.net/biostats/pubs/Gabe/disparities.html).

<sup>ii</sup> [www.wilsoncenter.org/index.cfm?topic\\_id=116811&fuseaction=topics.event\\_summary&event\\_id=224806](http://www.wilsoncenter.org/index.cfm?topic_id=116811&fuseaction=topics.event_summary&event_id=224806)

<sup>iii</sup> [www.wilsoncenter.org/index.cfm?topic\\_id=116811&fuseaction=topics.event\\_summary&event\\_id=224806](http://www.wilsoncenter.org/index.cfm?topic_id=116811&fuseaction=topics.event_summary&event_id=224806)

<sup>iv</sup> [www.dsf.health.state.pa.us/health/cwp/view.asp?A=175&Q=240950](http://www.dsf.health.state.pa.us/health/cwp/view.asp?A=175&Q=240950).

<sup>v</sup> [www.dsf.health.state.pa.us/health/cwp/view.asp?A=175&Q=240950](http://www.dsf.health.state.pa.us/health/cwp/view.asp?A=175&Q=240950).

## MOVING FORWARD ON ACHIEVING HEALTH EQUITY IN PITTSBURGH

More than one hundred years ago, in 1909, the first effort to capture racial health disparities in Pittsburgh was published as part of *The Pittsburgh Survey*, a pioneering work in urban sociology. The one chart on health in the six volumes of the survey documented infant mortality in Homestead. It defined three racial groups: 1) Slavs; 2) English-speaking Europeans; and 3) native whites and coloreds. The English-speaking Europeans had the least infant mortality, the Slavs the most, and native whites and coloreds were in-between.

You are reading that correctly. At one point in history, race was determined differently in Pittsburgh. And Slavs, using infant mortality as a standard, appear to have had the worst health status. Since then, neither the categories nor the findings have stayed fixed.

Ten years ago, I approached Ralph Bangs (who today serves as the Associate Director of the Center on Race and Social Problems at the University of Pittsburgh), who had been documenting the social and material circumstances of African Americans in Pittsburgh, to see what information existed about their health status. In doing so, I was influenced by work emerging out of the United Kingdom, which clearly tied health status and health equity<sup>1</sup> to the material and social determinants of health and not solely to health care services.

Esther Bush and the Urban League of Greater Pittsburgh shared our interest and passion for the topic, which led to the birth of the first edition of the *Black Papers on African American Health in Allegheny County (Black Papers)*. Bangs found two willing graduate students, Haslyn Hunt and Trista Sims, to help us pull the data together.

Our goal was to develop local information for local use—to prompt action to achieve health equity. In this I was hoping to capitalize on Bangs' previous method, which had emphasized the importance of local data in prompting local mobilizations for action. I had seen how his Benchmark studies hit a nerve in Pittsburgh.

The first *Black Papers* was successful—to some degree. The dismal news the papers announced got some local attention, especially in the African American community. It helped bring Pittsburgh into the national health equity dialogue.

Given our desire for action, in an attempt to create a framework of accountability, we hoped at some time to issue future volumes to capture what happened as time passed. It has taken some time, more than we would have liked, but you now hold the result of that hope in your hands. These papers document in much greater detail than the first *Black Papers* what is occurring in multiple health/illness domains in Pittsburgh's African American community. It is good to see that we now have many more people and institutions tackling critical aspects of the problem. This is real progress.

But it is slow progress. Almost 10 years have passed. Our interventions remain largely focused on health care services. Important as they are, they do not have the power to mitigate the deeper socioeconomic determinants of health that continue to injure and kill African Americans in Allegheny County earlier and in greater number than other racial/ethnic groups.

What can be done about this? It is essential that we keep working on improving our health care services and broaden their capacity to promote and protect the health of African Americans. I do not want to detract from current efforts in any way, but we must not pretend that they are enough to get us to the destination of health equity. Rather, I hope that the dismal news again found in these pages will not be viewed as being in the domain of health services alone. No, we need to mobilize a broad inter-sectoral approach, one that links economic and community development with health by connecting educational institutions, business, labor, religious organizations, civil society, health and human services, and government in an effort to overcome the historic exclusion from the region's resources that continues to plague the Black community. We need to create a politics that will support this.

Perhaps an example might help. In cities in the United Kingdom, arguably many years ahead of us in the struggle for health equity,<sup>ii</sup> inter-sectoral work to eliminate health inequities (and a host of other co-occurring bad social outcomes) has come to focus on two measurable primary goals: 1) achieving equity in employment between social groups at the highest rate of employment possible; and 2) eliminating child poverty.

Obviously, these are not just health outcomes. They are far upstream—in the realm of Bangs' original Benchmark studies. Nonetheless, overcoming joblessness and child poverty is critical to achieving health equity. They are, by their nature, not based on race/ethnicity alone. Significant portions of the European American population suffer from their effects, as does our small but growing Latin American community. This does not mean that addressing race/ethnicity is unimportant. Rather, it means that we as a community have to develop strategies of social inclusion that can work for different populations when those differences are critical, but can pull them together when the shared issues are stronger than those that separate them (and us).

Perhaps we should be as bold as cities in the United Kingdom in our aspirations. I look forward to a third volume of the *Black Papers* (in much less than 10 years) that documents improvements in the health and well-being of Black Pittsburgh, and other socially excluded persons and communities, and that charts the evolution of a broad coalition of persons and institutions striving for social inclusion and equity in health for all. Why shouldn't Pittsburgh reach as far as it can for its people?

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## Endnotes

<sup>i</sup> I have long preferred the term “health equity” to “health disparities” for several reasons: 1) it suggests the goal in a positive sense; 2) it connotes an effort to overcome injustice; and 3) another meaning of the word equity is that of ownership—achieving health equity in this sense implies having gained a share of the health of the community.

<sup>ii</sup> The British coined the term.

## CHAPTER 1. HEALTH CHALLENGES FACED BY AFRICAN AMERICANS

Anthony G. Robins, PhD

### Introduction

To wrangle over the obvious is imprudent. Yet, scientists, politicians, policy makers, and power brokers find it easy to dispute the health crisis among African Americans in the United States. However, anyone who reads the local newspaper, engages the popular press, or scans national media is often struck by the persistent widening differences in health status between African Americans and U.S. whites. Interestingly, the evidence shows that African Americans have a lower life expectancy at birth than any racial group in either gender. More, African Americans have higher overall rates of death than white Americans and a higher prevalence of preventable diseases. Overall, African Americans are less likely to have health insurance—and less likely to access health care services—than white Americans in the United States. When they do access health care, they are more likely to receive inadequate care compared with white Americans. Add to this the fact that African Americans experience higher levels of poverty, unemployment, incarceration, and discrimination than their white counterparts, and the scope and depth of the health crisis are clearer still.

Health challenges faced by African Americans are complex and multilayered. At the core of these challenges lies the misunderstanding of cultural influences that tailor responses to these issues. At another level, issues of race and ethnicity— notions of race as biology rather than an understanding of the socially constructed nature of race and racism—contribute to disparities in health. These disparities are driven by the tension between the effect of structural barriers African Americans face within the health system and beliefs about the individual's responsibility for healthy behaviors to promote and preserve health. These layers are interrelated and represent the essential foundation for a set of strategies to improve the health of African Americans. By looking critically at both the health issues affecting African Americans and the influences that shape them, we can grow to understand the challenges, identify the policy opportunities, and develop promising approaches to improving health outcomes.

The intent of this chapter is to provide information about the health status of African Americans and to detail some of the underlying causes that have the potential to change the landscape of African Americans' health status. These images and stories give life to the problems of those who combat poor health outcomes. However, these chronicles do not address the size and changing nature of these differences, nor do they give their causes and effects. When the argument is considered at a national level, evidence that speaks to unique challenges faced by this population is lost in analysis. Often, the numbers appear too small to measure any true effect. This begs of researchers to study the problem at geographic designations other than national. This chapter takes a snapshot of challenges faced by African Americans living in Allegheny County, Pennsylvania—a county with one of the top health care systems in the United States. Because Allegheny County can boast of such status, this region makes an ideal site to engage surveillance work to gauge alleged health challenges faced by African Americans.

Results from such work have strong implications for advocacy and policy changes at national levels.

### **Allegheny County's African American Population**

The majority of Allegheny County's African American population lives in the eastern section of the county, with the largest representation in Pittsburgh, Pennsylvania (the county seat). The demographics of Allegheny County show a predominantly white (82.8%), female (52.4%) group where more than 78 percent are 18 years and older. Nearly 90.5 percent of the population are high school graduates (includes equivalency). More than 8 percent of all families live below poverty. The total population of Pittsburgh is 47.6 percent male and 52.4 percent female, more than 80 percent are at least 18 years of age, nearly 15 percent of families live below the poverty level, and more than 80 percent have at least a high school diploma. African Americans make up 27.1 percent of Pittsburgh's population, a little more than two times the African American population represented by the U.S. population (12.4%). (See Table 1.)

### **The Health Crisis Among African Americans**

African Americans suffer a disproportionate burden of preventable morbidity and mortality. African Americans have historically had less access to care in terms of insurance coverage, availability of culturally competent providers, adequate availability of providers and services within communities, and appropriate outreach and education. What follows is a brief review of some data that speak to health challenges that disproportionately affect African Americans. While not exhaustive, the review is intended to highlight the pervasive nature of the disparities across health issues.

### **Mortality and Life Expectancy**

In Allegheny County, African Americans live an average of 5.7 years less than whites. African American females outlive white males by an average of 2.4 years and African American males by an average of 7.8 years. The death rate of African American females in the county is 1.8 times the Healthy People 2010 (HP 2010) goal for colorectal cancer, 1.7 times the goal for heart disease, 1.5 times the goal for breast cancer, 1.4 times the goal for stroke, and 1.3 times the HB 2010 goal for unintentional injuries. African American males in the county die from homicide at 19 times the national goal and from unintentional injuries at 3.8 times the goal.

According to local reports, mortality rates for lung, colorectal, and prostate cancers are more than two times the national goals. In relation to African American infant mortality, the local rate is about four times the Healthy People 2010 goal, higher than state and national rates, and more than three times the white rate.

When the top 10 leading causes of death among African Americans are considered at both at the county and national levels, an interesting picture emerges. (See Table 2.) While heart disease ranks as number one nationally, homicide is the leading cause of preventable death in Allegheny County. Heart disease ranks second in the county. When we mull over the top causes

of preventable deaths, diabetes finds itself as the tenth leading cause. This ranking lends itself to strong implications of appropriating funds to combat the most pressing causes, as well as developing policies to address factors that drive these causes.

When deciding who is at greater risk for certain health outcomes, African Americans' probability of being exposed to and dying from certain challenges is higher than other populations. (See Table 3.) The list is long and disturbing. For example, African Americans are 17.1 times more likely to die from homicide, 11.7 times more likely to die from HIV, 2.9 times more likely to die from nephritis, 2.3 times more likely to die from diabetes, and 2.0 times more likely to die from congenital anomalies than their white counterparts. Table 3 also reports trends over time. With the exception of homicide, HIV, diabetes, nephritis, and congenital anomalies, African Americans have continued to die at increased numbers, although the Black/White ratios have changed little over time.

When one considers the age at death in addition to the number of deaths, a different picture emerges. (See Table 4.) This alternative method measures years of potential life lost (YPLL) and yields a different rank ordering. Based on potential life lost, the leading challenge to Allegheny County residents is cancer (8,569 YPLL). This cause has robbed more prematurely productive years from residents than other leading causes of death. Unintentional injuries emerge as the second leading cause when based on potential life lost (7,897 YPLL). Similarly, heart disease (which ranks first under the traditional rankings) falls to third based on potential life lost (6,873 YPLL). "Violent deaths," defined as deaths due to unintentional injuries, suicide and homicide, take on notably higher rankings. In terms of potential years of life lost, unintentional injuries, suicide, and homicide would rank second, sixth, and fifth, respectively. If all "violent deaths" were taken together as a single group, they would rank first in terms of years of potential life lost (14,861 YPLL).

The YPLL also yields strikingly different results within the race and gender groups. For males, the two leading causes are unintentional injuries and heart disease. For females, the leading causes are cancer and unintentional injuries. For whites, the leading causes are cancer and unintentional injuries, while for Blacks, the leading causes are homicide and perinatal conditions.

## **Morbidity**

Early detection and treatment of diseases can reduce morbidity and mortality from ailments associated with certain chronic diseases. Although effective strategies have been identified to reduce risks of morbidity and mortality, African Americans continue to be disproportionately burdened by disease and illness, resulting in the pain and suffering of individuals and families. Excess morbidity and mortality among African Americans is due to barriers to care that result in low use of health services, lack of appropriate and targeted health promotion activities for African Americans, and increased risks due to unnatural causes (e.g., poverty, racism, unemployment).

A thumbnail sketch of morbidity found in African Americans in Allegheny County can be shown by engaging surveillance efforts in selected zip codes found in the eastern portion of the county. The majority of Allegheny County's African American population lives in the eastern portion of the county, with the largest representation in Pittsburgh, Pennsylvania. To secure that there would be an adequate amount of population to engage these efforts, only zip codes with census tracts that had at least 60 percent African American population were included in the randomization. Eight zip codes met criteria. (See Table 5.) The top three illnesses found in this sample were heart disease, stroke, and diabetes.

African Americans living in the 15219 zip were 30 percent more likely to have the diagnosis of cardiovascular disease at discharge from a local hospital as compared to whites in the same zip code. (See Table 6.) In the 15208 zip code, African Americans were 80 percent more likely to have the diagnosis of stroke at discharge as compared to whites in the same zip code. (See Table 7.) In the 15213 zip code, African Americans were 30 percent more likely to have the diagnosis of stroke at discharge as compared to whites (Table 7). In zip 15219, African Americans were 120 percent more likely to have been diagnosed with stroke at discharge as compared to their white counterparts (Table 7). In the 15147 zip code, Blacks were 180 percent more likely to have a diagnosis of type 2 diabetes at discharge as compared to whites in the same zip code. (See Table 8.) African Americans in zip 15206 were 250 percent more likely to have a diagnosis of type 2 diabetes at discharge as compared to whites (Table 8). In the 15207 zip code, African Americans were 200 percent more likely to have a diagnosis of diabetes at discharge as compared to whites (Table 8). For the 15208 zip code, African Americans were 240 percent more likely to have a diagnosis of diabetes at discharge as compared to whites (Table 8). In the 15213 zip code, African Americans were 670 percent more likely to have a diagnosis of diabetes at discharge as compared to whites (Table 8).

## **Conclusion**

This chapter is a call for both dialogue and action. In tandem, the scientists, politicians, policy makers, power brokers, and African Americans in affected communities must consider the dramatic disparities in health found in Allegheny County, Pennsylvania, and respond. A coordinated response to the health issues affecting African Americans will help us to reclaim a lost potential for health and productivity and to contribute much to our health as a community.

Rather than focusing on specific diseases, a more integrative model of African Americans' health should be developed, with a well-defined set of core issues that affect the health of the population overall and the African American population in particular. This framework could be applied not only to the development of clinical services but also to the formulation of funding initiatives and to the training of medical and other health professionals.

In sum, Allegheny County, Pennsylvania, is a microcosm of what is happening at the national levels: the burden of disease, mortality risk, and rates of hospitalization are concentrated in those parts of the population with the poorest health. The need for a preventive focus is reflected in higher rates of potentially preventable mortality and morbidity in disadvantaged

populations. Developing expertise in tailoring programs/ interventions to those with the highest level of risk will be essential.

Characteristic	Pittsburgh (n = 297,061)	Allegheny County (n = 1,223,411)	U.S. (n = 301,139,947)
% Black	27.1	12.8	12.4
% White	67.6	82.8	73.9
% Male	47.6	47.6	49.2
% Female	52.4	52.4	50.8
% 18 years and older	82.4	78.7	75.4
% high school graduate	86.3	90.5	84.1
% family living below poverty	14.9	8.4	9.8

Rank	Causes	
	U.S.	Allegheny County
1	Heart Disease	Homicide
2	Cancer	Heart Disease
3	Cerebrovascular problems (stroke)	Cancer
4	Diabetes	Perinatal conditions
5	Unintentional injury	Unintentional injury
6	Homicide	Congenital anomalies
7	Nephritis or kidney disease	Cirrhosis and chronic liver disease
8	Chronic lower respiratory disease	HIV
9	HIV	Suicide
10	Septicemia or bacteria in the blood	Diabetes

Table 3. Selected Causes of Death Among Allegheny County Residents, Black/White Ratio of Age-Adjusted Rates, 2000-2004, per 100,000 population					
Cause of Death	2004	2003	2002	2001	2000
Heart disease	1.3	1.3	1.3	1.2	1.4
Cancer	1.3	1.2	1.3	1.4	1.4
Stroke	1.3	1.6	1.4	1.3	1.7
CLRD	1.0	1.1	1.0	0.8	1.1
Unintentional injuries	1.2	1.4	1.3	1.3	1.8
Diabetes	2.3	2.1	1.9	2.1	2.2
Nephritis (kidney disease)	2.9	2.4	1.8	2.1	2.0
Pneumonia & influenza	1.0	1.0	1.2	0.9	1.4
Septicemia	1.7	1.7	1.6	2.4	2.1
Suicide	0.8	0.8	0.9	0.5	1.2
Cirrhosis and chronic liver disease	1.5	1.4	1.0	1.5	1.8
Homicide & legal intervention	17.1	22.8	18.2	17.7	11.6
Congenital anomalies	2.0	1.6	1.9	1.1	1.3
HIV	11.7	10.6	13.0	9.8	9.5
Total Causes	1.4	1.4	1.4	1.4	1.5

Cause of Death	Total		Male		Female		White		Black	
	Rank	Years								
Heart Disease	3 <sup>rd</sup>	6,873	2 <sup>nd</sup>	4,803	3 <sup>rd</sup>	2,070	3 <sup>rd</sup>	5,283	4 <sup>th</sup>	1,580
Cancer	1 <sup>st</sup>	8,569	3 <sup>rd</sup>	4,399	1 <sup>st</sup>	4,170	1 <sup>st</sup>	7,217	5 <sup>th</sup>	1,282
Stroke	8 <sup>th</sup>	1,232	9 <sup>th</sup>	610	7 <sup>th</sup>	622	7 <sup>th</sup>	857	8 <sup>th</sup>	375
CLRD		655		285	9 <sup>th</sup>	370		465		175
Pneumonia & Influenza		562		310		252		422		95
Unintentional injuries	2 <sup>nd</sup>	7,897	1 <sup>st</sup>	5,283	2 <sup>nd</sup>	2,614	2 <sup>nd</sup>	6,182	3 <sup>rd</sup>	1,605
Motor vehicle accidents		2,094		1,429		665		1,500		534
Diabetes	10 <sup>th</sup>	830	10 <sup>th</sup>	545		285	10 <sup>th</sup>	535	10 <sup>th</sup>	280
Nephritis, kidney disease		430		225		205		225		205
Other diseases of the arteries		80		15		65		60		20
Septicemia		455		295		160		310		145
Cirrhosis and chronic liver disease	9 <sup>th</sup>	1,040	7 <sup>th</sup>	685	10 <sup>th</sup>	355	8 <sup>th</sup>	855		185
Suicide	6 <sup>th</sup>	3,305	6 <sup>th</sup>	2,595	5 <sup>th</sup>	710	5 <sup>th</sup>	2,760	6 <sup>th</sup>	530
Parkinson's disease		5		5		0		5		0
Alzheimer's disease		25		0		25		25		0
Homicide & legal intervention	5 <sup>th</sup>	3,659	5 <sup>th</sup>	3,060	8 <sup>th</sup>	600	9 <sup>th</sup>	610	1 <sup>st</sup>	3,050
Atherosclerosis		5		5		0		0		5
Perinatal conditions	4 <sup>th</sup>	5,612	4 <sup>th</sup>	3,870	4 <sup>th</sup>	1,742	4 <sup>th</sup>	3,096	2 <sup>nd</sup>	2,516
Benign & unspecified cancer		220		120		100		180		40
Congenital anomalies	7 <sup>th</sup>	1,284	8 <sup>th</sup>	628	6 <sup>th</sup>	657	6 <sup>th</sup>	971	9 <sup>th</sup>	314
HIV		785		435		350		305	7 <sup>th</sup>	480
All other causes		7,167		4,353		2,813		4,849		2,276
<b>Total All Causes</b>		<b>50,690</b>		<b>32,526</b>		<b>18,165</b>		<b>35,212</b>		<b>15,158</b>

Zip Codes with Census tracts made up of 60% African American population	Neighborhoods
15147	Penn Hills
15206	Lincoln-Lemington-Belmar
	East Liberty
	Larimer
	Garfield
15207	Glen Hazel
15208	Point Breeze North
	Homewood South
	Homewood North
	Homewood West
15213	Terrace Village
	Upper Hill
15219	Crawford Roberts
	Terrace Village
	Middle Hill
	Bedford Dwellings
	Upper Hill
15221	Homewood North
	East Hills
	Wilksburg
15224	Garfield

Zip Code	African American Age-Adjusted Rate	White Age-Adjusted Rate	Rate Ratio*
15147	1971.75	3685.85	0.5
15206	2132.85	2391.38	0.9
15207	2468.64	2993.89	0.8
15208	2248.64	2993.89	0.8
15213	1345.50	1366.02	1.0
15219	1968.44	1508.42	<b>1.3</b>
15221	2134.90	3301.86	0.6
15224	1707.63	3176.28	0.5

\*Bolted item represents racial disparity where African Americans are significantly at greater risk for cardiovascular disease as compared to their white counterpart.

Table 7. Stroke Morbidity found in Allegheny County Residents Living in Selected Zip Codes (2001-2005), per 100,000 population			
Zip Code	African American Age-Adjusted Rate	White Age-Adjusted Rate	Rate Ratio*
15147	1706.89	2093.12	0.8
15206	1894.52	1397.29	<b>1.4</b>
15207	1416.43	1703.76	0.8
15208	1950.92	1076.26	<b>1.8</b>
15213	1185.86	896.28	<b>1.3</b>
15219	1514.19	682.76	<b>2.2</b>
15221	1684.84	1931.16	0.9
15224	1216.04	1799.89	0.7

\*Bolted item represents racial disparity where African Americans are significantly at greater risk for cardiovascular disease as compared to their white counterpart.

Table 8. Diabetes Morbidity found in Allegheny County Residents Living in Selected Zip Codes (2001-2005), per 100,000 population			
Zip Code	African American Age-Adjusted Rate	White Age-Adjusted Rate	Rate Ratio*
15147	1059.45	378.35	<b>2.8</b>
15206	1008.37	291.97	<b>3.5</b>
15207	1740.19	571.20	<b>3.0</b>
15208	1242.43	369.00	<b>3.4</b>
15213	1254.28	161.98	<b>7.7</b>
15219	1028.05	269.93	<b>3.8</b>
15221	1280.94	383.80	<b>3.3</b>
15224	1060.80	595.55	<b>1.8</b>

\*Bolted item represents racial disparity where African Americans are significantly at greater risk for cardiovascular disease as compared to their white counterpart.

## **CHAPTER 2. CHILD AND ADOLESCENT DISPARITIES IN ALLEGHENY COUNTY**

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### **Introduction**

Good health for our nation's children and adolescents is essential for growth, cognitive development, and academic performance. Although gains have been made in overall health over the years, racial disparity in child and adolescent health still remains a prominent feature of the American experience. According to Pokras and Baquet (2002), health disparity is a chain of events that is signified by differences in environment; access to, utilization of, and quality of care; and health status. It is represented by indices such as heightened mortality and morbidity and a truncated life span. Today, African American children and adolescents have poorer health and higher death rates than their white counterparts.

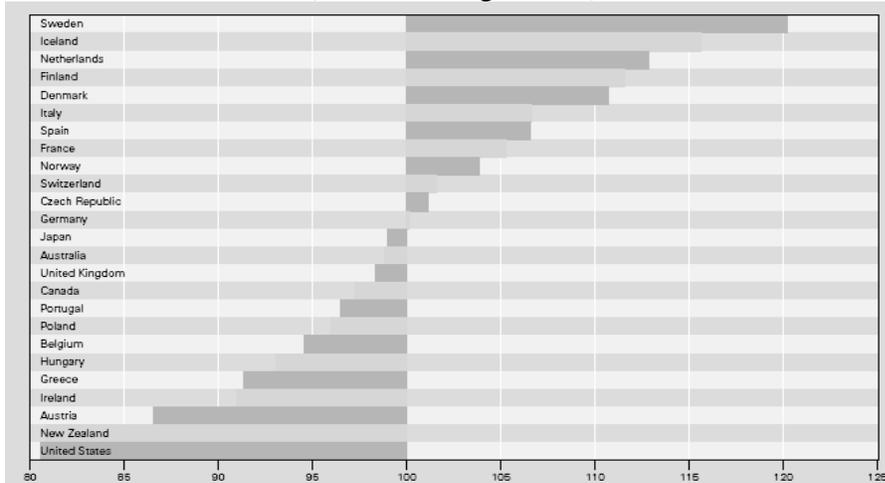
This chapter will focus on child and adolescent health disparities in the United States, with particular emphasis on Allegheny County. It will highlight the current status and trends in health disparity and identify the root causes of the disparity, as well as the consequences. Finally, the chapter will offer suggestions on how the racial gap in adolescent and children's health could be narrowed or eliminated.

### **Snapshot of Child and Adolescent Health in America**

The UNICEF Report Card provides a comprehensive assessment of the lives and well-being of children and young people in 21 nations of the industrialized world. The report uses income poverty as a proxy measure for overall countries. The study measures and compares child well-being under six different headings or dimensions, with one being child health and safety. When assessing child health and safety, three components and indicators are used to measure each OECD country. For example, component one is a child's health at birth to 1 year old, with emphasis on the number of infants dying before age one per 1,000 births and the percentage of infants born with low birth weight (< 2,500 g.). Component two is preventative health service, which is the percentage of children ages 12-23 months immunized against measles, DPT, and polio. And, last, component three focuses on death from accidents and injuries per 100,000 from birth to age 19.

Figure 1 displays how each country is measured above or below the OECD average of 100. In 2007, the United States was below the average and last among other countries when it came to the health and safety of American children.

Figure 1. Index for Child Health and Safety in OECD Countries  
(OECD average = 100)

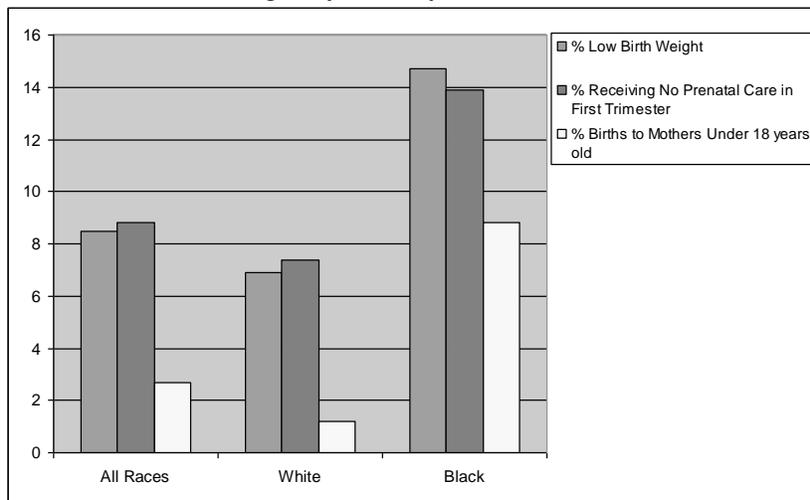


Source: *UNICEF*, Innocenti Research Center Report Card 7, 2007 on-line site [www.unicef-irc.org/publications/pdf/rc7\\_eng.pdf](http://www.unicef-irc.org/publications/pdf/rc7_eng.pdf)

### Conditions and Trends in Allegheny County

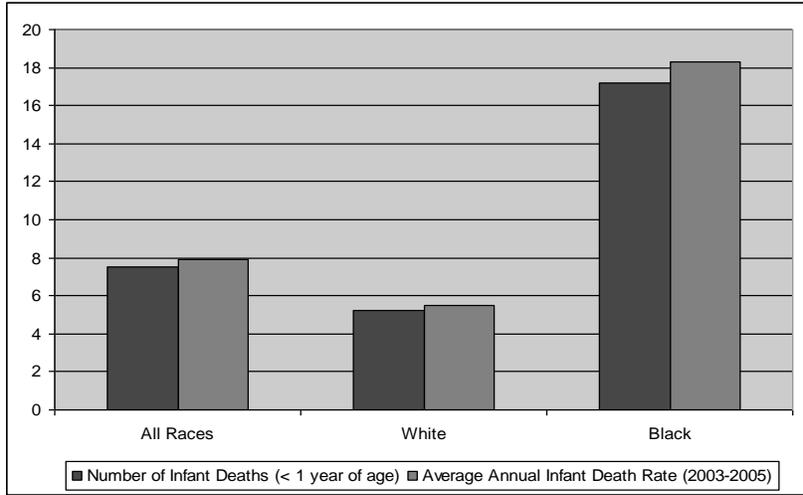
From birth, African American children in the United States and Allegheny County fare worse than their white counterparts. Figure 2 shows the natality and the number of reported pregnancies in 2005. According to the data for Allegheny County, the percentage of African American babies with low birth rate roughly doubles that of white babies in 2005. Figure 3 shows that Black infants were more likely to die and lead in infancy death rates between 2003 and 2005 than white infants.

Figure 2. Natality and Reported Pregnancies by Race  
in Allegheny County, 2005 Residents



Source: Allegheny County, Health Profile 2007 [www.dsf.health.state.pa.us/health/countyprofiles/2007/allegheny.pdf](http://www.dsf.health.state.pa.us/health/countyprofiles/2007/allegheny.pdf)

Figure 3. Mortality by Race in Allegheny County, 2005 Residents



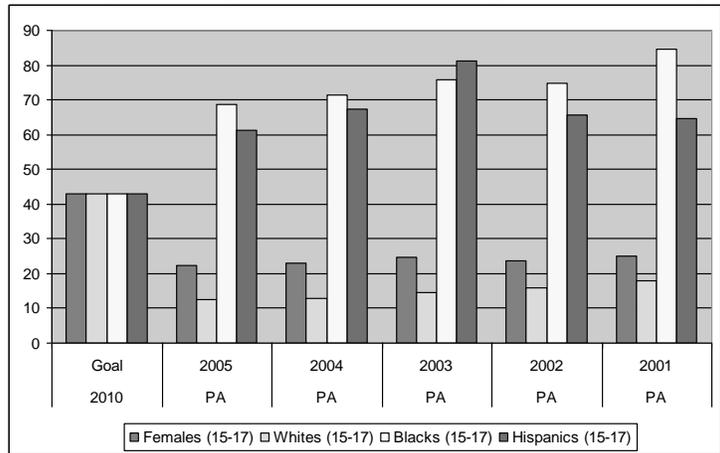
Source: Allegheny County, Health Profile 2007  
[www.dsf.health.state.pa.us/health/countyprofiles/2007/allegheny.pdf](http://www.dsf.health.state.pa.us/health/countyprofiles/2007/allegheny.pdf)

In addition to the racial disparity in infant birth rate and mortality, evidence of grave disparities exists in other areas of health, particularly teenage pregnancies, dental care, asthma, and obesity. These disparities are highlighted below.

*Teenage Pregnancy*

In terms of adolescent pregnancy, African American and Hispanic adolescent females overwhelmingly continued to have high pregnancy rates compared to white adolescent females in the state of Pennsylvania (see Figure 4).

Figure 4. Pregnancies per 1,000 Females Age 15-17, Pennsylvania



"Tracking Healthy People 2010 Objectives: Family Health Statistics for Pennsylvania and Counties-2005 Report," Pennsylvania Department of Health, Bureau of Health Statistics and Research, Harrisburg, PA, Sept. 2005.

## *Dental Health*

Tooth decay is an infectious disease that continues to affect a high percentage of U.S. children despite clinical advances. Social, economic, and other environmental factors like regular checkups can influence one's outcome for dental health. "Children from low-income households, particularly African American and Hispanic children, are likely to experience more severe forms of the disease and more likely to have greater difficulty accessing the services necessary to control this disease and restore the damage it causes" (NHSA Dialog Briefs, Spring 2007).

The Allegheny County Health Department Dental Program provides preventive and corrective treatment for children 1-20 years of age. Data obtained on this program show that minorities are overrepresented as clients. They make up 38 percent of the program's clients but only 12.5 percent of the population of Allegheny County (Allegheny County Health Department).

If left untreated, serious biological consequences of tooth decay may occur. This could include severe abscess of the tooth (pain, swelling of jaws and face) that can spread infection to other areas of the body (brain, heart, blood stream). This was the unfortunate circumstance for one African American 12-year-old child in 2007. The homeless Maryland boy died in a hospital after a dental infection from a molar spread to his brain. The family's Medicaid lapsed and even on the state plan, the children lacked regular dental care and also had difficulty seeking a dentist.

## *Asthma*

Asthma is another major health problem among children and adolescents in the United States and Allegheny County. Asthma is defined as a chronic disease that creates breathing difficulties and affects the entire respiratory system. The Centers for Disease Control and Prevention<sup>1</sup> (CDC) reported that asthma affects children and adolescents in the following ways: (1) asthma accounts for 14 million lost days of school missed annually. [In fact, the Pennsylvania Department of Health report showed that during the 2005-2006 school year, the health data indicated that of the 188,686 students enrolled, more than 20,000 (11%) of the students were reported to have asthma in Allegheny County.]; (2) asthma is the third-ranking cause of hospitalization among those younger than 15 years of age; (3) the number of children who died from asthma increased threefold—from 93 in 1979 to 266 in 1996; and (4) the estimated cost of treating asthma in those younger than 18 years old is \$3.2 billion a year.

African American children are more exposed to environmental pollutants that are risk factors for asthma. Some of these factors include dampness, mold, lead, and inadequate ventilation in impoverished urban settings. Consequently, African American children have higher rates of asthma than whites. (See Table 1.) The U.S. Department of Health and Human Services reported in Healthy People 2010 that African Americans are almost three to four times as likely as whites to be hospitalized for asthma.

Table 1. Child and Youth Asthma Rates by Race in the U.S.

Race	Ages 1 to 18	Ages 6 to 18
Black, non-Hispanic	19.2	19.7
White, non-Hispanic	13.9	14.8

Source: 2001-2002 National Health and Nutrition Examination Survey.  
Calculations by the Children’s Defense Fund.

### *Obesity*

Childhood obesity has become a major epidemic in American society. Obesity is defined as an individual being significantly overweight, which can, in turn, lead to chronic diseases and disabilities such as diabetes, high blood pressure/hypertension, heart disease, and joint/muscular problems. According to epidemiologist Cynthia Ogden,<sup>ii</sup> the percentage of 6- to 11-year-olds classified as obese rose from 6.5 percent in 1980 to 16.3 percent in 2002. More than one in six adolescents ages 12-19 were overweight in the United States in 2003-2004, which was more than triple the rate in 1976-1980 (Child Trends, 2006). A recent CDC study by Ogden published in the *Journal of the American Medical Association (JAMA)* suggested that child obesity rates may have leveled off to around 32 percent within recent years. However, Ogden cautions that this is not a comfortable position to be in. She elaborates that having more than 30 percent of children overweight is still not a healthy statistic.

There is a large disparity in the prevalence of obesity between Blacks and whites. In 2003-2004, non-Hispanic Blacks ages 12-19 were more likely to be overweight (25%) than non-Hispanic whites (15%), and Mexican Americans (14%). A closer look at the differences by gender reveals that in that same year, more than a quarter of non-Hispanic Black females ages 6-19 were overweight. It is postulated that the increase in obesity in the United States and other OECD countries will have significant implications for future incidence of health problems and spending (OECD Health Data 2008).

### **Root of the Problem**

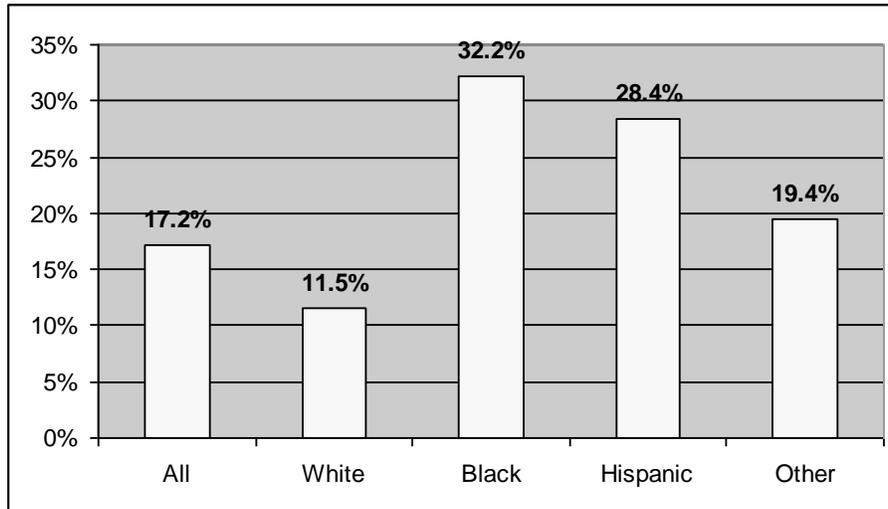
For decades, a myriad of theories have been offered as possible explanations for the disparity in health between Blacks and whites. Three of the more common explanations presented are socioeconomic factors, lack of access to quality care, and environmental conditions (Children’s Defense Fund, 2006).

### *Socioeconomic Factors*

About 39 percent of the nation’s children, nearly 29 million in 2006, live in families with low incomes—that is, incomes below twice the official poverty level (\$42,400 for a family of four in 2008). Approximately 60 percent of Black and Latino children live in low-income families, compared to about 26 percent of white and Asian children (National Center for Children in Poverty, 2008). The Children’s Defense Fund 2006 Black Child Health fact sheet also provides support for this situation. According to its report, one in three Black children is poor; and the number of Black children increased by 196,000 in the past six years, to reach 3.8

million in the United States. Also, of the 5.5 million children living in “extreme poverty”<sup>iii</sup> in America, 1.8 million are Black. As a result, these parents do not always have the resources to devote to making healthy choices for their children. Figure 5 demonstrates the percentage of the population living in poverty by race.

Figure 5. U.S. Poverty Rates by Race/Ethnicity, 2006-2007



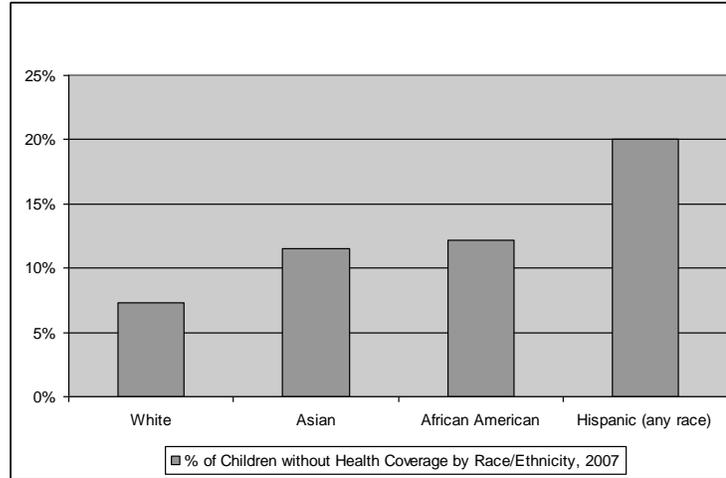
Source: Urban Institute and KCMU Analysis of the Current Population Survey, March 2007 and 2008, from *Kaiser Family Foundation*, 2009

Similarly, the educational level of the parents is significantly related to the health of the children. Children with fair to poor health are more likely to live in impoverished households where the parents have the least level of education. “Eighty-two percent of children whose parents have less than a high school diploma live in low-income families (Koball et al., 2006).”

#### *Access to Health Care*

Another reason for the disparity in child and adolescent health is the lack of access to quality care. Many minorities do not have health coverage and, consequently, have poorer health outcomes than whites. A recent fact sheet by Families USA<sup>iv</sup> reported that there were 8.1 million uninsured children in the United States and more than 5 million of them were children of color. Figure 6 demonstrates the racial disparity in health insurance coverage in 2007.

Figure 6. Percentage of Children without Health Coverage by Race/Ethnicity, U.S., 2007



Source: U.S. Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States 2007*, on-line site <http://www.census.gov/prod/2008pubs/p60-235.pdf>.

*Environmental Conditions*

Environmental conditions are another explanatory factor for the racial disparity in health outcomes. A 2007 report by Dr. Goutham Rao<sup>v</sup> noted, “There is evidence that there are important racial disparities in the quality of our built environment.” For example, lead toxicity in homes has been recognized as having a strong link to asthma. According to 2006 child health statistics by *Child Trends*, one out of every 20 children in the United States has had some lead poisoning but has not necessarily exhibited visible signs or symptoms. More African American children than whites live in homes with high lead contents. The rates of lead poisoning among children by race are shown in Table 2.

Table 2. Lead Poisoning among Children in the U.S. (with lead levels over 5  $\mu$ g/dL)<sup>vi</sup>

Race	All Children (1 to 18)	Ages 1 to 5
Black, non-Hispanic	7.0	17.4
White, non-Hispanic	2.5	7.0
Hispanic	2.8	6.3

Source: 1997-2000 and 2001-2002 National Health and Nutrition Examination Survey, Calculations by the Children’s Defense Fund, October 2004.

In terms of obesity, where one lives can have a tremendous impact on food options and, consequently, on one’s weight. It is suggested that low-income African Americans, including those in Allegheny County, are much more likely to live in communities where the only food available comes from fast-food restaurants and gas stations.

## Consequences

Racial health disparities can have far-reaching and enduring impacts on other social aspects of the lives of African Americans. Two of the more direct ways are cognitive development and educational achievement.

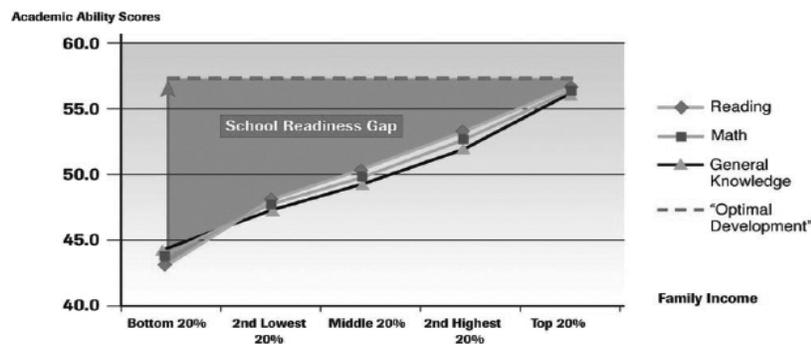
### *The Correlation Between Health and Cognitive Development*

One of the ways poor health impacts children and adolescents is to slow their brain, cognitive, and behavioral development. “Children who suffer from poor nutrition during the brain’s most formative years score much lower on tests of vocabulary, reading comprehension, arithmetic, and general knowledge (Brown and Pollitt, 1996).” “Six to eleven year old children from food insufficient families had significantly lower arithmetic scores and were more likely to have repeated a grade (Alaimo et al., 2001).” Children who do not receive the proper nutritional foods not only have stifled physical health but also cognitive problems that ultimately affect their academic performance.

### *Educational Achievement*

A 2008 *Action for Healthy Kids* report<sup>vii</sup> showed that a growing body of research indicates that poor nutrition, physical inactivity, and obesity are associated with lower student achievement. These conditions are particularly common among underserved children and children in high-risk areas, many of whom are minorities. The relationship between low income and academic achievement is depicted in Figure 7. “The links between children’s development may involve ‘connecting the dots’ through effects on important social outcomes including educational attainment and/or health-related behaviors (Robert Wood Johnson Foundation, 2008).”

Figure 7. School Readiness



Source: U.S Department of Education, National Center for Education Statistics, Early Childhood Longitudinal Study, Kindergarten Class of 1998-99.

### *Higher Rates of Delinquency*

In addition to affecting academic outcomes, poor health in children can lead to higher rates of delinquency and arrests later in adolescence (Robert Wood Johnson Foundation, page 3).

This is evident in the huge disparity in incarceration rates in the United States. African American youths made up 12 percent of the population but were arrested at rates double those for Caucasian youth (Center on Juvenile and Criminal Justice).

### *Social Exclusion*

Disparities in health can lead to differences in social outcomes. For example, obesity can have psychosocial effects on an individual, which can, in turn, affect his or her inclusion in groups. Obese children and adolescents face social isolation in environments including school, society, and even in their home life. Part of a healthy childhood is positive social development such as attitude and self-esteem. However, in educational settings, teasing and bullying increase for obese children because these children are depicted as lazy and unsociable. If intervention is not applied, this can lead to obese children and adolescents emotionally scarred well into their adult lives.

### **Policy Initiatives/Implementations**

The topic of health disparities emerged as a national policy agenda in the 1990s because the problem of certain diseases and health discrepancies became more prevalent within urban minority communities. Some policy initiatives have been implemented and programs have been expanded to help decrease these disparities.

The Healthy People 2010<sup>viii</sup> campaign was launched in 1998 as a set of public health objectives for the nation to achieve over the first decade of the new century. There are 467 objectives for 28 focus areas, as well as a set of leading health indicators. Since its implementation, some progress has been made in counties like Allegheny to narrow the gap in health inequities among Blacks and whites; however there is still significant work to be done in low-income communities, especially among minority children and adolescents.

The CDC also created the National Asthma Control Program in 1999. The program supports the goals and objectives of Healthy People 2010 for asthma and is based on three public health principles: *tracking*—collecting and analyzing data on an ongoing basis to understand the “who, what, and where” of asthma; *interventions*—ensuring that scientific information is transferred into public health practices and programs to reduce the burden of asthma; and *partnerships*—ensuring that all stakeholders have the opportunity to be involved in developing, implementing, and evaluating local asthma control programs.

The Pennsylvania Department of Health recognizes that while national benchmarks such as the CDC’s asthma objectives are vital for improving medical care, they fall short in changing individual behavior, creating practical policies for schools and clinics, and improving long-term clinical economic outcomes. As a result, the Department released its 2006 Asthma Action Plan that aims to bridge the gap between the macro-visions of national policymakers and the efforts of Pennsylvania’s many independent, community-based, and regional asthma resources, including those community-based resources in Allegheny County. The action plan has six specific components, with two of the components focusing on disparities and public policy. The disparity component addresses reducing the unequal and disproportionate asthma burdens experienced

among racial and ethnic minorities, by gender, and among other underserved populations. The public policy component is defined as changing Pennsylvania’s laws, standards, and funding in ways to improve asthma care and decrease health disparities. “The Plan considers asthma in children a ‘high priority’ for improvement with racial and ethnic minorities, also low-income patients as populations of special focus (pg.19).”

Lastly, Medicaid and the State Children’s Health Insurance Program (SCHIP) continue to be two leading forms of health insurance coverage for low-income children and their families. SCHIP was established as Title XXI of the Social Security Act over a decade ago as part of the Balanced Budget Act of 1997 and, together with Medicaid, helped to reduce the number of low-income uninsured children. “In 2005, SCHIP covered 6 million low-income children and about 4 million with an annual cost of \$7 billion in state and federal funds. During that same year, Medicaid strengthened SCHIP and covered 28 million more low-income children (Kaiser Family Foundation, 2007).”

Both programs are important because SCHIP is defined as benchmark coverage or modeled as a private insurance, which means the coverage is equal to the benefits provided by the Federal Employee Health Benefits Program Blue Cross/Blue Shield Standard Option or a health benefits plan offered by the state to its own employees. However, SCHIP alone does not cover a myriad of services offered by Medicaid. For example, Medicaid includes the Early and Periodic Screening, Diagnosis and Treatment services. This coverage provides children with a range of screening and treatment services such as dental and vision care, personal care services, mental health therapies, and other services/special needs—key services critical for the healthy development of impoverished children.

Medical expenses are lower for people in public programs like Medicaid and SCHIP compared to private insurance, according to a 2008 report by *Health Affairs*. Expanding these programs would be more cost effective to cover uninsured low-to- moderate-income families. The Center for Budget and Policy Priorities (CBPP) reported that when controlling for health and demographic factors, medical expenditures are significantly higher under private insurance.

These lower expenses under Medicaid and SCHIP are particularly helpful for children. Overall, the uninsured through Medicaid would cost less in terms of total medical expenditures, costs paid by insurance, and out-of-pocket cost per individual. According to 2005 data provided by CBPP, the total savings under Medicaid/SCHIP was over \$200 for children alone.

## **Recommendations**

This chapter demonstrates wide racial disparity in health for children and adolescents in Allegheny County and the United States. In order for minorities to have better health outcomes, the following recommendations must be considered:

- For the parents of these children, there must be better opportunities/services such as jobs that provide proper health insurance coverage. There also needs to be improved health services, such as the continued assistance of Medicaid and SCHIP.

- Strengthen and expand Medicaid and SCHIP.
- Have incentives for improving and expanding employer-provided health insurance.
- Continue to educate families about health risks, preventative measures, available assistance mechanisms, and the navigation of the health care system.
- Improve the quality of care and access to care in poor communities and address the safety and environmental concerns of inner-city urban communities, such as Allegheny County.
- Increase the availability and affordability of nutritious food choices in urban communities so that children and families within these communities will have *equal access* to better health care and lifestyles as those in advantaged neighborhoods and communities.

## **Conclusion**

Research evidence has long determined that good, quality health promotes positive growth, development, and academic performance for children and adolescents. However, for many children in the United States, particularly for low-income minority children (African American and Hispanic), this goal has been unattainable. Poor uninsured minority children and adolescents face significant health disparities compared to their affluent peers. According to a 2008 report by the American Psychological Association,<sup>ix</sup> Black children suffer serious public health problems, including childhood obesity, where current obesity rates are higher among African American and Hispanic youth. Poor Black youth are much less likely than their middle-class peers to visit a dentist prior to kindergarten, resulting in a higher risk for periodontal disease, which makes them more susceptible to diabetes and cardiovascular disease. High rates of asthma are also associated with family and socioeconomic factors.

National campaigns and programs like the Healthy People 2010 Campaign and the Center for Disease Control and Prevention National Asthma Control Program have helped transform thoughts about health. Some progress has been made to narrow the gap in health inequalities between Blacks and whites; however, more work is needed in low-income communities, especially among minority children and adolescents. Combined efforts from national, state, and local programs will help provide early health education and positive models that will not only empower communities but also teach families to monitor their lifestyles (food, nutrition, exercise) and make critical health choices for the betterment of their children's cognitive, social, emotional, and physical development.

## **Acknowledgment**

*I would like to thank Eboni Morris, Health Policy Fellow of the National Urban League Policy Institute, for her input.*

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<sup>iv</sup> “Health Coverage in Communities of Color: Talking about the New Census Number,” Fact Sheet from Minority Health Initiatives, *Families USA*, September 2008.

<sup>v</sup> Rao, G. “Obesity,” *Black Paper Series*, 2007.

<sup>vi</sup> Blood lead levels of greater than 5 micrograms per deciliter (approximately 3.38 oz.) of blood.

<sup>vii</sup> “Progress or Promises? What’s Working For and Against Healthy Schools,” *Action for Healthy Kids* Report, Fall 2008.

<sup>viii</sup> Healthy People 2010 is a Department of Health and Human Services-led effort to establish a set of key indicators for the nation and measure health improvement over time. Particularly emphasized is the importance of measuring differences in health outcomes by race and ethnicity as a first step towards the elimination of disparities. <http://www.healthypeople.gov>.

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## CHAPTER 3. DIABETES DISPARITIES IN ALLEGHENY COUNTY

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### Introduction

Diabetes is a major public health challenge due to the enormous impact on the affected individuals, their families, and the health care system. Almost 24 million people have diabetes in the United States, with African Americans about twice as likely to be diagnosed with the disease as non-Hispanic whites<sup>i</sup>. There are two major types of diabetes, with Type 2 diabetes accounting for 90-95 percent of all cases in the United States. Type 2 diabetes is characterized by the failure of the pancreas to secrete an adequate amount of insulin or decreased sensitivity to the insulin produced by the pancreas<sup>ii</sup>. Once considered a disease of middle and “old” age, type 2 diabetes is now seen in adolescents, particularly in minority populations. Type 1 diabetes is an autoimmune disease that develops when the body’s immune system destroys pancreatic cells responsible for making insulin<sup>ii</sup>. While it is the third most prevalent chronic disease of childhood, type 1 diabetes accounts for only 5-10 percent of all cases of diabetes in the United States. This chapter will report on current status and trends, root of the problem, consequences, and preventive strategies.

### Current Status and Trends

As shown in Table 1, 9 percent of non-Hispanic whites and 16 percent of non-whites who are non-Hispanic in Allegheny County reported ever having diabetes. In addition, less than half of the adults in the county exercise at recommended levels to help prevent diabetes, and more than one-quarter of adults in the county are obese, which contributes to diabetes.

Death rates from diabetes are twice as high among Black residents of Allegheny County as among white residents. The Black rate in the county during the period 1999-2005 was 45 per 100,000 population, while the white rate was 22. (See Table 2.)

Future projections for diabetes indicate that approximately 29 million people will be affected by the disease by the year 2050<sup>iii</sup>. The largest increase in prevalence is expected to occur in Black males +363% (2000-2050) and Black females +217% (2000-2050). Overall, the estimated risk of developing diabetes in those individuals born in 2000 is roughly one in three. The lifetime risk is even higher among minority populations, where non-Hispanic Blacks and Hispanics have a two in five chance of developing diabetes if current trends continue<sup>iv</sup>. This increased diabetes prevalence is beginning to present itself at a much earlier age than it has in past generations.

Table 1. Diabetes in Allegheny County Adults, Behavioral Risk Factor Surveillance Survey, 2007<sup>v</sup>

	<i>Total No.</i>	Ever Told Had Diabetes		Physical Activity*		Obesity**	
		<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
All Adults	642	63	9.8	280	43.6	173	26.9
White non-Hispanic	574	52	9.1	254	44.3	155	27.0
Non-white non-Hispanic	68	11	16.2	26	38.2	18	26.5

\*Adults that have reported participating in either moderate physical activity defined as 30 or more minutes per day for 5 or more days per week or vigorous activity for 20 or more minutes per day on 3 or more days

\*\*BMI 30.0 & above

Table 2. Diabetes Mortality in Allegheny County, 1999-2005<sup>vi</sup>

Race	Count	Population	Crude Rate per 100,000	Age Adjusted Rate Per 100,000
Black or African American	458	1,161,984	39.4	44.8
White	2,451	7,483,200	32.8	22.1
Other	7	197,536	3.5 (Unreliable)	7.8 (Unreliable)
Total	2,916	8,842,720	33.0	24.1

-Death rates are flagged as 'Unreliable' when the rate is calculated with a numerator of 20 or less.

## Diabetes in Youth

Once seen only in adults, type 2 diabetes has been rising steadily in youth, especially minority youth, mirroring the increase in obesity and inactivity seen in children and adolescents. The prevalence of obesity among children aged 6-11 more than doubled in the past 20 years, going from 6.5 percent in 1980 to 17.0 percent in 2006. The rate among adolescents aged 12-19 more than tripled, increasing from 5 percent to 17.6 percent<sup>vii</sup>.

While national data are not available, studies done in several cities conclude that cases of type 2 diabetes in youth have risen dramatically<sup>viii-ix</sup>. In Greater Cincinnati, the incidence of adolescent type 2 diabetes increased tenfold from .7/100,000 per year in 1982 to 7.2/100,000 per year in 1994. While African Americans represent only 14.5 percent of the population, 69 percent of the youth presenting with type 2 diabetes were Black. The majority of these adolescents were obese and 65 percent had a first degree relative with type 2 diabetes<sup>ix</sup>.

The obesity epidemic, with its related increased incidence of diabetes and other chronic diseases developing in youth, may make this generation the first one to experience a decrease in life expectancy<sup>x</sup>. In fact, researchers found that people with youth-onset diabetes were eight times more likely to have kidney failure, or end-stage renal disease (ESRD), between the ages of 25 and 34 than those diagnosed after age 20. The youth-onset group also was five times more likely to have kidney failure between the ages of 35 and 44 and four times more likely to have ESRD between the ages of 45 and 54 than those who developed diabetes later in life<sup>xi</sup>.

Preventing obesity and inactivity in childhood is key to preventing the development of type 2 diabetes in children and adolescents.

Although pre-diabetes can lead to diabetes and diabetes can lead to devastating complications and early mortality, this progression may not be inevitable. People can adopt lifestyle behaviors that may prevent the development of type 2 diabetes and, if they have diabetes, lower their risk of developing complications<sup>xiii-xiv</sup>. Reversing the diabetes epidemic is possible, but it will require a dedicated partnership of public health policy makers, medical and health insurance providers, the community, and people at risk for or suffering from diabetes.

## **Causes of the Problem**

### *Type 1 Diabetes*

When the body's immune system destroys cells in the pancreas responsible for making insulin, type 1 diabetes develops. It accounts for 5-10 percent of all cases of diabetes, and we know of no way to prevent its development. Several hypotheses exist about the causes of type 1 diabetes, including viruses, vitamin deficiencies, and food additives<sup>xv</sup>. There is a genetic predisposition to type 1 diabetes. The incidence rate for type 1 diabetes in non-whites in Allegheny County rose significantly between 1990 and 1994. The incidence in the 15-19 years age group was almost three times higher for non-whites than whites and more than two times higher than that in the previous period (1985-1989)<sup>xvi</sup>. As with most spikes in the incidence of type 1 diabetes, the cause of this rise is unknown. Possibly, type 1 diabetes in Black children is more diverse in its etiology than in white children, as atypical presentations have been described<sup>xvi</sup>. Research continues on this topic.

### *Type 2 Diabetes*

Conversely, type 2 diabetes is characterized by the failure of the pancreas to secrete an adequate amount of insulin or a decrease in the body's sensitivity to the insulin that it produces. Type 2 diabetes accounts for 90-95 percent of diabetes cases seen in this nation. While there are no widely available prevention strategies for type 1 diabetes, type 2 diabetes can be prevented or delayed. In fact, type 2 diabetes may develop over approximately 10 years prior to diagnoses, with lifestyle factors largely contributing to its onset<sup>xvii</sup>. Given the early morbidity and mortality associated with this disease, type 2 diabetes is an ideal condition for public health primary prevention efforts.

Prevention efforts are ideally implemented throughout the lifetime but are most important and are proven effective in those with pre-diabetes<sup>xviii</sup>. Pre-diabetes is defined as a state where blood glucose is elevated (fasting glucose of 100-125mg/dl) but not high enough to be classified as diabetes (fasting glucose of 126mg/dl or greater). In 2007, it was estimated that pre-diabetes affected 57 million U.S. adults.<sup>i</sup>

*Primary Prevention: Obesity, Inactivity, and Type 2 Diabetes*

An individual is at high risk for developing type 2 diabetes when the modifiable risk factors of obesity and inactivity interact with genetic susceptibility, age, and race<sup>xxix</sup>. The American Diabetes Association lists non-modifiable risk factors for type 2 diabetes (greater than 45 years of age, minority race or being of Hispanic ethnicity, family history, high blood pressure, gestational diabetes<sup>xx</sup>) and modifiable risk factors (limited physical activity and overweight<sup>xxi</sup>). Prevention efforts focus on the modifiable risk factors.

Overweight and obesity occur when there is an imbalance between energy intake (food) and energy expenditure (physical activity). United States Department of Agriculture (USDA) survey data suggest that an increase in foods eaten away from home, increased portion sizes, and increased consumption of snacks and soft drinks have contributed to this increase<sup>xxii</sup>. Obesity and overweight are defined by relating body weight in kilograms (kg) to height in meters squared (m<sup>2</sup>) in a standard equation to determine “Body Mass Index” or BMI. In adults, *overweight* is a BMI of 25 - 29.9 kg/m<sup>2</sup>, while *obesity* is a BMI of 30.0 kg/m<sup>2</sup> or greater, with distinctions made for progressively severe obesity as BMI increases.

As shown in Tables 3 and 4, we have an obesity epidemic in this country, with two-thirds of the adult population overweight or obese<sup>xxiii</sup>. In Allegheny County, according to the 2002 Behavior Risk Factor Surveillance Survey (BRFSS) done by the Allegheny County Health Department, 69 percent of African Americans responding to the survey could be considered overweight or obese, compared with 58 percent of whites<sup>xxiv</sup>. This rate is consistent with national survey data.

Table 3. Age-adjusted percentage of persons 20 years of age and over who are overweight,\* 2001-2004. National Health and Nutrition Examination Survey (NHANES)<sup>xxiii</sup>

	<i>African American</i>	<i>Non-Hispanic White (NHW)</i>	<i>African American/NHW Ratio</i>
Men	67.0	71.0	0.9
Women	79.6	57.6	1.4

\*Persons are considered overweight if they have a Body Mass Index (BMI) of 25 or greater.

Table 4. Age-adjusted percentage of persons 20 years of age and over who are obese,\* 2001-2004. National Health and Nutrition Examination Survey (NHANES)<sup>xxiii</sup>

	<i>African American</i>	<i>Non-Hispanic White (NHW)</i>	<i>African American/NHW Ratio</i>
Men	31.2	31.0	1.0
Women	51.6	31.5	1.7

\*Persons are considered obese if they have a Body Mass Index (BMI) of 30 or greater.

While inactivity is a major contributor to obesity, it may be a risk factor for diabetes independent of obesity. Some ecological studies suggest that type 2 diabetes prevalence is consistently lower in populations with higher levels of habitual physical activity<sup>xxv</sup>.

Jobs requiring physical labor have declined over the recent decades. According to the National Health Interview Survey, 39.9 percent of adults spent most of their day sitting in 2005,

and the percentage of adults who engaged in no leisure time physical activity was 40% percent. These numbers were similar to the 2000 rates.

The United States Department of Health and Human Services recommends that adults get at least 30 minutes of moderate physical activity five or more days a week to promote health. The United States, in general, is falling significantly below these recommendations<sup>xxvi</sup>. Further, according to the 2006 Pennsylvania BRFSS, there was a statistically significant difference between whites and Blacks with regard to achieving this goal (50.7% v. 42% respectively).<sup>xxvii</sup>

Although obesity is a major determinant in the incidence of type 2 diabetes, only a small proportion of obese individuals develop the disease. Therefore, other factors beyond family history and obesity seem to influence the development of type 2 diabetes in any one individual.<sup>xxviii</sup> However, focusing on the modifiable risk factors is a key element for primary prevention.

### *Secondary Prevention: Avoiding Complications of Diabetes*

Poorly controlled diabetes may have devastating consequences. These include cardiovascular disease, visual impairment, blindness, kidney failure, and lower extremity amputations. Individuals diagnosed with diabetes have large reductions in life expectancy. For example, if diagnosed at age 40, a man will lose 11.6 years and a woman will lose 14.3 years.<sup>vi</sup> The consequences of diabetes are particularly problematic in African Americans. Of those with diabetes, African Americans are 1.7 times more likely than whites to be hospitalized<sup>xxix</sup> and 2.2 times as likely as non-Hispanic whites to die from diabetes.<sup>xxx</sup>

Consequently, once diabetes is diagnosed, the new objective becomes “secondary prevention” to avoid or at least delay the damage diabetes can cause to multiple body systems. Complications are divided into two categories: acute and chronic. Acute complications are those related to *daily* glycemic (blood glucose) control and include severe episodes of hypo- and hyperglycemia. Chronic complications develop over time in those with *ongoing* poor control of blood glucose, blood pressure, and lipids (cholesterol), as well as other risk factors.<sup>xiii</sup> Glycemic control is measured by a quarterly hemoglobin A1C test, a blood test that measures a person’s average blood glucose over the past two-to-three months. In an effort to avoid debilitating complications, people with diabetes must manage risk factors for complications.

### *Self-Management*

Successfully managing the risk factors for complications requires a patient-provider partnership. Since people with diabetes spend the majority of their time outside of the health care system, it is imperative that people with diabetes are well versed in self-management. Whether a person manages diabetes through oral diabetes medications, insulin injections, or both, best practices require the person to perform many daily tasks. The person with diabetes is responsible for self-monitoring blood glucose at least once, but usually several times, a day; controlling *what* is eaten and, often, *when* it is eaten; exercising in a safe manner; checking the feet for cuts or sores; and taking medication and/or insulin as prescribed. Along with these daily tasks, the person with diabetes requires regular medical and dental visits for early detection of

problems and visits with a diabetes educator and/or dietitian, as needed. The family of the person with diabetes often shares the burden of these self-care behaviors and, indeed, may perform some or all of them for the affected family member.

### *Quality Medical Care*

Successful management of diabetes also requires access to quality medical care by providers who understand the disease process. In some communities, access to quality care is limited and some clinical settings in which minorities receive care may not adequately comply with recommended standards<sup>xxx</sup>. Research demonstrates that many providers see diabetes as a difficult disease to treat, with little support from health care systems<sup>xxxi</sup>. Further, many health care providers suffer from “clinical inertia.” This is the failure to treat or intensify treatment when it is clearly indicated<sup>xxxii</sup>. Quality indicators for patients and providers are outlined below. Patients need to be empowered to understand and take an active role in their diabetes care in order to avoid or delay the onset of complications. People with diabetes should have an A1C performed at least twice a year. If they are not meeting goals or are changing therapy, A1C should be measured quarterly. Annually, people with diabetes should have a fasting lipid profile, test for kidney function (urine albumin excretion), annual dilated eye exam, and comprehensive foot exam. Blood pressure should be checked at each visit<sup>xxxiii</sup>.

External risk factors may also contribute to the development of complications. While low socioeconomic status (SES) may contribute to poor diabetes management, race, per se, may not play a significant role<sup>xxxiv,xxxv</sup>. In general, lower rates of blood glucose self-monitoring are seen in people with diabetes who meet low SES criteria<sup>xxxiv</sup>. Diabetic patients without health insurance are more likely to report high blood glucose levels and less likely to perform diabetes self-care or receive screening for complications<sup>xxxvi</sup>. For example, people with diabetes who have insurance are three times more likely to have an eye exam than the uninsured, and the uninsured person with diabetes has seven times the odds of having diabetic eye disease<sup>xxxvii</sup>.

According to Project DIRECT, a multiyear community diabetes demonstration project funded by the Centers for Disease Control and Prevention (CDC) and focused on reducing the burden of diabetes and its complications in an exclusively African American community (SE Raleigh, NC) through a community diabetes demonstration project, nearly half of the people with diabetes never received any form of diabetes education; less than half did not have annual A1C exams; more people were considered “sedentary” than either irregularly active or regularly active; and more than half monitored their blood glucose once a day or less<sup>xxxviii</sup>.

Although Project DIRECT’s findings show poor self-care behaviors in its target population (African Americans), it is possible that these poor self-care behaviors are pervasive among all people with diabetes<sup>xxxv,xxxix</sup>. While Harris found a significantly lower proportion of African American and Mexican American patients treated with insulin self-monitored their blood glucose compared to Caucasians, in other measures of self-care and physician care, she found little difference among race and ethnic groups<sup>xxxix</sup>. When Harris et al. studied health care access and health outcomes by race and by ethnic origin in people with type 2 diabetes, they found that in each race and ethnic group, there were high rates of health care access and utilization, screening for diabetes complications, and treatment of hyperglycemia, hypertension, and

dyslipidemia. Nevertheless, in each group, glycemic control was poor; many patients were obese and had albuminuria; and much of the hypertension and dyslipidemia was not controlled. One-fourth of patients had to be hospitalized in the previous year, and one-fifth of patients smoked cigarettes. Harris et al. concluded that health outcomes for patients with diabetes are determined by multiple factors, including intractability of diabetes to current therapies, patient self-care practices, physician medical care practices, and characteristics of U.S. health care systems, rather than by race and ethnicity<sup>xxxv,xxxix</sup>. In fact, the 2005 PA BRFSS<sup>xi</sup> showed similar rates of self-care behaviors between whites and non-whites statewide, demonstrating local evidence for this hypothesis (Table 5).

Table 5. PA Behavioral Risk Factor Surveillance Survey, 2005<sup>xi</sup>

Questions asked of adults with diabetes	Allegheny County, White <sup>a</sup>	PA, White <sup>a</sup>	PA, Non-White <sup>b</sup>
Have taken course on how to self-manage diabetes	36%	53%	51%
Told by MD that their eyes have been affected	20%	23%	17%
Had dilated eye exam in past year	68%	69%	70%
Self monitor blood glucose at least once daily	55%	62%	60%
Check feet for sores or irritations at least once daily	68%	69%	76%
Had foot sores or irritations taking longer than 4 weeks to heal	13%	15%	12%
Had feet checked for sores and irritations by MD in past year	74%	77%	78%
Seen an MD for their diabetes 4 or more times in past year	35%	47%	48%
Had Hgb A1c test 4 or more times in past year	28%	32%	23%

(a) Non-Hispanic white (Data not available for non-white in county due to small sample.)

(b) Including Hispanic

National data from the National Healthcare Disparities Report 2007 published by the Agency for Healthcare Research and Quality show that for people with diabetes age 40+, no significant difference exists between Blacks and whites (46.7% compared to 47.4%, respectively) for having all three recommended services (A1c, foot, eye) checked in the past year<sup>xli</sup>. However, when looking at having these same three services, the data reveal a gap based on educational level (< HS, 35.2%; HS graduate, 45.7%; some college, + 55.9%).

Blood pressure control was significantly lower among poor (53.6% had blood pressure under control) and middle-income (51.3%) individuals as compared to high-income people (70.4% under control)<sup>xliii</sup>. Further, African Americans had much less control of A1c and blood pressure than whites (Table 6).

Table 6. Management of the ABCs, US, 1999-2004<sup>xlii</sup>

	A1c	Total Cholesterol	Blood Pressure
	<i>% Controlled</i>	<i>% Controlled</i>	<i>% Controlled</i>
African American	36.6	48.2	45.0
White	55.7	48.2	63.4

### Consequences of the Problem for Individuals, Families, and Communities

The many costs associated with diabetes occur at the individual, family, and society levels. The total (direct and indirect) cost of diabetes in the United States in 2007 was \$174 billion—\$116 billion for direct medical costs and \$58 billion for indirect costs (disability, work loss, premature mortality<sup>i,xliii</sup>). After adjusting for population age and sex differences, average medical expenditures among people with diagnosed diabetes were 2.3 times higher than what expenditures would be in the absence of diabetes<sup>xliii</sup>.

The increased costs associated with diabetes are often difficult for patients and their families to manage. Adults with diabetes who have lower incomes pay a higher share of total expenditures out of pocket when compared to adults with heart disease, hypertension, and cancer<sup>xliv</sup>. More than 23 percent of the uninsured and more than 20 percent of those with public coverage spend more than half of their disposable income on health care<sup>xliv</sup>. The cost of diabetes management can negatively influence diabetes control, regardless of income. Even for those with health insurance, as co-pays increase, use of medical services and needed medications and supplies decrease<sup>xl</sup>. For those people with diabetes who are of low income and have no health insurance, the cost of managing their diabetes may be prohibitive. For example, 21 percent of 18- to 64-year-old non-Hispanic Blacks in Pennsylvania have no health insurance, compared to 11 percent of non-Hispanic whites<sup>xlv</sup>. This disparity in health insurance coverage could account for the differences in outcomes observed by race.

#### *Hospitalizations*

People with diabetes are hospitalized more often than people without the disease, and African Americans with diabetes are hospitalized more than twice as often as whites with diabetes. (See Table 7)<sup>xxix</sup>. Hypoglycemia (low blood sugar) is one of the largest contributors to these hospitalizations, with 64 percent of hospital records listing hypoglycemia in the discharge summary<sup>xlvi</sup>. In general, hypoglycemia represents a greater proportion of hospitalizations in female and African American patients<sup>xlvi</sup>. Prevention of hypoglycemia depends on resources that have a cost: education regarding diabetes management and self-care, self-monitoring of glucose levels, and awareness of factors that may precipitate hypoglycemia<sup>xlvi</sup>.

Table 7. Age-adjusted rate of hospitalization per 1,000 diabetic population, US, 2003<sup>xxix</sup>

<i>African American</i>	<i>White</i>	<i>African American/White Ratio</i>
80.5	47.2	1.7

## Complications of Diabetes

Much of the financial and human toll of diabetes is due to the development of complications such as cardiovascular diseases, retinopathy, nephropathy, peripheral vascular disease, and neuropathy.

### Macrovascular Complications: Cardiovascular Disease and Peripheral Vascular Disease

Cardiovascular disease, which includes complications of the large blood vessels or macrovasculature, is the leading cause of death for people with type 2 diabetes. Coronary heart disease (narrowing of the arteries that supply blood to the heart) is two to four times more common in those with diabetes as compared to those without diabetes<sup>xlvii</sup>. Further, heart disease appears earlier in life, affects women as often as men, and is more fatal than in those people without diabetes. Stroke is two to four times more common in people with diabetes as compared to those without diabetes.

Peripheral vascular disease, also referred to as lower extremity arterial disease, includes such conditions as foot ulceration and gangrene and may lead to lower-limb amputations<sup>xlvii</sup>. In fact, more than 60 percent of nontraumatic lower-limb amputations occur in people with diabetes<sup>1</sup>. African Americans are disproportionately affected by this condition. (See Table 8.)

Table 8. Age-adjusted rate for lower extremity amputation per 1,000 diabetic population, US, 2003<sup>xlviii</sup>

<i>African American</i>	<i>White</i>	<i>African American/White Ratio</i>
5.0	3.2	1.6

### Microvascular Complications: Retinopathy and End Stage Renal Disease

Retinopathy is a disease of the small blood vessels of the eye. In the 20 to 74 year-old age group, diabetes is the leading cause of blindness in the United States and is responsible for approximately 12,000-24,000 new cases of blindness each year<sup>1</sup>. African Americans and whites are affected similarly by diabetic retinopathy. In 2005, the age-adjusted prevalence of visual impairment was 18 percent for whites and 17.7 percent for Blacks<sup>xlix</sup>.

Table 9. Age-adjusted prevalence of visual impairment per 100 adults with diabetes, US, 2005<sup>xlvi</sup>

	<i>African American</i>	<i>White</i>	<i>African American/White Ratio</i>
Men	14.4	16.6	0.9
Women	20.0	19.5	1.0

In Pennsylvania, according to the 2005 BRFSS, 23 percent of whites with diabetes and 17 percent of non-whites with diabetes reported that they had been told by a doctor that diabetes had affected their eyes or that they have retinopathy<sup>iii</sup>.

End Stage Renal Disease (ESRD) includes failure of the kidney to function, resulting in dialysis or transplant. The risk for ESRD is two to three times higher for African Americans with

diabetes than for whites<sup>1</sup>. The primary cause of ESRD is diabetic nephropathy (kidney disease)<sup>1</sup>. More than half of the dialysis cases in the United States are caused by diabetes. The other most common cause of dialysis is hypertension, which is also more prevalent in African Americans.

Table 10. Rate of initiation of treatment for end stage renal disease related to diabetes per 100,000 diabetic population, US, 2002<sup>li</sup>

	<i>African American</i>	<i>White</i>	<i>African American/White Ratio</i>
Men and Women	395.6	192.3	2.1
Men	470.2	222.7	2.1
Women	344.5	165.8	2.1

### *Diabetic neuropathy*

Diabetic neuropathy includes complications in the nerves of the feet and hands. There are different degrees of neuropathy and it is thought to be present in as many as 60 percent of patients with diabetes. Neuropathy affects the body in various ways. Diabetic neuropathy can cause limb muscle atrophy (wasting), alter the ability to feel pain, affect blood circulation, and decrease the stomach’s ability to digest food. Neuropathy contributes to the “diabetic foot” that often results in amputations. Like the other complications of diabetes, the prevalence of neuropathy increases with age, poor glucose control, and duration of diabetes<sup>lii</sup>. Racial differences have not been observed.

One of the common co-morbid conditions of diabetes is depression. Persons with diabetes have double the odds of suffering from depression as compared to the general population. Approximately 8.3 percent of those with diabetes suffer from major depression<sup>1</sup>. Further, adults with diabetes who have less years of education have higher rates of depression<sup>xxxiv</sup>. Depression appears to negatively influence diabetes self- management and other behaviors needed to achieve good diabetes control. Consequently, among persons with diabetes, those with depression report more primary care and emergency department visits, more hospitalizations, and a fourfold increase in the cost of care<sup>xxxiv</sup>.

### **Solutions – Current and Alternate Programs and Policies**

“Primary prevention” is the best “solution” to the epidemic of type 2 diabetes. That is, we need to prevent children and adults from becoming obese and inactive, which should, according to research, prevent or at least delay the onset of the disease. Additionally, as type 2 diabetes develops gradually over time, people *at risk* can and must be identified by health care providers and referred to the appropriate services.

Specifically:

- ✓ Health care providers need to screen patients for overweight and obesity and refer them to programs that address eating and activity behaviors.
- ✓ Health care providers need to screen patients for pre-diabetes and metabolic syndrome, refer them to lifestyle programs that address eating and activity behaviors focusing on the

prevention of diabetes and cardiovascular disease, and prescribe appropriate medications as needed.

- ✓ Health insurance companies need to cover the cost of lifestyle programs that address eating and activity behaviors as well as weight management and weight maintenance programs.
- ✓ Schools need to teach and model in the cafeterias and physical education sessions lifestyle behaviors that promote healthy eating and activity.

Secondary prevention entails appropriate self-management and medical management of people with diabetes to prevent the costly and debilitating complications of poorly controlled diabetes.

- ✓ Once diabetes is diagnosed, quality medical care and self-management are key.
- ✓ Providers need to be more aggressive in managing diabetes.
- ✓ The person with diabetes is a full partner in managing the disease and must be educated in self-care behaviors such as self-management and medical care.
- ✓ Co-morbid conditions like depression are common in people with diabetes, must be identified, and must be addressed by health care providers to better enable the person with diabetes to manage the disease.
- ✓ Health insurance companies need to cover the cost of diabetes self-management education, nutrition counseling, and all supplies and medications needed by people with diabetes.

### **Action Steps for Policymakers, Providers and Insurers, Community-Based Organizations, Individuals, and Researchers<sup>liii</sup>**

- ✓ Surveillance - establish solid knowledge base about populations at risk; collect and monitor data for diabetes trends.
- ✓ Standards of Care - ensure that all people with diabetes receive the same level of excellent care; increase awareness of importance of early diagnosis and effective prevention.
- ✓ Pay-for-performance initiatives should reward both processes and outcomes.
- ✓ Health Policy - utilize Pennsylvania laws, regulations, standards, enforcement, authority, and funding in ways that improve diabetes care, decrease health disparities, and expand the scope of practice for ancillary health care providers.

- ✓ Eliminate health disparities - to decrease prevalence of diabetes in the minority community and to improve management once one has the disease.
- ✓ Evaluation - measure the impact of prevention and control activities.
- ✓ Focus on the power of lifestyle changes to prevent diabetes and to prevent complications in people who already have diabetes.
- ✓ Ensure access to quality diabetes care and treatment.
- ✓ Use evidence-based research and best practices to design prevention and treatment programs.
- ✓ Employ technology like the Internet to dispense and gather information and provide guidance to patients, providers, and payers.
- ✓ Coordinate efforts and create partnerships to reduce the burden of diabetes and to establish metrics for tracking costs, performance measures, processes, and outcomes.

## Appendix

Allegheny County Adults, Behavioral Risk Factor Surveillance Survey, 2007 <sup>iii</sup>

	<i>Total No.</i>	Ever Told Had Diabetes		Physical Activity*		Obesity**	
		<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>	<i>No.</i>	<i>%</i>
All Adults	642	63	9.8	280	43.6	173	26.9
<b>Race:</b>							
White non-Hispanic	574	52	9.1	254	44.3	155	27.0
Other than white or Hispanic	68	11	16.2	26	38.2	18	26.5
<b>Age:</b>							
18-34	70	0	0.0	40	57.1	20	28.6
35-44	104	4	3.9	50	48.1	20	19.2
45-64	267	26	9.7	119	44.6	81	30.3
65+	201	33	16.4	71	35.3	52	25.9
<b>Education:</b>							
<High School	36	10	27.8	12	33.3	8	22.2
High School	187	25	13.4	66	35.3	59	31.6
Some College	144	17	11.8	55	38.2	48	33.3
College Degree	273	11	4.0	146	53.5	58	21.3
<b>Income:</b>							
<\$15,000	62	19	30.7	18	29.0	20	32.3
\$15,000 to \$24,999	87	13	14.9	28	32.2	35	40.2
\$25,000 to \$49,999	62	5	8.1	21	33.9	24	38.7
\$50,000 to \$74,999	87	7	8.1	36	41.4	26	29.9
\$75,000+	249	8	3.2	134	53.8	52	20.9
<b>Health care Access:</b>							
Have coverage	400	27	6.8	188	47.0	111	27.8
Do not have coverage	32	2	6.3	18	56.3	9	28.1
Male	223	21	9.4	96	43.1	58	26.0
Female	419	42	10.0	184	43.9	115	27.5

\*Adults that have reported participating in either moderate physical activity defined as 30 or more minutes per day for 5 or more days per week, or vigorous activity for 20 or more minutes per day on 3 or more days

\*\*BMI 30.0 & above

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## CHAPTER 4. OBESITY IN ALLEGHENY COUNTY

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### Introduction

Not a single day passes without another news report about the epidemic of obesity. We are constantly bombarded with information about a problem that is spiraling out of control. Furthermore, numerous books, videos, supplements, and types of exercise equipment are continuously advertised to consumers. Stand in a supermarket line and at least one weekly tabloid is likely to feature a miracle diet. Turn on the television late at night and infomercials feature “magic bullet” solutions to help people lose weight. Even on the World Wide Web, unwanted “pop-up” ads often feature quick and easy solutions to obesity. Despite the enormous amount of attention this problem receives, Americans, including the residents of Allegheny County, are getting heavier and the medical, psychological, and social consequences of obesity are getting worse.

Few of the strategies currently being promoted to combat obesity address its root causes. A well-intentioned schoolteacher from a small town near Pittsburgh approached me recently seeking advice on how to fight alarming rates of obesity in his community. His own idea was to start a series of weekly after-school aerobics classes for children. Obesity is the end result of a complex interaction between individuals with varying predispositions to gain weight and an *obesigenic* environment that encourages consumption of high calorie foods and discourages everyday physical activity. There were no aerobics classes for children 50 years ago when child obesity wasn't a major problem. Such approaches are unlikely to succeed for a number of reasons, the most important of which is failure to recognize the root causes of the problem among individuals and communities.

The purpose of this paper is to describe the epidemiology and consequences of obesity among Americans in general and African Americans in particular. I will also provide specific information about our region and how it compares to other parts of the country.

### Definitions and Trends

The body mass index (BMI), defined as body weight in kilograms divided by the square of the height in meters ( $\text{kg}/\text{m}^2$ ), is used to define levels of weight associated with different health risks. Among adults (age 20 and over), an individual with a BMI between 18.9 and 24.9  $\text{kg}/\text{m}^2$  has a healthy weight. An individual with a BMI between 25.0 and 29.9  $\text{kg}/\text{m}^2$  is *overweight*, and one with a BMI of 30  $\text{kg}/\text{m}^2$  or greater is classified as *obese*. The degree of obesity is designated separately. A BMI between 30 and 35  $\text{kg}/\text{m}^2$  defines *Stage I obesity*. BMIs of 35 to 40 and above

40 kg/m<sup>2</sup> define *Stage II* and *Stage III* obesity, respectively.<sup>i</sup> BMI is simple to calculate but is an imperfect measure of body fat or *adiposity*. Identical threshold levels that define overweight and obesity are used for both men and women, though men have greater lean body mass and lower body fat percentage than women. Some people, including those with a very muscular physique, have a high BMI but relatively low adiposity. Though based only on the BMI, the degree of adiposity of such individuals would be overestimated, although the number of such people is extremely small. All things considered, the imperfect nature of the BMI as a measure of adiposity (due to such exceptions) is outweighed by its relative simplicity.

Children are not classified according to absolute levels of BMI but according to *BMI percentiles*, which are based on data collected nationally over the past two decades. As children mature, their BMI changes in natural and predictable ways. A 14-year-old girl who is the same height as an 11-year-old girl, for example, would be expected to weigh more since the onset of puberty is associated with natural weight gain. Boys and girls mature at different rates. A child with a BMI between the 5<sup>th</sup> and 85<sup>th</sup> percentiles, adjusted for age and sex, is classified as having a healthy weight. A BMI between the 85<sup>th</sup> and 95<sup>th</sup> percentiles, adjusted for age and sex, defines *at risk for overweight*. A BMI above the 95<sup>th</sup> percentile defines *overweight*. The Centers for Disease Control and Prevention (CDC) do not use the term *obese* to classify children. *Obese* was regarded as too pejorative a label for children. Unfortunately, this classification scheme is a frequent source of confusion, since *overweight* among children is equivalent to *obese* among adults, and *at risk for overweight* among children is equivalent to *overweight* among adults. There are calls to use the same classification scheme for children as for adults. In this paper, to avoid confusion, the term obesity when applied to children refers to *overweight* according to the CDC's criterion. The term *overweight* when applied to children refers to *at risk for overweight* according to the CDC's criterion.

National estimates of the rates of obesity come primarily from two sources. The National Health and Nutrition Examination Survey (NHANES) includes a representative sample of Americans and direct measurements of BMI. NHANES data is most recently available from 2001-2002. At that time, 30.6 percent of adults sampled were obese and 65.7 percent of adults were either overweight or obese. The same data reported that 16.5 percent of children ages 6 to 19 were obese and 31.5 percent of children were either overweight or obese.<sup>ii</sup> The Behavioral Risk Factor Surveillance System (BRFSS) is a nationally administered telephone survey of adults conducted annually to determine the prevalence of a wide variety of medical problems and health-related behaviors. Survey participants are asked to self-report their height and weight. According to 2005 data, 60.5 percent of adults were either overweight or obese and 23.9 percent were obese.<sup>iii</sup> Rates of obesity based upon self-reported height and weight are generally lower than those obtained from NHANES since survey participants tend to overestimate their height and underestimate their weight.

As alarmingly high as these recent rates of obesity are, two aspects of the epidemic are even more shocking. One is the rate at which the problem got worse. In 1995 and 2000, the adult rates of obesity according to the BRFSS were 15.6 and 19.8 percent, respectively.<sup>iii</sup> Figure 1 illustrates the growing problem among children according to NHANES data.<sup>iv</sup> Notice that the prevalence of obesity (overweight as per CDC definition) among both younger children and

adolescents was relatively low and stable between 1963 and 1980. From 1988 to 1994 and from 1999 to 2002, the rate of obesity among children and adolescents accelerated remarkably.

Another disturbing aspect of the epidemic is its disproportionate impact upon certain minority populations. In 2001-2002, 49 percent of African American women and 38.4 percent of Mexican American women were obese. An astonishing 77.2 percent of African American women and 71.7 percent of Mexican American women were either overweight or obese.<sup>ii</sup> Obesity is also much more common among minority children. Twenty percent of African American children ages 6 to 11 were either overweight or obese between 1999 and 2002 compared with just 13 percent of white children of the same age. Twenty-two percent of African American children ages 12 to 17 were overweight or obese during the same time period, compared to 13 percent of white children of the same age.<sup>v</sup> There is no evidence to suggest that this trend has abated over the last five years. If anything, things have likely gotten worse.

Obesity in Allegheny County largely mirrors national trends. In 2002, 69 percent of African American adults (men and women combined) were either overweight or obese, compared with 58 percent of whites.<sup>vi</sup> That same year, 70 percent of African American adults in Pennsylvania and 69.8 percent of African American adults nationwide were either overweight or obese. Differences between Allegheny County, the state as a whole, and the country were not significant. In 2006, 67.8 percent of African American adults in Pennsylvania and 71.8 percent of African American adults nationwide were either overweight or obese. Such recent data for Allegheny County is unavailable. The prevalence of obesity among African American adults state and nationwide remains high but has not changed dramatically.

## **Medical and Psychosocial Complications of Obesity**

### *Medical Complications of Obesity*

Bray describes an elegant way to classify complications of obesity.<sup>vii</sup> Complications can be due to increased *mass* of fat or to increased *size* of fat cells. Increased fat cell mass results in osteoarthritis, sleep apnea, and important psychological and social responses to obesity, such as its associated stigma. Metabolic consequences associated with increased size of fat cells include diabetes mellitus, gallbladder disease, hypertension, cardiovascular disease, and certain cancers.

No discussion of the metabolic consequences of obesity is complete without a description of the *insulin resistance syndrome* (alternatively called the *metabolic syndrome* or *syndrome X*). First described by Reaven in 1988,<sup>viii</sup> the insulin resistance syndrome refers to a cluster of cardiovascular risk factors—including diabetes, dyslipidemia, and hypertension—related to the impaired tissue response to insulin. The ability of insulin to stimulate the uptake of glucose into tissues varies significantly among individuals and depends upon both genetics and the degree of obesity. As an individual becomes more obese, tissues become less responsive to insulin. The pancreas compensates by secreting more insulin to keep blood sugar in check. When hyperinsulinemia can no longer compensate for insulin resistance, blood sugar begins to rise and frank diabetes results. Many of the other cardiovascular abnormalities in insulin resistance syndrome are thought to result from hyperinsulinemia.

What follows is a description of the medical, social, and psychological complications of obesity, together with a measure of risk. Key evidence of risk rather than an exhaustive review of evidence is provided. Risks that may be unfamiliar to some health care professionals (such as cancer) are emphasized. Mechanisms through which obesity confers increased risk are still being studied and are not discussed in detail.

### Obesity Increases the Risk of Type 2 Diabetes

Not surprisingly, since obesity increases insulin resistance, it is also associated with an increased risk of type 2 diabetes. Women with a BMI less than 22 kg/m<sup>2</sup> have the lowest risk of type 2 diabetes. On the other hand, women with a BMI of 35 kg/m<sup>2</sup> have a 40-fold, or 4000 percent, increased relative risk (RR) of developing diabetes.<sup>ix</sup> Men at age 21 with a BMI equal to or greater than 35 kg/m<sup>2</sup> have a RR of approximately 42 of developing diabetes between ages 40 and 75, compared with men with a BMI of less than 23.0 kg/m<sup>2</sup> at age 21.<sup>x</sup> More disturbingly, increasing rates of obesity among children have made pediatric type 2 diabetes common. A generation ago, nearly all cases of diabetes among children were type 1. Today nearly half are type 2.<sup>xi</sup>

### Obesity Increases the Risk of Hypertension

A strong relationship between obesity and hypertension was established more than two decades ago. Roughly 30 percent of hypertension in the general population is attributable to obesity. In men under age 45, 60 percent is attributable to obesity.<sup>xii</sup> Among women, each 1 kg of weight gain over the age of 18 is associated with a 5 percent increased risk of hypertension.<sup>xiii</sup>

### Obesity and Lipid Disturbances

In the 2001 BRFSS, compared to adults with normal weight, those with a BMI greater than 40 kg/m<sup>2</sup> had an odds ratio (OR) of 1.88 (95% CI, 1.67-2.13) for high cholesterol levels.<sup>xiv</sup> Obesity is commonly associated with several specific lipid disturbances, which are associated with increased cardiovascular risk. Compared with healthy adults with a BMI less than 25 kg/m<sup>2</sup>, the OR for low high density lipoprotein levels (HDL) among adults with a BMI greater than 30 kg/m<sup>2</sup> is 5.9 for men and 5.8 for women.<sup>xv</sup> Obesity also has a direct relationship with increased triglyceride levels and decreased size of low-density lipoprotein (LDL) particles, two emerging risk factors for heart disease.<sup>xvi</sup> Such lipid disturbances are not confined to obese adults. Compared with non-obese children, obese children ages 5 to 10 have an OR of 7.1 for elevated triglycerides, 3.4 for low HDL cholesterol, and 3.0 for elevated LDL cholesterol.<sup>xvii</sup>

### Obesity and Heart Disease

Since cardiovascular risk factors are much more common in obese people, obesity increases the risk of heart disease. The risk of developing coronary heart disease (CHD) is increased 3.3-fold among women with a BMI of 29 kg/m<sup>2</sup> compared with women with a BMI of less than 21 kg/m<sup>2</sup>.<sup>xviii</sup> According to the Framingham offspring study, a gain in weight of 2.25 kg (5 pounds) or more over 16 years increases a numerical score for risk of CHD by 20 percent in men and 37 percent in women.<sup>xix</sup> There is evidence that in addition to increasing the risk of

known risk factors for heart disease discussed above, obesity increases the risk of heart disease through other independent mechanisms. The distribution of body fat is also important. An increase in abdominal fat, even with a normal BMI, is both a risk factor for heart disease and a component of the insulin resistance syndrome (as measured by waist circumference).<sup>xx</sup>

## Obesity and Cancer

Obesity has been associated with an increased risk of several different types of cancer. Bianchini, Kaaks, and Vainio quantified the relationship between cancer and obesity in a detailed, comprehensive meta-analysis.<sup>xxi</sup> Twenty case-control and cohort studies describe an association between risk of colorectal cancer and adiposity. Obesity, as opposed to normal weight, is associated with a RR of colorectal cancer of 1.6 among men and 1.3 among women. Excess weight is related to the development of large colorectal adenomas, which suggests that cancer in obese subjects is the result of progression of adenomas to malignancies.

Case-control studies report a roughly 40 percent increase in the risk of breast cancer among obese post-menopausal women. Cohort studies report a more modest 20 percent increase with obesity. Interestingly, obesity appears to be protective against breast cancer among pre-menopausal women (RR of 0.7 for development of breast cancer before menopause). Obesity is also associated with an increased risk of endometrial cancer. The relative risk of endometrial cancer among obese women was estimated as 3.6 among case-control studies and 2.2 among cohort studies.<sup>xxiv</sup>

- A. Obesity is strongly associated with an increase in risk of renal-cell cancer (RR of 1.7 for men and 2.0 for women). Finally, there is a strong relationship between adenocarcinoma of the esophagus and gastric cardia and obesity (RR 2.7). There are conflicting reports of an association of obesity with cancers of the ovary, cervix, thyroid, liver, pancreas, gallbladder, testis, and head and neck. Unlike with colon, breast, endometrial, esophageal, and renal-cell cancer, the evidence is simply not convincing enough to draw firm conclusions.<sup>xxiv</sup> Bergstrom et al. have estimated that 40 percent of endometrial cancers, 25 percent of renal cancers, and 10 percent of breast and colon cancers could be prevented by maintaining a BMI of less than 25 kg/m<sup>2</sup>.<sup>xxii</sup>

## Obesity and Hepatobiliary Disease

Cholelithiasis has long been associated with obesity. Epidemiological studies have confirmed the increased risk of gallstones with increasing BMI. Even overweight but not obese men and women have a relative risk of developing gallstones of approximately 1.9 compared to men and women of normal weight.<sup>xxiii</sup> Cholelithiasis is also common during weight loss because of supersaturation of bile with cholesterol.<sup>xxiv</sup>

Nonalcoholic fatty liver disease (NAFLD) refers to fatty infiltration (steatosis) of the liver in obese persons. It is associated with a spectrum of other hepatic abnormalities, including hepatomegaly, elevated liver enzymes, steatohepatitis, and even cirrhosis. Analysis of liver

biopsies in one study has revealed that roughly 75 percent of obese persons have steatosis, 20 percent have steatohepatitis, and 2 percent have cirrhosis.<sup>xxv</sup>

### Obesity and Pulmonary Disease

The prevalence of asthma has been increasing, particularly among African American and Latino children. Not coincidentally, obesity among children is also increasing, especially among minorities. Though the mechanisms through which obesity influences the likelihood and severity of asthma among children and adults are still being worked out, cross-sectional studies confirm a relationship between asthma and obesity.<sup>xxvi</sup> It was once thought that asthma restricted one's ability to exercise and, therefore, that asthmatics were more likely to become obese as a result of physical inactivity. Prospective cohort studies, however, have confirmed that obesity precedes the development of asthma in girls and adult women.<sup>xxvii, xxviii</sup> The incidence of asthma among girls who become obese after the age of 11 is five to sevenfold higher than the incidence among lean girls. This relationship has not been found in males.

Obesity has long been associated with sleep problems. Burwell first coined the term *Pickwickian* syndrome in 1956 to describe the coexistent findings of obesity, chronic daytime hypercapnia and hypoxemia, polycythaemia, hypersomnolence, and right heart failure.<sup>xxix</sup> (Pickwick, an extremely obese character in Charles Dickens' *The Pickwick Papers*, couldn't help falling asleep during the day.) More recently, a strong association between obesity and *sleep disordered breathing* (SDB) has been described. Most studies of SDB involve subjects presenting to sleep laboratories. By contrast, the "Sleep Heart Health Study" enrolled only community-dwelling adults ages 40 to 98 who completed questionnaires, clinical examinations, and in-home polysomnography.<sup>xxx</sup> The degree of sleep apnea (either *obstructive* [OSA] or *central*) is commonly measured using the apnea-hypopnea index (AHI)—the number of apneic and hypopneic events per hour of sleep. A threshold AHI of 15 or greater was used to define SDB. The OR for SDB for every 5.3 kg/m<sup>2</sup> increase in BMI was approximately 1.6 among all patients studied. In other words, an adult with a BMI of 30.3 kg/m<sup>2</sup> compared with an adult with a BMI of 25 kg/m<sup>2</sup> has 1.6 times the odds of developing SDB. Interestingly, the relationship between increasing BMI and SDB diminished among older subjects. SDB is an extremely serious condition associated with a number of cardiovascular abnormalities, including hypertension, rhythm disturbances, coronary heart disease, stroke, heart failure, and death.<sup>xxxi</sup>

### Obesity and Gastroesophageal Reflux Disease (GERD)

Many studies have reported an increase in GERD symptoms (such as heartburn) with obesity. A recent systematic review by Hampel, Abraham, and El-Serag of studies published between 1966 and 2004 confirms a relationship between BMI and likelihood of GERD symptoms. Compared with adults with a BMI of less than 25 kg/m<sup>2</sup>, the OR for GERD symptoms is 1.43, 95 percent CI (1.158, 1.774) for adults with a BMI of between 25 and 30 kg/m<sup>2</sup>, and 1.94, 95 percent CI (1.468, 2.566) for adults with a BMI of greater than 30 kg/m<sup>2</sup>. The meta-analysis also reveals that complications of GERD, including erosive esophagitis and esophageal adenocarcinoma, are more common among obese adults.

## Obesity Increases the Risk of Musculoskeletal Problems

Musculoskeletal complications of obesity get far less attention than cardiovascular and metabolic complications. Obesity is a significant risk factor for osteoarthritis, a major cause of disability, especially among the elderly. Obesity increases the risk of developing osteoarthritis approximately fivefold among adults.<sup>xxxii</sup>

Children also are vulnerable to the musculoskeletal complications of obesity. Obesity has long been associated with slipped capital femoral epiphyses (SCFE) and *Blount's disease* (also known as *tibia vara – varus deformity of tibia*). These two conditions are still relatively uncommon. More recently, Taylor and colleagues studied the impact of obesity on more common musculoskeletal problems. The OR for having had a fracture among obese children compared with normal weight children was 4.54, 95 percent CI (1.6, 13.2). The OR for having any type of musculoskeletal pain among obese children compared with normal weight children was 4.04, 95 percent CI (1.5, 10.6).<sup>xxxiii</sup> Furthermore, obese children reported significantly poorer general mobility than normal weight children. Obesity, therefore, is not only the cause of relatively rare bone and joint problems but also is associated with increased trauma, pain, and decreased mobility among children.

### *Psychosocial Complications of Obesity*

To many overweight and obese people, the social and psychological impact of their condition is obvious. I care for obese children, and their stories of maltreatment and isolation are heartbreaking. Obesity has a profound impact upon mental and social well-being, which can be just as devastating as its medical complications. Unfortunately, compared with obesity-related illnesses such as diabetes, the psychosocial complications receive far less attention. Much of the research into the social impact of obesity is decades old, though there is no evidence to suggest that the social standing of the obese has improved.

### Bias and Discrimination

Negative attitudes toward the obese begin early in childhood. In one well-known study, children as young as 6 were shown silhouettes of obese children and asked to describe them. Common descriptors included, “lazy, dirty, stupid, ugly, cheats, and liars.”<sup>xxxiv</sup> Negative qualities that have nothing to do with excess weight, therefore, are ascribed to the obese. Such attitudes persist into adulthood and in employment and educational settings. Women report the greatest desire to work with thin women and the least desire to work with obese women.<sup>xxxv</sup> One study revealed that obese female applicants for sales and business positions were judged by surveyed study participants to lack self-discipline and have low supervisory potential, poor personal hygiene, and poor professional appearance.<sup>xxxvi</sup> Comprehensive reviews of studies of attitudes toward the obese reveal a variety of similar and other stereotypes. Obese employees are believed to be lazy, less conscientious, less competent, sloppy, disagreeable, emotionally unstable, and less intelligent.<sup>xxxvii, xxxviii</sup> Such attitudes likely have a significant influence upon work prospects. Obese women, for example, earn 12 percent less than non-obese women.<sup>xxxix</sup>

Discrimination in educational settings has not been limited to teasing or abuse among young children. In the 1960s, Canning and Mayer found that among high school students applying to college, obese students were significantly less likely to be accepted compared to non-obese peers, despite having equivalent qualifications. This was especially true for female applicants.<sup>x1</sup>

Sadly, there is even evidence that health care professionals are also guilty of rampant discrimination against the obese. A 1982 survey of family physicians revealed that obesity was associated with poor hygiene, non-compliance, hostility, and dishonesty.<sup>xli</sup> Another study revealed that 24 percent of nurses feel that caring for obese patients is repulsive and that 12 percent prefer not to touch obese patients.<sup>xlii</sup>

Unlike discrimination on the basis of sex, race, ethnicity, religion, or physical or mental disability, discrimination against the obese is still seen as “acceptable.”<sup>xliii</sup> Furthermore, individuals discriminated against on the basis of weight have little legal recourse. Few jurisdictions in the United States prohibit discrimination on the basis of weight (except for the extremely obese, who are classified as disabled).<sup>xliiv</sup>

### Obesity and Psychiatric Disease

Obesity is associated with depression and other psychiatric disorders. A large cross-sectional epidemiologic survey of adults revealed that compared with non-obese adults, among obese adults the OR for a lifetime diagnosis of depression was 1.21, 95 percent (1.09, 1.35). The ORs for bipolar disorder and panic disorder or agoraphobia were 1.47, 95 percent CI (1.12, 1.93) and 1.27, 95 percent (1.01, 1.60), respectively.<sup>xlv</sup> Cross-sectional studies do not answer the question as to whether the obese are more likely to develop depression or whether depression is a cause of obesity. Longitudinal studies have shown mixed results. Depression has been shown to be predictive of obesity in adults<sup>xlvi</sup> and adolescents.<sup>xlvii</sup> The precise mechanisms involved have not yet been clearly delineated. Increased appetite and weight gain are common symptoms of depression that may lead to obesity. On the other hand, it has been suggested that the stigma associated with obesity may contribute to future depression.<sup>xlviii</sup> There is also evidence that depression and obesity share underlying mechanisms related to serotonin.<sup>xlix</sup>

### *Overall Impact of Obesity*

Measures of the overall impact of obesity upon life expectancy and mortality have been estimated. Peeters and colleagues estimate that compared to nonsmoking women of a healthy weight at age 40, overweight women lose 3.3 years and obese women lose 7.1 years of life. Nonsmoking overweight men lose 3.1 years and nonsmoking obese men lose 5.8 years of life.<sup>1</sup> Allison et al. have estimated that obesity is responsible for between 280,000 and 320,000 deaths in the United States annually.<sup>li</sup> Not surprisingly, obese adults with chronic illness rate their own quality of life in a number of health-related domains as poorer than that of non-obese adults with chronic illness.<sup>lii</sup>

## **Impact of Obesity upon African Americans**

Since obesity is more common among African Americans, so are its associated cardiovascular risks and consequences. The BRFSS and NHANES provide valuable information in this area. Based on the 2002 BRFSS, 10.3 percent of African American adults nationwide reported a history of diabetes,<sup>liii</sup> which is comparable to the 10 percent rate among African Americans in Allegheny County. This is still substantially higher than the mean prevalence of the county as a whole, which was 7 percent.<sup>liv</sup>

Thirty-four percent of African Americans in Allegheny County reported a history of high blood pressure compared with 26 percent of whites. This is comparable to nationwide data from the 2003 BRFSS, when 32.5 percent of African Americans reported a history of high blood pressure.<sup>lv, lvi</sup>

Obesity and its associated risk factors together with smoking and genetics have a profound influence on cardiovascular morbidity and mortality. Interestingly, the 2002 BRFSS reveals no statistically significant differences by race in self-reports of myocardial infarction, coronary artery disease, or stroke in Allegheny County. Nationally, however, death rates from heart disease and stroke are consistently higher among African Americans than other racial groups.<sup>lvii</sup>

## **Causes of Obesity**

Obesity and its consequences affect virtually every segment of our society. There have always been obese individuals, but today's high prevalence of obesity is the result of the interaction of people with an environment that encourages consumption of high calorie foods and discourages physical activity. The ultimate solution will involve transforming what is known as our "built environment"—essentially the man-made structures, facilities, and services in our communities—to promote healthier living. There is evidence that there are important racial disparities in the quality of our built environment. African Americans, including those in Allegheny County, are much more likely to live in communities where the only food available comes from convenience stores, gas stations, and fast food restaurants; where recreational facilities are scarce; and where sidewalks are in a state of disrepair. For many years, for example, there was no supermarket in the predominantly African American Hill District, limiting residents' access to fresh and nutritious food. The magnitude of change required to create a healthier built environment is massive and will take many years. With alarming rates of obesity, particularly among African Americans, we health care professionals cannot wait for such a transformation. We can and should advocate for change. More important, we can identify specific behaviors contributing to obesity among groups of individuals and promote behavioral change. If individuals and communities adopt healthy behaviors, even in the face of the temptations of an unhealthy built environment, rates of obesity will eventually decrease.

Any number of behaviors may contribute to obesity in a given individual. For example, one obese individual may exercise fairly regularly but frequent fast food restaurants daily. Certain common behaviors contribute disproportionately to the obesity epidemic among both adults and children and among all racial groups. Furthermore the contribution of certain

behaviors to obesity has been studied carefully. Focusing on these specific behaviors is simple, rational, and more likely to be effective than promoting fad diets, intensive weight loss boot camps, or other expensive and largely ineffective approaches. Table 1 lists some common behaviors and evidence for their contribution to obesity. There are significant racial disparities for some behaviors. African Americans, for example, are more likely to frequent fast food restaurants than other racial groups.<sup>lviii</sup>

## **A Simple Approach**

I have developed a relatively simple approach to promoting positive behavior change that is now being evaluated in community-based pediatrics practices. It has also been introduced to a number of different groups, including community leaders and school nurses. The essential steps are to assist individuals in identifying key behaviors contributing to obesity, encourage them to set goals to change these behaviors over a certain time period, and assist them with meeting these goals. An example of a useful tool for identifying key behaviors responsible for obesity is shown in Figure 2. The “Big Five” are five common behaviors responsible for obesity in children and adolescents. While it is true that cultural differences (including greater acceptance of overweight and obesity) between African Americans and other segments of obesity do, to some extent, influence rates of obesity and approaches to the problem that are likely to succeed, there is no question that many obesity-promoting behaviors are common among all segments of society. Heavy soft drink consumption, for example, is a cause of obesity among all racial groups, the young and old, and in all regions of the country. Tools such as The Big Five Scoring Worksheet (Figure 2) can be adapted for adults, for example, by replacing the family meals behavior with another common behavior associated with obesity, such as skipping breakfast. Most important, everyone—whether obese or not—can benefit from an approach that focuses on healthy behaviors. A thin child who eats fast food everyday has a strong chance of becoming obese eventually and should change his behavior. By focusing on adopting healthy behaviors, we can avoid stigmatizing overweight and obese people.

When the opportunity presents itself, encourage individuals to identify common obesity-promoting behaviors using tools such as The Big Five Scoring Worksheet. Inform them about the role such behaviors play in obesity. Encourage them to set goals to change behaviors. Provide them with reinforcement and support as they go through this process. It is neither easy nor quick, but until our built environment becomes less obesigenic, it is the most rational strategy.

## Case Study

Below is an excerpt from my book *Child Obesity: A Parent's Guide to a Fit, Trim and Happy Child*.<sup>lix</sup> It is a case study from the end of the book in which the reader is encouraged to put into practice the knowledge he has learned to that point about the causes, consequences, and solutions to the childhood obesity problem. The subject of the case is an African American boy from Buffalo, New York. Think carefully about “A Question for You to Consider,” which appears at the end of the case study, before moving on.

### Darryl's Story

Anyone who meets him would describe Darryl as quite a character. Known to his friends at school as a prankster, Darryl has managed to stay out of trouble by winning over his teachers and classmates with his charm. On his most recent report card, Darryl's homeroom teacher wrote, “Darryl is an average student. I think he could do better if he would take his schoolwork more seriously and stopped joking around as much. That having been said, I sure will miss Darryl next year!”

Darryl is an 11-year-old African American boy who lives with his mother, Glenda, and 9-year-old sister, Taja, in an apartment in the Hamlin Park area of Buffalo, New York. Darryl's parents divorced when he was 7. Glenda works as a receptionist for an insurance company. Early in the school year she received a note from a school nurse who expressed her concern about Darryl's weight. The nurse included a pamphlet about healthy eating habits. Darryl is 4'10" tall and weighs 135 pounds. His BMI is 28.3 kg/m<sup>2</sup>, which is greater than the 97<sup>th</sup> percentile for boys his age. At first, Darryl's mother wasn't too concerned. She herself has always been very heavy. At 5'5" tall, Glenda weighs well over 200 pounds. Her daughter, Taja, is also, according to Glenda, “a little chunky.” Darryl also dismissed the issue of his weight. In his words, “I'm not that big. There are plenty of kids bigger than me at school.”

Glenda's attitude began to change after she visited her family doctor for a checkup. Just 32 years old, Glenda's doctor found that Glenda not only was obese but also had high cholesterol and high blood pressure. With a stern warning, he urged Glenda and her family to pursue a healthier lifestyle. Glenda's father died of a heart attack at age 39. Gradually, this fact and her doctor's advice persuaded Glenda to commit to changes that would benefit her family.

Darryl eats whatever is available at home and at school. He is actually very physically active. He plays baseball in the summer and basketball with his friends almost every day indoors after school during the colder months. Darryl has a television in his bedroom that he likes to watch for an hour or two before going to bed. He also spends a lot of time watching television on weekends. Glenda takes her kids to fast food restaurants roughly once per week for dinner. The usual family meals are frozen dinners and pizzas. Glenda and her kids always eat dinner together. Darryl's biggest problem is his gargantuan thirst for soft drinks. A convenience store near his school offers “any size” of fountain drink for \$0.89. Darryl always chooses a huge, 32-ounce drink of root beer. His mom keeps the refrigerator well stocked with 2-liter plastic bottles of regular root beer and Pepsi. In addition to an almost daily 32-ounce fountain drink, Darryl goes through nearly an entire 2-liter bottle of root beer at home.

## A Question for You to Consider

Glenda is a busy single mother with limited resources. What one or two simple changes could she make to help her entire family achieve a healthier weight?

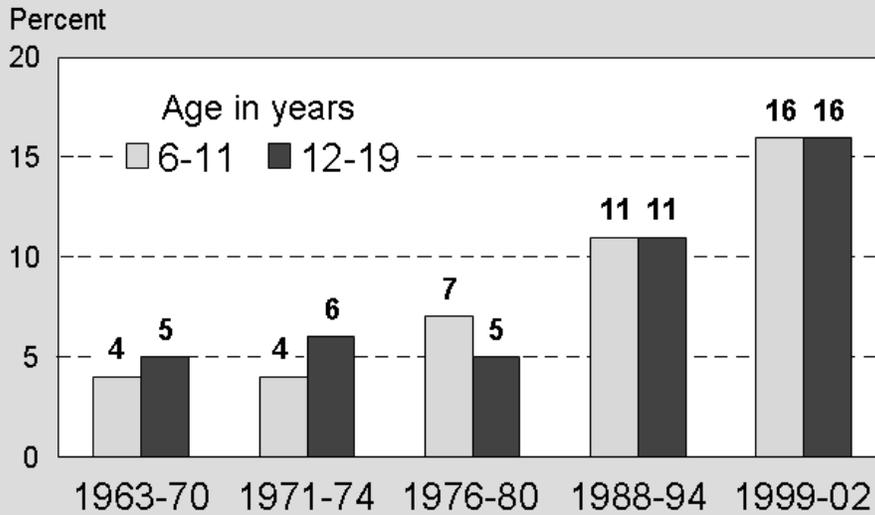
### On His Way to a Healthier Weight

Glenda began by establishing two very ambitious behavioral goals: making her home “television free” and eliminating soft drinks from the family’s diet. Glenda has always realized that Darryl doesn’t live up to his academic potential. She felt that getting rid of television would encourage him to read and do better in school. She rarely watches television. A week of monitoring revealed that Darryl watches an average of three hours of TV daily. The family does not have a computer or video game console at home. Glenda sold both of the family’s televisions to a secondhand store for \$25 each. The first couple of weeks were painful. Darryl felt like his entire bedtime routine had been disrupted. Glenda bought him some comic books and, gradually, Darryl made reading comics part of his bedtime routine. Taja made more of a fuss. She was in the habit of watching television after school. Glenda encouraged her to listen to the radio or read. Instead, Taja has been going over to a friend’s home to watch TV in the evenings.

Glenda carefully measured how much soft drinks Darryl consumed at home over the course of a week and asked him to tell her when he purchased fountain drinks, either at school or from a convenience store. She estimated that her son consumes roughly 2.5 liters of regular soft drinks a day—the equivalent of a staggering 1200 calories. Glenda then immediately replaced all soft drinks at home with refrigerated, ordinary tap water. Darryl still buys large servings of soda about three times per week and on occasion has soft drinks at the homes of friends. Glenda is trying to encourage him to get smaller serving sizes.

Darryl’s school performance did not improve substantially within six months of the changes described above. His teacher did remark, however, on a recent report card that Darryl seems “less fidgety than usual.” Glenda has noticed the same thing. Darryl’s interest in comic books has blossomed. He no longer misses television. Six months after the family made a commitment to pursue a healthier lifestyle, Darryl now weighs 127 pounds, which is a more significant change than you might think at first, given that he is still growing. He is drinking roughly a third of the amount of soft drinks he drank before.

**Figure 1. Prevalence of overweight among children and adolescents ages 6-19 years**



NOTE: Excludes pregnant women starting with 1971-74. Pregnancy status not available for 1963-65 and 1966-70. Data for 1963-65 are for children 6-11 years of age; data for 1966-70 are for adolescents 12-17 years of age, not 12-19 years.  
SOURCE: CDC/NCHS, NHES and NHANES

Source: Centers for Disease Control.

<http://www.cdc.gov/nchs/products/pubs/pubd/hestats/overwght99.htm#Table%201>. Accessed 4 December 2006.

Table 1: Key obesity-related behaviors

Behavior	*Key evidence
Eating breakfast	<p>Rampersaud GC, Pereira MA, Girard BL, Adams J, Metz J. Breakfast habits, nutritional status, body weight, and academic performance in children and adolescents. <i>J Am Diet Assoc</i> 2005;105(5): 743-60 (<i>Systematic review. Conclusions include that children and adolescents who eat breakfast consistently are less likely to be overweight.</i>)</p> <p>Cho S, Dietrich M, Brown CJ, Clark CA, Block G. <i>J Am Coll Nutr</i> 2003;22(4): 296-302. (<i>Secondary analysis of NHANES III data. Skipping breakfast is ineffective in controlling weight. Eating breakfast regularly is associated with a lower BMI.</i>)</p>
Soft drinks and other sweet drinks	<p>Malik VS, Schulze MB, Hu FB. Intake of sugar-sweetened beverages and weight gain: a systematic review. (<i>Considerable evidence that intake of sugar-sweetened beverages contributes to weight gain both among children and adults.</i>)</p> <p>Dennison BA, Rockwell HL, Baker SL. Excess fruit juice consumption by preschool-aged is associated with short stature and obesity. <i>Pediatrics</i> 1997;99(1): 15-22. (<i>Consumption of &gt;= 12 oz of fruit juice a day was associated with short stature and obesity in this cross-section study.</i>)</p>
Fast food consumption	<p>Bowman SA, Vinyard BT. Fast food consumption of U.S. adults: impact on energy and nutrient intakes and overweight status. <i>J Am Coll Nutr</i> 2004;23(2): 163-8. (<i>Higher frequency of fast food consumption associated with higher daily energy intake and higher BMI among adults in this large cross-sectional survey.</i>)</p> <p>Bowman SA, Gortmaker SL, Ebbeling CB, Pereira MA, Ludwig DS. Effects of fast-food consumption on energy intake and diet quality among children in a national household survey. <i>Pediatrics</i> 2004;113 (1 Pt. 1): 112-8. (<i>Children who consume fast food have poorer quality diets and higher energy intakes compared to those who do not based on this large cross-sectional survey.</i>)</p>
Television (and other media) time	<p>Salmon J, Bauman A, Crawford D, Timperio A, Owen N. The association between television viewing and overweight among Australian adults participating in varying levels of leisure-time physical activity. <i>Int J Obes Relat Metab Disord</i>.2000; 24 :600 –6 (<i>Adults who watch 4 or more hours of television a day are four times as likely to be overweight as those who watch less than 1 hour per day.</i>)</p> <p>Gortmaker SL, Must A, Sobol AM, Peterson K, Colditz GA, Dietz WH. Television viewing as a cause of increasing obesity among children in the United States, 1986–1990. <i>Arch Pediatr Adolesc Med</i>.1996; 150: 356 –62. (<i>In this large cohort study, the OR of being overweight was 4.6 (95% confidence interval, 2.2 to 9.6) among youth who watched more than 5 hours of television per day compared with those watching 0 to 2 hours.</i>)</p>

	Robinson TN. Reducing children's television viewing to prevent obesity: a randomized controlled trial. JAMA.1999; 282: 1561 –7. ( <i>A school-based intervention designed to reduce television viewing resulted in a statistically significant relative decrease in BMI compared to no intervention.</i> )
Physical activity	<p>Shaw K, Gennat H, O'Rourke P, Del Mar C. Exercise for overweight or obesity. Cochrane Database Syst Rev 2006;(4): CD003817. (<i>Authors conclude that exercise, particularly in combination with dietary changes, is effective in promoting weight loss among adults.</i>)</p> <p>Floodmark CE, Marcus C, Britton M. Interventions to prevent obesity in children and adolescents: a systematic literature review. Int J Obes 2006;30(4): 579-89. (<i>School-based programs that include promotion of physical activity are effective in preventing obesity among children.</i>)</p>
Family meals (for children and adolescents)	<p>Taveras EM, Rifas-Shiman SL, Berkey CS, Rockett HR, Field AE, Frazier AL, Colditz GA, Gillman MW. Family dinner and adolescent overweight. Obes Res 2005;13(5): 900-6. (<i>Frequency of eating dinner with the family associated with a lower baseline risk of being overweight among adolescents, though not an increased longitudinal risk of becoming overweight in this cross-sectional and longitudinal study.</i>)</p> <p>Gillman MW, Rifas-Shiman SL, Frazier AL, Rockett HR, Camargo CA Jr, Field AE, Berkey CS, Colditz GA. Family dinner and diet quality among older children and adolescents. Arch Fam Med 2000;9(3): 235-40. (<i>Family dinner associated with healthful dietary intake patterns in this cross-sectional study.</i>)</p>

\*These citations represent only a fraction of the evidence supporting the roles of these behaviors in obesity.

Figure 2: “The Big Five” --- Scoring Worksheet  
Goutham Rao, MD

1. Sweet Beverages

*Sweet beverages include fruit juices (either whole juice or from concentrate), fruit drinks and punches, regular sweetened soda pop, sports drinks (e.g., Gatorade), energy drinks, regular sweetened iced tea, and chocolate or other flavored milk. One serving of a sweet beverage is 12 ounces.*

How many servings of sweet beverage does your child consume in a typical day? (Round up any half servings to the next whole number of servings.)

- a. One or none ----- Score = 0
- b. Two ----- Score = 5
- c. Three ----- Score = 10
- d. Four ----- Score = 15
- e. Five or more ----- Score = 20

Record your child’s score here: \_\_\_\_\_

2. Fast food (excluding sweet beverages)

*“Traditional fast food” includes the following: burgers (with any type of meat), hot dogs, French fries, chicken nuggets, onion rings, etc.*

In a typical week, how often does your child eat traditional fast food?

- a. One time or zero times ----- Score = 0
- b. Twice ----- Score = 5
- c. Three ----- Score = 10
- d. Four ----- Score = 15
- e. Five or more ----- Score = 20

Record your child’s score here: \_\_\_\_\_

3. Family meals

*Eating dinner while supervised by at least one parent is protective against obesity.*

How often does your child eat dinner with at least one parent during a typical week?

- a. One time or zero times ----- Score = 20
- b. Two or three times ----- Score = 10
- c. Four or five times ----- Score = 5
- d. Six or seven times ----- Score = 0

Record your child’s score here: \_\_\_\_\_

4. Media time

*Media time is defined as the amount of time your child spends watching television, using a computer (apart from for home work), playing video games, or listening to a music device while sitting or lying still.*

In a typical day how much total media time does your child have?

- a. One hour or less ----- Score = 0
- b. One to two hours ----- Score = 5
- c. Two to three hours ----- Score = 10
- d. Three to four hours ----- Score = 15
- e. More than four hours ----- Score = 20

Record your child's score here: \_\_\_\_\_

5. Habitual physical activity

*Regular physical activity is protective against obesity. This can include sports as long as your child is out of breath at least once while playing. (Softball and bowling don't usually count). It can also include walking or riding a bike, skateboarding, etc., whether your child is out of breath or not. Gym class does not count.*

In a typical week, on how many days does your child participate in physical activity (sports to the point of being out of breath) or walking, riding a bike, etc. for at least 30 minutes total per day?

- a. One or zero ----- Score = 20
- b. Two or three ----- Score = 10
- c. Four or five ----- Score = 5
- d. Six or seven ----- Score = 0

Record your child's score here: \_\_\_\_\_

To calculate your child's total score, add up the scores above, and then subtract from 100. For example, if the sum of the scores above is 60, your child's score would be:

$$100 - 60 = 40$$

Scoring Guide:

80 – 100 Excellent! Though there is always room for improvement, it's obvious that your child is practicing habits that will help him or her achieve or maintain a healthy weight.

60 – 80 Good. Your child has many good habits, but there is still significant room for improvement.

40 – 60 Fair. To achieve or maintain a healthy weight, there are many healthy behaviors your child needs to adopt.

< 40 Poor. Your child is at high risk of either becoming obese or remaining obese. You should speak to your doctor about helping him or her achieve a healthy weight.

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## Endnotes

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## **CHAPTER 5. CANCER BY RACE**

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### **Introduction**

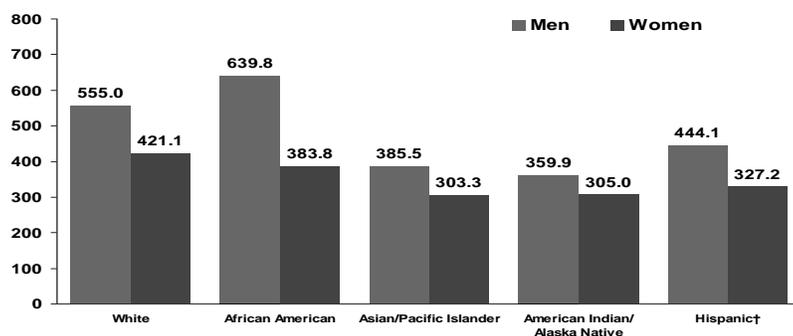
According to Cancer Trends Progress Report-2007, the nation's investment in cancer research is making a difference. The total number of deaths from cancer in the United States has dropped for the first time since 1993: incidence rates appear stable and individuals with cancer are surviving longer and living quality lives. However, cancer remains a major public health problem. Cancer has become the leading cause of death in people under the age of 85, surpassing heart disease (Jemal et al., 2005 and Jemal et al., 2008), and was expected to claim approximately 565,650 Americans in 2008 (Jemal et al., 2008). Cancers of the breast, lung, colon and rectum, and female reproductive organs (uterus, ovaries) account for 65 percent of the new cancer cases and 59 percent of the cancer deaths among American women. Cancers of the prostate, lung, colon and rectum, and bladder account for about 64 percent of new cancer cases and 54 percent of the cancer deaths in American men (Siminoff, 2005).

Despite a decrease in age-standardized death rates, there were 5,424 more cancer deaths reported in 2005, the most recent year for which actual data were recorded, than 2004 (Jemal, 2008). Although the recent decrease in cancer death rates in the United States is encouraging, it needs to be noted that U.S. cancer death rates have not declined for all cancers. Between 1990-91 and 2004, death rates increased substantially for lung cancer in women and for liver and intrahepatic bile duct cancer in men. Lung cancer incidence rates are declining in men and plateauing in women after increasing for many decades, reflecting that cigarette smoking in women peaked about 20 years later than in men (Jemal et al., 2008). The incidence rates for cancers of the liver, pancreas, kidney, esophagus and thyroid, non-Hodgkin's lymphoma, leukemia, and myeloma, as well as childhood cancers, continue to rise. The rates of brain cancer, bladder cancer, and melanoma in women and testicular cancer in men are on the rise. The death rates for cancer of the liver, thyroid, and esophagus are increasing.

All Americans are not at equal risk for cancer and disparities exist among sub-populations, contributing to poor outcomes in certain groups. (See figures below.) The National Institutes for Health defines health disparities as "the differences in the incidence, prevalence, mortality and burden of disease and other adverse health conditions that exist among specific population groups

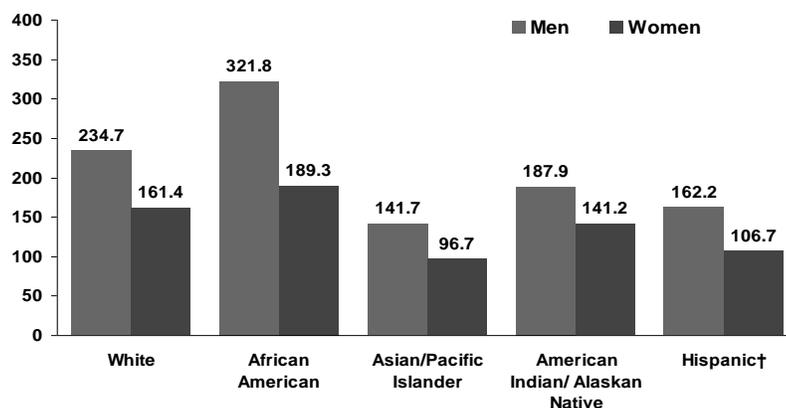
in the United States” ([www.aehd.net/biostats/pubs/Gabe/disparities.html](http://www.aehd.net/biostats/pubs/Gabe/disparities.html)). These differences have been shown to independently affect outcomes in mortality patterns. The socio-demographic factors of education, race, and socioeconomic status (SES) have been shown to directly impact the mortality rates of a population. Minorities have higher mortality rates for multiple reasons, most notably because of adverse social conditions such as lack of access to health care, disparities in educational attainment, and poverty (Woolf, 2007). African Americans are the largest racial minority in the United States, comprising approximately 12 percent of the total population. Irrespective of race, individuals from a lower SES experience a higher prevalence and mortality from cancer than individuals from a higher SES (Siminoff, 2005).

**Cancer Incidence Rates\* by Race and Ethnicity, 1999-2003**  
Rate Per 100,000



\*Age-adjusted to the 2000 US standard population.  
†Person of Hispanic origin may be of any race.  
Sources: Howe HL, et al. Annual report to the nation on the status of cancer 1975-2003; SEER, 1975-2003, Division of Cancer Control and Population Sciences, National Cancer Institute, 2006.

**Cancer Death Rates\* by Race and Ethnicity, US, 2000-2004**



\*Per 100,000, age-adjusted to the 2000 US standard population.  
†Persons of Hispanic origin may be of any race.  
Source: Surveillance, Epidemiology, and End Results Program, 1975-2004, Division of Cancer Control and Population Sciences, National Cancer Institute, 2007.

## U.S. Cancer Incidence and Mortality Trends (African Americans and Hispanic/Latinos)

African Americans face a considerable disparity with regard to cancer incidence and mortality. African American men have a 25 percent higher incidence and a 43 percent higher mortality rate for all cancer sites combined when compared to white men (Lisovicz, 2008). Although African American women have a lower incidence rate for all cancers combined than white women, they have a 20 percent higher mortality rate. The breast cancer mortality rate in African American women is 28 percent higher, and cervical cancer mortality rates are twice that of white women.

African Americans tend to be diagnosed at more advanced stages of cancer than whites, which decreases their chances of survival or cure. In addition, African Americans have a lower five-year relative survival rate for almost every type of cancer than whites at each stage of diagnosis. (See tables below.) Survival rates in African Americans have increased from 27 percent during 1960-63 to 53 percent during 1992-1998, lagging behind the five-year survival rate of whites, which has increased from 39 percent to 64 percent during that same reporting period (Ghafoor, 2002). This suggests that there may be disparities in access, receipt of state-of-the-art care, and differences in co-morbid conditions.

Cancer Sites in Which African American Death Rates\* Exceed White Death Rates\* for Men, US, 1999-2003

Site	African American	White	Ratio of African American/White
All sites	331.0	239.2	1.4
Prostate	65.1	26.7	2.4
Larynx	5.1	2.2	2.3
Stomach	12.4	5.4	2.3
Myeloma	8.6	4.4	2.0
Oral cavity and pharynx	6.9	3.8	1.8
Esophagus	10.7	7.6	1.4
Liver and intrahepatic bile duct	9.6	6.3	1.5
Small intestine	0.7	0.4	1.8
Colon and rectum	33.6	23.7	1.4
Lung and bronchus	98.4	73.8	1.3
Pancreas	15.7	12.0	1.3

\*Per 100,000, age-adjusted to the 2000 US standard population.  
Source: Surveillance, Epidemiology, and End Results Program, 1975-2003, Division of Cancer Control and Population Sciences, National Cancer Institute, 2006.

Cancer Sites in Which African American Death Rates\* Exceed White Death Rates\* for Women, US, 1999-2003

Site	African American	White	Ratio of African American/White
All sites	192.4	163.4	1.2
Stomach	6.0	2.7	2.2
Myeloma	6.4	2.9	2.2
Uterine cervix	5.1	2.4	2.1
Esophagus	3.0	1.7	1.8
Larynx	0.9	0.5	1.8
Uterine corpus	7.1	3.9	1.8
Small intestine	0.5	0.3	1.7
Pancreas	12.5	9.0	1.4
Colon and rectum	23.7	16.4	1.4
Liver and intrahepatic bile duct	3.8	2.8	1.4
Breast	34.4	25.4	1.4
Urinary bladder	2.9	2.3	1.3
Gallbladder	1.0	0.8	1.3
Oral cavity and pharynx	1.8	1.5	1.2

\*Per 100,000, age-adjusted to the 2000 US standard population.  
Source: Surveillance, Epidemiology, and End Results Program, 1975-2003, Division of Cancer Control and Population Sciences, National Cancer Institute, 2006.

Hispanics/Latinos (the terms are used interchangeably to refer to the same ethnic group) in the United States had lower incidence and death rates for all cancers combined, including the most common cancers (prostate, female breast, colon and rectum, and lung) from 2000 through 2003 than non-Hispanic whites. However, during that same time period, it was noted that U. S. Hispanic residents had higher rates of acute lymphocytic leukemia and cancers of the stomach, liver, gallbladder, and cervix than did non-Hispanic whites (U.S. Cancer Statistics Working Group, 2007). The incidence of stomach cancer is 75 percent higher in Hispanics than in non-Hispanic whites. Hispanic women also have twice the incidence of cervical cancer than non-Hispanic white women, with a 40 percent higher death rate. Although Hispanics have lower incidence and death rates than non-Hispanic whites, for most common cancers, they are generally diagnosed at more advanced stages (Cancer Facts & Figures for Hispanics/ Latinos, 2006-2008). This may be the result of cultural differences, immigration status, and elevated exposures to environmental risks in living places and workplaces. In addition, language barriers, reduced use of screening services, barriers to access to care, lack of insurance, lower education, health literacy, and income levels may also play a role (Young, 2006). Cancers with the higher incidence rates in Hispanics are associated with infections, such as human papilloma virus (HPV) in cervical cancer, helicobacter pylori in stomach cancer, and hepatitis B and C in liver cancer (U.S. Cancer Statistics Working Group, 2007). It is important to note that the number of new cases of cancers per site differ among Hispanics depending on their country of origin. Hispanics are the fastest growing ethnic minority group in the United States. It is estimated that by the year 2050, they will comprise 25 percent of the nation's population. The Hispanic population in southwestern Pennsylvania increased more than 50 percent from 1990 to 2000 (U.S. Census, 2000).

The incidence rates of all cancers combined for men in the United States for 2004 were highest among Blacks, followed by whites, Hispanics, Asian/Pacific Islanders (API), and American Indian/Alaska Native. Male cancer-related death rates during this same period were highest among Blacks, followed by whites, Hispanics, American Indian/Alaska Native, and Asian/Pacific Islanders (API). The incidence rates for females are highest among white, followed by Black,

Hispanic, Asian/Pacific Islanders, and American Indian/Alaska Native. Death rates among females during 2004 were highest among Blacks, followed by whites, American Indian/Alaska Native, Hispanic, and Asian/Pacific Islanders. In general, among the four races, American Indian/Alaska Native males have the lowest incidence rates of cancer, and Asian/Pacific Islander males have the lowest death rates from cancer in the United States. White females have the highest incidence rates of cancer and Black women the highest death rates. American Indian/Alaska Native females have the lowest incidence rates of cancer and the third highest death rates (U.S. Cancer Statistics Working Group, 2007).

Among African Americans, incidence has:

- decreased significantly<sup>1</sup> by 0.2 percent per year from 1980 to 2004 among men and women combined,
- remained level from 1980 to 2004 among men, and
- remained level from 1975 to 2004 among women.

Among Hispanics, incidence has

- remained level from 1995 to 2004 among men and women combined,
- remained level from 1995 to 2004 among men, and
- remained level from 1995 to 2004 among women.

Among African Americans, deaths have decreased between the periods of 2001 to 2004 by:

- 3.4 percent per year for men and women combined,
- 4.9 percent per year among men, and
- 4.0 percent per year among women.

Among Hispanics, between the period of 1995 to 2004 deaths have:

- decreased by 0.9 percent per year for men and women combined,
- decreased by 1.4 percent per year among men, and
- remained level from 1995 to 2004 among women.

## **Overview of the Major Cancers in the United States**

### *Breast Cancer*

In the United States, breast cancer is the most common cancer in women. One in eight women will develop breast cancer during their lives. It is the most common cause of death from cancer among Hispanic women. Breast cancer is the second most common cause of death from cancer among white, Black, Asian/Pacific Islander, and American Indian/Alaska Native women. Japanese women have the highest incidence of breast cancer among Asian Americans. Filipino women have the highest breast cancer death rate and the second-highest breast cancer incidence rate of Asian American women. One factor that may contribute to this is the percentage of overweight women in the Filipino community, which is the highest of all the ethnic groups studied. Being a woman is the greatest risk factor for developing breast cancer. The chance of developing breast cancer increases as a woman ages. Studies show that only about 5 percent of breast cancer

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<sup>1</sup> The word "significantly" refers to statistical significance. The year 2004 is the latest year for which data are available.

cases result from inherited BRCA1 or BRCA2 gene mutations. Women who carry one of these mutations have a lifetime risk of developing breast cancer between 35 to 85 percent. Additional risk factors include: postmenopausal hormone therapy, overweight (especially weight gain after menopause), use of alcohol (one or more drinks daily), physical inactivity, periods before age 12, menopause after age 55, having one's first child after age 35, or not having children.

### *Cervical Cancer*

Prior to the use of the Pap smear in 1955, cervical cancer was one of the most common cancers found in American women. In 2004, 11,892 women in the United States were diagnosed with cervical cancer, and 3,850 died from the disease. Vietnamese women have the highest incidence and death rates for cervical cancer of all Asian groups. This is thought to be due to the fact that screening for cervical cancer with a Pap test is less common among Vietnamese women than it is among several other Asian groups. Korean women have the lowest screening rate for cervical cancer and the second highest incidence and death rate from that disease. There are several risk factors that increase a woman's chance of developing cervical cancer. It is rare that a woman without any of these risk factors will develop cervical cancer. The most important risk factor is exposure to the human papillomavirus (HPV). HPV is a group of more than 100 types of viruses. Some types of HPV cause genital warts and other types cause cervical cancer. HPV is passed from one person to another during vaginal, anal, or oral sex through direct skin-to-skin contact. Women who have unprotected sex, particularly at a young age, are at increased risk. Women who have multiple sex partners (or who have sex with men who have had many partners) have a greater chance of getting HPV.

Other risk factors for cervical cancer include smoking, infections, diets low in fruits and vegetables, being overweight, birth control pills, multiple pregnancies, diethylstilbestrol (DES), and family history. Cervical cancer disproportionately affects women of minority and low-income status. When found and treated early, cervical cancer can often be cured.

### *Colorectal Cancer*

Colorectal cancer (CRC) is the third most common cancer in men and in women (U.S. Cancer Statistics Working Group, 2007). More than 90 percent of the colorectal cancers are diagnosed in individuals over the age of 50. The incidence and death rate of CRC varies by race and ethnicity. African Americans have the highest incidence rate for CRC in the United States. Whites have the second highest incidence rate of CRC, followed by Asian/Pacific Islander, Hispanic, and American Indian/Alaska Natives. Jews of eastern European descent also have a higher rate of colon cancer. While the risk for this type of cancer is low in China, it is higher among Chinese who have been in the United States longer, possibly the result of adopting a western lifestyle. CRC rates are higher among Chinese Americans than most other Asian groups. Chinese Americans are more likely than other Asian groups to be screened for CRC. Still, only about 40 percent of men and 42 percent of women report having a colonoscopy in the past five years. The findings from the Centers for Disease Control's (CDC) 2000 National Health Interview Survey indicate that many people who are at risk for CRC are not being screened. Although screening rates are beginning to rise, they remain too low to achieve the Healthy People 2010 objective for reducing mortality from colorectal cancer. In 2004, approximately 57 percent of

adults aged 50 years or older reported having received a fecal occult blood test (FOBT) or lower endoscopy within one year of being surveyed by the CDC's Behavioral Risk Factor Surveillance System, compared with 54 percent of adults surveyed in 2002 (Seeff et al., 2002).

Less than 10 percent of CRCs are inherited. A benign colon polyp known as adenomatous polyp may increase an individual's risk of developing colon cancer. Other risk factors include personal history of CRC, previously treated CRC, and inflammatory bowel disease. In addition, obesity, smoking, and alcohol use are risk factors.

### *Lung Cancer*

According to the *United States Cancer Statistics: 2004 Incidence and Mortality* report, lung cancer is the second most common cancer among white, Black, Asian/Pacific Islander, and American Indian/Alaska Native men, and the third most common cancer among Hispanic men in the United States. Lung cancer rates are high among Chinese American women, which may be due to exposure to secondhand smoke at home and at work, as well as exposure to smoke from high-temperature frying, since comparatively few Chinese American women smoke.

The death rate from lung cancer for U.S. females is among the highest in the world. Death rates for U.S. males are lower than rates among males in several other countries, although rates among males are still higher than rates among females in the United States. Decreases in lung cancer cases and death rates among males stem from reductions in smoking that began several decades ago. Among females, reductions in smoking are more recent, beginning in the late 1970s.

Tobacco use is the greatest risk factor for lung cancer. Other risk factors include: exposure to secondhand smoke, asbestos, and cancer causing agents in the workplace (arsenic, vinyl chloride, coal products, and radioactive ores like uranium). Individuals who smoke in addition to being exposed to these agents are at particularly increased risk.

### *Prostate Cancer*

Prostate cancer is the most common form of cancer, other than some kinds of skin cancer, among men in the United States. It is the second leading cause of cancer deaths among men in the United States after lung cancer, and the seventh leading cause of death overall for men in this country. African American males die of prostate cancer more than any other race/ethnic group. More than 60 percent of prostate cancer is diagnosed in men over 65 years. Prostate cancer is the most commonly diagnosed cancer among Asian American men of all ethnicities, and Filipino men have the highest incidence and death rates from this cancer of all Asian American groups.

Though all men are at risk, African American men have higher rates of getting and dying from prostate cancer than men of other racial or ethnic groups in the United States. Scientists are studying possible reasons, including culture, environment, and differences in the biology of the disease in African American men.

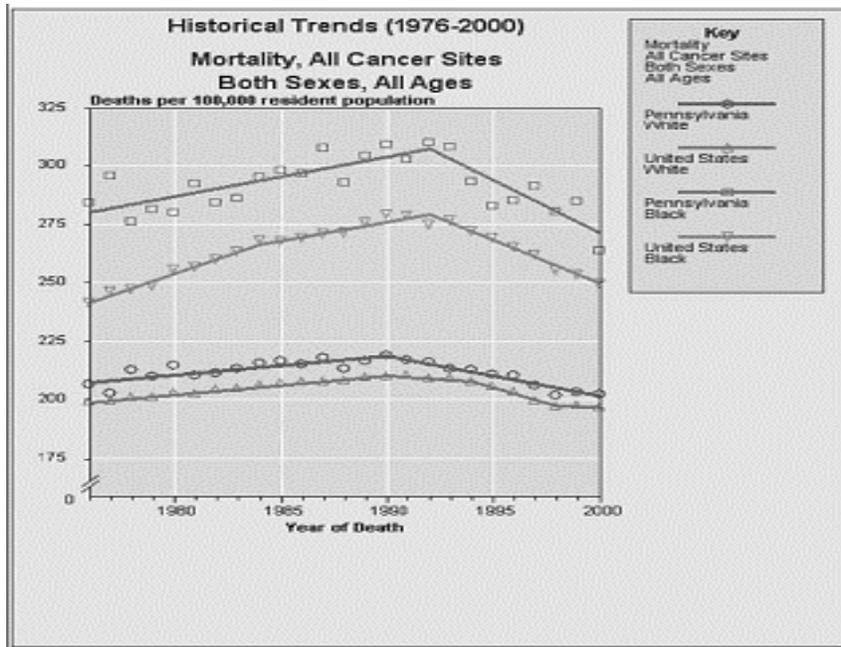
In general, the incidence of prostate cancer in the United States has remained level among men of all races and ethnic groups from 1995–2004. Deaths from prostate cancer in the United States decreased significantly by 4.0 percent per year from 1994–2004 (Swan et al., 2003).

### **Problem Conditions and Trends (Five-to-Ten Years of Data for Whites and Blacks in Pennsylvania and Allegheny County, Where Available)**

Cancer is the second leading cause of death in Pennsylvania. Progress has been made in reducing the numbers of individuals who die from cancer yearly; however, in Pennsylvania, the mortality rate is higher than for the nation as a whole. (See figure on following page.) In addition, there is a marked disparity between the death rates for African Americans and whites in the state. As the number of cancer survivors increases, resuming normal routines remains a significant challenge for a growing number of cancer survivors and their families in Pennsylvania.

In 2003, there were 5,644 new cases of invasive cancer diagnosed among African Americans and 2,558 cancer-related deaths in Pennsylvania (PA Dept of Health, 2006). The African American cancer incidence rates for all cancers were consistently higher than the rates for whites during the period between the years 1993-2003. The 2003 cancer incidence rate for African Americans was 7.1 percent higher than the rate for whites. The Pennsylvania cancer incidence rates for African Americans were approximately 5 percent higher than the rates recorded by the National Cancer Institute's SEER Program. (See figure on following page.)

There were 71,788 cases of invasive (and in situ urinary bladder) cancers diagnosed among residents of the state and reported to the Pennsylvania Cancer Registry (PCR) for 2005. An additional 5,069 cases of non-invasive cancers were diagnosed among residents. The breakdown of the nine primary sites that had over 2,000 cases of invasive cancer were: lung and bronchus (10,487), female breast (9,505), prostate (9,435), colon and rectum (8,199), urinary bladder (includes in situ cases) (3,678), non-Hodgkin's lymphoma (2,983), melanoma (2,494), corpus/uterus, NOS (2,363), and kidney/renal (2,248). Combined, these nine primary sites comprise about 72 percent of the cancers diagnosed in Pennsylvania in 2005.



The age-adjusted incidence rates by sex and race for 2005 showed that the highest rates in white males were for prostate, lung and bronchus, colon and rectum, urinary bladder cancers, and non-Hodgkin’s lymphoma. Among Black males, their highest rates occurred for the same top four sites, followed by kidney/renal pelvis cancer. White females’ highest cancer rates were breast, lung and bronchus, colon and rectum, corpus/uterus, NOS, and thyroid cancers. The four top sites of cancer among Black females were the same as for white women, with the fifth being cancer of the pancreas (Pennsylvania Department of Health, March 2008).

There were 29,355 cancer deaths reported among Pennsylvania residents in 2005. Seven sites had over 1,000 deaths: lung and bronchus (8,086); colon and rectum (2,914); female breast (2,114); pancreas (1,714); non-Hodgkin’s lymphoma (1,150); and leukemia (1,113). This comprises about 63 percent of cancer related deaths among Pennsylvania residents in 2005.

Age-adjusted death rate by sex and race shows that white males had their highest death rates for cancers of the lung and bronchus, prostate, colon/rectum, pancreas, and non-Hodgkin’s lymphoma. Among Black males, the order was the same as for white males for the highest three types of cancer, followed by liver/intrahepatic, bile duct, and pancreas. The highest age-adjusted rates for white females were from cancers of the lung and bronchus, breast, colon and rectum, ovary, and pancreas. The top three cancer sites with highest death rates among Black females were the same as those in white females, followed by cancer of the pancreas and corpus/uterus, NOS.

Similar to the U.S. statistics, in Pennsylvania, breast cancer is the most commonly diagnosed invasive breast cancer in both white females (26.8 percent of all invasive cancers) and Black females (27 percent).

Pennsylvania has the sixth highest rate of cervical cancer in the United States. In 2003, 510 cases of invasive cervical cancer were diagnosed. The average age-adjusted incidence rates for cervical cancer were 56 percent higher for Black women as compared to white women, and the death rate among Black women was twice as high as the rate among white women (PA Department of Health, 2003).

Pennsylvania's CRC incidence and mortality rates are higher than the national average (57.9 per 100,000 compared to U.S. average of 52.0) (PA Department of Health: [www.dsf.health.state.pa.us/health/cwp/view.asp?A=174&Q=198285](http://www.dsf.health.state.pa.us/health/cwp/view.asp?A=174&Q=198285)). Approximately 1.8 million people in Pennsylvania are eligible for CRC screening but have not yet been screened ([www.pac3.org](http://www.pac3.org)).

Based on the 2000 U.S. Census Bureau's Decennial Census, the population of Allegheny County is 1,281,666 persons, with Pittsburgh being the most populated municipality in the county (334,563 residents). There are 128 municipalities within Allegheny County located within 730 square miles. Significant relationships are seen between educational attainment and age-adjusted mortality rates ( $p < 0.001$ ), race and education ( $p < 0.001$ ), and mortality and race ( $p < 0.001$ ). The highest age-adjusted mortality rates occur in municipalities with the lowest educational attainment. Among these municipalities are McKees Rocks, Millvale, McKeesport, North Braddock, and Duquesne, which rank lowest in education and highest in age-adjusted mortality rates. A community with a less educated populace is likely to have less access to quality healthcare, which may lead to higher mortality rates. Municipalities with the highest population of Blacks have the highest age-adjusted mortality rates and rank lower in educational attainment. Braddock, Homestead, Duquesne, North Braddock, McKeesport, and McKees Rocks were all in the lowest decile for educational attainment, the highest in age-adjusted mortality rates, and among the highest in percent of Black population ([www.achd.net/biostats/pubs/Gabe/disparities.html](http://www.achd.net/biostats/pubs/Gabe/disparities.html)).

The racial disparities seen in cancer in the United States and Pennsylvania in general are also apparent in the Western Pennsylvania region. In Allegheny County, compared to whites, African American males experienced 40 percent higher mortality from all cancers and 210 percent higher mortality from prostate cancer during 1994 to 1998, adjusted for age (Hunte, Bangs, & Thompson, 2002). African American females had 30 percent higher mortality from colorectal cancer and 10 percent higher mortality from breast cancer as compared to whites. Similar patterns are seen for other cancer sites. For both whites and Blacks, the long-term trend showed a decline in mortality. However, a sizeable disparity between the two races existed between 1971 and 2005. Although the width of this disparity fluctuated from year to year, it has not narrowed over the long term. Malignant neoplasms account for 24 percent of mortality, exceeded only by heart disease at 29 percent (Allegheny County Mortality statistics, 2005).

### **Causes of the Problem**

The most obvious factors associated with disparities in cancer incidence and death among racial, ethnic, and underserved groups are lack of health care coverage and low socioeconomic status (SES). However, there are also other complex and interrelated factors that contribute to African Americans/Blacks in the United States having the greatest burden for each of the most common types of cancer (NCI, 2008).

SES is based on a person's income, education level, occupation, and other factors, such as social status in the community and where he or she lives. Studies have found that SES, more than race or ethnicity, predicts the likelihood of an individual's access to education, certain occupations, health insurance, and living conditions. Living conditions include exposure to environmental toxins, which may be associated with the increased risk of developing and surviving cancer. SES also appears to play a major role in influencing the prevalence of behavioral risk factors for cancer such as smoking, lack of physical activity, obesity, excessive use of alcohol, and adherence to cancer screening recommendations (NCI, 2008).

Individuals who are medically underserved are more likely to be diagnosed with advanced stages of cancer. Often the cancers that are diagnosed at late stages are cancers that can be cured if detected and treated early. In addition, financial, physical, and cultural beliefs are barriers that prevent individuals or groups from obtaining effective health care.

In the most recent issue of *Healthy Choices, Healthy Lives*, published by the University of Pittsburgh Cancer Institute's (UPCI) Center for Environmental Oncology in cooperation with Magee-Womens Hospital of UPMC, Drs. Lyn Robertson and Beth Simon wrote an article based on their experiences and insights into racial disparities and health and outlined a local approach to reducing health disparities through risk reduction and community resilience.

While it is well known that socioeconomic factors contribute to health disparities, not enough attention is given to the environmental factors such as air pollution and workplace hazards that plague communities in disadvantaged areas, many of which also can contribute to disparities in health effects (Smedley, 2000). The "natural" environment such as air, water, and soil has a direct influence on health. Individuals of color or individuals with a low SES are five times more likely to live in areas where the environment is of poorer quality. While one in eight Americans is Black, one in two Blacks works in lower-paying, often more hazardous blue-collar jobs. In addition, according to the Environmental Protection Agency, Blacks and Hispanics are much more likely to live near hazardous waste facilities or in more degraded neighborhoods.

Social and community environments affect health, both directly and indirectly, by influencing behavior and choices (Lee, 2002). Individual behavior is affected by various aspects of the environment (Husain, 2002). For instance, there are fewer supermarkets in African American neighborhoods. Fruit and vegetable intake, known to lower the risk of some cancer, was 32 percent higher in African American neighborhoods that were close to supermarkets.

Focusing on individual behavior change alone ignores the larger environmental factors that can interfere with the educational message that can either conflict with or reinforce interventions. However, the environment cannot be the only focus since individual behaviors such as tobacco use, inactivity, and high fat diets are also critical (Adler, 2002). It is a challenge that must be effectively met—to help people change their personal behavior—when there are so many other pressures, many of them not within the individual's control, working against that change.

## **Consequences for Individuals, Families, and Communities**

The consequences for individuals, families, and communities are many. In addition to the health consequences of individual behaviors such as tobacco use, poor diet, and inactivity, environmental factors influence the health of the community. Air and water pollution, common in disadvantaged areas, are associated with negative health outcomes. Low SES neighborhood conditions often produce higher levels of stress, which contributes to poorer mental health and health outcomes. The lack of access to healthy foods, such as fruits and vegetables, puts individuals at higher risk for diseases such as cancer. The chances of incurring workplace and other hazards are much greater for minorities.

By including well-documented individual behavioral risk factors with those in the environment, several UPCI/UPMC Cancer Control Programs are providing a unique combination of efforts aimed at reducing the burden of the personal and general environment for cancer. There remain many opportunities for improvement (Robertson & Simon, 2008).

## **Solutions to the Problem: Current and Alternative Programs and Policies**

For more than 20 years, the U.S. Department of Health and Human Services (DHHS) and the Pennsylvania Department of Health (DOH) have led many initiatives aimed at reducing health care disparities and improving quality of care. There are also numerous private organizations that have taken key roles in this endeavor. In 2005, the National Healthcare Disparities Report (NHDR) undertook efforts to track changes in core measures related to health care disparities. These studies have demonstrated that although some disparities are diminishing, others are increasing. For Blacks, Asians, and Hispanics, disparities involved all domains of quality of life that could be tracked, including access to preventative services, treatment of acute illness, chronic illness and disability management, timeliness, and patient centeredness.

The Pennsylvania Comprehensive Cancer Control Plan is an excellent blueprint for advancing cancer control in the state. Throughout Pennsylvania, vast resources exist to address the fight against cancer. The vision of the Pennsylvania Cancer Control Consortium (PAC<sup>3</sup>) and this Plan is to pull together both people and resources across the state to significantly reduce the burden of cancer for all citizens.

The CDC, along with the National Cancer Institute (NCI) and the American Cancer Society, have set ambitious goals for the elimination of suffering and death due to cancer by the year 2015. The goals and objectives of the Pennsylvania Comprehensive Cancer Control Plan span the continuum that begins with lifestyle behaviors; continues with screening, diagnosis, treatment, recovery, and potential/possible recurrence; and addresses quality of life throughout the cancer experience. The plan outlines the means and methods necessary to achieve success across this continuum. In addition, the plan, as outlined at [www.pac3.org](http://www.pac3.org), embodies two overarching principles necessary for successful implementation:

- I.* Our full potential for impact will only be realized through collaboration, both within the Commonwealth and with national partners.

2. We must ensure that cancer-related health disparities are addressed so that ALL citizens of the Commonwealth benefit from the efforts of this Plan.

The University of Pittsburgh Cancer Institute (UPCI) has had a long-term commitment to enhancing cancer care in traditionally underserved communities, including minority populations. Since no one can explain why the chance of getting some types of cancer is greater for Blacks than for whites, UPCI faculty and staff are working directly with those who are affected to understand and address this problem.

More than a decade ago, the African American Cancer Program (AACP) was established by UPCI with the major goal of increasing participation in clinical research by minority populations, although it was considerably broader in order to address a variety of key issues. The general goals were to build trust, comfort, and familiarity between the UPCI and UPMC Cancer Centers and underserved populations, most notably African Americans; to provide screening and early detection outreach and educational programs to promote early detection; and to narrow or eliminate disparities in knowledge or access to knowledge about cancer, cancer prevention, and cancer treatment.

In 2005, the AACP was restructured, with a major focus being on developing partnerships within the minority community with key agencies and leaders. The purpose of the partnership was to increase the ability to meet established goals. The first partnership was with the University of Pittsburgh Center for Minority Health (CMH) at Pitt's Graduate School of Public Health in collaboration with Dr. Stephen Thomas. This partnership led to the establishment of the African American Cancer Care Partnership (AACCP), chaired by Dr. Lyn Robertson and Dr. Thomas. The AACCP is composed of working hospital, community, and University partners—including the CMH, UPMC Cancer Centers, the American Cancer Society, and various community organizations and individuals—to identify and implement effective strategies to reduce health disparities. This collaboration has strengthened the services that any organization or individual could accomplish alone and the reach has been extensive within the Pittsburgh area and surrounding counties.

In 2007, additional partnerships were developed with the Gay/Lesbian community and Healthcare for the Homeless, both of which serve large numbers of African Americans. The partnerships have considerably expanded existing educational, outreach, screening, and community support activities and continue to build trust and familiarity between the healthcare system and minority communities.

### *Patient Navigation*

UPCI/UPMC Cancer Centers offer three unique patient navigator programs aimed at addressing disparities in cancer care. UPMC McKeesport was the recipient of a Cooperative Planning Grant for Cancer Disparities Research Partnerships (RFA CA-03-018) in 2003. The goals of this planning grant were to increase the number of patients on clinical trials in the community setting, improve access to quality radiotherapy, ensure an adequate choice of treatment approaches, and improve recruitment to clinical research studies at earlier stages of disease for ethnic minorities and economically disadvantaged groups. This decentralized approach brings services to the people who need them—in their communities.

To initiate the opportunity to participate in clinical research at the community level, a collaborative regional network, the Radiation Oncology Community Outreach Group (ROCOG), was developed. This effort is under the leadership of Dr. Dwight Heron, Associate Professor and Vice Chairman for Clinical Affairs, Department of Radiation Oncology, University of Pittsburgh School of Medicine, and is based at UPMC McKeesport.

Two important components of this grant are the patient navigator program and the clinical trials program. The addition of an on-site Clinical Research Coordinator (CRC) has provided the infrastructure necessary to facilitate clinical trial accrual and, as a result, accrual rates to clinical trials have increased substantially. Patient navigators have been successful, both in identifying potential clinical trials patients and in working to eliminate all barriers to participation. Funding was recently secured to hire a Breast Care navigator to improve the quality of women's care for members of the community having mammograms.

A community navigation model was initiated in 2005 at the Hillman Cancer Center to serve the minority and underserved populations in Pittsburgh. The Community Outreach Navigator Volunteer (CONV) program brings the important message that prevention and early detection save lives. CONVs are trained and supported by Cancer Control staff at the Hillman Cancer Center and then take their knowledge into the communities in which they live in providing outreach education related to healthy lifestyle, cancer prevention, and early detection.

#### *Diversity Pilot Project (DPP)*

UPMC has become increasingly concerned about the late diagnosis, disproportionate tumor burden, and shorter survivals in African Americans with cancer. This concern resulted in the development of a pilot program designed to address the disparities among African Americans in Allegheny County by providing a specifically tailored program for individuals with breast, prostate, lung, and colorectal cancer. The pilot program at the Hillman Cancer Center, Magee-Womens Hospital of UPMC, UPMC McKeesport, or UPMC Braddock is specifically designed to address the issues that individuals who are uninsured or underinsured face when confronting a diagnosis of cancer. The program has resulted in the development of an additional navigator program at UPCI/UPMC. The program was developed in 2006 and is implemented by Dr. Robertson and several of her colleagues. To date, 285 newly diagnosed African Americans have been enrolled, representing approximately 78.5 percent of newly diagnosed African American cancer patients who seek care in these UPMC facilities. Twenty-two percent of the referrals to the program have been from new referral sources. The program has a dedicated telephone number that is answered by a social worker who, at the time of initial patient contact, conducts a routine assessment that includes the identification of any potential barriers to care. Each participant is offered the services of a culturally competent patient navigator to help the patient navigate through the health care system, answer questions, and offer support. With this focused navigation, it has been possible to work out insurance coverage and transportation problems for a high percentage of the DPP participants. The navigator also maintains contact at least bimonthly so that any potential barriers to care can be identified early. The early identification of potential barriers has been instrumental in patients complying with prescribed treatment regimes. The compliance rate in this group of individuals has been remarkably high—98 percent. The most commonly identified

barriers to care have been lack of or inadequate health insurance and transportation. The biggest barrier to entry into a clinical trial has been that many of the individuals who are enrolled in the program have co-morbidities that make them ineligible—21.8 percent have three or more co-morbidities at the time of diagnosis. Despite these barriers, 12.2 percent of the patients served by the DPP enrolled in a clinical trial.

### *Cancer Screenings*

Free cancer screenings are held at the Hillman Cancer Center and various locations in the Pittsburgh metropolitan area. As a key component of efforts to reduce mortality from cancer, these early detection efforts are brought to the community. Screenings include breast, colorectal, and prostate cancer exams. During these exams, the individuals' skin and oral cavities are also examined. Cancer-related screenings have increased 450 percent between 2006 and 2007. In addition, individuals who have positive findings can be referred to the DPP. This has been a benefit to those individuals who do not have health care insurance or have other barriers to care.

### *Healthcare for the Homeless Collaboration*

In January 2008, Cancer Control professionals teamed with Healthcare for the Homeless to provide cancer education and screening to women and men—many of whom were African American—in homeless shelters, residential treatment facilities, and drop-in centers throughout the City of Pittsburgh and McKeesport, Pennsylvania. Between February and October 2008, 11 programs and screenings were done in the following centers: Salvation Army-North Side, Salvation Army-Harbor Light Center, East End Cooperative Ministry, Pleasant Valley Men's Shelter, Bethlehem Haven, Wood Street Commons Shelter, Miryams, Wellspring, Jubilee Kitchen, the Centre Avenue YMCA, and the YWCA in McKeesport. These programs provided women's health education and screening (clinical breast examination and mammogram screening, mammogram voucher procurement, PAP/HPV tests) and men's health education and prostate cancer education and screening (DRE/PSA). All programs and services focused upon healthy living, with education geared toward each individual's circumstances. Mechanisms for follow-up have been established and the two organizations collaborate effectively in providing follow-up of positive/suspicious findings and health counseling for follow-up care. We have begun to revisit each of these centers with plans for ongoing collaboration at every site. Eighty-one of the 125 individuals educated have been screened for prostate, breast, or cervical cancer. Approximately 25 percent of the individuals screened required further follow-up for other health-related conditions such as findings on a clinical breast exam, vaginal infection, and other health-related symptoms. The compliance rate for individuals who required further follow-up either related to a cancer screening or other symptoms has been 98 percent. Our program is gaining recognition throughout the area, and we have begun securing foundation funding to enhance current efforts through data collection and use of navigation services.

### *Additional Outreach Efforts*

Cancer Control personnel extended outreach in 2008 to the Garfield section of Pittsburgh and to McKeesport to provide cancer education and screenings. In addition to regular screenings, the AACP collaborates on event-related activities with Us TOO International, the American Cancer

Society's *Lets Talk About It* program, the Center for Minority Health's *Adopt a Shop*, and a coalition of seven local churches in minority neighborhoods.

The African American Self-Help Cancer Group, established in 1994 and with current membership of 140 survivors, continues to meet monthly at the Hillman Cancer Center. This group provides support and information to African American cancer survivors and their friends and families.

### *Palliative and End of Life Care*

Over the last two years, efforts have also been directed to addressing other health care-related issues within the African American community. Dr. Robertson was invited to become a member of the UPMC Institute of Palliative Care and the Coalition for Quality at the End of Life in Western Pennsylvania (CQEL) in 2006. Through this membership, she has been able to collaborate with other organizations throughout Western Pennsylvania in their efforts to address issues of racial disparities in the medical treatment of African Americans and other minorities. As part of CQEL's regional implementation of the call for ending racial disparities in palliative and end-of-life care by the Governor's Task Force on Quality at the End of Life, CQEL held a major training conference for health professionals in 2008 in the Herberman Conference Center. The conference was titled "APPEAL"—A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End. The curriculum is designed by African American faculty and palliative care experts to help health professionals provide state-of-the-art, culturally appropriate end-of-life care to African Americans. These efforts are in collaboration with Duke University's Institute on End-of-Life Care and UPMC.

### **Action Steps for Policymaker, Providers and Insurers, Community-Based Organizations, Individuals, and Researchers**

There are important policy issues at the state and local level that could make a major impact on cancer risk and public health in Pennsylvania. The governor recently signed Senate Bill 246 into law, prohibiting smoking in public places. The bill allows for some exceptions, including a private residence (except those licensed as a child-care facility), a private social function where the site involved is under the control of the sponsor, and a wholesale or retail tobacco shop. Although a fairly effective law, there are major loopholes that are of particular concern for young and minority workers who need to work in environments such as bars, social clubs, and casinos that have been exempted from this regulation.

It is essential that insurers participate in cancer prevention programs, including wellness programs and screenings. It is also in the best interest of the insurers. By reducing cancer in those at risk, insurers will avoid the very high costs associated with dealing with cancer when diagnosed at a late stage.

Although excellent plans exist to address the key problems in Pennsylvania with regard to cancer, there is currently a lack of public funding to fully implement these plans. Major new funding is needed for effective cancer control in Pennsylvania, especially for the minorities who disproportionately bear an undue burden of cancer.

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## CHAPTER 6. HIV/AIDS HEALTH DISPARITIES IN ALLEGHENY COUNTY

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### Introduction

In August 2008, the Black AIDS Institute released the report, *Left Behind, Black America: A Neglected Priority in the Global AIDS Epidemic*. The report addresses the misperception that HIV/AIDS is no longer a national crisis. “Widespread belief that AIDS is a foe that has been vanquished in the U.S. reflects something more – the astonishing invisibility of the continuing AIDS crisis in Black America ... HIV-related health disparities between whites and blacks have actually widened as medical advances have made HIV treatable.”<sup>1</sup> Allegheny County has not been spared the HIV/AIDS epidemic. AIDS activism during the early part of the epidemic assured high visibility in the Pittsburgh region. Local grassroots organizations like the Pittsburgh AIDS Task Force, Shepherd Wellness Center, and Persad marshaled local support, and the yearly AIDS Walk raised needed funds. The Pitt Men’s Study began recruiting gay men to gain epidemiological understanding of a disease killing too many men in the prime of life. Dedicated local physicians provided specialized HIV/AIDS medical care even though treatment options were few and many patients were dying. By 1996, the outlook for people living with HIV/AIDS improved with the development of new drugs. The risk of mother-infant HIV transmission was also greatly reduced. However, the rates of new HIV infection in the United States and Allegheny County did not diminish and the number of infected women has steadily increased. African Americans, nationally and locally, have been disproportionately represented throughout the epidemic. Disparities in incidence and prevalence of HIV/AIDS in Allegheny County echo the national trends. Although white men who have sex with men continue to represent the greatest number of people impacted by this epidemic, African American men, women, and youth are disproportionately living with and dying from HIV/AIDS in Allegheny County.

### Problem Conditions and Trends

The 2008 XVII International AIDS Conference announced findings indicating that the annual incidence of new HIV infections was underestimated. The number of estimated annual HIV infections was adjusted upwards from 40,000 to 56,300 people. The study, “Estimation of HIV Incidence in the United States,” published in the *Journal of the American Medical Association* (JAMA), found new HIV infections have been increasing steadily among gay and

bisexual men since the early 1990s, and the number of new HIV infections among African Americans, though stable, has historically remained disproportionately higher than any other racial/ethnic group.<sup>ii</sup> The most recent data from the HIV/AIDS Incidence Surveillance System estimates 54,230 new infections in 2006 in the United States and 46 percent occurred among Blacks.<sup>iii</sup>

The major risk factors for African Americans are unprotected sex, including men who have sex with men (MSM), and heterosexual contact. The Centers for Disease Control and Prevention (CDC) describes the HIV/AIDS epidemic as a health crisis for African Americans. Subpopulation HIV estimates drawn from 2006 surveillance data are:

Among both males and females, the highest rates of new infections occurred among blacks (115.7 and 55.7 per 100,000 population respectively). Among black males, the incidence rate was 5.9 times the rate among white males; the rate among black males aged 13-29 years was 7.1 times the rate among white males in the same age group. Among black females, the incidence rate was 14.7 times the rate of white females.... Among black and Hispanic MSM, most new infections were in persons aged 13-29, whereas, among white MSM, most new infections were in persons aged 30-39 years.<sup>iv</sup>

Contributing to the HIV epidemic and disease progression among all race and ethnic groups are the numbers living with HIV who do not know they are infected. The CDC reported that by the end of 2003, roughly one-fourth of the estimated one million persons living with HIV were unaware of their HIV infection. This has led to people entering HIV treatment at later stages in their illness; and by 2005, 38 percent received an AIDS diagnosis within one year of their first positive HIV test.<sup>v</sup> The report also describes results of a study of MSM done in five cities as part of the CDC's National HIV Behavioral Surveillance System, which found that "46% of the black MSM were HIV positive, compared with 21% of the white MSM and...the study also showed that of participating black MSM who tested positive for HIV, 67% were unaware of their infection."<sup>vi</sup> The CDC points to lack of awareness of HIV serostatus, homophobia, and socioeconomic issues as significant barriers to HIV education, prevention, and treatment efforts.

In Pennsylvania in 2006, 32 percent of the people living with AIDS were white, 47 percent were Black, and 14 percent were Hispanic. Blacks, who make up 10 percent of Pennsylvania's total population, are overrepresented among the AIDS population. Recent data from Healthy People 2010 highlight alarming disparities in HIV-infection deaths in Pennsylvania for 2005—17.8 per 100,000 for Black residents and 1.2 per 100,000 for white residents. The Healthy People 2010 goal is 0.7 per 100,000.<sup>vii</sup>

In Allegheny County, African Americans are again disproportionately represented among people living with HIV/AIDS. From 2000 to 2005, Black non-Hispanics ranged from 44 percent to 46 percent of people living with AIDS in Allegheny County despite representing only 12 percent of the population. Whites in the county accounted for 49 percent of all AIDS cases compared to their share (75.6%) of Allegheny County's population.<sup>viii</sup> The Southwestern Pennsylvania AIDS Planning Coalition (SWPAPC) issues updates to the Pennsylvania

Department of Health for the 11-county southwestern Pennsylvania region. Titled the Coalition Regional Services and Strategic Plan (CRSSP), it reviews epidemiological data for the region along with HIV/AIDS needs and service utilization for southwestern Pennsylvania.<sup>ix</sup> The CRSSP is vital to understanding the HIV epidemic in Allegheny County because the county, and more specifically the urban region, is the epicenter of HIV/AIDS for African Americans. The SWPAPC CRSSP 2007/2009 cites these regional trends:

- an increase in the female share of AIDS cases from 12 percent (1980-1990) to 21 percent (2000-2005); and
- an increase in the Black (non-Hispanic) share of AIDS cases from 33 percent (1980-1990) to 48 percent (2000-2005).

In the same time period, injection drug use (IDU) as a transmission mode remained the same at 17 percent, and heterosexual transmission increased from 6 percent to 24 percent. However, the majority of women living with HIV/AIDS in Allegheny County are African American, and heterosexual transmission is the primary transmission mode.

In 2001, 28 states, excluding Pennsylvania, had HIV reporting in addition to AIDS case reporting. Dr. Bruce Dixon, director of the Allegheny County Health Department, successfully championed legislation in 2001-2002 for confidential HIV reporting in Allegheny County. Name-based HIV reporting became statewide, except for Philadelphia County, in October 2002. HIV reporting quantifies the number of people who do not have an AIDS diagnosis but who are infected with the HIV virus.

In 2007, 219 new cases of HIV/AIDS were reported to the Allegheny County Health Department. African Americans accounted for 46 percent (100) of these cases.<sup>x</sup> The breakdown is alarming. Eighty-five percent (6/7) of youth ages 13-19 diagnosed with HIV were African Americans, and 58 percent (21/36) of young adults ages 20-29 were African Americans diagnosed with HIV/AIDS. The Allegheny County Health Department reports 107 newly-diagnosed HIV/AIDS cases for the first seven months of 2008, of which 58 percent (63/107) are African American.<sup>xi</sup>

Regionally, a little over 2,000 people sought HIV/AIDS medical care at the University of Pittsburgh Medical Center (UPMC), Allegheny General Hospital (AGH), and the Allegheny County Health Department in 2007. This patient population is primarily composed of whites and Blacks, with a very small percentage of Hispanic (3%) and African immigrants (1%). The majority of the patient population resides within Allegheny County. African Americans comprise 36 percent of those receiving treatment at the Ryan White-funded HIV/AIDS outpatient medical programs at UPMC and AGH.<sup>xii</sup> Roughly 60 percent of patients receiving HIV/AIDS care at the Allegheny County Health Department are African American.<sup>xiii</sup>

Allegheny County data from 2005 on sexually transmitted diseases (STDs)— including gonorrhea, Chlamydia, and primary and secondary syphilis—are relevant to this discussion because they are indicators of unprotected sex and increased HIV risk associated with STDs. Similar to the incidence of HIV/AIDS, the disparities associated with these sexually transmitted

diseases are staggering. African Americans have three times the rate of gonorrhea as whites and are twice as likely to have had primary and secondary syphilis reported.<sup>xiv</sup>

## Causes of the Problem

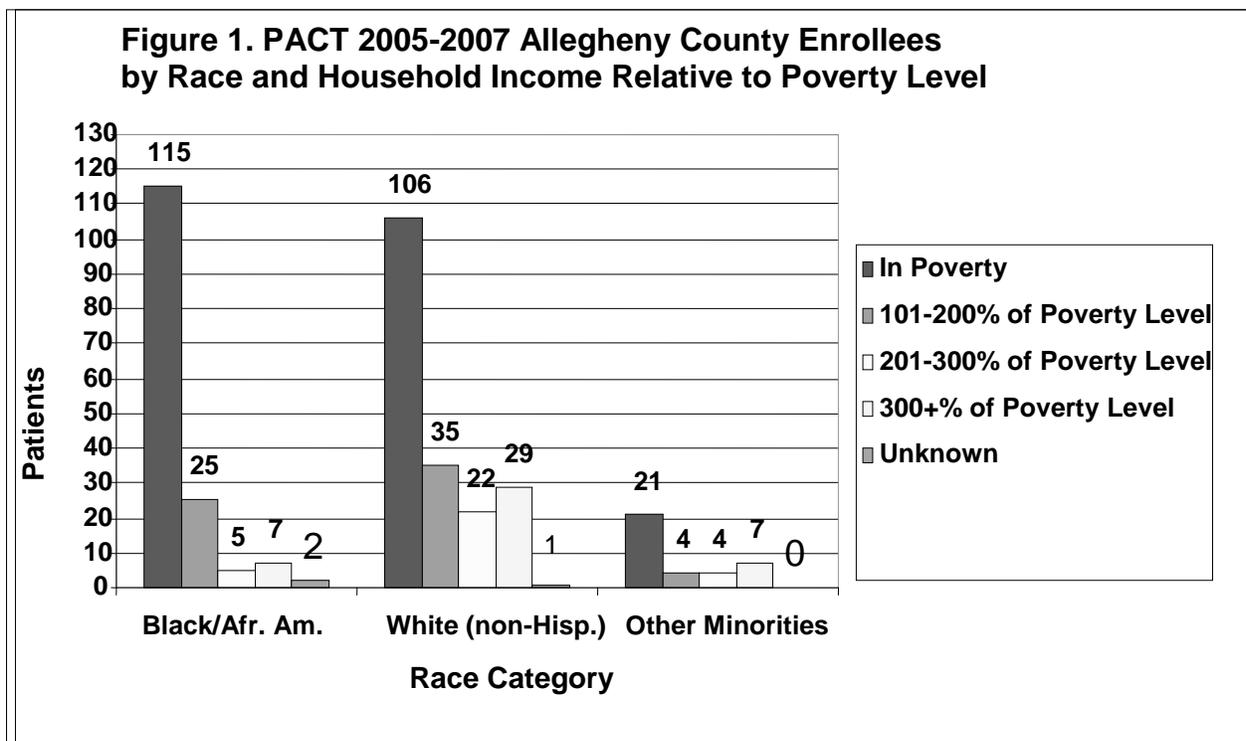
In 2007, Healthy People 2010 reviewed the progress toward reduction of HIV and cited key challenges: “complex socioeconomic dysfunctionalities including poverty, homelessness, racism, homophobia, gender inequality, and mental illness.”<sup>xv</sup> The complex interplay of these challenges is the dynamic fueling the epidemic nationally and within Allegheny County’s African American communities. The University of Pittsburgh’s Center on Race and Social Problems (CRSP) published a 2007 report, *Pittsburgh’s Racial Demographics: Differences and Disparities*, which describes a disparate quality of life in Allegheny County. There is disproportionate representation of African Americans in Allegheny County who live in poverty and experience serious mental illness and/or substance abuse.<sup>xvi</sup> The U.S. Census Bureau’s 2004 American Community Survey indicates that Allegheny County has less than 2 percent of Asian and Hispanic residents and less than 1 percent of American Indian and Alaska Native residents. The CRSP report also describes the Pittsburgh region as being highly segregated, with African Americans “not well dispersed” and most African Americans in southwestern Pennsylvania living in Allegheny County.

The University of Pittsburgh’s Graduate School of Public Health initiated the Healthy Black Family Project in 2005, targeting several neighborhoods in the East End of Pittsburgh as “Health Empowerment Zones.” The neighborhoods—East Hills, East Liberty, Homewood North, Homewood South, Homewood West, Larimer, Lincoln-Larimer, and Wilksburg—were targeted because these communities are 80 percent African American, with 26 percent of that population living below the federal poverty level (University of Pittsburgh *Research Review*, Spring 2005). Add to this the findings of the Allegheny County Jail Collaborative, whose goal is to reduce recidivism. Phase 2 of the study provides an analysis of gaps in human services in areas identified as having a concentration of offenders. The study reports that communities such as East Liberty, Wilksburg, and the Hill District contain some of the highest density of offenders per residential block in the county.<sup>xvii</sup> The domino effect of a criminal record, no income, unstable housing, and mental health/substance abuse all too often marginalize and lead individuals at high risk for HIV to ignore opportunities for HIV testing and treatment. For the HIV-infected person in and out of the county jail, discomfort with disclosure of HIV status or asking to see the nurse to make sure HIV medications are continued contributes to higher risk for the development of AIDS drug resistance.

Poverty is also disproportionately represented among whites and Blacks in treatment at the HIV/AIDS treatment centers in Allegheny County. Fifty-four percent of all patients seeking HIV medical care at UPMC’s Pittsburgh AIDS Center for Treatment (PACT) or AGH’s Positive Health Clinic live at or below the federal poverty level.<sup>xviii</sup> Figure 1 reveals the demographics of poverty for new patients beginning care at UPMC/PACT from 2005 through 2007.

Traveling out of their neighborhoods to places such as McKeesport, Braddock, or McKees Rocks to receive HIV/AIDS specialty care poses challenges for individuals with fixed

or low incomes. It is similar to seeking treatment for other major illnesses—no money for the bus, no money for prescriptions, no child care, and missed time and loss of pay. Single adults living below the poverty level cannot obtain medical assistance if they are diagnosed with HIV and do not have symptoms that make it impossible for them to work. Regulations that allow for the nondisabled worker to obtain medical assistance are so restrictive and become irrelevant for most poor single adults with asymptomatic HIV. Unfortunately, despite the efforts of many local AIDS Service Organizations, education about the availability of Ryan White funds to pay for HIV/AIDS drugs, transportation, and health care does not reach all who would benefit from it.



Source: Ryan White Program Data (CAREWARE) from University of Pittsburgh Early Intervention Program.

AGH and UPMC hospitals receive Ryan White Care Act funds from the federal government to provide comprehensive HIV primary care, including care for the uninsured. Currently the uninsured represent 19 percent of all patients receiving HIV/AIDS care at AGH and UPMC.<sup>xix</sup> Ryan White funds distributed by the state also provide access to a large formulary of prescription medications, including the most current arsenal of HIV/AIDS prescription medications. Guidelines allow a single Pennsylvania resident to be eligible if income is less than \$35,000. The amount increases if the HIV patient has dependents.

Gender inequality and the spread of HIV/AIDS are manifested in the alarming increase of HIV/AIDS among African American women, accompanied by the increase in heterosexual transmission as a major HIV/AIDS risk factor. The CDC reported in 2004, “HIV infection was the leading cause of death for black women (including African American women) aged 25-34 years.” The report states, “even though the annual estimated rate of HIV diagnosis for black

women decreased significantly—from 82.7 per 100,000 population in 2001 to 60.2 per 100,000 population in 2005—it remained 20 times the rate for white women.”<sup>xx</sup> The University of Pittsburgh’s HIV Early Intervention Project, which includes PACT, was awarded Ryan White Part D funds in 2001 to establish a collaborative with Children’s Hospital of Pittsburgh of UPMC (Children’s Hospital), Magee-Womens Hospital of UPMC (Magee-Womens), and AGH to improve and standardize HIV counseling, testing, and treatment for women receiving prenatal care. The program has been successful in testing women for HIV, providing intensive support during pregnancy, and virtually eliminating mother-infant transmission of HIV for women in care. What concerns HIV care providers is the disproportionate representation of African American single mothers living in poverty, with weak or nonexistent support systems and little self-esteem, seemingly locked into a lifestyle without hope. Fears related to suggesting condom use, disclosure of HIV status, loss of intimacy, and verbal and/or physical violence weigh heavily on the minds of these women. These problems challenge HIV prevention and treatment efforts here in Allegheny County and in larger U.S. cities.

HIV/AIDS presents unique challenges that span all races and socioeconomic groups. Homophobia, shame, and stigma prevent people of all ages and races from seeking education, HIV testing, and medical care. The shame and stigma attached to HIV within the African American culture is complex. The Black AIDS Institute’s recent report assesses HIV/AIDS in Black America within the context of the global epidemic. Stressing it is not an attempt to define the epidemic as similar in severity and depth to African nations, the report is a call to action to acknowledge the crisis in the United States and to recognize the pertinence of global public health strategies for America’s Black communities.

Much more so than white men in the U.S., black gay and bisexual men share many behavioral and cultural characteristics with their peers in other regions...Homosexually active black men are markedly less likely to self-identify as ‘gay’ than their peers from other racial or ethnic groups in the U.S. The fluidity of sexual identification among homosexually active men is also common in many low- and middle-income countries, where development of gay community consciousness is often in a nascent stage.<sup>xxi</sup>

The study suggests looking at prevention efforts successful in other parts of the world where homosexuality is taboo and discrimination is sanctioned. The high level of stigma and shame felt by many African Americans testing positive for HIV resonates in Allegheny County. What barriers do experts in the fields of HIV and minority health nationally and locally recognize as confronting local prevention and treatment efforts in African American communities? The fear of being seen while being tested for HIV, fear of being recognized if seeking HIV medical care, uneasiness if identified as “gay,” and a pervasive hopelessness—all have been tenacious challenges in this epidemic.

### **Consequences of the Problem for Individuals, Families, and Communities**

In a National Health Interview Study done in 2006, the CDC estimated 10.4 percent of all Americans, and 21.7 percent of non-Hispanic Blacks, obtained testing for HIV in the 12 months preceding the study.<sup>xxii</sup> The study estimates that excluding blood donations, 53.2 percent of

Americans who were tested in the previous 12-month period obtained the test through a private doctor/HMO, while 17.6 percent obtained HIV testing in an emergency room. Given the rise in heterosexual transmission among African American women, HIV testing in family planning and prenatal clinics is disturbingly low—fewer than 2 percent tested in the past 12 months. Equally unsettling is the low percentage (2.1%) of those tested receiving HIV testing at community health clinics. Community health centers serve the poor, both insured and uninsured, and may be federally designated to serve medically underserved communities. Only 23 percent of those acknowledging HIV risk factors had HIV testing in the previous 12 months. Are we reaching the groups most at risk for HIV? The study’s authors conclude:

These findings indicate that many persons in the U.S. have never been tested for HIV infection. Health-care providers should routinely screen all patients aged 13-64 years for HIV in accordance with CDC recommendations. New strategies are warranted to increase HIV testing, particularly among persons who are disproportionately affected by HIV infection.<sup>xxiii</sup>

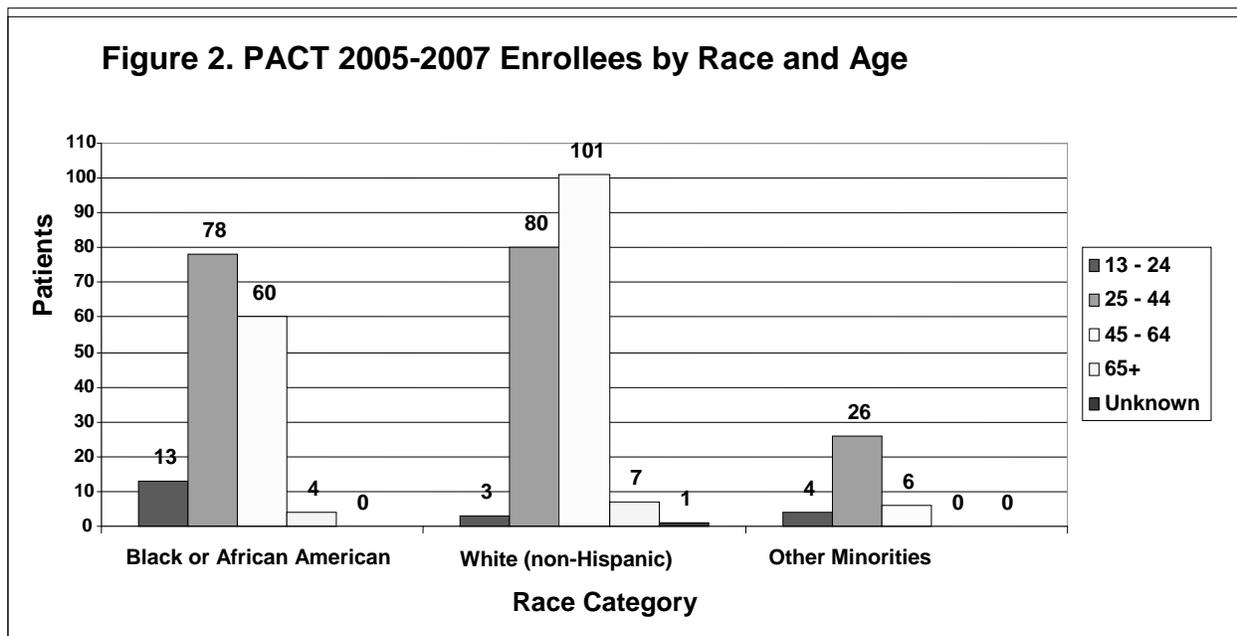
Lack of awareness, discomfort, and insufficient staffing contribute to providers not offering HIV testing routinely. The stigma and discrimination accompanying HIV/AIDS early in the epidemic linger and sabotage the benefits of early diagnosis and treatment. To protect the rights and privacy of people living with HIV, Pennsylvania passed the Pennsylvania Confidentiality of HIV-Related Information ACT (Act 148). Early in the epidemic, Act 148 established much-needed guidelines regarding the rights of people living with HIV. The revised CDC guidelines of 2006 (referenced above) currently are in conflict with Act 148, and Pennsylvania legislators are considering amending Act 148 to meet public health needs and the CDC recommendations. Currently, Pennsylvania has “opt-in testing,” which requires a separate consent for HIV testing. For some individuals, the physician’s request to do testing may cause the patient to infer a judgment about engaging in risky behavior and subsequently lead to rejecting the test.<sup>xxiv</sup> For example, testing for STDs does not include HIV; a separate consent is needed. “Opt-out” testing, which the CDC recommends, makes HIV testing a routine part of established medical care unless the patient declines testing.

Avoiding medical care when one is aware of his/her HIV/AIDS diagnosis is due to multiple socioeconomic, homophobic, and mental health issues associated with this epidemic. The Health Resources and Services Administration’s (HRSA) definition of unmet need is “the need for HIV-related health services by individuals with HIV who know their HIV status, but are not receiving regular primary health care.”<sup>xxv</sup> The Southwestern Pennsylvania AIDS Planning Coalition’s CRSSP goes on to explain that of people estimated to be living with HIV/AIDS in the 11-county southwestern Pennsylvania region, an estimated 31 percent have unmet need. For Allegheny County, it is estimated that 33 percent of people living with HIV/AIDS have unmet need. The CRSSP states that the “Southwest PA Coalition region is third at 30% after the Philadelphia AIDS Consortium (TPAC) at 40% and AIDSNET (counties north of Philadelphia at 36%) in the percent of people living with AIDS with unmet need.”<sup>xxvi</sup> Simply put, too many individuals ignore their HIV status until it progresses and they become symptomatic or seriously ill. The lack of good information about funded HIV medical care and medications for the uninsured, chronic mental health/substance abuse, and fear and stigma are common reasons for

delaying care. Ryan White B Minority AIDS Initiative Funds, which can be used to identify and link African Americans with unmet need, have not been available for Allegheny County since 2007.

Barriers intensify in resource-strapped and impoverished communities where poor health outcomes become all too predictable. One hundred and forty-three African American patients initiated HIV care at UPMC from 2005 through 2007. Among these patients, 39 percent (56/143) had CD4 counts below 350/mm.<sup>xxvii</sup> This value reflects the immunologic threshold at which HIV treatment is currently recommended by the U.S. Public Health Service.<sup>xxviii</sup> Of these 56 patients, more than half (31/56) were newly diagnosed or seeking HIV treatment for the first time. HIV/AIDS is exacerbated for the individual late to care, when other medical problems disproportionate in the Black community—including heart disease, kidney disease, and Hepatitis C co-infection—are present.

AGH’s Positive Health Clinic and UPMC’s PACT Clinic are seeing increasing numbers of youth ages 18-24 seeking treatment. Youth living with HIV/AIDS were not alive during the start of this epidemic, and many do not view or have yet to comprehend HIV/AIDS as a serious, life-threatening disease illness. Advances in HIV/AIDS treatment diminish fear of HIV, and lack of comprehensive sex education leaves youth unprepared for risks associated with sexual intercourse. The social, religious, and cultural injunctions regarding men who have sex with men complicate efforts at sex education and increase isolation risks for adolescents and youth who are attracted to the same sex. African American youth ages 13-24 seeking medical care, were disproportionately represented among new youth seeking care at UPMC/PACT from 2005-2007 [81% (13/16)] (Figure 2). Physicians are treating youth entering care with advanced HIV infection, as indicated by low CD4 counts.



Source: Ryan White Program Data (CAREWARE) from University of Pittsburgh Early Intervention Program.

## **Solutions to the Problem: Current and Alternate Programs and Policies**

The Ryan White Care Act of 2006 is federal funding designed to provide comprehensive care for HIV/AIDS-diagnosed individuals. This funding has raised the hopes and extended the lives of many low-income people living with HIV/AIDS in the United States. AIDS Drug Assistance Programs are available in every state and are funded through the Ryan White Care Act. Each state has its own guidelines. In Pennsylvania, the program is known as the Pennsylvania Special Pharmaceutical Benefits Program and provides eligible Pennsylvania residents with complete access to HIV/AIDS-related medications, in addition to a broad spectrum of other prescription medications. Ryan White B funds administered by the Pennsylvania Department of Health are also distributed to southwestern Pennsylvania for various services, including oral health care, case management, mental health care, support services, and transportation assistance. Many of the larger AIDS Service Organizations, including the Pittsburgh AIDS Task Force and Shepherd Wellness Community, rely on this funding for HIV/AIDS services. UPMC and AGH receive Ryan White Part C funds directly from the federal government to provide comprehensive HIV primary care medical services to the uninsured. This funding also enables HIV primary care programs to provide multiple services on site, such as pharmacy, labs, mental health, gynecological, and nutrition services. Additionally, the University of Pittsburgh's HIV Early Intervention Program, which includes PACT, in collaboration with Magee-Womens and Children's Hospital, receives Ryan White Part D funding from HRSA for women, infants, children, and youth living with HIV/AIDS. A primary aim of this funding is to reduce perinatal transmission of HIV/AIDS. Additional Part D funding enables outreach to increase HIV testing among high-risk populations. Ryan White funds also serve the region via funding for the Pennsylvania/MidAtlantic Education and Treatment Center housed at the University of Pittsburgh's Graduate School of Public Health. This program serves the region by providing up-to-date HIV/AIDS education to physicians, nurses, dentists, and other health care providers. Mini-residencies are also offered to health care providers interested in expanding their understanding of HIV/AIDS treatment.

Other funds available in southwestern Pennsylvania include State 656 funds for prevention and support services and HUD Housing Opportunities for People With AIDS (HOPWA) funding. Minority AIDS Initiative (MAI) funds were available in this region until the Ryan White Reauthorization Act of 2006. After the reauthorization, states were required to apply to the federal government separately for this funding. Unfortunately, Pennsylvania did not apply and much needed funds were not available to address unmet needs among African Americans living with HIV/AIDS in this region. HIV/AIDS advocates in this region are acutely aware of the need for this funding and will push for the state to apply when MAI funds hopefully become available again in 2010.

HIV testing and routine HIV primary care for individuals living with HIV/AIDS can also help reduce the spread of HIV. Increasingly, the CDC is focused on "secondary prevention." Secondary prevention directs efforts towards people living with HIV with culturally competent counseling to increase understanding of HIV transmission risks and to learn skills related to safer sex and IVDU harm reduction strategies. Within Pitt's Graduate School of Public Health, the

Pennsylvania Prevention Project (PPP) provides technical assistance to community-based agencies throughout the state on HIV prevention planning. PPP is an integral part of the state health department's capacity-building efforts by providing training and technical assistance on the CDC-sponsored Diffusion of Effective Behavioral Intervention Project (DEBI) to community groups throughout the state. Efforts in the past few years are increasingly directed towards people living with HIV/AIDS and towards learning strategies to reduce the risk of HIV/AIDS transmission. The interventions stress the need to tailor interventions to meet the needs of a diverse group of people. An example of a DEBI intervention is titled "Healthy Relationships" and works from the common sense premise that disclosing one's HIV status and/or discussing safer sex is stressful. The group works towards building skills to manage stress and reduce risk behavior.<sup>xxix</sup>

Prevention Point Pittsburgh advocated early and steadily for HIV/AIDS prevention through needle exchange. This "harm reduction" approach reduces the spread of HIV/AIDS and Hepatitis C. After several years of "underground" operations in Allegheny County, the program became legal in 2002. The program receives funding from private organizations. At the AGH and UPMC HIV/AIDS primary care programs, almost 11 percent of patients receiving care for HIV/AIDS indicate injection drug use as a risk factor. African Americans account for 70 percent of this group.<sup>xxx</sup>

Early in the epidemic, small grassroots organizations energized by gay men played a major role in advocating for people living with HIV/AIDS. HIV activists within the Allegheny County African American community are attempting to raise awareness with the same urgency as occurred early in the epidemic. For example, Central Outreach Ministry in the Hill District provides education and HIV counseling and testing in its work with high-risk substance abusers. Macedonia F.A.C.E Inc., also located in the Hill District, provides HIV/AIDS education and awareness to middle and high school students through funding from the Pittsburgh Board of Education. In the mid-1990s, a grass roots organization, The Seven Project, provided counseling and support as the first African American AIDS Service Organization in the region but was unable to sustain itself financially. Having several sources of funding is generally acknowledged as necessary to sustain a program; many federal grants encourage the value of partnerships with larger organizations to provide the stability needed to "grow" the program. Funding has been a barrier to stronger community-based programming. Yearly events in Allegheny County focused on HIV/AIDS awareness among African Americans, including health promotion activities during National Minority Health Month sponsored by Pitt's Center for Minority Health and Balm in Gilead Week. These are valuable but clearly more is needed.

### **Action Steps for Policymakers, Providers, Insurers, Community-Based Organizations, Individuals, and Researchers**

This chapter began with a quote from the recent Black AIDS Institute publication addressing the HIV/AIDS epidemic among African Americans. It presents seven key actions, including building a sense of urgency in Black America, along with vocal Black leadership; increased knowledge about HIV/AIDS, along with increased HIV testing; policies that promote needle exchange; culturally competent, age appropriate prevention efforts; and a massive effort

to reduce stigma. The report states, “The only way to end the AIDS epidemic in Black America is to build a broad base mass mobilization.”<sup>xxxix</sup>

Experts in the fields of HIV/AIDS and minority health are acutely aware of the urgent and increasing threat HIV/AIDS poses to African Americans in Allegheny County. Key actions recommended echo those of the Black AIDS Institute’s national call to action:

- Strengthen grassroots organizations and leadership in the African American community to mobilize against HIV/AIDS, with funding to sustain the effort. Acknowledgement of the urgency of this issue should be supported by local philanthropies targeting funding for African American organizations that wish to address HIV/AIDS in their community.
- Conduct comprehensive community-wide HIV education through extensive social marketing and targeted outreach. Pittsburgh has virtually no public health messages routinely raising awareness about HIV/AIDS. This had led many to assume the epidemic has passed by Allegheny County. Marketing at bus stops, on buses, radio, and TV is needed.
- Expand HIV/AIDS education in the Pittsburgh Public Schools and surrounding school districts. The school board and administration should support and promote activities that raise HIV awareness among African American youth and their families. All staff should have routine opportunities for education about HIV/AIDS and sexual diversity.
- Develop public health technical assistance and capacity building that are culturally competent, and assist spiritual and other community leaders in African American communities with the skills needed to confront the HIV/AIDS crisis in Allegheny County. The University of Pittsburgh’s Center for Minority Health and Center for Race and Social Problems should take the initiative to empower local Black leaders regarding this serious health disparity.
- Promote community programs that support and empower African Americans stigmatized by HIV/AIDS, sexual orientation, or substance abuse.
- Encourage Allegheny County medical providers, whether in clinics or private practice, to utilize HIV/AIDS education updates/training available through the HRSA-funded Pennsylvania/MidAtlantic AIDS Education and Training Center at the University of Pittsburgh, and in accordance with CDC guidelines, routinely screen all patients age 16-64 for HIV infection.
- Continue support for the Pittsburgh Needle Exchange program.
- Expand awareness of the availability of comprehensive HIV/AIDS health care, regardless of the individual’s ability to pay, at the University of Pittsburgh Medical Center and Allegheny General Hospital, which both received the Ryan White Care Act funding from HRSA.
- Expand HIV counseling and testing at major emergency rooms in Allegheny County. Currently, Allegheny General Hospital’s emergency room is the only emergency room providing routine HIV counseling and testing.
- Perform a system-wide assessment by the Allegheny County Department of Human Services of the role it should play in addressing the county’s HIV/AIDS epidemic, especially within the African American community. Although HIV/AIDS is a health concern, Allegheny County’s Department of Human Service’s many programs address

the needs of some of the most vulnerable groups in the county. A concerted effort on its part to address the epidemic among African American men, women, and youth through outreach and education could have a significant impact in reducing HIV/AIDS health disparities.

*We wish to acknowledge the guidance and expertise of the following people: Debra Dennison, MSPH, University of Pittsburgh, Pennsylvania Prevention Project; Valerie Stallworth, MSPH, Veterans Hospital; Rev. Cliff Foster, Central Outreach Ministry; Dana Davis, MSW, AGH Positive Health Clinic; Anthony Robbins, PhD, University of Pittsburgh Center for Minority Health; Barbara Williams MSW, Macedonia F.A.C.E, Inc.; Doyin Desalu, PhD, Southwestern PA AIDS Planning Organization; and Diana Harrington, BSRN, University of Pittsburgh Early Intervention Program.*

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## Endnotes

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<sup>x</sup> Correspondence Allegheny County Health Department, September 2008.

<sup>xi</sup> Correspondence Allegheny County Health Department, August 5, 2008.

<sup>xii</sup> CAREWARE Data.

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## **CHAPTER 7. VIOLENCE IN ALLEGHENY COUNTY AND PITTSBURGH**

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### **Violence as a Public Health Concern**

Community violence persists as a major public health concern in the United States and within many urban, impoverished communities of color despite considerable resources and attention from public officials, researchers, law enforcement officials, and community-based individuals and organizations. An essential element to effectively addressing and preventing community violence through strategic intervention and prevention activities is the critical understanding of the local characteristics of violence. The purpose of this report is to illustrate the characteristics of community violence in Allegheny County, Pennsylvania, and to specifically examine the racial disparity of this public health epidemic.

For the purposes of this report, the World Health Organization's (WHO) definition of violence is used, which asserts that violence is "the intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation."<sup>i</sup> While the importance of preventing violent acts committed upon oneself is acknowledged, this report focuses on acts that occur between a victim and a separate offender or perpetrator.

### **The Public Health Approach to Violence**

Understanding why, when, and where violence occurs is important in preventing future violence. A widely popular approach to tackling violence is the public health approach, which the Violence Prevention Alliance (VPA)<sup>ii</sup> describes as seeking to improve the health and safety of individuals through an exploration of the root causes and factors that make a person susceptible to becoming either a victim or perpetrator of violence. This approach focuses on implementing interventions that will have a population-level effect by influencing modifiable risk and strengthening protective factors where community violence occurs. The four elements

\*The Department of Human Services (DHS) is responsible for providing and administering human services to Allegheny County residents. DHS is dedicated to meeting these human services needs, most particularly to the county's most vulnerable populations, through an extensive range of prevention, early intervention, crisis management, and after-care services provided through its program offices. DHS services include programs serving the elderly; mental health services (includes 24-hour crisis counseling); drug and alcohol services; child protective services; at-risk child development and education; hunger services; emergency shelters and housing for the homeless; energy assistance; non-emergency medical transportation; job training and placement for youth and adults; and services for individuals with mental retardation and developmental disabilities. In 2006, DHS provided services to 182,000 individuals, nearly 16 percent of the population of Allegheny County.

of this primary prevention approach include:

1. Define the problem through systematic data collection;
2. Determine causes of the problem through local and global research;
3. Determine what works to prevent youth violence by designing, implementing, and evaluating intervention and prevention initiatives; and
4. Implement effective and promising interventions in a variety of settings and assess their impact.

Examining violence through the lens of the preceding steps, we find the following:

*Step 1: Define the problem.*

Within the United States, there is a heavy focus on preventing violence among youth and young adults (defined as individuals who are age 24 years and younger) in response to the high number of violence-related deaths among this group. Homicide remains the leading cause of death among 15- to 24-year-old African American males, the second leading cause of death for African American females, the third leading cause of death among whites ages 15-24, and the fifth for whites ages 25-34.<sup>iii</sup> Focusing on homicides alone, however, underestimates the true magnitude of violence as a public health epidemic. Recent research indicates that the ratio of intentional but nonfatal injuries to homicides is 94 to 1, suggesting the health impact of violence is far more substantial.<sup>iv</sup> For example, in 2004, the Centers for Disease Control and Prevention (CDC) reported that more than 750,000 individuals between the ages of 10 and 24 years were treated for violence-related injuries. Furthermore, males are more susceptible to violence than females: male students are 16 percent more likely to be involved in a physical fight than female students,<sup>v</sup> and in 2003, 86 percent of the 5,570 homicide victims ages 10-24 years were male.<sup>vi</sup>

*Step 2: Determine causes of the problem through local and global research.*

The ecological framework of the public health philosophy of violence takes a holistic approach, identifying the causes and risks for violence as well as the preventive measures that can lessen the likelihood of incidents. Briefly, this framework asserts that in addition to being responsible for one's own actions, an individual is influenced, either positively or negatively, by his or her family, community, and surrounding environment (see Figure 1).

Although these external factors cannot be substantiated as direct causes of violence, the following are some risk factors<sup>vii</sup> within each of the aforementioned categories that can influence an individual's susceptibility to violence:

### Individual risk factors\*

- Low IQ
- Poor behavioral control
- Social, cognitive, or information-processing deficits
- Use or dependence on drugs, alcohol, or tobacco
- Attention deficits/ hyperactivity
- Antisocial beliefs/attitudes
- History of early aggressive behavior

### Relationship (family and peer) risk factors

#### Family:

- Authoritarian childrearing attitudes of caregivers
- Exposure to violence and family conflict
- Harsh, lax, or inconsistent disciplinary practices of caregivers
- Lack of parental involvement in child's life
- Low emotional attachment to parents or caregivers

#### Peer:

- Association with delinquent peers
- Involvement in gangs
- Social rejection by peers
- Lack of involvement in conventional activities
- Poor academic performance

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\* Current research indicates that the presence of a single risk factor in an individual does not, by itself, cause antisocial or violent behavior (NIMH, 2000).

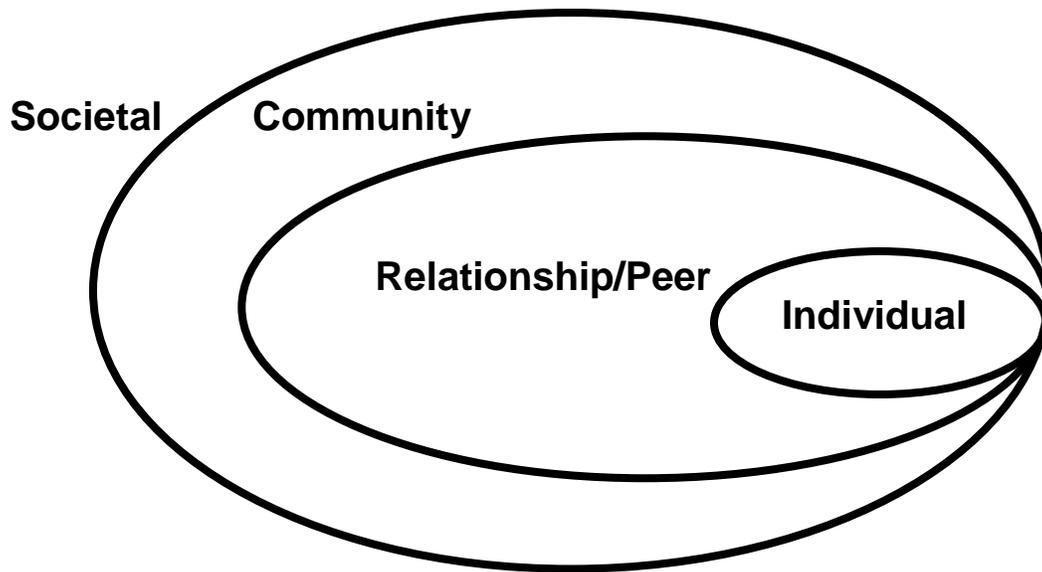


Figure 1. Socio-Ecological Model<sup>viii</sup>  
 Source: Bronfrenbrenner, 1979

Community risk factors

- Low level of community participation
- Socially disorganized neighborhoods
- Diminished economic opportunity
- High concentrations of poverty and lack of local resources
- Availability of drugs and weapons
- Lack of recreational amenities
- High crime rates
- Presence of gangs
- Deterioration/blight

Environment risk factors

- Rapid demographic and social changes
- Economic crises
- Lack of overall investment in marginalized and often high-risk communities

It is important to note the factors that can decrease the likelihood of violence. The following are examples of protective factors<sup>ix</sup> within each of the categories of influence:

#### Individual protective factors

- Intolerant attitude toward deviance
- High IQ
- Positive social orientation

#### Family protective factors

- Positive role models and involvement of adult figure
- Commitment to school valued by caregivers
- Involvement in social activities

#### Community protective factors

- Collective efficacy
- Formal and informal social control
- Caring and supportive relationships

#### Environmental protective factors

- Availability of recreational activities
- Policies at the local, state, and national levels aimed at violence prevention efforts

*Step 3: Determine what works to prevent youth violence by designing, implementing, and evaluating effective intervention and prevention initiatives.*

Organizations such as the CDC, U.S. Department of Justice, and U.S. Department of Health and Human Services support violence prevention and intervention projects that are implemented across the country. For example, the CDC's Division of Violence Prevention offers support to projects that utilize the public health approach. Furthermore, the U.S. Department of Justice's Office of Juvenile Justice and Delinquency Prevention (OJJDP) focuses on violence affecting youth ages 18 and younger through programs such as the Causes and Correlates of Juvenile Delinquency Program, which strives to understand the many factors that impact a person's susceptibility to victimization by or perpetration of violence.

*Step 4: Implement effective and promising interventions in a variety of settings and assess their impact.*

Dissemination of new knowledge and translation of such evidence into practice in a timely and efficient manner are essential. There are many different structural, political, behavioral, and economic elements associated with the process and actual movement of evidence into practice. One of the reasons that translation has lagged, specifically in the field of injury prevention and control, is that researchers and practitioners have adopted the costly assumption that effective interventions will simply translate naturally into evidence-based practice. They have not spent the time developing translational strategies and working with practitioners.<sup>x</sup> Without the effective translation of successful interventions, policies, and practices from

researchers to practitioners, advocates, and policy makers, there is little hope of realizing the desired public health impact on the reduction of morbidity and mortality.<sup>xi</sup> Effective and strategic evaluation of innovative and ongoing violence prevention efforts is central to ongoing violence prevention and intervention efforts.

## **Methodology**

### *Definitions*

This report limits its study of violent incidents to homicides and aggravated assaults with a firearm. Where appropriate, violence is narrowed further to include only homicides and shootings, which are defined as aggravated assaults with a firearm in which injury has occurred.

### *Data Sources*

#### City of Pittsburgh Bureau of Police

Incident data from 1997 to 2007 were provided by the City of Pittsburgh Bureau of Police and contain information on all homicides and aggravated assaults with a firearm that were recorded by the City Police. Homicide data include date, time, location of offense by address and census tract, and victim's race, sex, and age. Aggravated assault data include date, time, offense (categorized as either firearm assault with injury, without injury, drive-by aggravated assaults resulting in injury, or drive-by assaults without injury), and location of offense by address, census tract, and neighborhood. Unlike the homicide data, demographic information is not provided for aggravated assault victims. Further, the offenses represented by the aggravated assault data from years 1997 to 2002 were coded in a different manner from more recent data, making it difficult to distinguish the different types of incident; therefore, only aggravated assault data from 2003 to 2007 are used.

It should be noted that incident data reflect only offenses that were reported to the police. Although reporting tends to be better for both homicides and aggravated assaults with a firearm than for other crimes, these data still undercount the actual level of victimization and violence in Pittsburgh and Allegheny County.

#### Allegheny County Medical Examiner's Office

This report relies on data extracted from the Allegheny County Medical Examiner's (ACME) records from 1997 to 2007 and the ACME Annual Reports from 2003 to 2006. The ACME is required to autopsy all premature and unexplained deaths that may have resulted from a sudden, violent, unexplained, or traumatic event. Incident information and victim demographics were manually compiled from the ACME records.

The ACME data do not always agree with the City Police data, but they add depth to this investigation by providing more information about the victims and offenders, as well as information about homicides occurring outside the City of Pittsburgh.

## Pennsylvania State Police

The Pennsylvania State Police collect Uniform Crime Report data from participating police departments. These data are available for query from their Web site.<sup>xiii</sup> These data include information on incidents, victims, offenders, relationships, weapons, and motives and were used primarily to provide information on offenders.

## U.S. Census

Population data for Allegheny County municipalities and Pittsburgh neighborhoods were obtained from the U.S. Census Bureau Web site. When possible, tables and figures in this report represent information points as rates (e.g., the number of violent crime victims per 100,000 persons).

### *Analytic Technique for Spatial Analysis*

Geographic mapping and cluster analysis were used to identify patterns of violence in Allegheny County and Pittsburgh from 1997 to 2007. Demographic information on each incident and, when possible, on each victim was used to create a geographic information system (GIS) to analyze the distribution of crime across Allegheny County municipalities and Pittsburgh neighborhoods and to map concentrations of crime.

Two types of spatial analysis were conducted using offense reports filed by the police and the Allegheny County Medical Examiner's Office. For more information, see Appendix A.

*About Allegheny County and the City of Pittsburgh*

This report examines violence that occurred between 1997 and 2007 in Allegheny County, focusing heavily on the core city of Pittsburgh. Population estimates from the 2000 census indicate that a total of 1,281,666 individuals reside in Allegheny County, with Pittsburgh accounting for 334,563 individuals (or 26 percent of the total population); Pittsburgh’s total population had dropped nearly 10 percent since the 1990 census. By studying the city’s demographic composition based on the 2000 census data (see Appendix A), we were able to calculate victimization rates for various gender, racial, and age groups in order to assess a group’s relative risk of victimization.

**Homicide Trends**

Nationally, violence increased sharply between 1960 and the early 1990s but began to drop after that point, as seen in Figure 2. Compared to other metropolitan regions, Pittsburgh’s murder rate falls below the national and benchmark city averages, ranking 10<sup>th</sup> out of 15 cities studied (see Figure 3).

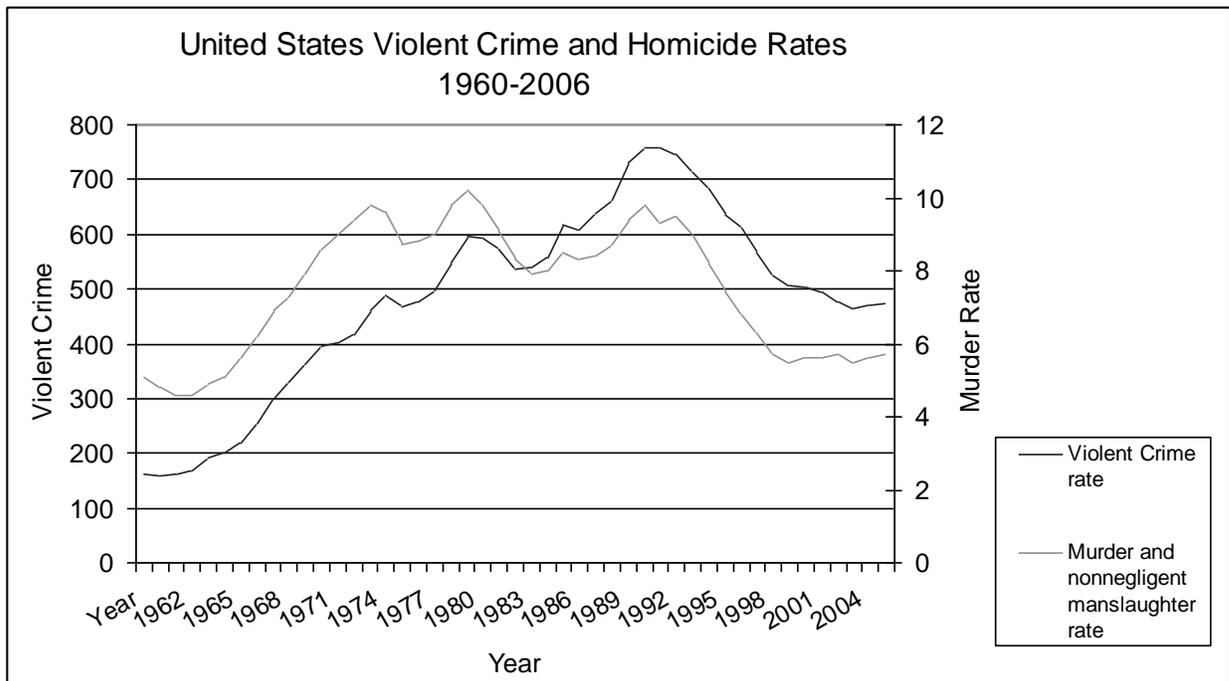


Figure 2. U.S. Violent Crime and Murder Rates per 100,000 Residents, 1960-2006

Source: U.S. Bureau of Justice Statistics

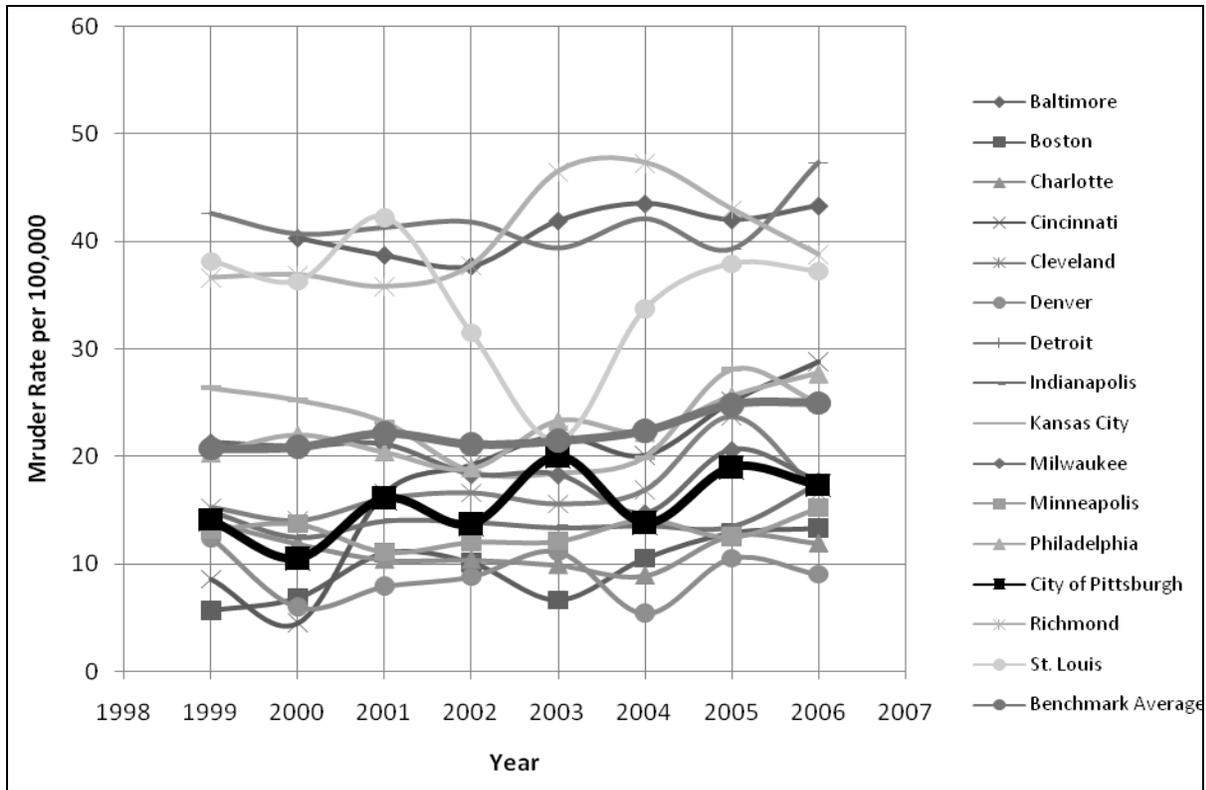


Figure 3. Murder Rates by City, 1999-2006

Source: Blumstein and Jun, 2007

Similar to the United States overall, homicides in the City of Pittsburgh have been on the rise since the late 1980s, spiking in the early 1990s before leveling off at a higher point throughout the 2000s (Figure 4).

Allegheny County's and the City of Pittsburgh's homicide trends tend to move together, with the city's incidents driving the county total. Between 1997 and 2007, an average of 55 percent of all county homicides occurred within the City of Pittsburgh (see Figure 5). This trend, coupled with the fact that the City of Pittsburgh accounts for just 25 percent of Allegheny County's total population, suggests that homicides are not uniformly distributed and disproportionately affect certain communities.

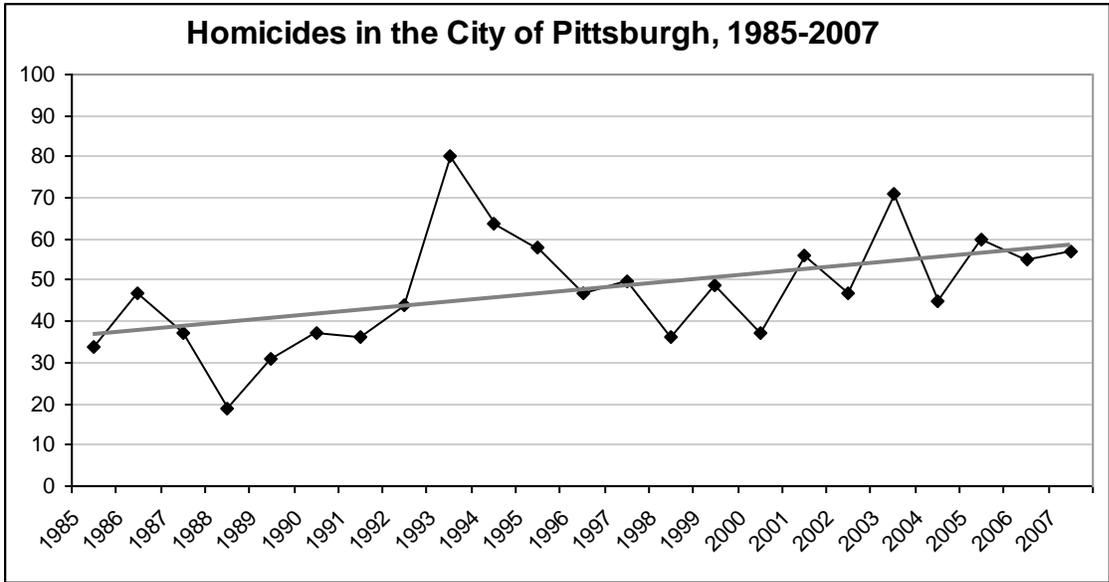
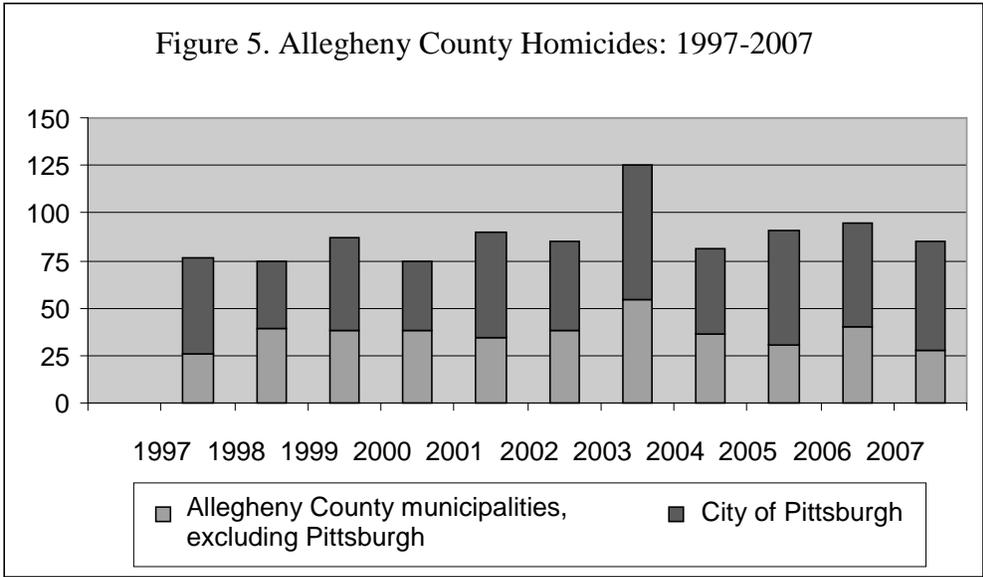
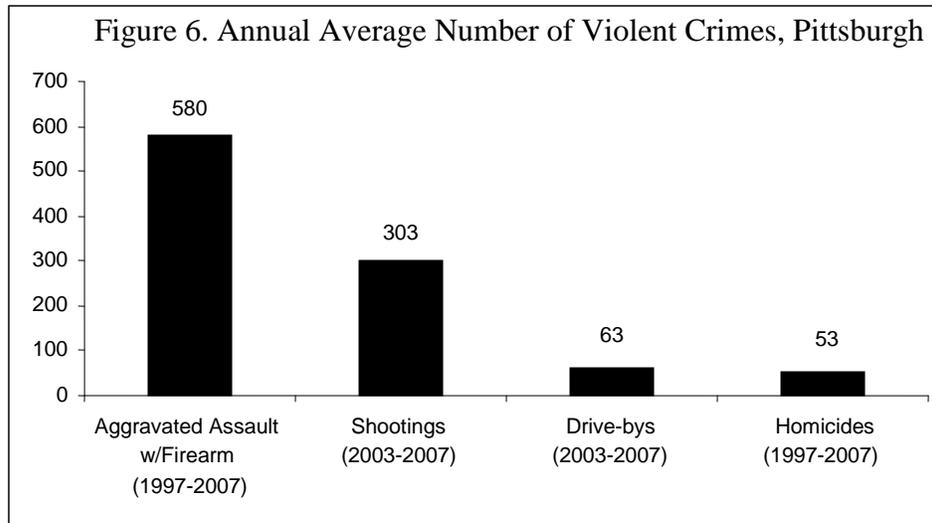


Figure 4. Homicides in the City of Pittsburgh, 1985-2007  
 Source: City of Pittsburgh Bureau of Police



Source: Allegheny County Medical Examiner

Although homicides and drive-by shootings tend to receive the most media coverage because of their dramatic and tragic outcomes, they actually make up a small percentage of all gun-related violent incidents (drive-by shootings account for only 8 percent of all aggravated assaults with a firearm). Aggravated assaults with a firearm are 10 times more frequent than homicides, and shootings are nearly six times more frequent than homicides (see Figure 6). Further, because more than one quarter of all aggravated assaults resulted in an injury, it is essential to examine non-fatal accidents in addition to homicides.



Source: City of Pittsburgh Bureau of Police

### Homicide Victims in Pittsburgh and Allegheny County

Many studies have confirmed that violence disproportionately affects certain groups, and young African American men are particularly susceptible to homicide victimization. An examination of homicide trends between 1986 and 1994 in eight U.S. cities (Atlanta, Detroit, Tampa, New Orleans, Richmond, Indianapolis, Miami and Washington, D.C.) demonstrated that even when controlling for population size, young Black men experience much higher incidence of homicide victimization than other groups; the authors also noted that “in cities where blacks were not in the majority (Tampa, Indianapolis, and Miami), the disproportionality for black males age 25 and over was larger”<sup>xiii</sup> (see Figure 7). More recent data from 2005 showed that the homicide rate for this subset of the U.S. population was 22 times the national rate.

Although homicide does not appear to be as acute a problem in Pittsburgh as in many other urban centers, violence remains at epidemic levels for some. Young people are more likely to be homicide victims than older adults; 12- to 29-year-olds are more than three times more likely to be homicide victims than the population as a whole. Young men are even more at risk (almost six times the national average) for violence. Mirroring trends documented in other urban areas, the homicide rate for young Black men in the City of Pittsburgh was nearly 60 times the citywide average and more than 50 times the national average (see Figures 8). It is the violence rate for this sub-population that grabs national and local headlines.

When considering these demographic characteristics together (gender, age, and race), a stark picture emerges. Young Black men are far more likely to be victims of homicide than any other group. Black women are also more likely than whites of either gender to be victimized (see Figure 9). Notably, the homicide rates for pre-adolescent or post-30s Black males are not strikingly dissimilar to other groups, confirming that the critical age range for intervention seems to be 18-35.

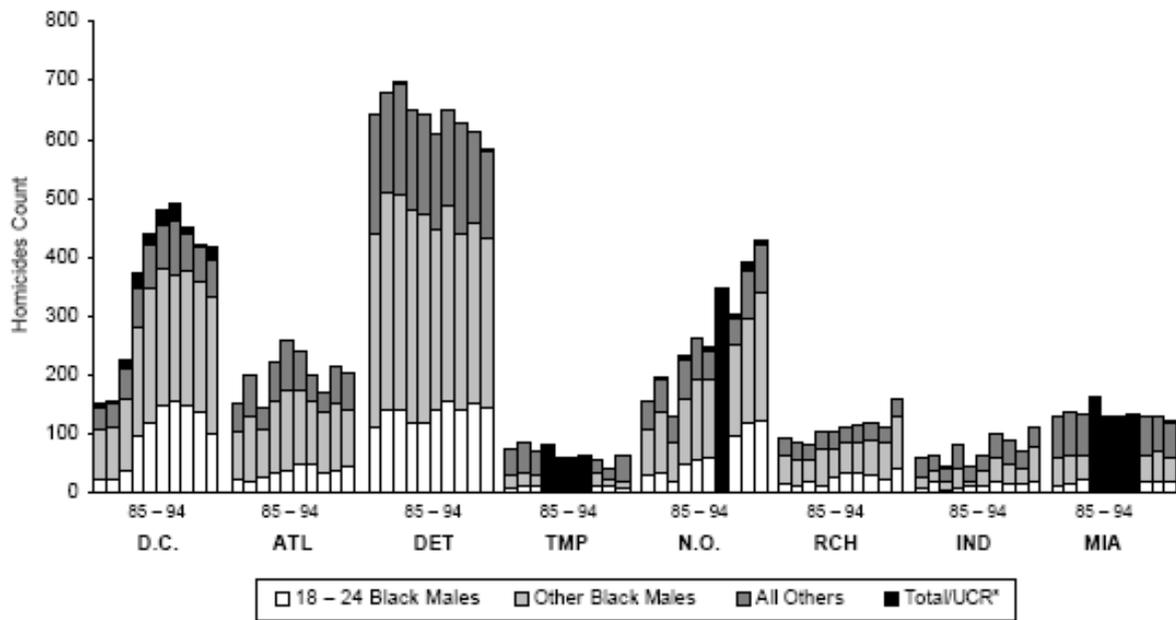
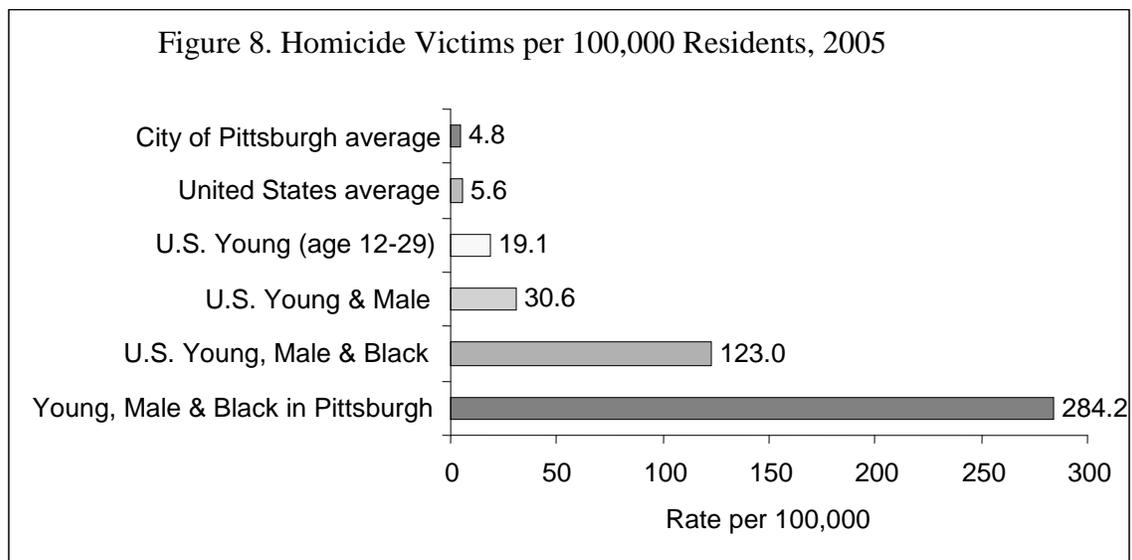


Figure 7. Homicide victimization for young African American males in eight American cities, 1985-1994  
*Source: Lattimore et al., 1997)*



Sources: City of Pittsburgh Bureau of Police; U.S. Bureau of Justice Statistics

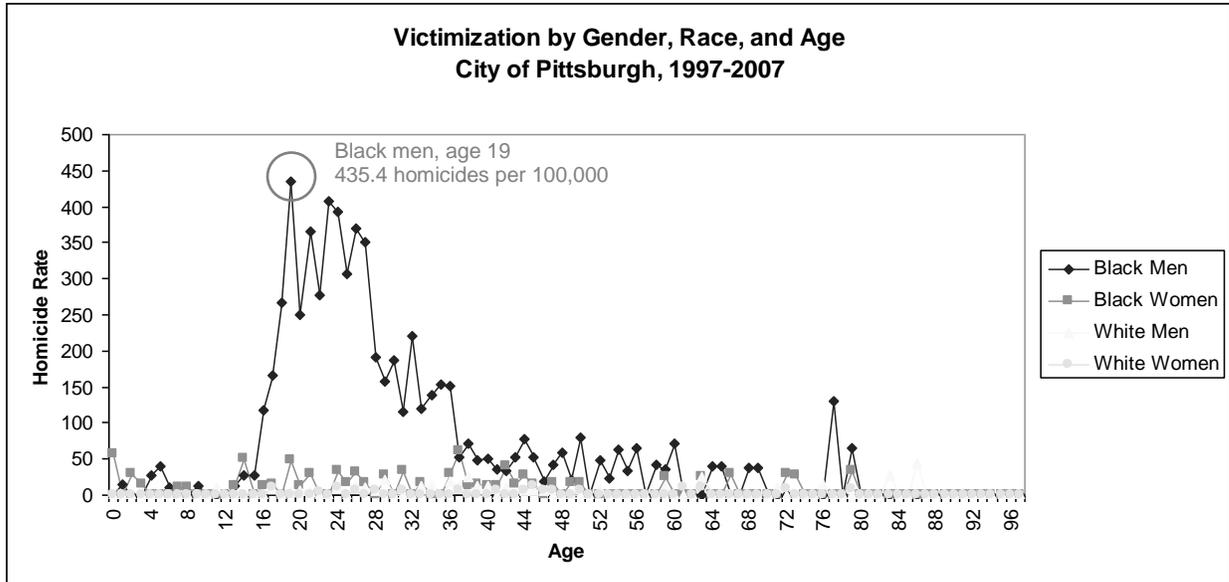


Figure 9. Victimization by Gender, Race, and Age, City of Pittsburgh, 1997-2007  
 Source: City of Pittsburgh Bureau of Police

*Residency Patterns for Victims – Distressed Neighborhoods*

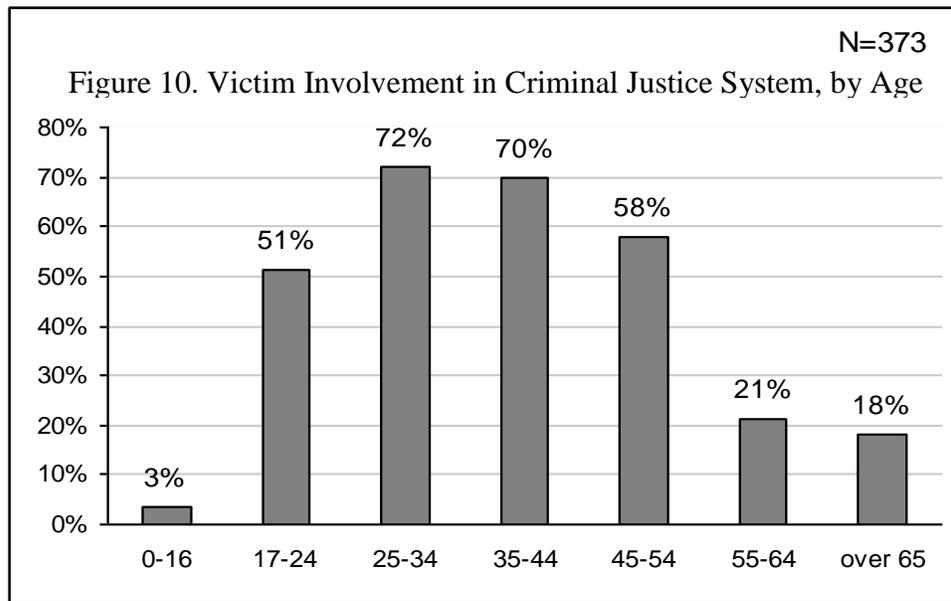
Extensive literature points to the strong connection between poverty, neighborhood distress, and violence.<sup>xiv</sup> To examine this issue locally, the Annie E. Casey distressed neighborhood criteria were used to determine the degree to which the victim’s neighborhood of residence was distressed<sup>xv</sup> (see Appendix C for additional information about the Casey criteria). Thirty percent of homicide victims reside in just 5 percent of neighborhoods in Pittsburgh, 67 percent of which are designated as severely distressed.

*Prior Criminal Activity of Homicide Victims*

While newspaper accounts highlight innocent victims—those murdered in a home invasion or caught in the cross fire of a drive-by shooting—those victims without criminal records are relatively rare; in fact, many homicide victims have criminal records themselves. By comparing the names of homicide victims between 2003 and 2005 to court records in the Court Information Management System and the Court of Common Pleas Online Web Docket Sheets system, we found that more than 70 percent of victims between the ages of 25 and 44 had some criminal record. Of victims ages 17 to 24 and 45 to 54, more than 50 percent had records. Male victims were more likely than females, and Black victims more likely than whites, to have criminal records (60 percent vs. 28 percent and 62 percent vs. 29 percent, respectively) (see Figure 10).

Because the data sources noted above only capture adult criminal cases and are unreliable before the early 1980s, the estimates above do not include homicide victims younger than 17 and may under-represent older victims as well. In addition, victim involvement in the criminal justice

system is likely to be further understated because this analysis does not consider cases charged in other jurisdictions.



Source: Court Information Management System; Court of Common Pleas Web Docket Sheets

## Homicide Offenders

Offender information from the Pennsylvania State Police (whose Uniform Crime Reports cover jurisdictions across the state and include data from the Pittsburgh Bureau of Police) was examined for homicide incidents reported by the Pittsburgh Police between 2000 and 2007. (Data were not available for the years 1997-1999.) During that time, 472 incidents were reported but, on average, offender information is known in only about half of those incidents.

### *Demographic Characteristics of Homicide Offenders*

The available information shows that in cases where age, race, and gender were known (49 percent, 51 percent, and 52 percent, respectively), 51 percent of the offenders were under the age of 25, 80 percent were African American, and 93 percent were male.<sup>xvi</sup> Overall, those at highest risk of being a victim of a violent crime have similar demographics as those most likely to commit a violent crime.

### *Prior Criminal Activity of Homicide Offenders*

Most homicide offenders had prior involvement with the justice system; 2002 data from the Pittsburgh Police Department's Annual Report indicate that 88 percent of homicide offenders had at least one prior arrest record and only 8 percent had never been arrested (N=48). More than two-thirds had been arrested on drug charges (64 percent) and nearly half for gun-related offenses (45 percent).

## Connections between Victims and Offenders

For homicides committed between 2000 and 2007, the relationship between the victim and offender was known in 32 percent of cases (N=151). In those cases, the victim and offender frequently knew each other—in 79 percent of incidents, the victim and offender were acquaintances or knew each other in some other way (45 percent), were family members (16 percent), or were friends/neighbors (18 percent). Only 21 percent of these cases occurred between strangers. See Figure 11.

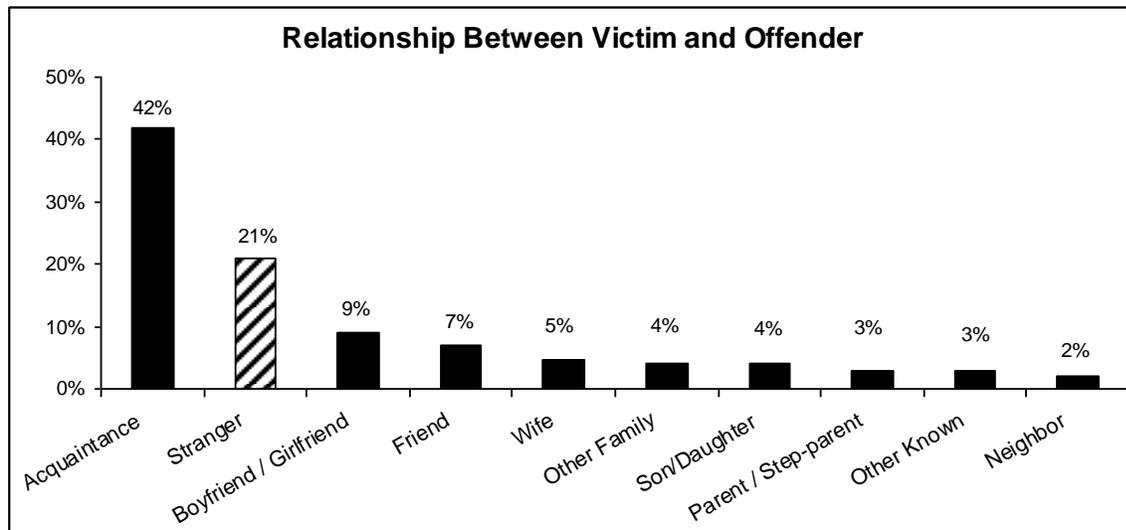


Figure 11. Relationship between Victim and Offender

Source: Pennsylvania Uniform Crime Reporting System

The race of both the victim and offender was known in 51 percent of homicide cases (N=207). In most cases, the victim and offender were of the same race; 74 percent of homicides were perpetrated by a Black offender against a Black victim and 11 percent were between a white offender and white victim. Only 6 percent of homicide cases were perpetrated by a Black offender against a white victim and 7 percent by a white offender against a Black victim.

In homicide cases where the gender of both the victim and offender was known (52 percent of cases; N=135), the victim and offender were usually the same gender; most often, both were males. Males were nearly five times as likely to kill another male (76 percent of total victims) than a female (16 percent of total victims). In contrast, 7 percent of homicides were perpetrated by a female offender against a male victim, and only 1 percent by a female offender against a female victim.

## Where Did Violence Occur?

Violence was heavily concentrated in a select group of county municipalities and city neighborhoods. By using municipality/neighborhood and cluster analyses, we were able to better understand where violence occurred most frequently. For detailed information about these methodologies, see Appendix B.

*Allegheny County*

Table 1 shows homicide incident locations (N=878) from 1997 to 2007. Violence was heavily concentrated in specific neighborhoods in the City of Pittsburgh, as well as in municipalities bordering yet outside the city limits. Outside the city, high victimization (defined as 11 or more incidents) occurred in Penn Hills, Wilksburg, West Mifflin, Duquesne, and McKeesport.

The municipalities in which the most homicide incidents occurred also tended to have the highest homicide rate per 100,000 people (Table 1). Nearly all have higher concentrations of African American residents than the county average of 12.8 percent.

*City of Pittsburgh*

We see a similar pattern within the City of Pittsburgh; 75 percent of homicides were clustered in just 25 neighborhoods, or 27 percent of neighborhoods within the city limits. The communities of Homewood, the Hill District, and the Northside experienced the highest levels of victimization. Fourteen percent of all homicides occurred in Homewood (made up of Homewood South, Homewood West, and Homewood North), 11 percent in the Hill District (Middle Hill, Terrace Village, and Crawford-Roberts) and 6 percent in the Northside (Perry South and Central Northside). Each of the neighborhoods with very high homicide rates is a predominantly African American community (see Table 2).

Neighborhood homicide rates and counts do not tell the full story of community violence. Cluster analysis demonstrates that there are concentrated pockets of violence within communities that sometimes cross neighborhood borders. See Appendix B for cluster maps of homicides, aggravated assaults with firearms, and shootings in the City of Pittsburgh.

<b>Homicide Counts, Top 10 County Municipalities, excluding City of Pittsburgh</b>				<b>Homicide Rates, Top 10 County Municipalities, excluding City of Pittsburgh</b>			
<b>Municipality</b>	<b>Homicides (1997-2007)</b>	<b>Percent African American</b>	<b>Percent in Poverty</b>	<b>Municipality</b>	<b>Homicide Rate (per 100,000)</b>	<b>Percent African American</b>	<b>Percent in Poverty</b>
Wilksburg	51	67%	19%	Wilksburg	685	67%	19%
Penn Hills	31	24%	8%	Braddock	275	67%	35%
McKeesport	26	25%	23%	Duquesne	232	48%	35%
Duquesne	17	48%	35%	Wilmerding	186	6%	17%
Swissvale	11	22%	15%	Homestead	168	51%	27%
Clairton	10	28%	20%	Sharpsburg	167	4%	17%
N. Braddock	9	35%	23%	E. Pittsburgh	149	21%	22%
Monroeville	8	8%	7%	N. Braddock	140	35%	23%
West Mifflin	8	9%	10%	Rankin	140	69%	45%
Braddock	8	67%	35%	Clairton	130	28%	20%

Table 1. Allegheny Co. Homicides, Incidents and Rates by Municipality, Excluding City of Pittsburgh, 1997-2007. (Allegheny Co. average, 2000: 12.4% African American, 11.2% in

poverty) *Source: Allegheny County Medical Examiner; Census 2000; University of Pittsburgh's University Center for Social and Urban Research*

Top 10 City of Pittsburgh Neighborhoods Counts and Percent of Total Homicides					Top 10 City of Pittsburgh Neighborhoods Homicide Rates			
Neighborhood	Homicides (1997-2007)	Percent of Total	Percent African American	Percent in Poverty	Neighborhood	Homicide Rate (per 100,000)	Percent African American	% in Poverty
Homewood South	41	9%	97%	38%	South Shore*	1,786	23%	60%
Middle Hill	24	5%	97%	34%	Strip District*	1,128	61%	37%
Larimer	21	4%	88%	29%	Homewood South	1,124	97%	38%
East Hills	20	4%	94%	37%	Middle Hill	1,120	97%	34%
Perry South	19	4%	65%	29%	Homewood West	1,077	94%	14%
Hazelwood	19	4%	34%	24%	Larimer	807	88%	29%
East Liberty	18	4%	73%	30%	Terrace Village	608	95%	62%
Lincoln-Lemington-Belmar	17	4%	89%	26%	Crawford-Roberts	514	87%	33%
Garfield	16	3%	83%	41%	California-Kirkbride	514	78%	40%
Terrace Village	16	3%	95%	62%	East Hills	506	94%	37%

Table 2. City of Pittsburgh Homicides, Incidents and Rates by Neighborhood, 1997-2007. (City of Pittsburgh averages, 2000: 27.1% African American, 20.4% in poverty)

*Source: City of Pittsburgh Bureau of Police; Census 2000; University of Pittsburgh's University Center for Social and Urban Research*

### *Location of Victims' Deaths*

Another approach to understanding incident location is to look at the type of venue most common for violent incidents (e.g., residence, street, bar or retail establishment, public park, etc.). Figure 12 shows that the majority of victims in Allegheny County from 1997 to 2007 died in either a residence or on the street. This data may be useful in developing targeted intervention policies for each specific venue of homicide incidents.

\*Note: The high homicide rates in the Strip District and the South Shore should be considered in the context of their small populations (the Strip District had 266 residents in 2000; the South Shore had only 56 residents).

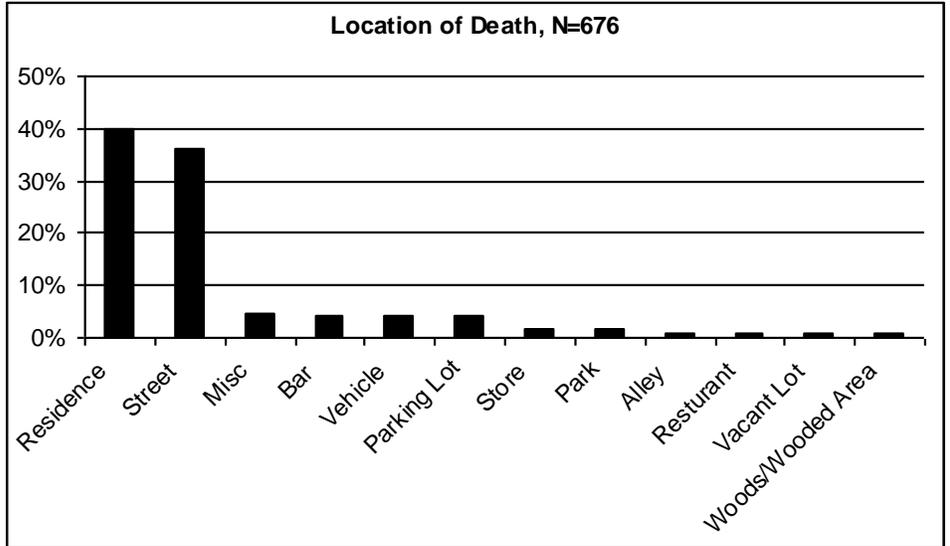


Figure 12. Specific Location of Homicides, Allegheny County, 1997-2007  
 Source: Allegheny County Medical Examiner

**When Did Violence Occur?**

*Month of Year*

The frequency of homicides and shootings tended to increase during the warmer months, with high points in June (homicides) and August (shootings). Monthly fluctuations were more pronounced for shootings than for homicides, which were more evenly distributed throughout the year (see Figure 13).

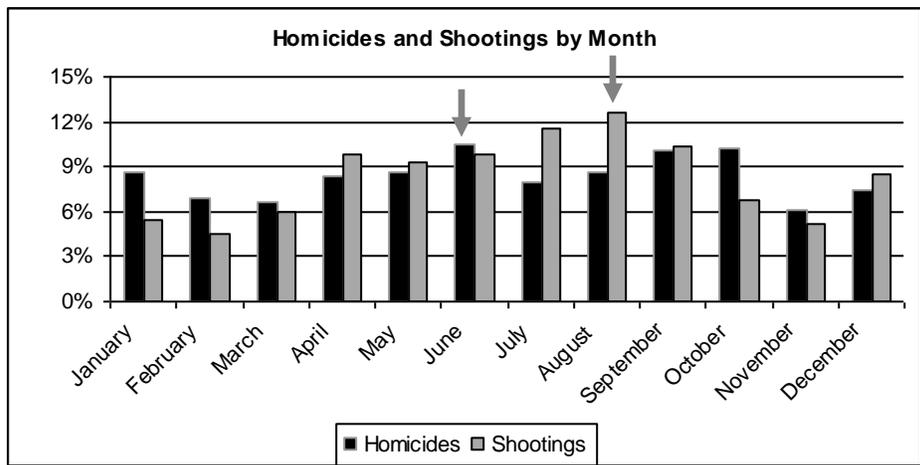


Figure 13. Homicides and Shootings by Month  
 Source: City of Pittsburgh Bureau of Police

*Day of Week*

Although homicides and shootings occurred slightly more often on weekends, they were fairly well distributed throughout the week (see Figure 14).

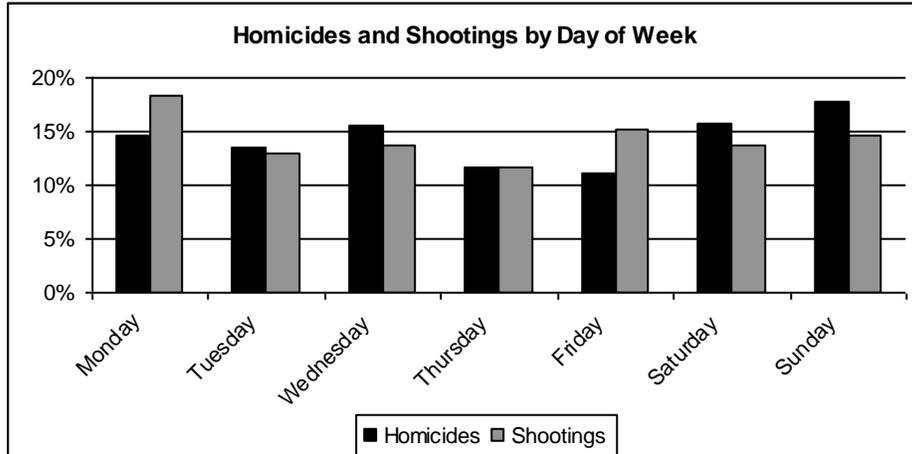


Figure 14. Homicides and Shootings by Day of Week  
 Source: City of Pittsburgh Bureau of Police

*Time of Day*

Homicides and shootings occurred most frequently in the morning hours between 12:00 midnight and 2:00 a.m. Incident frequency gradually increased throughout the day, with a notable rise after 2:00 p.m., corresponding with the end of the school day for many youth (see Figure 15).

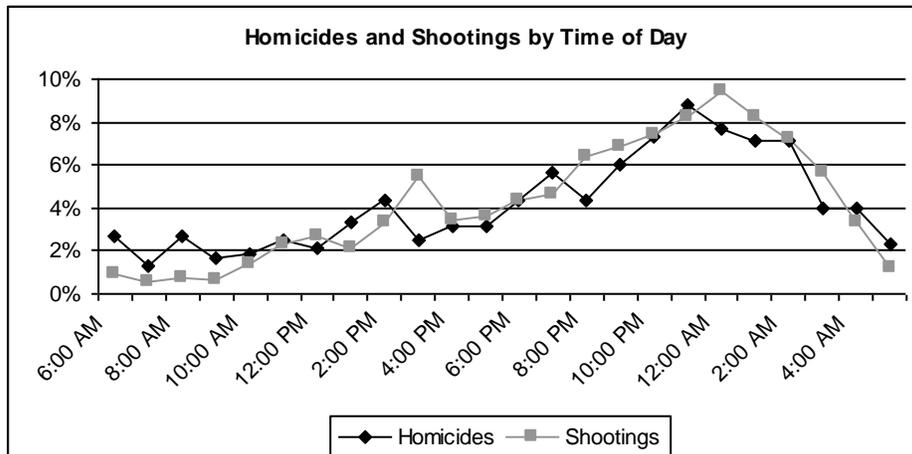


Figure 15. Homicides and Shootings by Time of Day  
 Source: City of Pittsburgh Bureau of Police; Allegheny County Medical Examiner

### Variation by Age in Time-of-Day Trends

We have already seen that young adults tend to be more susceptible to violence than young children or older adults. Among adults ages 13-34, though, we see distinct temporal patterns based on particular age ranges, and these patterns typically match the expected activity patterns of individuals in these age ranges. The age groups examined are 13-17 years, 18-24 years, and 25-34 years (see Figure 16).

Individuals aged 13-17 years were more often victimized mid-day and throughout the evening. Victimizations were uncommon in the mornings (6:00 a.m. – 10:00 a.m.) but became more frequent starting at 1:00 p.m., spiking at 6:00 p.m., and decreasing throughout the evening.

Like the teen cohort, 18- to 24-year-olds were victimized least in the morning. Incident frequency increased gradually after 10:00 a.m. but rose significantly after 9:00 p.m., suggesting that individuals within this group were more likely to be victimized at night and into the early morning hours (10:00 p.m.-1:00 a.m.).

Individuals aged 25-34 years were most often victimized during the early morning hours between 12:00 midnight and 2:00 a.m.

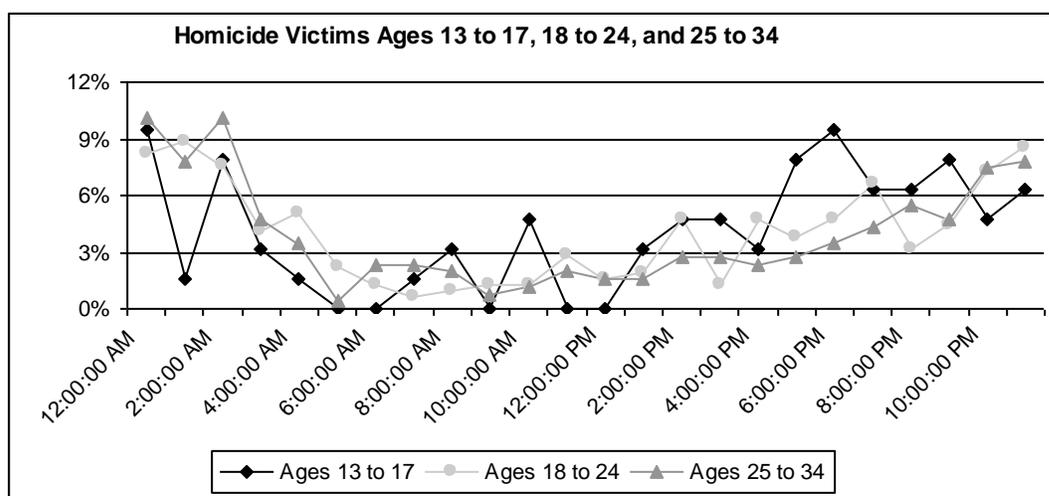
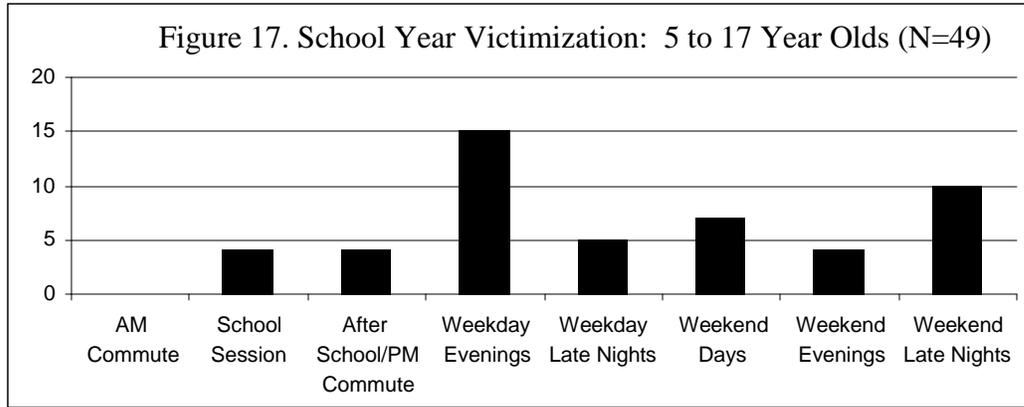


Figure 16. Homicide Trends by Time of Day for Specific Age Cohorts  
Source: Allegheny County Medical Examiner

### Using Routine Activity Theory to Understand Patterns

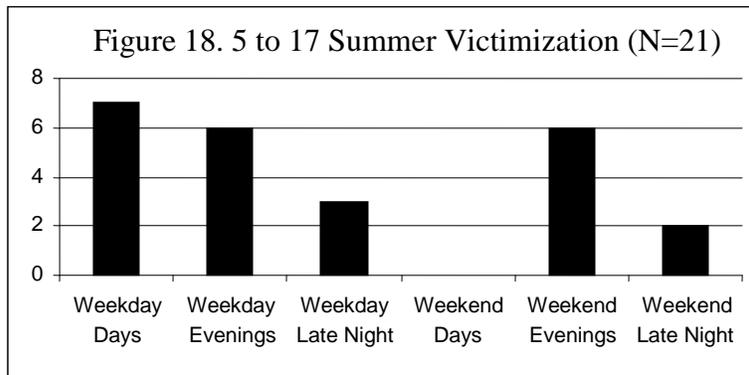
To better predict when children and young adults are at greatest risk of victimization, this report borrows methods used by Caterina Gouvis Roman in her analysis of crime in Washington, D.C. Roman categorized every hour of the week into one of eight temporal categories to correspond to the daily routine of youth ages 5 to 17 and to young adults ages 18 to 24. For those ages 5 to 17 years, the summer months were analyzed separately using a six-category scheme. More information on the specific time categories and corresponding activities can be found in Appendix C.

During the school year, victims ages 17 years and younger were most susceptible to violence during weekday evenings (Sunday through Thursday from 6:00 p.m. to 11:59 p.m.) and weekend late nights (Friday and Saturday from midnight to 6:59 a.m.) (see Figure 17).



Source: Allegheny County Medical Examiner

During the summer months, victimization for individuals ages 17 years and younger occurred more often during the week, particularly during daylight and evening hours, than during late nights or during daylight hours on the weekend (see Figure 18).



Source: Allegheny County Medical Examiner

The same analysis was conducted for 18-24 year-olds, using temporal categories appropriate for that age group. For this population, victimization was most common during late nights throughout the week and on the weekend (see Figure 19).

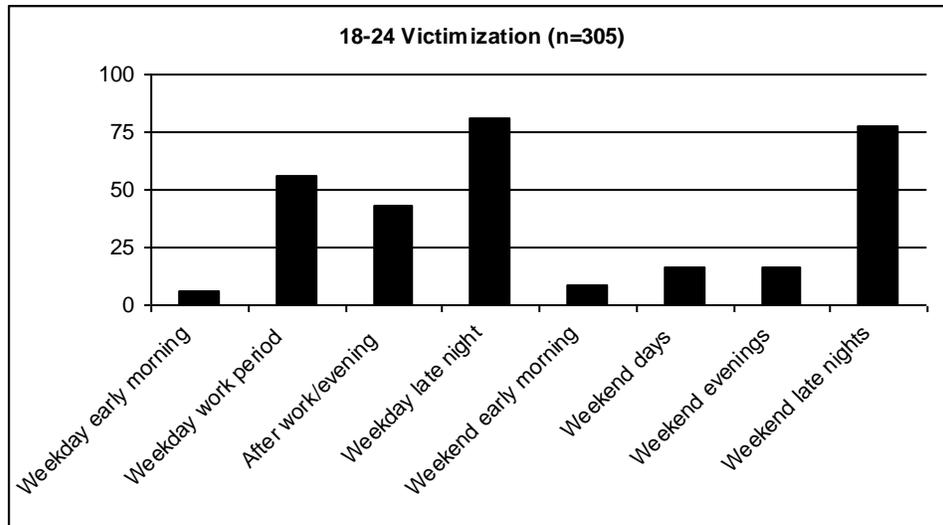


Figure 19. Victimization Patterns, young adults ages 18-24  
 Source: Allegheny County Medical Examiner

## Why Did Violence Occur?

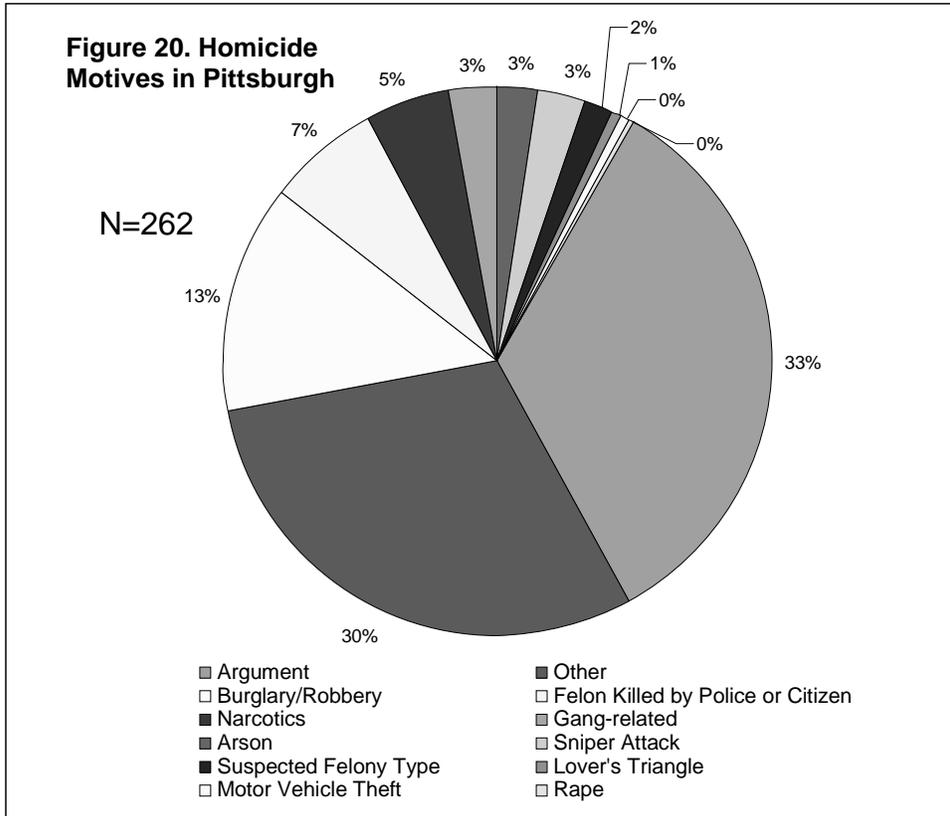
### *Motive*

Understanding why violence occurs is a key factor in the development of prevention methods. Using data from the Pennsylvania State Police, we were able to look at the motive for 186 homicides reported by the Pittsburgh Bureau of Police, representing the 43 percent of cases in which motive was identified (see Figure 20). Though this sample is small, it does shed some light on the potential impetus behind violent acts.

Argument was the most common motive, cited in 33 percent of the incidents. Burglary, robbery, and theft were cited in 13 percent of the incidents, and narcotics were cited in 5 percent of the incidents. In nearly one third of cases (30 percent), a motive other than those provided as a choice was identified. Furthermore, gang-related disputes were only identified as a motive in 3 percent of cases; this is probably significantly underestimated.

One major challenge to accurately identifying motive is the subjective nature of crime incident reviews. At incident review sessions, front-line staff with street-level knowledge of the crimes in question, along with representatives from across the criminal justice system (law enforcement officials, attorneys, probation and parole officers, etc.), come together to share “detailed information about specific types of crime, most often homicide, in the local criminal justice system and us[e] that information to develop strategic approaches to reduce that crime.”<sup>xvii</sup> One goal of these case reviews is to strategize ways to intervene in future situations and prevent poor outcomes by identifying trends and patterns across cases. The Uniform Crime Report (UCR) is typically the starting point for an incident review; the UCRs are made available by state reporting agencies or the FBI and include data on crime counts and rates. Other information, such as medical examiners’ reports, trial or case processing data, and court and correctional data on the prior criminal histories of victims and suspects, also is used to analyze

incidents; however, even this aggregate of official data does not paint a full picture, as it does not provide information on the personal dynamics or motives involved in homicides. The success of an incident review is largely dependent on the participation of many people with information to share, particularly “street knowledge.”



\*State Police File Used—filtered for Pittsburgh  
 Source: Pennsylvania Uniform Crime Reporting System

### *Consequences for Individuals, Families, and Community*

Violence transforms the lives of not only the offender and victim; those closest to the victim—family, friends, and neighbors—are also impacted and every facet of the community in turn suffers.

### *Risk and protective factors*

Strong macro-level social factors, such as poverty and unemployment, play a major role in determining one’s susceptibility to becoming a victim or offender of a violent act.<sup>xviii</sup> Poverty and unemployment influence individual and collective lack of opportunity and subsequent advancement in society, which can result in individuals turning to deviant behavior for social and economic survival.

Additional risk factors are associated with delinquent community and peer group behavior. Sociologists Clifford Shaw and Henry McKay described this phenomenon in their cultural transmission theory, which posits that behaviors such as crime are learned from

interactions and close relationships with those who practice such activities. In other words, all individuals are products of their environments and model what they see. In a study conducted by Durant et al. (1997), youth ages 11 to 19 years who resided in a community with high levels of unemployment, poverty, and criminal activity were interviewed about their involvement in violent acts. Of the 225 youth interviewed, 84 percent reported that they had some exposure to violence. Further, it was found that engagement in violence by a portion of these youth was correlated with higher exposure to violence, victimization in one's community, degree of family conflict, and severity of discipline.

As noted, previous research supports the cultural transmission theory and the notion that those who are victimized are more likely to victimize someone than those who have not been victimized. Within the Durant et al. (1997) study, nearly 16 percent of the participants never engaged in violence and an additional 31 percent had only engaged in one type of violence, indicating that risk exposure is not a determinant of violent behavior. Researchers attributed this to the factors associated with the theory of psychological resilience, first explored by developmental psychologist Emmy Werner,<sup>xix</sup> which describes one's ability to cope with stress and catastrophe, persevere in the face of adversity, and overcome obstacles. The nonviolent youth from this study were thought to possess a more positive attitude about themselves and life, which was attributed to protective factors found in family structure, parental socioeconomic status, religion, and parental employment status.

Another longitudinal study of violence predictors tracked students from grade seven to grade 12 to assess which factors influenced their susceptibility to violence. Researchers identified early deviant behavior, poor academic performance, attending multiple schools, and exposure to and using drugs as risk factors for violence.<sup>xx</sup> They also identified two protective factors: being white and being female were thought to decrease the likelihood that an individual would become involved with violence.

### **Promising Approaches and Best Practices**

Many of the efforts to curb and prevent violence are based on the notion that deficits in social problem-solving skills are linked to youth violence;<sup>xxi</sup> therefore, working with individuals to strengthen these skills reduces their likelihood of becoming involved with violence. This concept builds on Albert Bandura's social cognitive theory, which asserts that individuals learn and model their own behavior through observation and social interactions, experiences, and media influences, and that individuals act in self-directed ways to achieve their goals.

Violence prevention efforts using the social cognitive theory are widely instituted because young people "learn social skills by observing and interacting with parents, adult relatives and friends, teachers, peers, and others in the environment."<sup>xxii</sup> Young people are negotiating ongoing development transitions and developing their problem-solving skills. Methods like role-playing, modeling, and interventions teach nonviolent conflict mediation techniques and instill in individuals the value of being nonviolent. The steps for applying this approach include:<sup>xxiii</sup>

- Identify the target population;
- Consider the target population's demographics and cultural beliefs;
- Select a setting for intervention; and
- Involve the community.

The remaining components of this approach are programmatic considerations (e.g., determine goals and objectives).

This approach is not without limitations and, as with other approaches, there is still a lot to be learned in order to improve efficacy. For example, reductions in aggressive behavior have been short-lived. Furthermore, school-based efforts do not reach many high-risk youth who either do not attend school or attend non-traditional schools. Youth are also frequently unable to take the lessons learned within a controlled setting and apply them to their day-to-day life. Ongoing evaluation and review of these approaches is essential in assessing their long-term effects and outcomes. Finally, in order to strengthen any prevention effort, it is important to consider multiple theories so that the intervention is comprehensive and meets the diverse needs of the targeted population.

Appendix A. City of Pittsburgh Demographics, Census 2000

AGE	MALE	FEMALE	TOTAL	% OF TOTAL POPULATION
0-9	18,612	17,999	36,611	11%
10-17	15,220	14,677	29,897	9%
18-24	24,742	24,719	49,461	15%
25-34	25,148	23,712	48,860	15%
35-44	23,149	23,721	46,870	14%
45-54	19,698	21,384	41,082	12%
55-64	11,784	14,964	26,748	8%
65-74	11,149	15,334	26,483	8%
75-84	7,712	13,650	21,362	6%
85+	1,905	5,284	7,189	2%
<b>TOTAL</b>	<b>159,119</b>	<b>175,444</b>	<b>334,563</b>	

Table A-1. Population by Gender and Age Group, City of Pittsburgh, 2000

BLACK	NON-BLACK
90,750	243,813
27%	73%

Table A-2. Population by Race, City of Pittsburgh, 2000

Appendix B. Cluster Analyses of Homicides, Aggravated Assaults with Firearm, and Shootings

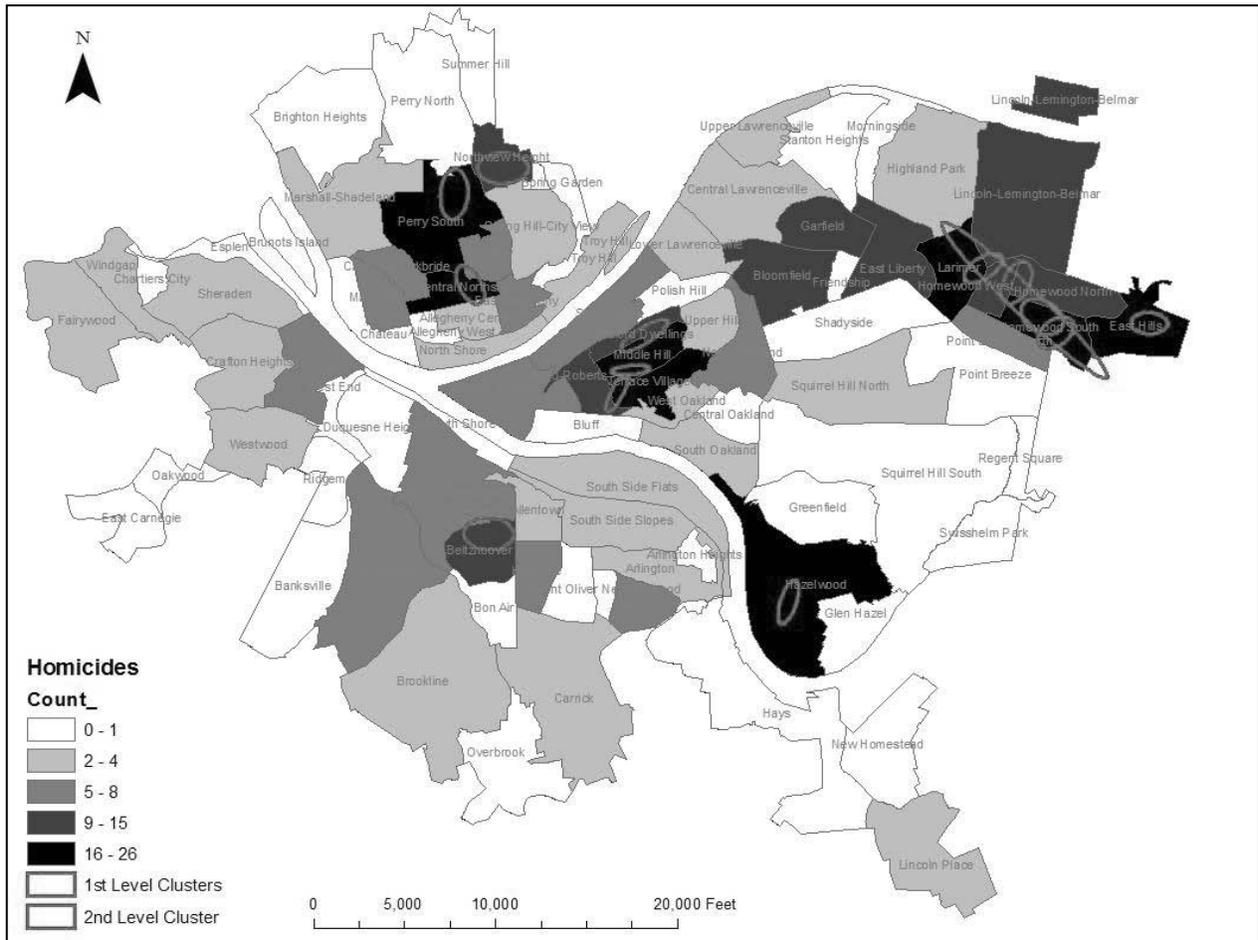


Figure B-1. Homicide Clusters with the City of Pittsburgh, 1997-2007  
 Source: City of Pittsburgh Bureau of Police

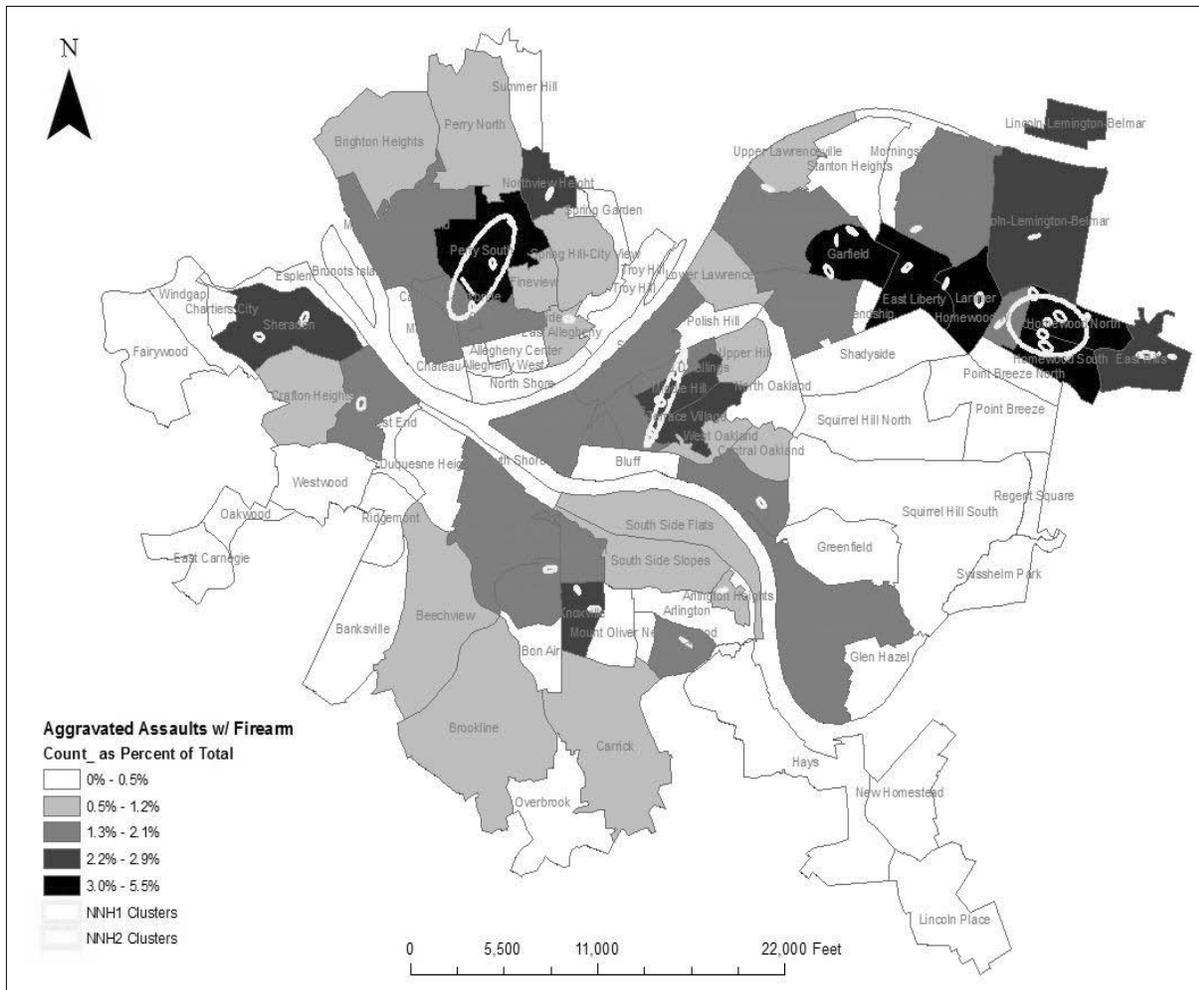


Figure B-2. Aggravated Assaults with Firearm Clusters with the City of Pittsburgh, 1997-2007

Source: City of Pittsburgh Bureau of Police

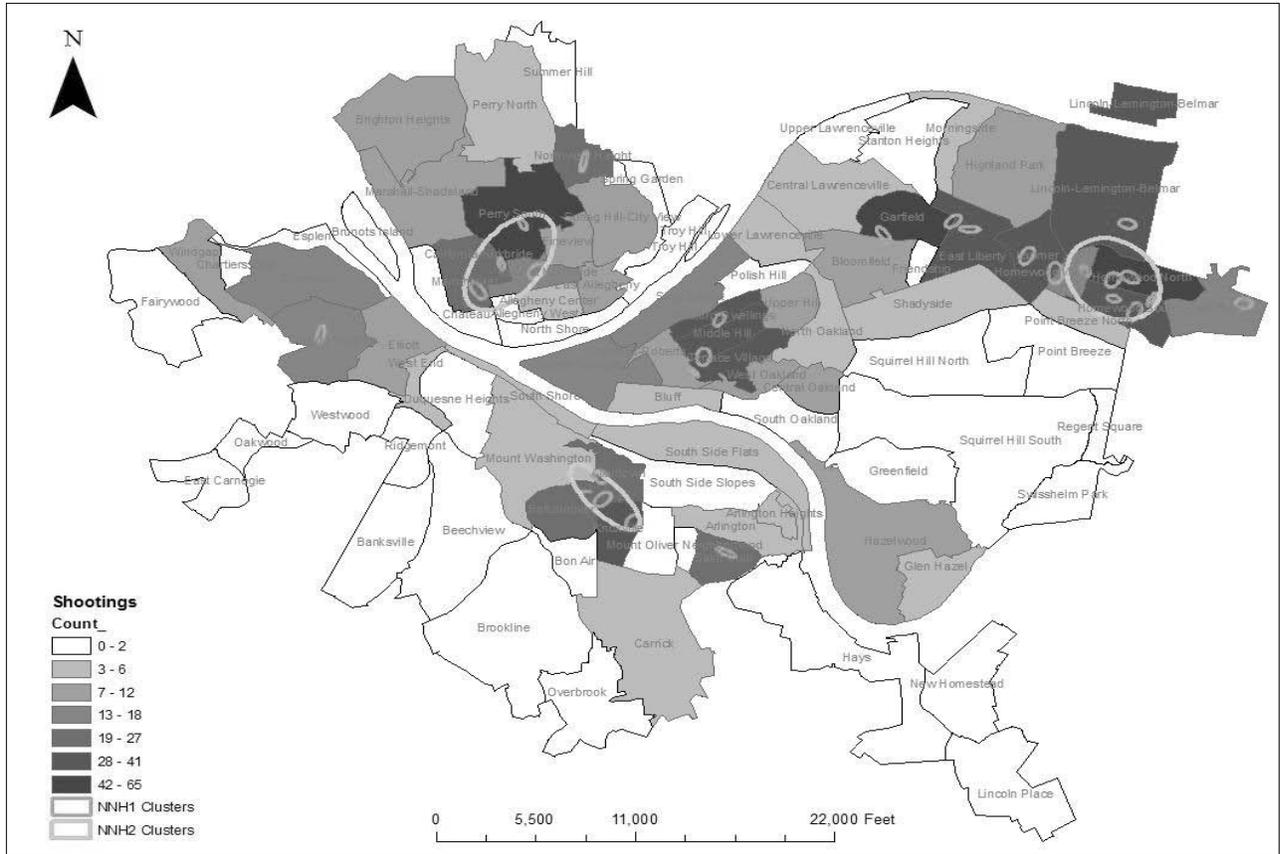


Figure B-3. Shooting Clusters with the City of Pittsburgh, 1997-2007  
 Source: City of Pittsburgh Bureau of Police

Appendix C. Routine Activity Theory

<b>Activity Categories, Youth Ages 5-17</b>		
<b>School Year</b>		
AM Commute	Monday-Friday	7:00 am-8:59 am
School Session	Monday-Friday	9:00 am-2:59 pm
After School/PM Commute	Monday-Friday	3:00 pm-5:59 pm
Weekday Evenings	Sunday-Thursday	6:00 pm-11:59 pm
Weekday Late Nights	Sunday-Thursday	12:00 am-6:59 am
Weekend Days	Saturday-Sunday	7:00 am-5:59 pm
Weekend Evenings	Friday-Sunday	6:00 pm-11:59 pm
Weekend Late Nights	Friday-Sunday	12:00 am-6:59 am
<b>Summer</b>		
Weekday Days	Monday-Friday	7:00 am-5:59 pm
Weekday Evenings	Sunday-Thursday	6:00 pm-11:59 pm
Weekday Late Nights	Sunday-Thursday	12:00 am-6:59 am
Weekend Days	Saturday-Sunday	7:00 am-5:59 pm
Weekend Evenings	Friday-Sunday	6:00 pm-11:59 pm
Weekend Late Nights	Friday-Sunday	12:00 am-6:59 am

Table C-1. Routine Activity Time Categories, Ages 5-17

<b>Activity Categories, Adults Ages 18-24</b>		
Weekday early morning	Monday-Friday	5:00 am-8:59 am
Weekday work period	Monday-Friday	9:00 am-5:59 pm
After work/evening	Monday-Friday	6:00 pm-9:59 pm
Weekday late night	Monday-Thursday	10:00 pm-4:59 am
Weekend early morning	Saturday-Sunday	5:00 am-8:59 am
Weekend days	Saturday-Sunday	9:00 am-5:59 pm
Weekend evenings	Saturday-Sunday	6:00 pm-9:59 pm
Weekend late nights	Friday-Sunday	10:00 pm-4:59 am

Table C-2. Routine Activity Time Categories, Ages 18-24

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## Endnotes

<sup>i</sup> World Health Organization. <http://www.who.int/topics/violence/en/>.

<sup>ii</sup> (2008, <http://www.who.int/violenceprevention/en/>).

<sup>iii</sup> CDC, 2006; CDC, 2004; Violence Policy Center, 2007.

<sup>iv</sup> CDC, 2002.

<sup>v</sup> 41percent vs. 25percent; CDC 2004.

<sup>vi</sup> CDC, 2005.

<sup>vii</sup> CDC.

<sup>viii</sup> (Bronfrenbrenner, 1977, 1989).

<sup>ix</sup> (1)SafeYouth.org (<http://www.safeyouth.org/scripts/facts/risk.asp>)

(2)CDC (<http://www.cdc.gov/ncipc/dvp/YVP/YVP-risk-p-factors.htm>)

(3) Surgeon General's Report

([http://mentalhealth.samhsa.gov/youthviolence/surgeongeneral/sg\\_site/chapter4/sec1.asp](http://mentalhealth.samhsa.gov/youthviolence/surgeongeneral/sg_site/chapter4/sec1.asp))

<sup>x</sup>Injury and violence prevention: behavioral science theories, methods and applications. Andrea C. Gielen, David A. Sleet, Ralph J. DiClemente (editors). Injury and violence prevention: behavioral science theories, methods and applications. San Francisco, California: Jossey-Bass, 2006.

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## **CHAPTER 8. PRIMARY CARE AND COMMUNITY HEALTH CENTERS IN PITTSBURGH**

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### **Introduction**

Specialty care is the pride of the American health care system. Yet the overall health of Americans is unacceptably low. The United States ranked 23rd in the world for male and female life expectancy in 2000. Barbara Starfield, a well-known health policy expert, notes that one major relationship in American health care that has received little attention is the predominance of specialist care over primary care. Primary care deals with most health problems for most people most of the time. Its priorities are to be accessible as health needs arise, to focus on individuals over the long term, to offer comprehensive care for all common problems, and to coordinate services when care from elsewhere is needed.<sup>1</sup> Thus, primary care is the foundation of health for every citizen, but it remains of utmost importance to the most vulnerable citizens in the nation—children, the disabled, racial/ethnic/social minorities, the poor, and the medically uninsured.

### **History and Purpose of Community Health Centers Nationwide**

Publically funded clinics have served as a major component of primary care in the United States for many years. Those clinics that have met certain requirements, to include serving a prescribed population, can be funded by federal dollars. The so-called federally qualified health centers (FQHCs) are designed to have one of five areas of focus: community health centers, migrant health centers, homeless health centers, school-based clinics, or public housing health centers. These centers are nonprofit, community-directed clinical entities designed to provide care by serving communities that otherwise confront financial, geographic, language, cultural, and/or other barriers.<sup>2</sup> FQHCs (1) are located in high-need areas identified as having elevated poverty, higher than average infant mortality, and where few physicians practice; (2) are open to all residents, regardless of insurance status or ability to pay; (3) tailor services to fit the special needs and priorities of their communities; (4) provide services in a linguistically and culturally appropriate

manner; (5) provide comprehensive primary and other health care services, including services that help their patients access care, such as transportation, language interpretation, and case management; (6) provide quality care that reduces health disparities and improves patient outcomes; and (7) are cost effective—reducing costly emergency, hospital, and specialty care—and save the health care system between \$9.9 to \$17.6 billion a year nationally.

The first community health center (CHC) in the United States was established in 1965 and launched a concept that has evolved into an essential component of the health care safety net<sup>3,4</sup> There are now more than 1,000 federally-funded and “look-alike” (the latter qualify for a specific, favorable reimbursement scale, but receive no grant funding) health centers that serve more than 15 million people, three quarters of whom are uninsured or covered by Medicaid, many of whom are members of groups who have been documented to receive low-quality care, and 64 percent of whom are members of immigrant or minority groups. In a nation in which there is no unified system of health care, CHCs (the term we will use to designate all of these clinics receiving substantial federal funding) serve as the nation’s largest primary care system, caring for one in five low-income uninsured persons and one in nine Medicaid beneficiaries. The number of health center sites increased almost 60 percent from 1997 to 2004, and the number of patients increased 90 percent over the same time period. Health centers rely heavily on Medicaid to finance their overall operations. Revenues from Medicaid account for more than one-third of total operating revenues, followed by federal grants at just under a quarter. In contrast, payments from Medicare and private payers each represent 6 percent of total operating revenues.

More than 97,000 health professionals were employed by CHCs in 2006.<sup>5</sup> From the year 2000, with ongoing federal support, they demonstrated a capacity to grow rapidly to meet patient needs through comprehensive primary medical and dental care. Health centers have both a direct and indirect economic impact within their communities, providing employment as well as facilitating health for a vulnerable population that is important to the overall workforce.

CHCs have become an increasingly important resource for health care in communities with high proportions of vulnerable populations.<sup>6</sup> Populations that are less educated and contain proportionately more minority, elderly, and female persons exhibit higher preventable hospitalization rates. One researcher has described ambulatory-care sensitive conditions (conditions for which hospitalizations are considered preventable)—angina, asthma, cellulitis, chronic obstructive pulmonary disease, congestive heart failure, dehydration, diabetes, gastroenteritis, grand mal seizures and epileptic convulsions, hypertension, hypoglycemia, kidney and urinary tract infections, pneumonia, and severe ear, nose, and throat infections—as best treated early in their course and in a non-urgent environment. Populations in medically underserved areas (MUAs) served by an FQHC have significantly lower preventable hospitalization rates than do other MUA populations. The presence of a [public] clinic was associated with lower preventable

hospitalization rates, and the availability of public ambulatory clinics was associated with better access to primary care among low-income and elderly populations.

Populations without usual access to health care do not do as well as those with a regular source of care. A study that examined the quality of care for patients with chronic disease in a nationally representative sample of federally funded CHCs noted that fewer than half of eligible patients received appropriate care for the majority of indicators measured, and uninsured patients received poorer care than insured patients (Hicks, O'Malley and Lieu).<sup>4</sup> Thus, receiving care in CHCs is more beneficial than what is usually available for many vulnerable populations, but there is still a need for better organized and more available resources. These investigators performed a baseline assessment of quality for hypertension, diabetes, and asthma as part of an ongoing evaluation of quality improvement collaboratives using quality-of-care indicators based on national guidelines. Findings are consistent with studies reporting that CHCs provide better quality care than other health care institutional models as measured by reduced hospitalizations and emergency department (ED) visits, higher rates of vaccination among children and the elderly, and higher rates of cancer screening among the poor and elderly.

### **Western Pennsylvania**

Pennsylvania benefited from the growth of community health centers during the past 10 years, as did the rest of the nation. Pennsylvania health center data from the National Association of Community Health Centers (NACHC) reveal the following:

Pennsylvania Federally-Supported Health Centers	
Number of Organizations	32
Number of Delivery Sites	189
Total Patients	521,194
Number Migrant/Seasonal Farmworker Patients	3,336
Number Homeless Patients	20,598

Of these patients, 40.7 percent are Medicaid, 23.6 percent are uninsured, and 9.2 percent are Medicare.<sup>2</sup>

The following description of patients served in Pennsylvania attests to the financial needs of the population served by these facilities in comparison to those across the nation.<sup>2</sup>

	<u>Health Ctr Pop</u>	<u>State Population</u>	<u>US Population</u>
Percent at or Below 100% of Poverty, 2007	67%	15%	17%
Percent Under 200% of Poverty, 2007	90%	33%	36%
Percent Uninsured, 2007	24%	10%	12%
Percent Medicaid, 2007	41%	12%	13%
Percent Medicare, 2007	9%	15%	15%
Percent Hispanic/Latino, 2007*	13%	4%	15%
Percent African American, 2007*	39%	11%	13%
Percent Asian/Pacific Islander, 2007*	2%	2%	5%
Percent American Indian/Alaska Native, 2007*	0%	0%	1%
Percent White (Including Hispanic/Latino), 2007*	57%	86%	80%
Percent Rural, 2007	34%	19%	16%

## Patient Visits and Patients by Selected Primary Diagnoses and Services

As shown below, the data from the state of Pennsylvania largely duplicate our findings in Pittsburgh and in the community health centers that are part of the University of Pittsburgh Medical Center (UPMC). The top three diagnoses in UPMC health centers are hypertension, diabetes, and depression.

	Patient Visits	Patients
<u>Medical Conditions</u>		
Hypertension	97,243	46,547
Diabetes mellitus	75,460	27,346
Heart Disease	26,876	12,569
(Selected)		
Asthma	27,015	17,003
Depression & Other	57,027	17,773
Mood Disorders		
All Mental Health & Substance Abuse	131,076	N/A

In order to address patient needs, the following percentage of health centers provide these services on-site:\*

<u>Professional Services</u>	
General Primary Medical Care	100%
Prenatal Care	81%
Preventive Dental Care	75%
Mental Health	75%
Treatment/Counseling	
Substance Abuse Treatment & Counseling	47%
Hearing Screening	100%
Vision Screening	91%
Pharmacy	19%

<u>Preventive Services</u>	
Smoking Cessation Program	72%
HIV Testing and Counseling	94%
Glycosylated Hemoglobin Measurement, Diabetes	78%
Blood Pressure Monitoring	100%
Blood Cholesterol Screening	84%
Weight Reduction Program	81%

### Enabling Services

Case Management	91%
Eligibility Assistance	88%
Health Education	100%
Interpretation/Translation Services	88%
Transportation	53%
Out stationed Eligibility Workers	13%

\* “On-site” includes services rendered by employees, contracted providers, volunteers, and others who render services in the health center's name. Health centers may also provide services through formal referral arrangements.

### **Workforce Issues**

#### *Unique Issues of Allegheny County*

The demographics of Allegheny County reflect those of the state and the nation—a large elderly population, second only in percentage of the total population to Dade County, Florida<sup>7</sup> (Musa, Seiler and Flora), and a median household (U.S. Census Bureau) income of \$46,402.<sup>8</sup> The largest employers in western Pennsylvania are the health care industry and institutions of higher education. The majority of health care providers are in specialty areas, reflecting the preferred career choices of physicians graduating from medical and osteopathic schools today. Thus, the county has a large, low-income, elderly population and decreasing numbers of primary care providers. Pennsylvania Medical Society data demonstrate that only about 4 percent of physicians in the state now who are not in training are less than 35 years of age. This combination of scenarios suggests a growing primary care need to ensure the ongoing health of the population.

#### *Current Primary Care Access Points*

The U.S. primary care safety net has been described as a loose network of community health centers, hospital outpatient departments, and physicians’ offices. A comparison of the type of patient presentation, diagnostic case-mix of patients, and predicted visit duration revealed the following: (1) primary care visits for new health problems were more likely in community health centers compared with physicians’ offices and hospital outpatient departments; (2) sicker patients were seen in hospital outpatient departments; and (3) the service intensity of hospital outpatient visits was higher, incorporating more imaging studies, minor surgery, and subspecialty referrals as compared to physicians’ offices.<sup>9</sup>

### *Private Practitioners*

Primary care practitioners include family physicians, general internists, general pediatricians, and nurse practitioners. As more and more clinicians are now employed by health care organizations as opposed to being self-employed, fewer uninsured or underinsured people are turning to them for care. Rather, this population tends to seek services in public clinics or emergency departments.

### *Academic Health Centers*

Academic health centers have provided the foundation of safety net services for many years, mostly through their emergency departments. Increasing financial constraints have stimulated these departments to turn away those presenting uninsured and with non-critical conditions. Much of their contributions center around their provision of uncompensated care. Some have recently established a system for the uninsured to apply for charity care in advance of receipt of medical services.

### *FQHCs*

One study compared claim costs for FQHC users to nonusers to determine if the centers were cost-effective, given that they receive supplemental payments from the Medicaid program for their services.<sup>10</sup> Based on the analysis of Medicaid fee-for-service claims for 2003 and 2004, FQHCs are cost-effective, and their patients incur lower total per-member per-month Medicaid costs than similarly situated non-Federally Qualified Health Center users. In fact, with the exception of emergency department visits, FQHC patients have fewer visits for each of the services analyzed. Fewer services used translates into lower costs for the FQHC group.

Having a usual source of care, or “medical home,” has been demonstrated to improve health status and outcomes.<sup>11</sup> The American Academy of Family Physicians, the American College of Physicians, the American Academy of Pediatrics, and the American Osteopathic Association together have proposed a patient-centered medical home model as a way to reduce cost and increase the quality of care. The essence of the medical home is anchored in a usual source of care but includes a comprehensive, coordinated system of essential services on-site or by referral, including oral health, behavioral health, substance abuse, and specialty care. In addition to these are a broad range of enhanced services designed to assure access to care, including outreach, patient education, translation and interpretation, labor coaching, childbirth education classes, child care, transportation vouchers, and assistance applying for health insurance coverage. Case management ties these together in order for patients to receive the full range of services they need.

### *Collaborative Systems*

In order to provide comprehensive primary care services to a diverse population in an environment of limited health care resources for the community and lack of public

funding, some areas of the country have implemented health care access through collaborations between primary care clinicians, pharmacies, and various community organizations.

One such collaboration in Allegheny County is the Coordinated Care Network (CCN). CCN is a nonprofit organization formed in 1996 that provides case management and 340B (a federal, discount pharmacy purchasing program) pharmacy services to underserved populations in 10 counties across southwestern Pennsylvania (including Pittsburgh). CCN's mission is to reduce "system" costs through its case management and prescription discount programs and, in the process, generate sufficient earned income to finance health care for its uninsured population. CCN is comprised of 13 nonprofit member agencies that provide medical, social, and behavioral health services to vulnerable populations through 194 programs at 79 sites. Creation of CCN was initially funded by 10 local and two national foundations and subsequently funded through the federal Community Access Program (CAP), which was recently renamed Healthy Communities Access Program.

CCN operates a 340B Physician Dispensing and Mail Order program that provides health centers and other eligible covered entities with an on-site physician dispensing system, prepackaged medications, and centralized refill services. Through this system, covered entities are able to obtain medications at 340B cost, offer significant discounts to both uninsured patients and public/private insurers, increase convenience and compliance, and generate new revenue streams for their organizations. CCN operates largely through health centers run by independent, not-for-profit health care entities within the county.<sup>12</sup>

In Montgomery County, Maryland, the Primary Care Coalition (PCC) was formed in order to create and coordinate a community-based health care system, address health disparities, and to attempt to achieve universal access to health care. PCC encompasses The Center for Health Care Access, The Center for Medicine Access, The Center for Community-Based Health Informatics, The Center for Health Improvement, and The Center for Children's Health. The Center for Health Care Access deals with care delivery networks for children and adults—specialty care, information and referral, oral health, behavioral health, and health care for the homeless. The Center for Medicine Access uses a point-of-care distribution system, the pharmaceutical industry's patient assistance programs, and a pharmacy-benefit management program to ensure that patients have access to generic and brand-name drugs. The Center for Community-Based Health Informatics designs and maintains electronic medical records for clinics in Montgomery County. The Center for Health Improvement has the responsibility of improving quality, efficiency, equity, and health outcomes for the adults and children in the county. The Center for Children's Health deals with the health issues of abused and neglected children.<sup>13</sup> This system offers expanded services through extensive collaboration in comparison to what CCN offers in Allegheny County, Pennsylvania.

The University of New Mexico (UNM) Health Sciences Center has committed itself to improving the existent provider network in order to reach the underserved rural residents,

who make up two-thirds of New Mexico's population. The Health Sciences Center's Community Voices Shared Solutions integrates primary care services by involving various health care providers and policy and advocacy groups together to form a network of care that makes the most efficient use of the state's limited health resources. Issues of health care access and quality have been targeted through this strengthening of the health care safety net. This coordinated system enhances the current health care provider network; assigns uninsured individuals to a primary care provider; provides behavioral, social, and dental care; improves the quality of care through the establishment of common goals and standards of care; and has created public policy reform on issues of health policy in the Albuquerque community.<sup>14</sup> Every uninsured individual who registers with the network receives a membership card that provides access to services. The safety net health care agencies pool their resources and manage equitable distribution of services to those enrolled in the program. After documenting substantially fewer uncompensated care visits to local emergency departments and crisis hospitalizations, the country surrounding Albuquerque noted a savings of more than \$2 million dollars within the first year following implementation of the program.

### **Faith-Based Institutions**

For many years and in communities across the nation, the care of the most vulnerable populations has been anchored by faith-based medical and social service institutions. By virtue of the rapidly rising costs of health care, many of the faith-based entities have chosen to focus on a defined area of need. Others have partnered with other organizations in the community and some have been forced to discontinue healthcare services entirely. This has been true in Allegheny County and is evident in several organizations.

#### *Center for Healthy Hearts and Souls*

The Center for Healthy Hearts and Souls (CHHS) began as a faith-based initiative in 1998. Local pastors and churches focused on decreasing health disparities. Highmark Blue Cross/Blue Shield Foundation, the UPMC Shadyside Foundation, and the Primary Care Institute provided financial, medical, and program development support. The original goal of CHHS was to address the high prevalence of heart disease in western Pennsylvania by bringing together local churches and the health care community to enhance physical and spiritual well-being. It has since grown to embrace an expanded health and wellness mission that incorporates many partners to include universities, health associations, schools, community collaboratives, citywide cancer institutes, corporations, and unions. CHHS programs address smoking cessation, diabetes support, exercise, nutrition, healthy lifestyles, cancer outreach, and a youth health corps throughout the greater Pittsburgh area.<sup>11</sup>

### *Decline of Catholic and other Faith-based Hospitals*

The largest system of faith-based health care entities has grown out of the Catholic Church. They had traditionally received large subsidies from the church and volunteer efforts of members of many parishes. With rising costs of health care and economic constraints, many faith-based hospitals and health care institutions have closed. This describes the closure of multiple faith-based institutions in Pittsburgh as well. Hospitals that are not religiously affiliated may have a chaplain on staff or on call. But at a faith-based institution, pastoral ministry staff members are viewed as an integral part of the healing team, helping to meet spiritual and emotional needs while physicians respond to medical concerns.<sup>12</sup>

At one time, funds from the affiliated faith-based organizations provided some operating expenses, particularly for charity care. But as health care costs skyrocketed, targeted faith-based allocations to hospitals became an increasingly minute fraction of their total operating budgets, and governing bodies of faith-based organizations shifted toward designating funds to pastoral ministry at the institutions.<sup>12</sup> But while the ability of denominations to provide direct financial support for charity care in their affiliated hospitals has lessened, the health care systems have maintained a commitment to providing medical attention for poor people in their communities. More than any other single factor, that commitment sets faith-based nonprofit hospitals apart from secular for-profit health care providers.

The demise of St. Francis Hospital in Pittsburgh required the shifting of physical and behavioral health services for thousands of patients to intensive and community-based centers for care. This loss of access continued and grew as the one remaining faith-based hospital in Allegheny County, Mercy Hospital, became more financially insolvent several years later. Not only inpatient services suffered, but also the many ambulatory and outreach activities that centered in this hospital (e.g., outreach to the homeless). The purchase of the hospital by UPMC has allowed the facility to remain open, as well as to receive an infusion of resources that has bolstered existing programs and expanded the scope of care to the community. What must be preserved in the careful planning required to sustain an inpatient facility and make it profitable is the equally important attention needed to sustain its ambulatory and primary care missions. The evidence of the primary care mission of hospitals is often the hospital-based clinics that are located in the communities surrounding the inpatient facility. An example of this model is seen in the nine hospital-based clinics affiliated with UPMC hospitals.

A creative approach to meeting the health care needs of an urban community can be seen at the New York-Presbyterian Hospital Ambulatory Care Network's Community Health Nursing – Faith-Based Partnership Program. This group partners with faith-based organizations to improve the health of members in these organizations and the community.<sup>13</sup> The Community Health Nursing - Faith Based Partnership Program partners with churches, mosques, and synagogues in Harlem, and the Building Bridges, Building Health, Building Knowledge Coalition (BBKH). BBKH is comprised of faith-

based and community-based organizations, academic institutions, and academic medical centers. The Coalition has been serving the low-income population of New York City for many years and provides a number of health care and health promotion services. The program aims to transform and revitalize the community's approaches to disease prevention and health promotion through (1) education and screening for the inner city's immigrant population; (2) providing opportunities for preteens to shadow department heads at the hospital for a day; (3) referral services to improve access to care; (4) stress management fairs; (5) a pharmacy assistance program; and (6) participation in the national Reach Out and Read program.

### **Chronic Diseases and Prevention**

#### *National Data: Health Centers Help to Reduce Health Disparities*

CHC patients often face chronic illness and multiple health problems. Effective management of chronic disease at health centers has improved outcomes and lowered the cost of treating patients with chronic illness. In a recent study, health center Medicaid patients with diabetes cost \$400 less per patient than diabetic Medicaid patients treated by family practice physicians, despite having more office visits per patient as well as more patients with multiple chronic diseases.<sup>9</sup> This difference was thought to be due to the more comprehensive range of services available in community-based health centers than in private physicians' offices.

*Data from UPMC Department of Family Medicine CHCs*

The demographics of patients seen in UPMC facilities are shown below.

	BG	Law	NK	Latt	SHY	Theiss	SqHill	Total
CY08								
Uniq Pts seen	2193	3676	2133	3897	8377	1550	3441	25267
Race								
African American	56.68%	15.04%	13.69%	35.00%	41.34%	65.10%	11.25%	32.89%
Asian	2.55%	3.51%	1.22%	1.92%	2.86%	2.39%	6.39%	3.10%
Caucasian	16.51%	55.88%	40.93%	48.06%	26.36%	16.06%	51.90%	37.22%
Hispanic	0.05%	0.14%	0.33%	0.26%	0.21%	0.65%	0.20%	0.23%
Other	1.92%	1.50%	1.59%	1.13%	1.09%	0.90%	1.98%	1.38%
Unreported	22.30%	23.91%	42.19%	13.63%	28.14%	14.90%	28.28%	25.17%
Gender								
Female	63.70%	61.59%	64.18%	68.49%	59.62%	70.39%	64.52%	63.34%
Male	36.30%	38.41%	35.82%	31.51%	40.38%	29.61%	35.48%	36.66%
Age								
0-9	366	545	419	780	1239	209	274	3832
10-19	574	607	390	823	945	211	233	3783
20-44	775	1443	830	1527	3954	609	1525	10663
45-59	319	699	312	497	1494	356	433	4110
60-74	126	291	137	166	553	239	233	1745
75+	33	91	45	104	192	32	132	629

The goal is not only to provide ambulatory, comprehensive primary care, but also to offer those services that are so essential to overall population health and well-being.

*Specific UPMC Community Health Center Coordinated Programs/Resources*

UPMC community health centers offer a variety of services in addition to primary medical care. Examples of these services appear in the following tables:

Area Addressed	Resources Provided
Social Services	
Bus/cab fare	Transportation to and from clinical services
Medication procurement	Patient assistance for free medications
Insurance procurement	Application assistance for all types of insurance
Counseling services	Medication management, family, stress, financial assistance
Supply procurement	Food, thermometers, blood pressure cuffs, cribs, car seats, bike helmets, toys, clothing
Health Promotion	

Classes	Smoking cessation, prenatal, diabetes/diet/nutrition, mind/body healthful eating
Early literacy and reading advocacy	Reach Out and Read
Clinical Services	
Consults	Pharm D for medication management, adult psychiatric
Clinical services	Continuing, comprehensive health care for individuals and families; home visits, Adagio, dermatology, sports medicine, colposcopy, gyne services, x-ray, phlebotomy, minor office surgery, RN case management/referral, substance use screening/referral/treatment, depression screening/referral/treatment
Community Partnerships/Participation	
School Health Partnerships	Entry physicals, sports pre-participation examinations, education on public health issues (asthma, dental decay prevention, nutrition and exercise, tobacco use prevention, violence prevention, puberty and human sexuality) education
Fitwits™	Collaboration with school, physician office, community, and CMU designed to help families achieve healthy lifestyles
Edible Schoolyards	Participation in Mercy Hospital's Operation Safety Net Ninth Street Clinic Catholic Charities Clinic Community Advisory Boards

### **Implications for the Future**

Community health centers offer quality primary care at an affordable price for millions of Americans. During difficult economic times, community health centers can provide both a direct and indirect economic impact on communities while providing care for a population with limited resources. Calculations from the Uniform Data System (UDS), which is administered and maintained by the Health Resources and Services Administration and tabulates financial, service, staffing, and patient data on all FQHCs, reports earnings of approximately \$3 in third-party revenue for every \$1 in health center grant funding.<sup>5</sup> An additional \$250 million invested in these facilities would translate into nearly \$750 million in additional third-party revenues. Using a per capita cost of serving a health center patient of \$538, health centers would be able to serve an additional

740,000 uninsured patients and 1.1 million publically or privately insured patients. More than 92 percent of these new patients would be low-income, 63 percent would be members of racial and ethnic minority groups, and 40 percent would be uninsured.

It is possible to predict the impact of investments targeting individual state economies, since UDS data capture state and federal revenues. For an additional \$1 million in health center grant funding in Pennsylvania, \$3.1 million in new revenues would be generated, \$7.3 million of total new economic activity, 86 FTEs of new jobs, and 10,100 new patients served.<sup>5</sup>

Senator Bernie Sanders (I, VT) and Representative Jim Clyburn (D, SC) recently noted that an up-front investment in community health centers would more than pay for itself since the overall medical expenses for health center patients are 41 percent lower than for patients seen elsewhere. “This is achieved by treating people when they should be treated, instead of relying on expensive emergency rooms and unnecessary hospital admissions.”<sup>18</sup>

## **Recommendations**

Health care should be community-based, community-oriented, community-located, and community-responsive. CHCs should provide comprehensive care, including primary care, behavioral health services, a pharmacy, podiatry, dental, social services, and coordinated access to specialty care across the life span of the patients. This care should be provided through collaboration with health care providers, social services agencies, health insurance providers, private foundations, and community institutions. CHCs also need to be geographically accessible, not just adjacent to large tertiary care institutions, as is usually the case. In order to ensure that these health care services are reaching the targeted population, culturally sensitive services need to be provided. There should be attention to literacy (i.e., the ability to read, write, and comprehend), health literacy, language literacy, accessibility for the disabled, and responsiveness to the needs of vulnerable families. A county-wide collaboration of all safety-net organizations is necessary to ensure the delivery of standardized, basic health services to the uninsured—similar to the model seen in Albuquerque, New Mexico. Through such a collaboration, health care can be available using a patient-centered, medical home model for all citizens—both the commercially insured as well as the most vulnerable. Only through providing comprehensive care for all can we demonstrate the moral imperative for universal health care!

*“If a free society cannot help the many who are poor, it cannot save the few who are rich.” John F. Kennedy*

(<http://www.jfklibrary.org/Historical+Resources/Archives/Reference+Desk/Speeches/JFK/003POF03Inaugural01201961.htm>; Accessed 5/3/09)

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## CHAPTER 9. DOCTOR/PATIENT COMMUNICATION

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### Introduction

With medical errors the eighth leading cause of death among Americans (exceeding those from motor vehicle accidents, breast cancer, or AIDS), communication among health professionals and between health professionals and patients has assumed a looming importance. According to the National Academy of Sciences' Institute of Medicine report, *To Err is Human: Building a Safer Health Care System*, better communication would prevent many hospital-based errors and thousands more, uncounted in the report, that occur in homes, doctor's offices, clinics, and nursing homes. While the U.S. Food and Drug Administration (FDA) is actively pursuing solutions to prescription errors, its expert on drug risk assessment, Dr. Peter Honig, has called consumer education the "secret weapon" in the war against medical errors, urging patients to be more vigilant about their health care and to ask more questions of their physician.

There is a crisis in communication between patients and physicians, which results in a negative impact on patient care. Thomas Starzl, MD, world famous transplant surgeon, reminds us that no matter how well trained or how experienced physicians may be, they do not deliver optimal care if they do not communicate with their patients. Learning is mutual when doctors and patients listen to and hear each other.<sup>i</sup>

At no time has communication been more important than in today's health care system. Poor communication—an error in dosage, misunderstood instructions, or a failure to stress the importance of compliance—can lead to deadly errors, in the hospital and in the home.

We are accustomed to hearing words with insufficient attention to tone or the clarity of speech. These factors determine much about the communication and the person to whom the communication is directed. We as a society are guilty of inattention to non-verbal communication, which has become the language of the disenfranchised. Those faces and bodies communicate the frustration, anger, and the inability to understand information as presented.

Nonverbal communication is the process of transmitting information without the use of words. It includes the way a person uses his or her body, such as facial expressions, eye contact, hand or arm gestures, posture, and various movements of the legs and feet. Nonverbal communication also includes paralinguistics—verbal qualities like tone, rhythm, pace and vibrancy, speech errors, and pauses or silence. It is often through the nonverbal aspects of communication that we apprehend another's feelings.<sup>ii</sup>

African American patients are often labeled as sullen or noncommunicative because the observer fails to “hear” the vibrancy of the nonverbal communication. The non-expressive face may be masking the fears the patients are experiencing based on the uninformed diagnosis they have made of their symptoms. These patients must assume more responsibility in assuring an equal partnership in their care. They must become empowered to participate in the discussions with the physicians by insisting that language used be understandable. At the same time, physicians must become more alert to the nuance of the body language of the patient.

Webster Universal College Dictionary defines communication as the imparting or interchange of thoughts, opinions, or information by speech, writing, or signs.<sup>iii</sup> Good communication, which must be considered the lynchpin of doctor/patient relationship, only occurs when the speaker and the listener hear and understand the same words.

The environment in which communication is dispatched may be viewed as friendly by the physician but hostile to the patient. The physician might view the outpatient clinic as convenient; however, the patient might view the clinic as much too public to discuss the very personal matters that need to be discussed in order for the physician to understand the psychosocial factors that impact on the patient’s life.

The often-crowded waiting room in the doctor’s office may resemble an assembly line to the patients, who will share their anger and frustration with the clerical or nursing staff but remain uncommunicative when the physician encounter finally occurs. Many patients have reported that they were intimidated or made to feel they were intruders in the physician’s space.

Good communication is particularly important in the treatment of chronic illnesses such as hypertension, diabetes, cardiovascular disease, and end-stage renal disease, among others. Over the many years of interaction with the physicians and their care teams (nurses, social workers, dieticians), patients ideally develop a relationship that should result in a partnership with their physician and care providers. Essential to this partnership is the commitment of both patient and physician to accomplish the best possible outcome. Patients must “own” their illness and the responsibility to follow medical direction, even when it means making significant lifestyle changes. Physicians must be willing to receive the patient as an equal in the relationship and afford the patient the opportunity to partner. Both partners must pay particular heed to the art of “hearing and listening.”<sup>1</sup>

In my book, *Doctor, Can You Hear Me? Patient, Are you Listening?*, I provide both the rationale for addressing the issue of effective communication and practical strategies for helping doctors and patients learn to listen to—and to hear—each other. My research was conducted over a three-year time frame through surveys, focus groups, and interviews of physicians, patients and other health professionals. The book represents the voices of more than 3,000 physicians, patients, and other health professionals across the country on such issues as:

- Quality of communication between doctors and patients
- Effect of good communication on patient compliance
- Physician sensitivity to patients' financial and cultural needs and preferences
- Accessibility of services
- Barriers to understanding and, consequently, to care

Demographic profiles of the respondents and quantitative analysis of their responses to the survey and in the focus groups and interviews provide a framework for the vibrant human portrait of doctor-patient relationships that emerges from the extensive use of direct quotations and vignettes from a broad range of medical specialists, patients, and health conditions. In addition to a final chapter, "Prescription for Progress," which includes model contracts for physicians and patients and a template for a patient-maintained personal medical history, the book contains physician and patient "wish lists" for one another's behavior.

Because it draws upon the feelings and ideas of so many individuals, the book speaks to a still broader audience of patients and enlightened health care providers who understand that we are all patients at some point in our lives and are seeking to improve both our own level of communication and the quality of health care delivery.

This chapter will provide a snapshot of the research process—problem identification, analysis of impact, possible solutions, and a plan to adequately address possible solutions.

### **Causes of the Problem**

By definition, partnership recognizes the "me" in "we" statements. Webster points out that being a partner implies "participation, association, and joint interest."<sup>iii</sup> The physician/patient partnerships that were observed or reported by my study participants, however, existed more often on paper than in practice. The "joint interest" in the definition implies that in successful partnerships, both partners benefit from the relationship: Physicians benefit from the tangible and intangible rewards of using their medical training to provide quality healthcare, and patients benefit from access to medical expertise, with the expectation of beneficial outcomes.

Both physicians and patients commented on the lack of common courtesy they experienced in health care encounters and suggested that such thoughtlessness and insensitivity could undermine doctor-patient communication. Both parties admitted that their reaction to discourtesy was to respond in kind. African American patients reported the discourtesy as another indication of the racism they believed permeates the health care arena. Patients reported the long waits in the doctor's office and poor scheduling in clinics as a statement of the professionals' disregard for patients' time and convenience.

Physicians cited patients who “challenge the doctors’ credentials” by disagreeing with recommended treatments and those who withhold information that is crucial to accurate diagnoses.

Patients and physicians agreed that neither apologizes for lateness nor seldom utters a simple “thank you.”

Patients and physicians were queried to provide a Wish List to identify the “good and bad” of communication. The list identified the following problems:

### *Physicians*

I wish my patients would not:

- Stop medication on their own without discussion with me.
- Discuss their medical problems with non-medical people and judge appropriateness of my care based on their judgment.
- Discount my advice.
- Take for granted that medicine will fix everything.
- Seek treatment over the phone.
- Blame me if the prognosis is not favorable.
- Miss appointments.
- Ask for medications promoted on television.

### *Patients*

I wish my doctor would not:

- Rush off when he doesn’t want to hear what I have to say.
- Become annoyed with me because I can’t tell indigestion from a heart attack.
- Interrupt me when I talk to him.
- Give vague answers to my questions and then get mad when I push for better answers.
- Assume I understand medical talk.
- Exhibit such a condescending attitude toward my family and me.
- Always hurry through my visit, just like an assembly line.
- Treat me like I have no brain.

Good communication is based on shared expectations and common assumptions, but—as the survey, focus groups, and interviews revealed—doctors and patients generally are not on the same page. Therein lies the source of many of the communication problems they experience. These problems individually or collectively are not beyond resolution. However, when you factor in the third-party payer and the suspicion that the quality of care is compromised by race, African American patients are suspect of the health care delivery system.

In conversations with African American participants in my research, a number of telling facts surfaced that validated their beliefs that racism played a major role in their care. The following observations or statements occurred:

Often African American patients in my research exhibited a resignation in terms of their expectations of care. The “system” does not pay for high-quality care; “you get what you pay for”; physicians were viewed as unapproachable; doctor is too busy, I don’t want to bother him; I don’t understand the words, but it’s not the doctor’s fault; you get used to waiting for a long time; my insurance won’t pay for the medicine I need so he prescribes what the insurance will pay for. The older African American patients commented that they were reluctant to report “new” symptoms for fear of hospitalization or a self-diagnosed terminal disease beyond cure. These patients also reported their resentment in being called by their first name by young physicians or other healthcare personnel. The problems identified with great consistency were lack of privacy with regard to personal questions raised by clerical staff while they were seated in the waiting room or doors left open or curtains not fully drawn in the examination area.

Younger African-American patients reported dissatisfaction with the convenience of office hours or clinic appointments, which caused them to lose time from work to seek medical treatment. Most patients admitted they allowed symptoms to become urgent to accommodate time off work. Younger African American patients embraced the concept of doctor/patient partnership but were convinced that most physicians were more comfortable with the old way of doing business—doctor speaks, patient listens and then does what the doctor says. These patients reported numerous scenarios where their questions about treatment, diagnosis, or prognosis were perceived by the physician as a challenge to the physician’s judgment.

Both older and younger African American patients reported that they were more at ease with an African American physician or a Caucasian physician who understood “Black culture.” These patients were very critical of foreign-born physicians who often spoke with accents difficult to understand and had preconceived attitudes about the patients’ status in society.

Ethnicity was found to present barriers to the seeking of care, provision of care, and the outcome of treatments. Patients believed a defined “caste” system operated in the health care system, with patients looked upon as diseases rather than as people. Cultural differences were blamed for much patient noncompliance, particularly with dietary restrictions. Patients believed that physicians should instruct dieticians to work with them to incorporate cultural eating patterns and preferences in designing therapeutic diets. Physicians and dieticians should also consider the patients’ financial situation before ordering diets that impose a hardship on the family by requiring special foods or supplements that are costly.<sup>i</sup>

National origin, however, was not the only source of cultural differences. A number of African American patients commented on their interactions with Caucasian doctors who, the patients said, conveyed the attitude that “you caused your problems

because of your chosen lifestyle, so stop complaining!” Patients perceived that the same racism they experience in the “outside” world is alive and well and thriving in many clinical settings.<sup>1</sup>

### **Consequences of the Problem for Individuals, Families and Communities**

The consequences of the problems enumerated are varied. Let us look at impact on individuals first. Patients who feel victimized by an uncaring, insensitive health care delivery system will suffer in myriad ways. Physical health will decline if patients believe they seek care in a hostile, unwelcoming environment. A system that has not taken the responsibility for a comprehensive health education initiative to reach patients at all academic levels will suffer the consequence of treating patients who present with significant morbidity with expected outcomes of increased mortality.

Patients who have not learned their families’ health history while they pursued their ethnic roots will be destined to cope with diseases for which they appear to be genetically predisposed (i.e., hypertension, diabetes). Patients who have not been empowered will continue not to seek full participation in the determination of their treatment plan as a full partner with their physician. They will experience usual treatment with the same dreary outcomes of years past.

Physicians who fail to recognize or acknowledge the negative effect of poor communication will continue to diagnose and treat with limited input from the patient. Physicians will see hospital readmissions occur when patients fail to follow unclear instructions related to their treatment regimen. Without the proper intervention, physicians’ staff members will continue to exhibit the rudeness identified by patients as one of the reasons they are reluctant to contact the physician unless an emergency exists.

Patients and physicians who fail to deal with the “person” before the disease are committed to failure in the art of effective communication.

Families who witness, without intervention, the poor communication between their loved ones and their physicians are destined to bear the consequence of increased morbidity and mortality.

And, finally, communities that do not heed the increased data that describe the continued health disparities compounded by poor doctor/patient communication have only themselves to blame. They must not accept the status quo of a health care system that reacts rather than responds, a health care system that plans for rather than plans with the community, and a health care system insensitive to the need for affordable quality health care for all rather than for a few privileged residents of Allegheny County.

## Action Steps for Patients

Patients must:

- Assume responsibility for self-managing their diagnosis based on sound medical advice and not on observations of others with similar diagnoses.
- Take an active role in their care, ask questions, listen, and take responsibility for lifestyle changes.
- Make commitments to learn about their illness and to use their physicians as resources in the learning process.
- Understand the importance of communicating their fears and frustrations in a manner that does not blame the doctor, but rather seeks a clearer understanding.
- Assume responsibility for outcomes that result from their own inability or unwillingness to follow the prescribed treatment regimen.
- Commit to make their health a priority everyday.
- Learn how to describe their symptoms in a more precise, meaningful way. Comments like, “I’m feeling poorly,” or “I’m doing alright, I guess,” don’t tell the doctor much about one’s condition. A more descriptive report (i.e., “I get short of breath when I climb stairs,”) may be the first step towards a diagnosis.
- Understand and keep track of numbers (blood pressure for hypertension, glucose levels for diabetes) as an integral component of daily living.
- Become familiar with their medications and follow dosage instructions.
- Prepare for physician encounters by writing down their concerns and questions prior to the visit and taking a family member or friend to the visit.
- Insist that the physician and the health care team use words that the patient understands.
- Be aware of their rights as informed consumers. They have the right to all information in their medical records.

In addition, patients have the right to know the risks involved in any prescribed test or treatment and the right to refuse treatment if they have been told and understand the potential consequences of doing so. When physician-patient concerns, priorities, or beliefs come into conflict, the ultimate decision rests with the patient.

Patients who are thinking about refusing treatment should discuss their concerns with the physician. There may be a compromise course of action that will satisfy both.

## Action Steps for Physicians

The physician’s role and challenge is to be a catalyst for improved communication between doctor and patient. Physicians must:

- Embrace the concept of a viable partnership with patients that will allow and encourage patients to assume responsibility for their care. They must encourage patients to share information that might be personal but is essential in making the

proper diagnosis. They must encourage patients to learn about their illness and welcome questions as a learning initiative rather than as a challenge to their competence.

- Help patients learn about access to the health care system and the appropriate use of the system, and patients must empower themselves to become an integral component of that system. Physicians and patients should work together to become more proactive with insurers and regulatory agencies and assure the availability of the necessary resources to provide and receive good patient care.
- Ensure that their clerical staff members recognize the vulnerability of the patient and respond, rather than react, to patient “acting-out” behaviors. Both physicians and their clerical staff must be sensitive to patient scheduling and avoid long waits while encouraging patients to keep their scheduled appointments.
- Ultimately be responsible for teaching, learning, and partnering with their patients. They must see each patient encounter as an opportunity to broaden the patient’s knowledge base with reference to the illness and to learn more about the patient as a person. Physicians must review with patients their medications and the purpose of each, acknowledge patient efforts to be compliant, and explore with patients the barriers that lead to noncompliance to arrive at a satisfactory resolution. Physicians must develop open dialogue with patients who have chronic illnesses to reinforce the importance of self-management. Those who treat acutely or chronically ill patients must recognize the patients’ fear of the onset of illness and their lack of emotional and intellectual preparedness for its life-threatening potential.

More specifically, participants in our survey and focus groups offered the following suggestions for physicians:

- New technology is fine for diagnostic purposes, but doctors should invest in a human being to remind patients of appointments. One respondent said she was offended by an automated message that initially “sounded like the recorded pitch I receive periodically from a burial insurance telemarketer” and then proceeded to threaten all patients, regardless of their payment histories, that *“all co-payments and outstanding balances are due at the time of the appointment, or you will not be seen by the doctor.”*
- Physicians should find time to discuss current concerns by *not* asking patients to repeat most of their medical history at the start of each appointment. Since doctors presumably learned to take good notes in medical school, they should use that training to maintain patients’ charts and take a moment to review the notes before entering the examining room.
- Greeting patients by first name does not necessarily break the ice. It’s not safe to assume that everyone is normally addressed by the first name or by a common nickname (e.g., Patty for Patricia or Walt for Walter). It’s always safe to use the formal title (Mrs., Ms., Mr.), particularly when the doctor is

half the patient's age. Ditto for the medical assistants, who may be young enough to be the patient's grandchild.

- Physicians should not be offended or condescending when patients refer to what they have read on the Web or in medical encyclopedias. They're not questioning the professional's judgment; they're trying to understand their condition and treatment. Most patients are perfectly capable of learning; physicians should be grateful for their interest and the confidence they are expressing in the physician as a source of reliable information.
- As to information-sharing, patients want to know the results of those tests they take, particularly when "we" are tracking changes or effects of medications, and they want to hear them promptly—not a month after the blood is drawn and other changes are underway. And, yes, the "numbers" do mean something to the patient, especially when the provider takes the time to provide the normal range. Dropping the report in the mail is also acceptable, if there's no time to call. Not knowing test results can cause patient anxiety.
- And, finally, physicians should insist that the office staff members are reasonable when they schedule appointments. Patients should be asked their preference (i.e., morning or afternoon appointment). Nobody is going to see five patients at 1 p.m., and patients who wait, often an hour or longer, for an overscheduled doctor may become angry enough to look for a new referral.

The ingredients of disrespect, mistrust, lack of cultural competency (failure to understand and accommodate racial, ethnic, and cultural differences), insensitivity, and poor communication of concerns combine to create a "conflict pie." Acknowledgment of the existence of the "pie" is the first step towards eliminating the conflict. Each partner (patient and doctor) must be willing to own responsibility for some slices in the pie (i.e., lack of availability, withholding information, mistrust, etc.). Once the ownership of the conflict slice is acknowledged, the owner must recognize how it contributes to the problem of communication and look for ways to eliminate or modify its impact. The ingredients serve as barriers to listening and hearing of patient and doctor concerns and frustrations. Mutual respect, open communication, and a willingness to accept responsibility for change will create a meaningful partnership for health—a partnership where each partner has an accepted, specific role and responsibility to make it work. For many physicians and patients, this will be difficult initially, but if each makes the commitment, the outcome will be satisfactory for both.

### **Action Steps for Insurers**

Third-party payers must recognize the negative impact of poor communication between doctors and patients, which result in higher treatment costs. Physicians who blame "paperwork" from the insurer share their frustrations with patients by blaming the insurer for "assembly-line" treatment to meet quotas. Patients equate poor quality of care with short, hurried visits. Insurers must come to the table with physicians and patients to

agree upon treatment goals that are attainable, while providing patients with the best care possible. Physicians must be able to prescribe medications that have proven efficacy when they are not included on insurer formularies.

Providers, as insurers, must recognize that business as usual is not satisfactory. Their reliance on patient satisfaction instruments must be revisited. Surveys must be complemented by opportunities for patients to speak outside of the clinical setting. Providers must insist that physicians identified as poor communicators undergo the necessary training to address the communication issues. Concurrently, the provider must provide necessary patient education opportunities to empower patients to become informed partners with physicians. Community-based organizations must understand that advocacy must not be adversarial. These organizations speak for the disenfranchised and, as such, must be careful to look at the problem from both sides. Failure to do so will continue the blame game where everyone is a loser—patients, physicians, and community.

## **Research**

It is expected that doctor/patient communication will be enhanced in this community by three specific initiatives underway.

### *HCAHPS*

The Centers for Medicare and Medicaid Services (CMS) have developed a program, HCAHPS, “to collect data on care from the patient’s perspective for general acute care hospitals.” Patients will be randomly selected after hospital discharge to complete a 27-item questionnaire on their hospital experience. Hospitals are required to receive 300 completed questionnaires over a nine-month period. The survey covers the following composites:

- Communication with doctors
- Communication with nurses
- Responsiveness of hospital staff
- Pain control
- Communication about medicines
- Cleanliness and quiet of environment
- Discharge information

The analysis of this data by CMS will be reflected in a market basket adjustment in the reimbursement to participating hospitals. Hospitals will use this data to identify areas of excellence, areas in need of improvement, and areas found deficient that require immediate attention.<sup>iv</sup>

### *Patient and Physician Peer Assessment*

In 2000, the American Board of Internal Medicine (ABIM) introduced Continuous Professional Development (CPD), an innovative program that is committed to the maintenance of certification, which is targeted for full implementation by 2009. The goals of the CPD Program are to improve the quality of patient care, demonstrate professional accountability by setting high standards of clinical competence, and foster scholarship over a lifetime of practice.

What makes this initiative unique is the three-part evaluation of the physician. The components are self-evaluation, physician peer assessment, and patient assessment. Patients are asked to rate their physician on a scale of 1 to 5. The questions cover truthfulness, respect, not “talking down,” providing ample time to share symptoms and concerns, listening carefully, explaining in detail the physical exam, discussing options for care, encouraging dialogue, and using words that patient can understand.

Physicians who participate are provided with an analysis of the data collected to be used as a learning experience. Patients will surely benefit from this initiative.<sup>v</sup>

### *The Clinical and Translational Science Institute*

The Clinical and Translational Science Institute is a partnership between the University of Pittsburgh, the University of Pittsburgh Medical Center, Carnegie Mellon University, the RAND Corporation, the Intel Research Pittsburgh Lab and the Urban League of Greater Pittsburgh. The Institute is funded by the National Institutes of Health with an \$83.5 million grant over a five-year period.

Dr. Elias Zerhouni, NIH Director, issued the following statement: “The effort is aimed in part at better addressing chronic disease, whose treatment consumes about 75 percent of the nation’s healthcare resources. We expect to see new approaches reach underserved populations, local community organizations and healthcare providers to ensure that medical advances are reaching the people who need them.”

The areas identified for focus will be a CTSI Braddock Minority Health Program and a Research Center with focus on provision of health information and educational materials to a low-income, disproportionately minority community. Another focus will be forming a partnership with the Urban League of Greater Pittsburgh to reduce minority health disparities. These initiatives should result in empowered patients who will communicate their fears, needs and expectations from a front row seat.

**When all is said and done, doctors must learn to hear their patients’ concerns, while patients must learn to listen to the advice of their doctors.**

**Appendix A.**

A Patient's Contract for Effective Communication

I promise to become a full partner with my physician in the management of my illness.

I promise to speak to my doctor in the same tone of respect that I expect.

I promise to prepare for my visit with a written list of my concerns so that I can maximize the time I spend with my doctor.

I promise to recognize my doctors' busy schedule and arrange a time to speak that is mutually convenient in non-emergency situations.

I promise to keep scheduled appointments on time or telephone my doctor's office to cancel and reschedule.

I promise to show the same courtesy that I expect to receive.

I promise to take responsibility to learn about my illness and to ask questions to improve my understanding.

I promise not to withhold information from my doctor that may affect a suggested treatment plan.

I promise to discuss with my doctor any situations that will prevent me from following the recommendations or medications prescribed.

I promise to make my health a priority.

I understand that this relationship may be terminated if my doctor and I are unable to communicate to ensure the provision of the best medical care.

\_\_\_\_\_  
Patient's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Physician's Signature

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## Endnotes

<sup>i</sup> Washington, M.S., “Doctor, Can You Hear Me? Patient, Are You Listening?” © 2003, Second Printing 2005, Washington Associates, Pittsburgh, PA.

<sup>ii</sup> Coulehan, J.L., Block, M.R., “The Medical Interview,” F.A. Davis Company, Philadelphia, PA © 1997.

<sup>iii</sup> Merriam-Webster (1997) Universal College Dictionary, New York Gramercy Books.

<sup>iv</sup> CMS: Supporting Statement for the National Implementation of the Hospital CAHPS Survey.

<sup>v</sup> American Board of Internal Medicine Clinical Competence and Communications, 510 Walnut Street, Suite 1700, Philadelphia, PA 19106-3699.



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