



ISSUE BRIEF

The Massachusetts Health Policy Forum

Eliminating Racial and Ethnic Health Disparities: Opportunities and Challenges for the Commonwealth

Thursday, February 15, 2001
8:30 to 9:00 – Breakfast
9:00 to 11:00 – Discussion

Omni Parker House Hotel
School and Tremont Streets
Boston

A Discussion Featuring:

Albert Yee, M.D., M.P.H.
Regional Administrator
U.S. Dept. of Health and Human Services
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Executive Director
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Registration: Please call Sue Thomson at 617-338-2726 as soon as possible.

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Executive Summary

Multiple federal health agencies have set a national public health priority to eliminate racial and ethnic health disparities. On a practical level, however, the onus is on states both to develop the infrastructure and to implement the agenda within which to achieve the goals of relieving the disproportionate burden of disease on ethnic, racial and linguistic minority populations. Racial and ethnic population density varies widely among states, presenting challenges in collecting the data to identify disparities, addressing the underlying factors of disparate health status among minorities, and, ultimately, in reducing the disparity of illness and disease among the entire population.

There is great value in the information we already have about health disparities. However, on a national and state basis, gaps in research and data collection do exist, and present challenges to our goals. It is in confronting what we don't know about disparities that we will be able to make progress toward a public health agenda that is responsive to all populations. Once able to understand fully the health status of minorities, new approaches to state and community health planning that cut across all populations will be required, as well as changes in messages about health behavior and prevention.

Nationally, as data collection and reporting methodologies are adapted and revised to capture more adequately health disparities and the burden of disease, partnerships and collaborations among various public and private stakeholders are essential to identifying particular needs and strategies to improve the overall health of diverse populations. In Massachusetts, there are a number of new and ongoing initiatives in addressing health and social needs of its diverse population, only some of which are mentioned here. Many of these initiatives preceded the announcement of the President's Race and Health Initiative in 1998. Indeed,

minority health has been prominent in the discourse on health improvement for all of the Commonwealth's residents for several decades.

Successful partnership and collaboration between and among government health agencies, private entities, and community-based organizations is not new in Massachusetts. The past several years of success in expanding access to health insurance for large segments of the population, and the overall good health of the Commonwealth's population contribute to the strength and momentum of a movement to improve it even further. A commitment on the part of all stakeholders is needed to achieve goals of eliminating disparities. State oversight agencies, health care providers, community-based organizations, advocacy groups, and consumers must be supported in collaborations that facilitate these goals.

From an examination of the federal information on racial and health disparities, along with some of the statewide and local initiatives addressing health disparities in Massachusetts, a three-pronged approach to eliminating disparities emerges, related to strengthening and enhancing the infrastructure within which minority health is delivered and researched:

- Increase the cultural competence and diversity of the health care workforce in the Commonwealth;
- Improve data collection and reporting capacity; and
- Sustain the capacity for community-based organizations to participate in research and health interventions that target populations of need at the local level.

The President's Initiative has set goals for eliminating racial and ethnic disparities in the areas of infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV Infection/AIDS, and child and adult immunization rates. Achieving these goals will be possible only if issues related to infrastructure and capacity building are addressed. An investment must be made in building an infrastructure to address and accomplish health disparity reduction. Data limitations must be addressed, and a health care workforce that is responsive to multiple cultural and social needs of diverse populations is a predicate to the effective delivery of both messages of prevention and good health care.

This approach forms the basis for recommendations to public and private health policymakers who are positioned to benefit racial and ethnic minorities by cre-

ating and supporting efforts to improve their overall health:

- I. *Develop the cultural competence and diversity of the health care workforce in Massachusetts*
- II. *Promote the implementation of community-driven initiatives*
- III. *Improve data collection and reporting methodologies*
- IV. *Support community-based organizations' capacity building efforts in data management and systems integration*
- V. *Maintain an infrastructure for a public health research agenda*

Reducing and eliminating disparities is a worthy goal; there are moral, ethical and legal reasons to do so. Longstanding societal goals of preventing discrimination based on race are intersecting with innovations and changes in collection of health data of racial minorities. However, there are many questions related to how best to implement new data collection and reporting methodologies to yield consistent, reliable quantification of those disparities. The complexity of capturing such data is discussed here. A survey of some of the statewide and local initiatives addressing health disparities in Massachusetts reveals both the challenges inherent in accomplishing the goal and the opportunities to form new collaborations and make new connections between oversight agencies and the core of minority populations, in the communities where they live. Recommendations for public and private health policymakers in the Commonwealth must be informed by what we know already, as much as by what we have yet to learn together.

INTRODUCTION

The same racial and ethnic diversity that enriches the United States now presents one of the greatest public health challenges of the 21st Century—documenting and eliminating racial and ethnic health disparities. At the root of efforts to achieve the goal of identifying and eliminating health disparities is the challenge of classifying multiracial and multiethnic groups and individuals into categories that yield useful data. Over the last decade, the racial and ethnic distribution in Massachusetts has changed. From 1990-1998, the number of Blacks, Hispanics, and other minorities combined increased from 12% to 15% of the total state population.¹ The most recent population estimates of the U.S.

Census Bureau reflect the state's racial and ethnic diversity, with White non-Hispanic composing the largest segment of the state's population (84.4%), followed by Black (6.6%), White Hispanic (5%), Asian/Pacific Islander (3.8%), and American Indian/Alaska Native (.2%). The total number of Hispanics, who can belong to any race category, total 6.3%.²

As the American Public Health Association held its 2000 Annual Meeting in Boston this past November with the theme of "Eliminating Health Disparities," our attention focused on the response in Massachusetts to the various federal initiatives aimed toward eliminating racial and ethnic health disparities. Health disparities exist on many bases, including gender, race, ethnicity, socioeconomic status, educational attainment, and access to health care. This Issue Brief focuses on six areas of racial and ethnic health disparities in Massachusetts, and the charge to the public health community to eliminate them.

While research regarding disparate health status and outcomes based on race and ethnicity has been ongoing, the momentum of a national research and policy agenda increased following President Clinton's February 1998 announcement. A component of the President's Initiative on Race, the goal was set to eliminate disparities based on race and ethnicity in the following six areas:³

- Infant Mortality
- Cancer Screening and Management
- Cardiovascular Disease
- Diabetes
- HIV Infection / AIDS
- Adult and Child Immunization

The call to eliminate health disparities has generated responses from a variety of sources, ranging from federal agencies and Congress to local, community-based, grassroots initiatives. *The Healthy People 2010* report was released by the U.S. Department of Health and Human Services in January 2000, with one of its two goals to eliminate health disparities.⁴

The goal of eliminating health disparities is a complex one, and involves many aspects of public health data collection and reporting, as well as health services delivery. Achieving the goal is not nearly as simple as

merely improving our ability to measure health outcomes by specific race or ethnicity. Nor, is it as simple as improving access to health care by expanding insurance coverage or providing language interpreter services to non-English speaking persons. Any systematic approach to addressing health disparities, particularly in a state as ethnically and racially diverse as Massachusetts, requires broad collaboration and coordination among state agencies, the health care delivery system, and local communities.

Our ability to address disparities in health may not exceed our ability to measure them. Current racial and ethnic categories are often too broad to reveal differences between racial and ethnic subgroups. Responsibility for the collection of health status data is shared by federal and state agencies and organizations, which may have a history of incompatible collection and reporting methodologies. The capacity for different government agencies and private organizations to share data sources is greatly limited by the inconsistency of elements across data sets, as well as common, inherent limitations in data.

In examining a policy and research agenda around eliminating racial and ethnic health disparities in Massachusetts, and in setting forth recommendations for consideration by policymakers in the Commonwealth, this Issue Brief first describes some of what we know about racial and ethnic health disparities. It then points the reader to some of the federal agencies most prominently engaged in initiatives to eliminate health disparities, which serve as major partners to the Commonwealth. In addition, the paper includes available Massachusetts data on the six focus areas of racial and ethnic health disparities. Some examples of statewide and local initiatives related to eliminating health disparities are included to illustrate the strength of collaboration between private and public sector health care providers and researchers. The Issue Brief concludes with policy recommendations for public and private sector health policy makers as they seek to address health disparities in 2001 and beyond.

The Context of Health Disparities

We know that many factors affect health status. Poverty, insured status, primary language, educational attainment, immigration status, and geography are all indicators of access to health care, which in turn affect the overall health status of any population. In many ways, the disparities in these factors is perhaps more significant to the prospect of eliminating health dispari-

ties than what we know of the present disparate burdens of the six measures that are the focus of a national data collection and reporting effort.

Recent national and state surveys describe the prevalence of these and related factors among minority populations. The Urban Institute's National Survey of American Families (NSAF) contains useful information regarding underlying social and economic factors of racial and ethnic health disparities. A component of its New Federalism project, the survey confirms racial and ethnic inequities in seven indicators of general well-being: poverty, family structure, child support, food hardship, housing hardship, health status, and health insurance coverage.⁵ Two particularly significant indicators of health are insurance coverage and utilization of health services.

Insurance Coverage

As a major determinant of health status, insurance coverage must be considered in any discussion regarding disparities in health outcomes. Nationally, ethnic minorities on the whole are more likely than Whites to be uninsured, and less likely than Whites to have job-based insurance. Latinos exhibit the greatest risk for being uninsured (37%) compared to other ethnic groups and they are two and a half times more likely to be uninsured compared to Whites (14%). Blacks fall in between with nearly 25% of the population uninsured. There is also variation within Latino subgroups in both uninsured rate and job-based coverage. Mexican-Americans and Central and South Americans have the highest rates of uninsurance among Latino subgroups (38% and 42%, respectively). Of further concern is the fact that the rates of uninsurance may not reflect the impact of barriers to health access beyond coverage, such as coverage that is not comprehensive and high deductibles and co-payments that prevent low and moderate income individuals from obtaining care.⁶

In Massachusetts, the percentage of non-elderly individuals with no health insurance is similar to the national picture with Latinos faring worse than any other racial or ethnic group (17.0%) compared to Whites (4.9%). African Americans are the next group most likely to be uninsured (10.9%), followed by Asians (2.3%). Since 1998, each of these categories has experienced a reduction in uninsured rates.⁷

Massachusetts is one of 11 grantee states of a U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA) pro-

gram to help states develop a plan to achieve universal access to health insurance. The Lead Agency under the grant is the Division of Medical Assistance, which is joined by a Core Work Team comprised of the Division of Health Care Finance and Policy, the Department of Public Health, and the Division of Insurance. The goal of the project is to develop a set of coverage options for residents of the Commonwealth that will be feasible and affordable. In the meantime, Massachusetts continues to make progress, and is considered a leader among states with respect to insurance coverage. All pregnant women and children through age 18 are now eligible for either private or public health insurance, and, while gaps remain, more adults are covered here than in most states.

Utilization of Health Services

Without regular access to health care, preventive treatment, including screenings for preventable and treatable illnesses, is impossible. Racial and ethnic differences in access to health care have been documented, and are a focus of a recent joint publication of the Henry J. Kaiser Family Foundation and the UCLA Center for Health Policy Research.⁶ Minority adults who reported that they were in "fair to poor health" were found to be less likely than their white counterparts to have visited a physician in the previous year. Latino and Asian American/Pacific Islander men were found to be less likely to have visited a physician within the past year, than were African American or Whites. The Kaiser/UCLA report also found that for all minorities insurance coverage improves access to care.⁶

Massachusetts data reflect the same national trends. In surveys conducted over three years (1997-1999) in Massachusetts, Hispanics ages 18 and over were found to be less likely to have a health plan than White Non-Hispanics, Black Non-Hispanics, or Asian/Pacific Islanders of the same age.⁸ Hispanic respondents to the same surveys were more likely to have not been able to see a doctor due to costs.

Setting a National Agenda: The U.S. Department of Health and Human Services

The U.S. Department of Health and Human Services (DHHS) and its agencies are the federal epicenter of initiatives and support for coordinated activities between the federal and state levels to address eliminating disparities in health care. The magnitude of the commitment on the federal level to partnering with states and regions to eliminate health disparities is clear

from the range of its agencies involved in the effort. The Centers for Disease Control and Prevention, Office for Civil Rights, Health Care Financing Administration, National Institutes of Health, and Health Resources and Services Administration are just some of the agencies with major roles in the federal effort to eliminate health disparities.

President's Initiative on Race

The President's Initiative on Race, announced by President Clinton in February 1998,³ served as the call to action for federal and state health agencies alike. The President's Initiative set the goal of eliminating racial and ethnic disparities with a focus on six areas of health status, by 2010. In an unprecedented attack on poor health status in the minority population, the President's Initiative set in motion a nationwide agenda of improving the health of minorities, while maintaining the overall health of the rest of the population.

Healthy People 2010

The DHHS issued its report, *Healthy People 2010*, in January 2000.⁴ The President's Initiative formed the basis for one of its two central goals – to eliminate health disparities, only one aspect of which is by race and ethnicity. A successor to *Healthy People 2000*, it sets forth an agenda to improve the overall health of the nation, with two central goals, the second of which is to eliminate health disparities by 2010. In addition to race and ethnicity, *Healthy People 2010* focuses on dimensions of disparity based on gender, income and education, disability, rural vs. urban residence, and sexual orientation. *Healthy People 2010* provides a framework within which to consider disparities, and offers ten Leading Health Indicators and many more objectives through which improvement in health status may be measured. The priorities stated in the *Healthy People 2010* initiative form the basis for the selection of the six health areas that are highlighted in this Issue Brief.

The U.S. Department of Health and Human Services (DHHS) announced that, for its part in addressing the President's Initiative, it would engage in a process of "dialogue, research and action." As an example of this dialogue, Boston was chosen to host a town meeting on June 26, 1998 entitled, "Addressing Racial and Ethnic Disparities in Health Through Impacting the System of Care." This town meeting brought together community leaders, health care professionals, and policymakers to discuss the issues of access, cultural competency, and workforce diversity as they relate to racial

disparities in health and to identify successful approaches to improving the health status of minority populations. Local public health leaders presented best practice models demonstrating success in reducing health disparities through improving access to care, addressing workforce diversity, and ensuring cultural competency in services provided to minority populations. The event succeeded in initiating a dialogue regarding potential policy recommendations and strategies for effective program implementation aimed at eliminating racial and ethnic health disparities.

Minority Health and Health Disparities Research and Education Act of 2000⁹

The recently enacted Minority Health and Health Disparities Research and Education Act, sponsored by Senator Edward M. Kennedy, promises to place minority health research more prominently on the national health agenda. The Act amends the Public Health Service Act with five sections that will improve the infrastructure for the study of racial and ethnic health disparities. The Act establishes a National Center on Minority and Health Disparities at the National Institutes of Health and provides for new NIH-funded opportunities to conduct research to eliminate health disparities. The Act also directs the National Academy of Sciences to conduct a study of the DHHS's systems related to the collection of health data by race or ethnicity. Grants and awards for the training and education of health professionals, including the provision of culturally competent care, are also required by the Act. Finally, the Act requires a national public awareness campaign on racial and ethnic health disparities.

Massachusetts Department of Public Health Minority Health Initiative

Healthy People 2010 illustrates the importance of supporting data collection and reporting improvement and coordination at the regional, state and local levels. The Massachusetts Department of Public Health (MDPH), in its capacity as the coordinating agency for so many health and prevention programs, has a prominent role in the dissemination of health status-related data at the statewide and local levels.

The MDPH set out early to establish mechanisms for dealing directly with the elimination of racial and ethnic health disparities, both programmatically and with respect to data collection and reporting. Current initiatives of the MDPH are described below, followed by a discussion of the issues related to obtaining and

disseminating accurate race- and ethnicity-specific data. A minority health status report and data set are forthcoming, and will advance statewide and regional knowledge about the health status of the Commonwealth's minority residents.

The MDPH Minority Health Initiative was established with three strategies in its approach to reinforcing the ability to address disparities for Massachusetts' minority population. The strategies fall into the three major categories of policy, research, and action. The stated goals in all three areas speak to the inclusiveness of the MDPH approach of disparity research, and the long-term vision of accomplishing those goals.

While the MDPH's prevention and surveillance programs extend far beyond the six focus areas of the President's Initiative, the MDPH has implemented several initiatives in response to the Federal Government's mandate for eliminating racial and ethnic disparities in health outcomes related to these areas: Infant Mortality, Cancer Screening and Management, Cardiovascular Disease, Diabetes, HIV Infection/AIDS, and Adult and Child Immunization. Programmatic information and data available by specific racial and ethnic groups are described below.

Infant Mortality

Infant mortality is a key indicator of the health and wellbeing of any nation. The infant mortality rate in the U.S. has declined steadily since 1950, reaching 7.2 deaths per thousand infants in 1998.¹⁰ Still, the U.S. continues to have a higher infant mortality rate than other developed countries. One reason is the higher infant death rates among minority groups, particularly Blacks, for whom infant mortality remains a serious public health problem.

Massachusetts documents some of the best maternal and child health outcomes in the U.S., with one of the lowest infant mortality (5.1 per 1,000 live births) and teen birth rates (28.6 per 1,000 females aged 15-19).¹¹ Data for infant deaths in Massachusetts in 1998, by specific race and ethnicity, demonstrate that Blacks and Puerto Ricans fare worst among all racial and ethnic groups.¹²

The MDPH has several programs and initiatives in place to improve pregnancy outcomes, reduce infant mortality, and promote infant health. They offer a continuum of services for women and adolescents of reproductive age, whether they are pregnant or not, as well as

services for infants and young children. These services are funded by a number of federal initiatives, including the Maternal and Child Health Title V Block Grant; Part C of Individuals with Disabilities Education Act (IDEA); Special Supplemental Nutrition Program for Women, Infants and Children, (WIC); and the Substance Abuse and Mental Health Services Administration (SAMHSA) Block Grant.

All of the programs and initiatives geared toward improving infant health administered by the MDPH are developed and implemented with the input of their targeted communities. The programs emphasize culturally competent and family-centered approaches. One of the critical features inherent to the success of MDPH's service delivery models is their ability to collaborate with other state agencies and integrate services in order to create a seamless service system, with few overlapping components. The emphasis that the MDPH continues to place on the integration of services, community input and cultural sensitivity in program development have been key to improving health status among women, infants and young children.

Cancer Screening and Management

Cancer is the second most common cause of mortality in the U.S. Many minority groups suffer disproportionately from both cancer-related morbidity and mortality, with African Americans exhibiting the highest incidence and death rates. Vietnamese women in the U.S. demonstrate a cervical cancer rate that is five times greater than White women, and African American and Latino women have higher cervical cancer death rates than the general U.S. population.¹³ In its 1999 report, the Institute of Medicine's Committee on Cancer Research Among Minorities and the Medically Underserved issued broad recommendations at a time when many research initiatives were already underway. While the report focused on disparities in cancer, the Committee's recommendations are well taken beyond that measure. Importantly, the Committee urged that surveillance data and population-based research be enhanced and more extensive (Recommendation 2-3).¹⁴

While Massachusetts continues to demonstrate an improvement over the national rate, 1998 age-adjusted rates showed that cancer deaths of Black males and females have increased since 1990, but decreased for White males and females.¹⁵ Data for all cancer deaths combined in Massachusetts for the 3-year period from 1996-98 illustrate the ongoing disparity among all racial and ethnic groups, with the age-adjusted rate for Black

non-Hispanics exceeding that for White non-Hispanics, Hispanics, and Asian/Pacific Islanders.¹⁶

The Massachusetts Comprehensive Cancer Prevention and Control Program has been developed with a broad preventive approach to the reduction of cancer risk. Current activities of the Program reflect the goals of reaching diverse populations with effective public health interventions. The MDPH uses its network of 27 regional Community Health Network Areas and 10 regional Massachusetts Prevention Centers to provide cancer prevention and control services through partnerships between the public, providers, community-based organizations, schools, and others.¹⁷

Consistent with a primary prevention approach to reducing cancer mortality, the MDPH seeks to reduce exposure to the following risk factors in its primary prevention efforts: tobacco, obesity, lack of physical activity, occupational and environmental hazards, alcohol, ultraviolet radiation, and sexually transmitted diseases. Culturally appropriate means of communication of preventive measures are a vital part of the MDPH's approach to addressing disparities in cancer occurrence.

Cardiovascular Disease

Despite improvements in the burden of cardiovascular mortality, minority and low-income individuals still suffer disproportionately from cardiovascular disease. The prevalence of coronary heart disease has increased over the past thirty years among African Americans, and they suffer higher (40%) coronary heart disease mortality rate as compared to Whites.¹³ Stroke is the third leading cause of death in the U.S., affecting approximately 150,000 Americans each year. African Americans experience the greatest burden, with a mortality rate that is 80% higher than Whites.¹⁸

Cardiovascular disease, including heart disease and stroke, is the leading cause of death for all racial and ethnic groups in Massachusetts, and certain minority populations and genders within those minority groups, are disproportionately affected by it. Much is known about the disparities that exist with respect to ischemic heart disease and stroke deaths among specific racial and ethnic groups. Recent data indicate a 65% higher rate of stroke death among Black women compared to White women in the Commonwealth. Black non-Hispanic males fare even worse when compared to White non-Hispanic men, with a stroke death rate that was 1.7 times higher in 1998.¹⁹ Data based on 1996-1998 Mortality records document that Blacks suffer

higher rates of death from stroke and heart disease than any other racial or ethnic group (see Appendix, Tables 3 and 4).

The Massachusetts Cardiovascular Disease Prevention Initiative seeks to eliminate disparities in cardiovascular disease incidence and mortality among the Commonwealth's residents. Known risk factors for cardiovascular disease, including smoking, physical inactivity, high-fat diets, high cholesterol, high blood pressure, diabetes and obesity, also are demonstrated disproportionately among minority groups in the Commonwealth. Extensive efforts related to the elimination of these risk factors are all part of the MDPH Initiative. The MDPH emphasizes policy and environmental strategies that support physical activity, heart-healthy eating and tobacco control.²⁰ The MDPH also recognizes that public-private partnerships are essential to eliminating disparities in premature death due to cardiovascular disease, and has tailored its approach to the problem accordingly. The MDPH is directing its efforts to improve coordination among stand-alone, but related community-level programs.

Diabetes

Diabetes disproportionately impacts racial and ethnic minorities in the U.S. Type 2 diabetes affects nearly 16 million Americans and causes nearly 300,000 deaths each year.¹³ According to CDC surveillance data from 1998, Latinos in the U.S. are almost twice as likely to have diabetes compared to their non-Latino White counterparts, while African Americans are 1.7 times as likely to have diabetes compared to Whites in the U.S.²¹ Prevalence data indicate that African Americans, Native Americans, Latinos, Alaskan Natives and some Asian Americans and Pacific Islanders are at increased risk for type 2 diabetes compared to the general population.¹³

Diabetes mortality rates for Massachusetts also reflect ongoing racial and ethnic disparities, particularly among Latinos and African Americans.²² The Massachusetts Diabetes Control Program (DCP), which is funded by the Centers for Disease Control and Prevention, was established to reduce the burden of diabetes among Massachusetts' residents and to improve the quality of care provided to people with diabetes by improving health systems, health communications, and diabetes surveillance efforts. The DCP Diabetes Surveillance System is intended to provide a broad picture of diabetes in Massachusetts and inform the planning and evaluation of DCP programs.

The Health Systems and Health Communications Initiatives are two major components of the Diabetes Control Program:²³

The Health Systems Initiatives are geared toward improving access to quality diabetes services and care within Massachusetts, especially for those most in need. There are three major initiatives: 1) *The State Diabetes Guidelines*- The DCP and its Advisory Board are developing diabetes practice guidelines and protocols to assist in their implementation, in order to advance quality diabetes care throughout the state. 2) *The Division of Medical Assistance (DMA)*- The DCP is collaborating with the DMA, which provides health coverage to more than 800,000 low-income children, families, and people with disabilities, to develop practice guidelines for adult diabetes care, quality improvement, and measurement initiatives aimed at improving the health outcomes of people with diabetes. 3) *Community Health Centers (CHCs)* - The DCP funds CHCs for diabetes services capacity building. More specifically, for adopting practice guidelines, developing flow sheets and educational protocols, implementing diabetes quality improvement projects and auditing charts to monitor improvement. The CHCs also receive training in the *Diabetes and You* peer education program.

The goals of the three health communications initiatives are to 1) raise public awareness about diabetes; 2) increase knowledge and use of diabetes resources and educational materials; and 3) increase the number of people with diabetes who receive an annual flu vaccine.

HIV Infection/AIDS

Nationally, the rate of new AIDS cases reported in 1998 per 100,000 population was 84.7 among Blacks, 37.8 among Latinos, 9.9 among Whites, 9.9 among Native Americans and Alaska Natives, and 4.8 among Asians and Pacific Islanders.²⁴ AIDS fatalities are disproportionately high among Latino and African American men in the U.S. compared to other racial and ethnic groups. Latino and African American women are also at greater risk for HIV compared to other groups. The proportion of AIDS cases among women has tripled between 1985 and 1998, with minorities representing 77% of women infected with AIDS (57% African American and 20% Hispanic).²⁵ The federal initiative aimed at eliminating racial and ethnic disparities has allocated \$156 million toward improving HIV/AIDS prevention and treatment programs. The funds are geared specifically towards increasing access to the lat-

est, more expensive drug treatments among minority populations.²⁶

The most recent surveillance update for Massachusetts indicates that there are more people living with AIDS in the state than at any other time in the history of the epidemic. Communities of color continue to represent a significant proportion of people living with HIV. Injection drug use continues to be the most important reported route of transmission among African American and Latino males while transmission through heterosexual relations continues to be the most common form for African American and Latina females.²⁷

The MDPH HIV/AIDS Surveillance Program, implemented for AIDS surveillance in 1983, with HIV surveillance added in 1999, contributes to a comprehensive understanding of the AIDS epidemic geared toward supporting prevention and health service activities delivered by the MDPH and a statewide system of health care organizations providing direct services. The program distributes specialized and routine data reports and publishes a monthly summary report. Program epidemiologists also work with health care providers, planning and policy groups and other Bureaus within the MDPH, providing surveillance information and assisting with assessment of resource allocation to meet the needs of people at risk or infected with HIV/AIDS.

Adult & Child Immunization

Massachusetts has one of the highest immunization rates for pregnant women and young children.¹¹ Massachusetts immunization rates for children age 19-35 months met or exceeded the national rates for Hispanic, White non-Hispanic, and Black non-Hispanic groups, according to the 1999 National Immunization Survey. (see Appendix, Table 7) While immunization rates in Massachusetts consistently exceed national rates year-to-year, the challenges presented by a culturally and ethnically diverse population and a burgeoning recent immigrant population, remain a focus of the MDPH's Massachusetts Immunization Program (MIP). Identifying and eliminating barriers to immunization against vaccine-preventable diseases, such as measles, mumps, rubella, polio, diphtheria, tetanus, pertussis, Haemophilus influenza, hepatitis B, and chickenpox, are components of the MIP. The MIP has identified "primary language other than English" as the most consistent factor associated with childhood under-immunization. For example, a survey performed in 1994 in the nine towns that comprise the New Bedford Community Health Network Area (CHNA) revealed that children in

families whose primary language is not English were 2.5 times more likely to be under-immunized than their English-speaking peers.

Based on the demographic and socioeconomic characteristics identified by the MIP through statewide surveys, national studies, and disease surveillance, pockets of need throughout the state have been targeted as high-risk for under-immunization. The MDPH has used surrogate indicators for under-immunization, such as population size, number of households where the primary language is not English, and poverty rates to identify the increased risk of several communities, including, Amherst, Boston, Brockton, Cambridge, Chelsea, Fall River, Fitchburg, Holyoke, Lawrence, Lowell, Lynn, New Bedford, Somerville, Springfield, and Worcester. Continued monitoring of state data and the National Immunization Survey (NIS) informs the MDPH of additional at-risk communities.

Several projects have been implemented by the MIP to improve immunization rates among all high-risk populations in the Commonwealth. The Hepatitis B Catch-up Immunization Program for Asian American / Pacific Islanders develops and disseminates culturally and linguistically appropriate materials and facilitates community linkages and community coalition building. The MIP also performs immunization assessments of both public and private providers to improve immunization levels. Finally, the MIP collaborates with key state agencies, private sector organizations and coalitions to target populations of need.

Because there is a paucity of data on immunization rates among minority adults in Massachusetts, the MDPH's efforts to improve access to immunizations for adults are particularly crucial. One example of the collaborations involving the MIP is the Massachusetts Adult Immunization Coalition. This coalition targets high-risk communities of color across the state through the combined efforts of private and public sector entities and clinicians. The MIP's strategy of targeting communities of color is supported by the National Vaccine Advisory Committee's recognition that accessibility to immunization and programs is a function of location and convenience for many minority populations. A recent report of the CDC's National Vaccine Advisory Committee focused on adult vaccines because vaccine coverage rates for adults continue to fall below national goals, while those for children sometimes exceed such goals. Adult immunization programs located in nontraditional settings, such as pharmacies and churches, were found to offer more convenience for those persons without a regular point of access to health care.²⁸

A Public Health Fact Sheet on adult immunizations is available on the MDPH's WWW site.²⁹ The fact sheet contains information on vaccine-preventable disease symptomatology as well as contacts for further information from the MDPH's regional immunization offices.

Developing an Infrastructure to Support the Elimination of Health Disparities

Looking forward to the formation and implementation of policy around eliminating racial and ethnic health disparities, it is important to consider what is required to support new and improved data collection and reporting methodologies as well as to develop the human resources required to target populations of need. Without valid and reliable health status data standards, efforts to measure and reduce disparities will be flawed from the outset. While valid and reliable data have the value of documenting both disparities in health status and success in their elimination, limitations of current data methodologies must be acknowledged.

Development of Cultural Competence and Diversity in the Health Care Workforce

"Health care providers should not only be able to communicate meaningfully with patients, they should also be culturally competent."

- Thomas Perez, Director, Office for Civil Rights, U.S.D.H.H.S.

The New England Regional Minority Health Conference, Providence, RI, April 13, 1999

A culturally competent health care workforce is a prerequisite to addressing the needs of a multiracial, multiethnic, and multicultural population. Chin surveyed the various public and private cultural competence initiatives in the Commonwealth for a Massachusetts Health Policy Forum in 1999.³⁰ That report set forth recommendations for improvement of the cultural competence of the health care workforce that are well taken even now, almost two years later. An understanding of the varied health beliefs and attitudes of a diverse patient population is critical to providing culturally competent health care. Beyond providing medical interpreter services, the recruitment and training of minority health care providers is critical to establishing the foundations of a workforce that can serve the racially and ethnically diverse population in the Commonwealth.

As a recent report from the Health Resources and Services Administration, Bureau of Health Professions documents, there continues to be a serious lack of racial and ethnic diversity in the health professions in Massa-

chusetts. According to the report, only 2% of active care physicians statewide in 1998 were Black/African American, and 3% were Hispanic/Latino, all below the percentages in the general population.³¹ Currently, HRSA spends \$4.1 billion on access-related activities and \$2.1 billion for targeted clinical or crosscutting health disparity activities. In Massachusetts, the Bureau of Primary Health Care's Health Disparity Collaboratives target vulnerable racial and ethnic minority populations, who are served in Community Health Centers and National Health Service Corps provider-supported practices, toward the goal of improving their health status in regard to chronic illness. Thus, healthcare providers are changing the way they deliver health care with targeted interventions for Latino, African American, and other racial and ethnic minority populations, by focusing on culturally/linguistically appropriate self management and collaborative care. (Personal communication, Roderick King, M.D.)

Other recent and ongoing agency and legislative efforts focus on improving the capacity for the health care workforce to deliver effective services to minority populations by assessing and reducing linguistic barriers to accessing health care. For example, the Massachusetts Division of Medical Assistance (DMA) conducted a cultural competency survey of approximately 1500 MassHealth primary care sites in 1998. Among the stated purposes of the survey were to understand the capacity of their providers to meet the language needs of members and to promote awareness among its providers about the cultural context within which patients benefit from treatment. It yielded information about the need for interpreter services among its members, and assessed the capacity of its providers to provide those services. Eighteen medical interpreter training programs have been conducted by DMA, in Spanish, Portuguese, Russian, Khmer, and Vietnamese, in 26 hospitals and 18 community health centers statewide.

In July 2001, a new law will require interpreter services for non-English-speaking patients in all Massachusetts hospital emergency departments and acute care mental health facilities.³² It seeks to improve access to linguistically competent health care for minority populations, and provides for monetary damages for violations. The MDPH is developing guidelines and regulations to implement the new law.

Community health workers have a long history in the Commonwealth of providing invaluable services to vulnerable populations. Legislation now pending in the Commonwealth seeks to expand access to health care

further. With the backing of a broad, statewide coalition called "Health Now!" this bill contains a provision that would create a community health worker outreach program with a strategy that targets factors underlying barriers to access to health care. Reducing barriers to health care access and improvement of the public health of communities are among the goals of this provision. A comprehensive outreach services plan would be charged with identifying barriers such as cultural and language differences between providers and patients, limited accessibility of health care facilities and providers, and lack of transportation to health care services.³³

Data Collection and Reporting

The greatest, and perhaps most fundamental, challenge lies in the collection of accurate race- and ethnicity-specific data, the subsequent analysis of often small and statistically insignificant numbers, and the protection of the privacy of individuals who may be identifiable if small counts are used. That is, the classification of racial and ethnic categories and the consistency of those classifications across different data sets are crucial to the ability to analyze such data accurately. The MDPH is a national model for data collection and reporting methodologies, yet challenges remain. Most data have limitations that merit some degree of caution in their interpretation, and the practical nature of some of those limitations is discussed here.

OMB Directive No. 15

The federal mandate with perhaps the most critical long-term impact on the collection of health-related data for minority populations is the Office of Management and Budget's (OMB) "Standards for Maintaining, Collecting and Presenting Federal Data on Race and Ethnicity" (known since 1978 as OMB Directive No. 15).³⁴ Issued in 1997, the revised Standards were used by the Bureau of the Census in the 2000 census, and are a reaction to perhaps one of the greatest challenges to health data collection—the accurate classification of racial and ethnic categories. All federal agencies and programs must adopt the standards no later than January 1, 2003. In their most recent form, the Standards attempt to reflect the diversity of the current population of the United States by expanding racial and ethnic categories to permit multiracial and Hispanic or Latino ethnicity selections. In describing the process used to review and revise the previous longstanding methodology of collecting population-based data, staff of the OMB trace the history of such data collection standards.³⁵ Civil rights laws of the 1960s were the initial

forces driving federal mandates and guidelines for collecting race- and ethnic-specific data.

The revised standards have five categories for race (American Indian or Alaskan Native, Asian, Native Hawaiian or other Pacific Islander, Black, and White) and two categories for ethnicity (Hispanic or Non-Hispanic). The most significant change in the federal data collection standard is that individuals are now able to select more than one race. Heretofore, those of mixed race or ethnicity have been faced with choosing only one race, or placing themselves in the "other" category. This failure of data collection has resulted in prevalent under-reporting of race and ethnicity classifications.

Implementation of the new standards will be complicated by the existing differences between the functions and roles of federal and state agencies with respect to data collection and reporting. Nonetheless, these new standards for census data collection translate into new opportunities and challenges for state level health data collection and reporting. In an effort to analyze the impact of the new standards on some of the data collection and reporting performed by the Massachusetts Department of Public Health, researchers there identified some of those opportunities and challenges.³⁶ While the new standards will facilitate better information about the links between race/ethnicity and health, they will impose on states the need to coordinate data systems that maximize data analysis efforts.

Civil Rights and Health Data Collection

"Ensuring that people who are limited English proficient have meaningful access to health care is an important priority."

- Thomas Perez, Director, Office for Civil Rights, Department of Health and Human Services

The New England Regional Minority Health Conference, Providence, RI, April 13, 1999

Legal issues pervade data collection and programmatic concerns in the elimination of racial and ethnic health disparities. National origin discrimination is the subject of a recent policy guidance issued by the Office for Civil Rights of the Department of Health and Human Services.³⁷ The guidance clarifies existing requirements for providing services to individuals with limited English proficiency. The application of Title VI of the Civil Rights Act of 1964 to programs of federal aid recipients is clear, as is the Justice Department's commitment to enforcing these nondiscrimination provisions. Under the Act, any entity that receives federal

financial assistance is prohibited from discriminating on the basis of race, color, or national origin. The Act thus extends to practices by public and private health care providers or entities considered a recipient of direct federal financial payments.³⁸ Thus, Office for Civil Rights policy encourages the collection of data by specific race and ethnicity. While not every instance of disparate impact would give rise to a successful claim of discrimination, disaggregating (or untangling) data by race contributes to the ability to document that services provided by recipients of federal funds comply with both the letter and the spirit of the law.

Massachusetts Community Health Information Profile (MassCHIP)

The MDPH has developed and maintains a free, online database, located on the Internet. MassCHIP offers community-level and statewide health and sociodemographic data. The database provides access to a number of data sources, including vital statistics, communicable disease incidence, population data, and MDPH program utilization. The data can be presented in standard or custom report form, at the user's preference. MassCHIP also contains a series of Minority Health Standard Reports, many of which are based on the Behavioral Risk Factor Surveillance System (BRFSS), a series of annual random-digit-dial telephone surveys of adults (aged 18+) using standardized questionnaires developed by the Centers for Disease Control and Prevention, along with some state-added questions. The standard reports contain statewide data only, but custom reports that provide community or regional data may be generated.

Data Limitations

There are limitations inherent in the ongoing data collection efforts that have been described. A primary concern is the issue of small numbers and the caution that needs to be taken in interpreting any analyses conducted with counts so small that they will most likely yield results that are statistically insignificant. The desire to capture accurate counts, however small, must be balanced with the preservation of client confidentiality. With the ever-increasing capacity of information systems and the sophisticated techniques employed by researchers, such as geocoding, there is a potential for individuals of a specific racial/ethnic group residing in a particular geographic area to be easily identifiable despite attempts to maintain their anonymity. This calls for the implementation of systems to effectively moni-

tor these databases and the development of protocols mandating confidentiality.

Ongoing data collection efforts have been hampered by outmoded methods that do not lend themselves to accurate reporting of multiple racial and ethnic categories. Historically, many biracial respondents, or respondents who do not wish to be identified as members any racial or ethnic group, may choose the catch-all "Other" category, instead of a specific race or ethnicity. This results in a loss of demographic data that inhibits accurate counting. Unfortunately, small numbers of individuals within certain racial and ethnic subgroups create an obstacle in determining their public health needs through traditional research methodologies. One mechanism to address the issue of small numbers and the underreporting that may result is to employ qualitative analysis to inform quantitative findings. Such qualitative analysis, including focus groups and interviews, may better allow the public health needs of these individuals to be identified.

The new federal, OMB 15 data standards purport to enhance the ability to reflect multiracial respondents by expanding these categories. As other state agencies join the MDPH in adopting new federal data guidelines, there will be more opportunity for interagency coordination of data sources and for more ethnicity- and race-specific health care access data. However, there are limitations inherent in the new OMB standards, which will greatly impact public health research. Data collected through the observation of untrained observers, or from self-reported survey instruments or administrative forms may always have limitations that render them somewhat unreliable.³⁶ The limitations of self-reports may be particularly relevant in questions related to certain health measures (e.g., substance abuse). Indeed, the *Healthy People 2010* target goals themselves have limits. Those goals are set with baseline data from the old federal data standards, yet it is the new OMB 15 standards by which the progress to those goals will be tracked.⁴⁰

Our ability to eliminate health disparities is clearly impacted by our capacity to collect, analyze and report valid and reliable data. As all state agencies adopt the new standards mandated by the federal government by January 2003, the capacity to share data across data sets may improve. Even with the introduction of the new standards, however, the reality of the small totals of racial and ethnic subgroups may defy traditional statistical analysis. The implication may be that we will be

challenged to meet the goals of eliminating disparities so difficult to quantify.

Behavioral Risk Factor Surveillance System (BRFSS)

The ongoing BRFSS and other surveillance systems provide the MDPH with necessary baseline data on various health indicators. Although it has served as a reliable data resource for the state, it too has inherent limitations. Telephone surveys have not always been a reliable resource for representing the general population. The surveys rely on self-reported data, which raise issues of data limitations such as recall bias. Self-reported data may also be limited in that individuals may not want to disclose personal information such as race/ethnicity in a telephone interview and may respond dishonestly or withhold this information. Although the survey does rely on random digit dial telephone calls there are potential limitations relating to the generalizability of the data due to small sample sizes. The data obtained would be most effective if the surveys were expanded to include more households. Finally, oversampling of racial and ethnic groups would also enhance the data and help to address some of the data limitations.

Community-based Responses and Initiatives

"To reduce disparities in the nation, we must reach out to communities."

- David Satcher, M.D., Ph.D., Assistant Secretary for Health and Surgeon General

Healthy People 2010 Launch, Washington, D.C., January 25, 2000

Many community-based initiatives have been established to address the issue of eliminating racial and ethnic disparities in health outcomes. They have been instrumental in developing mechanisms to overcome these disparities. These local efforts are demonstrative of the significant role that community driven responses play in developing successful strategies to ameliorate these issues. Some of these initiatives address particular areas of disparities while others target specific populations impacted by health disparities. In particular, community initiatives dealing with specific populations have been successful because they know the population they are serving, they understand their health beliefs, and they recognize strategies for approaching and engaging them in health services. Just some of the ongoing community-based initiatives in the Commonwealth are mentioned below.

Boston Public Health Commission

As the local health department for the City of Boston, The Boston Public Health Commission (BPHC) is responsible for monitoring and ensuring the health status of Boston residents. The BPHC has increased its monitoring and reporting as the need for health status data has increased. Its ongoing reports encompass data on: the health of Boston residents; natality—specifically birth, infants, and their mothers; health concerns impacting neighborhoods of Boston; and other public health concerns.

The BPHC also has initiated several programs aimed at addressing ongoing racial and ethnic disparities in the City of Boston. For example, the BPHC serves as the Central Coordinating Organization for two CDC-funded *Reach* projects. One of the projects is directed towards reducing racial disparities for breast and cervical cancer among African American women. The other targets African American elders emphasizing prevention and early screening to improve their chances for a healthy prognosis.

Latino Health Institute/Latino Health Policy Council

Latinos fare worse than the general Massachusetts population in terms of health access and insurance coverage, both major predictors of health status. Not surprisingly, their health status is poorer than the general population as well. Latinos nationally are at increased risk for several health indicators including, diabetes type 2, obesity, cancer (cervix, pancreas, prostate and stomach), AIDS, substance abuse, smoking, intentional and occupational injury, hypertension, stroke, tuberculosis, low birth weight, depression, anxiety, and alcoholism. Addressing the need for targeted interventions geared toward eliminating these disparities is of vital importance considering that Latinos are expected to become the largest minority group in the U.S. by the year 2010.

One of the major obstacles in addressing the increased risk for poor health outcomes experienced by the Latino population is the lack of available and appropriate health and vital statistics data. This lack of information in turn impedes the development of effective health policies. The Latino Health Institute in an attempt to contend with these issues has spearheaded the Latino Health Policy Council, which is comprised of health care consumers, providers, and advocates interested in Latino health outcomes. The goal of this new initiative is to forge an informed agenda for Latino Health in Massachusetts that coincides with the federal

government's announcement of *Healthy People 2010*. More specifically, the Council is targeting issues of accuracy and gaps in data collection efforts for Latinos in the Commonwealth and developing recommendations regarding the elimination of disparities in health status between Latinos and the general population.

Worcester Healthy Start Initiative

Infant mortality among racial and ethnic minorities, along with linguistic capacity of health care providers, are the focus of a community-based collaboration in Worcester, where the citywide infant mortality disproportionately affects Black and Latino infants, particularly in areas where poverty is prevalent. Coordinated by the Great Brook Valley Health Center, the project relies upon the participation of UMass Memorial Health Center and St. Vincent Hospital, the two birthing hospitals in the city of Worcester, and sets 100% access and 0% disparity among its goals. It is a model both for collaboration between providers, consumers and state agencies, and for the utilization of local data collection resources. The Worcester Healthy Start Initiative uses outreach and case management methods to reduce the disparity in negative birth outcomes among its minority patients.

Boston Health Access Project: Racial and Ethnic Disparities Committee

The Boston Health Access Project has formed a Committee to address the issue of eliminating racial and ethnic disparities in health. The committee is comprised of community health leaders and activists at the grass-roots level from 12 different population groups as follows: Somali, Sub-Saharan African, African American, Haitian, Cape Verdean, English-speaking Caribbean, Chinese, Vietnamese, Korean, Dominican, Puerto Rican, and North American Indian. A number of issues relating to linguistic, cultural and socio-economic access barriers have emerged from ongoing discussions about existing disparities. These have been translated into policy recommendations to the City of Boston, which are transferable to other communities of color throughout the Commonwealth. In addition, the Committee stresses the broader issue of increasing utilization to reduce disparities in health outcomes. Finally, the BHAP Committee recommends the formation of a private/public/community partnership that will address disparities over the next 10 years. They suggest that specific ethnic communities work with hospital, health center, or public health partners to eliminate barriers to good health and care within their communities.

Massachusetts League of Community Health Centers (MLCHC)

The MLCHC, as a network of health providers serving neighborhoods throughout the Commonwealth, is uniquely positioned to participate in programs that target communities of color. For example, the MLCHC is involved in a marketplace analysis project with health center members, which includes collecting data on health disparities in the health center planning process. It also engages in community development work on the mid-Cape and in Fitchburg to respond to documented access and health disparities issues. The MLCHC is also a grantee in Bureau of Primary Health Care programs that seek to develop cultural competence in health care and establish Health Disparities Collaboratives among federally funded health centers.

Harvard School of Public Health Division of Public Health Practice Program to Eliminate Health Disparities

The Program to Eliminate Health Disparities (PEHD) was established to address persistent, poor health outcomes among racial and ethnic minorities, particularly African Americans, by building and strengthening social capital within communities. Funded by the Ford Foundation, the PEHD attracts undergraduate and graduate students, Harvard School of Public Health faculty and other professionals from the fields of science, sociology, economics and health. By collaborating with community-based organizations, health centers, activists, educators, schools and youth service programs, the PEHD hopes to reduce health disparities impacting residents of Roxbury and communities of color throughout the world.

REACH 2010, Cherishing Our Hearts and Souls

REACH 2010, Cherishing Our Hearts and Souls, is a collaborative effort to improve the cardiovascular health of African Americans in Roxbury. Funded by the CDC, the project engages the Division of Public Health Practice at the Harvard School of Public Health in community coalition building efforts involving Roxbury Comprehensive Community Health Center, Inc., Dimock Community Health Center, the Sister Together Coalition, VISIONS, Inc., and Paige Academy as well as six community members who do outreach as Healthy Heart Advisors. The Project takes a Community Oriented Primary Care approach to address the unmet health needs of the Roxbury community. The project also aims to address the impact of racism on the health

of African Americans. The Project aims to improve the health of the entire community by fighting racism. The Project's goal is to have a positive impact on the cardiovascular health of African American residents, particularly elders, as well as significant policy implications for African Americans in general.

Mauricio Gastón Institute for Latino Community Development and Public Policy and the Doctoral Program in Public Policy at the University of Massachusetts

In the past 10 years the Gastón Institute has engaged in a number of minority health policy research projects designed to identify health disparities and policy recommendations for improving the health of minority consumers, with a special emphasis on Latinos. Much of the work has been conducted in conjunction with health policy doctoral students in the Public Policy Ph.D. Program, and at times in collaboration with the William Monroe Trotter Institute for the Study of Black Culture and the Institute for Asian American Studies. Major projects have included participation in a Division of Medical Assistance Cultural Competence Technical Assistance Project; evaluation of a five-year youth substance abuse prevention project with youth from all racial and ethnic backgrounds; and analysis of access and quality disparities by race and ethnicity among Massachusetts' MassHealth members, funded by a Health Care Financing Agency-Hispanic Health Services Research Grants Program. Findings of the HCFA study, which examined several utilization indicators, reveal a mixed pattern of disparities, yet comparable quality of care that varies by indicator and by racial/ethnic group. The study findings provide useful guidance for improving quality of care and reducing unnecessary costs across all racial/ethnic groups.

The Access Project

Based in Boston, The Access Project is a national initiative funded by a grant from the Robert Wood Johnson Foundation to the Heller School at Brandeis University. Focusing on the role of local healthcare initiatives in national reform, The Access Project works with community groups throughout the country to improve access to health insurance while informing local approaches. It offers strategic planning, policy analysis and leadership training services to communities in their efforts to advocate for their uninsured residents. Its recent publication, "Using Risk Factors to Assess Health Care Access in a Community,"* presents a model approach for increasing health care access for

communities by identifying risk factors that are known measures for access, such as uninsurance, unemployment, and rural vs. urban geography.

Conclusions

"(C)ommitment to eliminate disparities has already galvanized communities, states, and non-governmental organizations throughout the country to develop their own commitments and strategies."

David Satcher, M.D., Ph.D., Assistant Secretary for Health and Surgeon General

Healthy People 2010 Launch, Washington, D.C., January 25, 2000

Our desire to achieve equity in health status and health delivery for the diversity of races and ethnicities that we embrace is constrained by the realities of methodologies necessary to obtain valid and reliable data to inform targeted service for those groups. Massachusetts, a state in overall good health, among the healthiest in the country by many measures, has a unique wealth of ongoing efforts on the part of local, community-based organizations, state health agencies, and DHHS, Region I at the federal level. Many efforts statewide seek to address the challenges facing the Commonwealth in achieving racial, ethnic, and linguistic diversity in its health care workforce, but there is much progress to be made. Data collection on the health status of racial and ethnic minorities in Massachusetts, while a national model, will benefit from the new national data standards. Despite the immediate need for better data collection and reporting methodologies, these strengths can be cultivated to create the foundation, or infrastructure, for identifying and targeting populations of need.

The Strength of Collaboration

The potential for ongoing and increased collaborative efforts is evident in pursuing the common goal of eliminating health disparities. Many of Massachusetts' health-related state agencies already are engaged in work that furthers the goal of eliminating health disparities. Ongoing interagency collaboration, as well, is critical to maintaining the momentum of innovative approaches to improving minority health.

Partnerships between state and federal agencies also expand the opportunities for research and education with respect to minority health disparities. Already, these partnerships have contributed to the Commonwealth's capacity to achieve the goals stated in *Healthy*

* By Robert W. Seifert, Available from: URL: www.accessproject.org/downloads/fp_risk.pdf

People 2010. And, collaborations between federal and state agencies and community-based organizations have proven an effective model for addressing local health needs.

Statewide advocacy organizations can play a key role in outreach and support of minority health improvement efforts. For example, Health Care for All has demonstrated leadership in outreach to minority communities to increase access to health insurance, and to advocate for equity in health care. The Massachusetts Public Health Association (MPHA), the state affiliate of the American Public Health Association, is a statewide nonprofit organization dedicated to improving the health status of the state's residents through education, advocacy and coalition building. It has stated as one of its public policy priorities the elimination of health disparities among residents of the Commonwealth. The message of prevention is a foundation of improved health status, especially with respect to the six measures identified by the President's Race and Health Initiative, and MPHA is positioned to lend its expansive constituency to reinforcing that message.

Policy Implications / Recommendations

The information gathered for this policy brief raises several policy implications and calls for policy recommendations that follow from the three-pronged approach to eliminating health disparities stated above:

I. Develop the cultural competence and diversity of the health care workforce in Massachusetts

As a leading center of medical education and health research, Massachusetts must make a concerted effort to increase the ethnic, racial and linguistic diversity of its health care workforce. This calls for employing more aggressive recruitment and retention strategies among universities, hospitals, and other health care entities. It also highlights the need for joint partnerships that address this issue with the input of both public and private organizations. The Health Resources and Services Administration, Region I, for example, stands ready to secure new partners and collaborators to promote the recruitment, training, and retention of a culturally and linguistically competent, diverse health care work force.

II. Promote the implementation of community-driven initiatives

A. Support community-based technical capacity-building

Community-based organizations need to develop their capacity to facilitate the generation of data for effective documentation of need and service delivery. That is, systems need to be incorporated which allow for timely data reporting and utilization in response to external requirements as well as increased internal efficiency. A major obstacle to this is the lack of manpower, time and technical capacity among community based organizations required to access and manipulate available data sources, such as MassCHIP. These data sources need to be made more accessible and user friendly for community based organizations to effectively document their public health need.

B. Design interdisciplinary approaches

In order to promote community-driven research agendas that truly reflect the public health needs of the communities being targeted, individuals representing these communities must participate in developing the agenda. This calls for the development of interdisciplinary research teams that include academicians, practitioners, community leaders and *constituents*.

An Example of a Primary Care-Based Research Network

The Center for Community Health, Education, Research and Service (CCHERS) facilitates collaborative research initiatives that are focused on health care access, disease prevention and wellness issues that affect racial/ethnic minorities and underserved/vulnerable populations in urban communities. CCHERS helped establish the Boston Community Practice Research Collaborative, a primary care practice-based research initiative designed to increase and improve community health centers' ability to conduct relevant research and program evaluation. This collaborative, comprised of a group of academicians, researchers, community leaders, providers, and policymakers, works together to address such issues as asthma, diabetes, and hypertension through community-driven research initiatives and program implementation. These discussions have implications for the development of collaborative research agendas, initiatives, interventions, and programs.

The products of this collaborative illustrate the need among community-based organizations to understand and advocate for research capacity building resources, particularly with philanthropic entities that traditionally view research as separate from capacity building. This skill building will be essential to the survival of community based organizations, particularly as federal and state agencies increase the need for evaluation components as part of their funding criteria and stipulations. Foundations should in turn support and encourage research particularly as it relates to community development. Funding by private foundations to support community driven research agendas will improve the likelihood of innovative program development.

III. Improve data collection and reporting methodologies

A. Implement uniform data collection methodologies

Implementing a uniform and standard mechanism for data collection, maintenance, and monitoring at the state level would be effective in reducing difficulties with data inconsistencies and overlap. As state agencies adopt the new federal data collection standards, the lack of uniformity of data standards across datasets will be ameliorated. This transition, however, will be gradual and will require an investment of human and financial resources, as well as ongoing technical support. Health agencies in the Commonwealth must continue to be supported in their commitment to meet the requirements of the new standards. Working partnerships between state public health agencies and community groups and federal agencies are essential to successful implementation of the new data standards.³⁶

The adoption of new standards is critical to eliminating existing overlaps and gaps in current data reporting mechanisms. An integrated system that addresses local, state, and federal data collection and reporting requirements will ameliorate inefficient data management. Such an integrated system would also enhance the ability of community-based organizations to document their need accurately and effectively.

B. Encourage the role of managed care organizations as data sources

The significance of tracking health outcomes by race and ethnicity should motivate health care providers and insurers to collect more race- and ethnic-specific data for their patients and enrollees. With over 50% of the population in Massachusetts enrolled in some form

of managed care, there are great opportunities to improve our knowledge of health status and outcomes among the minority population in the Commonwealth. One way is to encourage managed care organizations to collect race- and ethnicity-specific data on all of their enrollees. Many managed care organizations in the Commonwealth already have demonstrated a commitment to culturally competent practices, and are an important partner in measuring the elimination of health disparities.

IV. Support community-based organizations' capacity-building efforts in data management and systems integration

Equity in resource allocation requires that community-based organizations be able to increase the technical capacity necessary to participate in the independent research that will benefit local communities of need. As data become essential to resource allocation and program implementation it will be vital for state and city departments of public health as well as community-based organizations to be able to document need. This will in turn lead to capacity building for information technology as well as alliances with entities providing this technical capacity.

In order to meet the goals of *Healthy People 2010*, relevant city and state data systems must be effectively coordinated. In order for these monitoring and surveillance systems to continue to meet the needs of our public health agenda, a sincere effort must be maintained to maximize the potential for ongoing data management and systems integration.

V. Maintain an infrastructure for a public health research agenda

A. Ensure community involvement

Data collection and reporting, along with research, form the foundation of effective reduction of the disproportionate burden of disease among minority populations. Successful program planning and implementation turns on its responsiveness to identified community needs. To ensure appropriate identification of these needs, inclusiveness at the decision making table is essential. This would lead to effective program implementation and policy development and, ultimately to successful outcomes. This calls for the development of more effective mechanisms aimed at recruiting and retaining community involvement throughout these processes. Community input at all levels of the public health response can only contribute to programmatic

success in eliminating health disparities and improving health outcomes.

B. Pursue sustainability

Maintaining Massachusetts' status as a national role model for data collection and reporting efforts aimed at eliminating disparities in health outcomes will require a sustained commitment by stable, long-term funding sources, including appropriations by the State Legislature. The need for support of ongoing research that involves communities and their state and federal partners must be presented persuasively to legislators, policymakers, and to appropriate private funders.

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Appendix

Table 1

**MassCHIP Custom Report
Massachusetts Community Health Information Profile
Infant Mortality by Race/Ethnicity – Massachusetts Totals 1998
Infant Deaths (Vital Records)**

Race/Ethnicity	All Causes of Death— Infant Deaths: Count	All Causes of Death— Infant Deaths: Infant Mortality Rate (IMR) Per 1000
White, Non-Hispanic	287	4.65
Black, Non-Hispanic	59	11.04
Puerto Rican	40	8.96
Central American	3	2.38
Dominican	13	8.71
Other or Unknown Hispanic	2	1.38
Cambodian	2	NA
Chinese	3	2.82
Vietnamese	2	3.50
Other or Unknown Asian	3	2.09

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Table 2

**MassCHIP Minority Health Standard Report
Cancer Deaths by Race/Hispanic Ethnicity (all ages)
Massachusetts Total
1996-1998 Mortality (Vital Records)**

Race/Hispanic Ethnicity	Area 3 Year Count	State Age- Adjusted Rate per 100,000	State 95% Confidence Interval
White, non-Hispanic	39,042	128.2	(126.7-129.6)
Black, non-Hispanic	1,359	169.7	(160.3-179.0)
Hispanic	461	66.0	(59.7-72.3)
Asian/Pacific Islander	371	87.5	(78.3-96.7)

Note: "Asian/Pacific Islander" category does not include persons of Hispanic origin

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Table 3

**MassCHIP Minority Health Standard Report
Heart Disease Deaths by Race/Hispanic Ethnicity (all ages)
Massachusetts Total
1996-1998 Mortality (Vital Records)**

Race/Hispanic Ethnicity	Area 3 Year Count	State Age-Adjusted Rate per 100,000	State 95% Confidence Interval
White, non-Hispanic	47,133	110.7	(109.5-112.0)
Black, non-Hispanic	1,287	143.3	(134.9-151.7)
Hispanic	445	60.3	(54.3-66.2)
Asian/Pacific Islander	239	52.3	(45.4-59.3)

Note: "Asian/Pacific Islander" category does not include persons of Hispanic origin
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Table 4

**MassCHIP Minority Health Standard Report
Stroke Deaths by Race/Hispanic Ethnicity (all ages)
Massachusetts Total
1996-1998 Mortality (Vital Records)**

Race/Hispanic Ethnicity	Area 3 Year Count	State Age-Adjusted Rate	State 95% Confidence Interval
White, non-Hispanic	9,564	18.7	(18.3-19.2)
Black, non-Hispanic	274	29.2	(25.5-32.9)
Hispanic	100	12.8	(10.1-15.5)
Asian/Pacific Islander	103	23.0	(18.3-27.6)

Note: "Asian/Pacific Islander" category does not include persons of Hispanic origin
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Table 5

**MassCHIP Minority Health Standard Report
Diabetes Mellitus Deaths by Race/Hispanic Ethnicity (all ages)
Massachusetts Total
1996-1998 Mortality (Vital Records)**

Race/Hispanic Ethnicity	Area 3 Year Count	State Age-Adjusted Rate per 100,000	State 95% Confidence Interval
White, non-Hispanic	3,730	10.9	(10.5-11.3)
Black, non-Hispanic	232	26.9	(23.2-30.6)
Hispanic	108	15.9	(12.7-19.0)
Asian/Pacific Islander	35	7.8	(5.1-10.5)

Note: "Asian/Pacific Islander" category does not include persons of Hispanic origin
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Table 6

**Alive Cases of HIV and AIDS as of January 1, 2001
Percent of Total by Race/Ethnicity**

Race/Ethnicity	HIV	AIDS	HIV/AIDS
White	50	48	49
Black	23	27	25
Hispanic	25	24	24
Other/Unknown	2	1	2

Source: Massachusetts HIV/AIDS Surveillance Program,
 HIV/AIDS Summary Report

Table 7

**National Immunization Survey (NIS)
Massachusetts vs. U.S. Series Complete¹ Immunization Levels
For Children Age 19-35 Months by Race/Ethnicity
1999²**

Race/Ethnicity	Massachusetts	U.S.
Total	85.2%	78.4%
Hispanic	77.7%	77.7%
White, non-Hispanic	86.5%	81.0%
Black, non-Hispanic	84.6%	73.8%
Native American/ Alaskan Native	NA	75.0%
Asian/Pacific Islander	NA	77.4%

[1] 4 doses of DTA_p/DTP, 3 doses of poliovirus vaccine, 1 dose of measles containing vaccine, and 3 doses Haemophilus influenza type b

[2] Only year race/ethnicity data available from the NIS

NA= Not Available