Development of The *National Stakeholder Strategy*

Changing health outcomes for many of the United States' racial and ethnic minorities, the poor, and other underserved populations is a critical need. Health and healthcare disparities are persistent and pervasive; they are harmful not only to the individuals and communities that experience them, but to the nation as a whole. Everyone benefits when health and healthcare disparities are eliminated and health equity becomes a reality: financial costs are greatly diminished; healthy children can grow into productive adults; healthy adults boost workforce capacity and capability; and values of social compassion are honored.

THE CONTEXT FOR THE *NATIONAL STAKEHOLDER STRATEGY*

In this effort to achieve health equity, the United States aligns itself with similar endeavors throughout the world. There has been significant global attention placed on the risk factors for adverse health outcomes — factors that may long predate the appearance of disease. Such factors are those that relate to social constructs rather than medical constructs and are fundamentally and particularly toxic to health. Well-known factors include low socioeconomic status, low educational status, and inadequate access to (or utilization of) quality health care. There are other adverse determinants of health as well. Examples include residence in geographic areas that have poor environmental conditions (e.g., violence, poor air quality, and inadequate access to healthy foods), racism, inadequate personal support systems, limited literacy, and limited English proficiency (LEP). These determinants are often associated with racial and ethnic minority and underserved communities, and are among the determinants of health.

Margaret Chan, Director-General of the World Health Organization (WHO), drew attention to the urgent worldwide problem of health inequities and its profound consequences when she said, "Health inequity really is a matter of life and death."[1] The significance of social determinants of health has increasingly become a matter of discussion and research, along with the recognition that, although social factors are at the root of many of the inequities in health and health care worldwide, they are not necessarily inevitable and are amenable to intervention.[2] In 2005, WHO formed an independent Commission on Social Determinants of Health (CSDH)[3] to make the case that health status is of concern to policymakers in all sectors (not just health) and to "link knowledge with action" regarding how these factors operate and how they can be changed to improve health and reduce health inequities.

> "Health inequity really is a matter of life and death."
>
> – Margaret Chan, MD, MPH
>
> Director-General, World Health
>
> Organization, 2008

The 2008 report of the CSDH,[3] "Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health," notes the powerful link between social factors and health. The report emphasizes that social and economic policies directly impact the health and well-being of those who live and work under them. The report further suggests that interventions and policies to achieve health equity must be based on evidence and result in action, and they must address daily living conditions and issues related to power, money, and resources.

WHO defines the *social determinants of health* as the "conditions in which people are born, grow, live, work, and age, including the health system. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels, which are in and of themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities."[4] Operatively, health inequities often play out as differences in opportunities for healthy lifestyles, differences in quality of care within the healthcare system, and differences in access to the healthcare system (both preventive and curative care).[5]

In the United States, there are examples of health and healthcare disparities by race, ethnicity, gender, literacy level, socioeconomic status, geographic location, disability status, and sexual orientation or gender identity. Examples include disparities in cardiovascular disease, diabetes, HIV/AIDS, infant mortality, oral health, mental health, and health care quality and access.

> "It is time to refocus, reinforce, and repeat the message that health disparities exist and that health equity benefits everyone."
> – Kathleen G. Sebelius, Secretary, HHS

Acknowledging that persistent health disparities are the manifestation and interplay of complex factors is critical to solving these problems. It is only as we develop a fuller understanding of the scope and magnitude of factors affecting health outcomes and evidence for what works to reduce disparities that the most effective advancement of appropriate policy and intervention strategies can occur. This will require the combined efforts of governments, academia, institutions, businesses, humanitarian and faith-based organizations, and individuals working across the entire spectrum of public, private, community, and individual enterprise.

Beyond the heavy burden that health and healthcare disparities represent for the individuals affected, there are additional social and financial burdens borne by the country as a whole. These burdens constitute both ethical and practical mandates to reduce health and healthcare disparities and achieve health equity.

DEFINITIONS

The terms — *health inequality*, *health disparity*, *healthcare disparity*, *health equity*, and *health inequity* — are widely used, often without clarification of meaning. Therefore, in an effort to distinguish between these terms, in this *National Stakeholder Strategy:*

◆ *Health inequality* is the "difference in health status or in the distribution of health determinants between different population groups."[6]

◆ *Health disparity* a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial and/or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.[7]

◆ *Healthcare disparity* relates to "differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions. These differences would include the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health-system levels."[8]

◆ *Health equity* is attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities.[9]

HISTORICAL BRIEF: WHAT THE PAST HAS TAUGHT US

The 1985 *Report of the Secretary's Task Force on Black and Minority Health (Heckler Report)* was the initial federal effort to identify and draw national attention to the tragedy of minority health disparities.[10] The report, issued by then-HHS Secretary Margaret Heckler, formally detailed for the American consciousness the existence and extent of racial and ethnic health disparities for Blacks and three other identified minority groups (defined during that time as Hispanics, Asians/Pacific Islanders, and Native Americans). With the exception of information on African Americans, there was limited data available in 1985 about the health and well-being of racial and ethnic minority populations.

Nevertheless, the *Heckler Report* concluded that similar patterns of health disparities existed for all the identified minority groups and called out six areas of particular concern: cancer, cardiovascular

disease/stroke, diabetes, infant mortality, chemical dependency, and homicide. Between 1979 and 1981, these six conditions together accounted for more than 80 percent of deaths in excess of that of the White population for African Americans and the other identified minority populations.

In his letter introducing the report, Task Force Chairman Thomas E. Malone (then Director of the National Institutes of Health [NIH]) expressed the hope that the report should serve "not only as a standard resource for department-wide strategy, but as the generating force for an accelerated national assault on the persistent health disparities … " In fact, the report did generate a plethora of public and private programs, entities, and initiatives aimed at reducing the disparity gap, including the immediate formation of the federal Office of Minority Health (OMH). However, while there have been dramatic improvements to both the healthcare delivery system and health outcomes (e.g., mortality and morbidity rates) for all populations in the United States since 1985,[11,12,13] many of the findings and recommendations of the *Heckler Report* are still pertinent. Health disparities still exist and are still serious.[8,13]

The evidence of persistent and pervasive health and healthcare disparities is clearly articulated in the 2002 landmark report of the Institute of Medicine (IOM), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (Unequal Treatment Report).*[8] Upon the release of the report, the IOM committee chair noted, "The real challenge lies not in debating whether disparities exist, but in developing and implementing strategies to reduce and eliminate them."[8] The *Unequal Treatment Report* identified multiple contributing factors, including the organization and operation of healthcare systems, the attitudes and behavior of patients, and the biases of healthcare providers. The recommendations in the *Heckler Report* are mirrored and complemented by the *Unequal Treatment Report* and are just as pertinent today.

> "The real challenge lies not in debating whether disparities exist, but in developing and implementing strategies to reduce and eliminate them."
>
> – Alan R. Nelson, Chair,
> IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care

Recommendations in the *Unequal Treatment Report* included avoiding fragmentation of health plans along socioeconomic lines; collecting and reporting data on healthcare access and utilization by patient race, ethnicity, socioeconomic status, and primary language; conducting further research to identify sources of racial and ethnic disparities; assessing promising intervention strategies; and implementing patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions. The report also provided important insights into the progress of setting and meeting local, state, tribal, regional, and national health disparities goals, and on effectively measuring and enhancing our collective knowledge of health and healthcare disparities.

A quarter of a century ago, the Secretary's Task Force acknowledged that "the factors responsible for health disparities are complex and defy simplistic solutions."[10] This analysis is just as fresh today for those who conduct health disparities research and/or implement it in practice, and who struggle to identify and combat the medical, social, economic, and other factors that lead to adverse health outcomes. New approaches and new partnerships are needed immediately to close the health gap for racial, ethnic, and underserved communities, and the nation.

CURRENT AND FUTURE REALITIES THAT IMPACT HEALTH DISPARITIES

The previous passage provides a historical frame of reference for considering the new approaches and partnerships that are the hallmark of the *National Stakeholder Strategy* for Achieving Health Equity. In this piece, we provide an overview of current realities that will significantly impact efforts to reduce health and healthcare disparities in the United States, and are the context in which the *National Stakeholder Strategy* will be operationalized and evaluated. These realities provide both challenges and opportunities for devising new methods of attacking the persistent problem of health and healthcare disparities in the United States.

Emphasis on Prevention and the Social Determinants of Health

The importance of preventing disease and promoting health — rather than just treating disease once it appears — has tremendous potential for reducing health disparities and improving our nation's health.[14,15] An emphasis on treatment after the fact instead of aggressively, widely, and prominently promoting health and prevention strategies undermines well-being and quality of life, and results in major adverse social and economic impacts.[15] Placing the emphasis on primary prevention through the promotion and support of children and strong families, healthy lifestyles, and healthy working/living conditions has often been undervalued as a means of achieving and maintaining wellness. A strong prevention strategy must ensure that children have stable homes, regular dental and medical checkups, physical activity and healthy foods at school, and safe living environments. It also must address adults' behaviors related to, for example, smoking, eating, and exercise. Removing disadvantages early on may be a powerful preventive measure in decreasing health disparities. The cumulative effect of chronic exposure to harmful factors throughout the life course increases the risk for poor health in adulthood.[16] This social determinant framework expands the concept and practice of health prevention beyond the traditional medical model. Thus, eliminating health disparities will necessitate behavioral, environmental, and social-level approaches to address issues such as inadequate housing, violence, and limited opportunities to earn a livable wage.[17]

Growing Racial and Ethnic Minority Populations

Minority populations now comprise 34 percent of the total U.S. population, are increasing in number faster than the White population, and are expected to represent 40 percent of the population by the year 2030. The District of Columbia and four states (Hawaii, New Mexico, California, and Texas) are now "majority-minority" states, meaning that more than 50 percent of their population is made up of people other than single-race, non-Hispanic Whites.[18] Addressing the health needs of our minority populations has always been an ethical mandate. As the aggregate of our various minority populations moves toward becoming a majority of the country's populace, health equity becomes even more critical. If health inequities are not adequately addressed, everyone suffers — through shared loss of economic capital, loss of human intellectual and leadership capital, and social instability.

> "We need to do all we can to close this gap and empower our communities to meet and master their health challenges in ways that acknowledge and celebrate our diverse American cultures."
>
> – Senator Edward M. Kennedy
>
> Message to Participants, Third National
>
> Leadership Summit on Eliminating Racial
>
> and Ethnic Disparities
>
> February 25, 2009

Broader Minority Health Constituency

Over the last several decades, a large number of minority health-related programs, organizations, advocacies, and initiatives have come into existence at all levels of society — local, state, tribal, regional, national, faith-based, public, private, academic, and business.[19] This sizeable and talented workforce is a significant and sometimes inadequately tapped resource for advancing health equity. Growth of the minority health constituency has also led to parallel growth in the health disparities knowledge base as evidence-based research, practical experience, and best-practice inquiries continue to be important avenues for finding solutions. The diversity of our communities and their languages has also fostered a greater emphasis on recruiting culturally and linguistically competent healthcare providers into the workforce.

Increasing Access for Persons with Disabilities

There are more than 54 million individuals (19 percent of the population) in the United States who experience some level of disability.[20] They became protected against discrimination on the basis of disability through the 1990 Americans with Disabilities Act and its later amendments.[21] A key target for reducing health disparities for disabled Americans is to increase accessibility across a broad spectrum of needs. Healthcare access in this context has the particular meaning of enabling disabled persons to access

the functionality, benefits, services, and information provided by healthcare systems to the same extent as those without disabilities. Such access includes the use and development of various assistive technologies. The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities[22] encourages healthcare providers to treat the whole person; educators to teach about disability; the public to see an individual's abilities; and communities to ensure accessible health care and wellness services for persons with disabilities.

Growing Awareness of Conditions Impacting Rural Health

In 2009, approximately 17 percent of the U.S. population (50 million individuals) resided in rural (nonmetropolitan) areas.[23] These areas extend throughout 80 percent of the U.S. land area. Since 2001, poverty has been higher in nonmetropolitan areas compared to the rest of the country: 15.4 percent versus 12.5 percent, respectively, in 2007.[24] Poverty is persistent and widespread for rural children.[24] Rural residents face a number of barriers in accessing quality health services, and they experience significant health disparities. Compared to their urban counterparts, rural residents were more likely to report poor-to-fair health; live with a chronic disease such as diabetes; die from heart disease; be admitted for uncontrolled diabetes; and they are less likely to report a dental visit within the past year.[25] Additionally, rural women have lower rates of breast cancer screenings.[26] Minorities living in rural communities are particularly disadvantaged.[25]

Challenges to Urban Health

Urban centers and metropolitan areas have their own set of sociological and environmental factors that can adversely affect health. In the midst of the wealth, commerce, and privilege that exist in most U.S. cities, there is also residential segregation, concentrated poverty, higher levels of poor indoor and outdoor pollution (e.g., noise and air pollution from motor vehicle traffic and industry; indoor exposure to allergens, carcinogens, and lead), and overcrowding (with higher rates of infectious diseases).[27,28,29,30] These factors, and the cumulative effects of social disadvantage, are significant for racial and ethnic minority and underserved populations that are often overrepresented in high-density areas. There is an uneven distribution of socioeconomic status at the neighborhood level in urban areas. An individual's status and place of residence is a social determinant of health across the lifespan.[31,32] The majority of the world's future population will reside in urban areas; seven out of 10 people will be city dwellers by 2050.[33] Urban population growth places a substantial infrastructure and safety burden on governments to provide for public safety and emergency preparedness, safe water and sanitation, solid waste disposal, and adequate education and housing options.

Increasing Knowledge of Health Concerns for LGBT Populations

Persons who identify as lesbian, gay, bisexual, and transgender (LGBT) have specific healthcare needs and face unique barriers in access to quality care.[34,35,36] Examples of barriers include reluctance to disclose sexual or gender identity when receiving medical care to avoid maltreatment and discrimination; lack of provider knowledge of risk factors; insurance policies that limit coverage for domestic partners; and lack of culturally appropriate prevention strategies and services. LGBT persons who also belong to other historically disadvantaged and other vulnerable populations experience compounded obstacles to care and wellness.

Expectations for Improved Data Collection, Reporting, and Diffusion

In the last decade, a greater awareness has developed regarding the importance of collecting reliable data on specific racial and ethnic subpopulations beyond long-standing categories of race and ethnicity.[37] Combining minority subgroups into generalized racial or ethnic categories for data collection can mask dramatic variability in outcomes and thereby inhibit the design of effective, targeted interventions. For example, health outcomes vary dramatically for the populations of the U.S. territories, including the residents of Puerto Rico (who are often placed in the general category of "Hispanics/Latinos"), the residents of the U.S. Virgin Islands (who are often placed in the general category of "African Americans"), and the residents of Guam, American Samoa and the Northern Mariana Islands (who are often placed in the general category of "Pacific Islanders"). Improvements in data collection and reporting hold potential for supporting evidence-based research to identify and solve health inequities.[13,38,39,40,41]

Major Advances in Technology

The increase of computing power and the development of the Internet and other advanced communication and information technologies have led to the enhanced capability to collect, analyze, store, and access massive amounts of data (e.g., products of the U.S. Census Bureau, Agency for Healthcare Research and Quality [AHRQ], Centers for Disease Control and Prevention [CDC], and expanded use of health information technology [HIT]). It has become increasingly necessary for policymakers and healthcare providers to search for efficient and effective means by which to deploy HIT to better manage personal and public health. In 2009, HHS began implementation of the Health Information Technology for Economic and Clinical Health Act (P.L. 111-5), which provides for a national HIT structure that will improve care coordination, enable more effective communication between healthcare providers and patients, and enable an efficient means for healthcare providers and departments of public health to more effectively monitor and analyze public health data. Just as important, the Act is creating programs that include national electronic health record adoption among healthcare providers, workforce training for HIT personnel, and the deployment of health information exchanges.

THE *NATIONAL STAKEHOLDER STRATEGY*: A NEW OPPORTUNITY

An impetus for establishing the *National Partnership for Action (NPA)* as a national movement grew in response to the voices of the nearly 2,000 leaders who attended the National Leadership Summit for Eliminating Racial and Ethnic Disparities in Health sponsored by OMH.[42] The summit broadened the national dialogue about health disparities from the more traditional disease-focused approach to a more systems-oriented approach that addresses crosscutting, multilevel issues. This broader approach can systematically tackle health disparities by bringing individuals and organizations within the health sector together with other individuals and organizations whose work influences health. This approach is in keeping with the mission of OMH to improve and protect the health of racial and ethnic minority populations in the United States through the development of health policies and programs that will eliminate health disparities. It also is aligned with the *Healthy People 2020* objectives to achieve health equity, eliminate disparities, and improve the health of all groups.[43]

In response to the summit, a clear mandate emerged around actions necessary to more effectively and efficiently address health disparities in this country. The views of summit participants were consistent with several recommendations of the *Heckler Report, the Unequal Treatment Report*, key findings in the *National Healthcare Disparities Report (NHDR)* and *National Healthcare Quality Report (NHQR)*, and findings from recent literature on health disparities. The summit honored the 20-year mark since the release of the *Heckler Report* and the remarkable growth since 1985 in health disparities knowledge, activities, and funding. In addition, the summit ushered in a new opportunity to coalesce around a national strategy to end health disparities.

Following the 2006 summit, OMH responded to the common concerns and comments of summit participants in order to begin to formulate NPA goals and principles. The original concept was that partnerships were the unique foundation on which to build the NPA. Refinements and additions to NPA goals and principles and to the *National Stakeholder Strategy* were ongoing via the process described below and were dependent on community and stakeholder input at every stage. The final versions of the NPA goals and principles are presented in detail later in this section.

Relationship Between the *National Partnership for Action* and the *National Stakeholder Strategy*

A prime activity of the NPA was to establish the priorities for a national strategy using a "bottom up" approach. The intent was to change the paradigm of strategy development by vesting individuals — particularly those at the front line of fighting health disparities — with identifying and helping to shape core actions for a coordinated national response.

The "bottom up" approach included focused, localized continuations of the National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health. Details of this process are provided later in this section.

Thus, the natural outcome of the NPA was the development of the *National Stakeholder Strategy* and its two other components: Blueprints for Action (which are being aligned with the *National Stakeholder Strategy* and focus on specific sectors), and targeted initiatives that are being undertaken by partners across the public and private sectors in support of the NPA. These other two components develop subsequent to the launch of the *National Stakeholder Strategy*.

Guiding Principles of the NPA and *National Stakeholder Strategy*

> "We may have all come on different ships, but we're in the same boat now."
>
> – Dr. Martin Luther King Jr.

Four fundamental principles have helped to guide the process by which input from community and other stakeholders was solicited, analyzed, and reviewed. These principles informed the development of the *National Stakeholder Strategy* and include: the importance of community engagement, the value of working via partnerships, the necessity of cultural and linguistic competency to meet the needs of all communities, and the requirement of non-discrimination in actions, services, leadership, and partnerships.

Community Engagement

Communities are made up of diverse individuals, institutions, networks, and organizations in the private and public sectors that may share a physical space (communities of geography) or a history and sense of connection due to a common experience (communities of identity).[44] We experience community where we live, work, learn, play, age, and many other facets of life. Each community has its own unique characteristics that must be considered when engaging their leaders, institutions, and members.

A national effort to end health disparities could not be successful without the input, support, and actions of communities across localities, states, tribes, and regions of the country. Communities experience the

consequences of disparities firsthand and understand the solutions needed to improve the conditions that contribute to them. The input of community leaders and members is critical to ensure the solutions to end health disparities are aligned with their community's history, norms, and needs. Leaders and traditional institutions of racial, ethnic, and underserved groups have been a long-overlooked resource for developing solutions for their communities.

When engaged appropriately, communities across the nation have successfully mobilized to fight violence, drug and alcohol abuse, HIV/AIDS, racism, and other problems. Social and medical research over the past 150 years has shown that five factors have the most far-reaching and powerful effect on the ability of communities to mobilize and develop solutions that best fit their values and needs.[45] These factors include:

- ◆ A sense of community, which forms when community members believe they have influence, can have their needs met, share similar values, experience feelings of mutual trust and caring, and share an emotional connection

- ◆ A community's connections to other communities, networks, and larger and more resourceful institutions that can provide access to opportunities and resources

- ◆ Community members' ability to exercise individual and collective control, which can in turn foster a sense of hope for improving the conditions that affect their lives

- ◆ Collective action through vehicles such as neighborhood associations, advocacy groups, youth organizing efforts, and other organized entities

- ◆ Adequate economic, financial, and other resources that allow individuals, families, and communities to access the opportunities they need to succeed and improve their living conditions and ultimately, their health.

Partnerships

Partnerships are a vehicle through which communities can mobilize and take action to end health disparities. When actual community involvement exists, partnerships can address community health concerns while aiding and developing capacity in those communities. Thus, partnerships are vehicles to increase community participation, leadership skills, resources, social and inter-organizational networks, sense of community, community power, and community problem solving.[46]

> "It's critical to know who our partners are in our efforts to eliminate health disparities. Listening to perspectives from nontraditional partners is essential for applying new ideas."
>
> – NPA Regional Meeting Participant

Thousands of partnerships, anchored by government or community organizations, have formed over the past two decades to support health-related activities. Health partnerships are collaborations in which organizations agree to work together to achieve shared or complementary goals that lead to improvements in health, safety, or well-being.[47] A partnership is action-oriented and focuses on reducing or preventing community problems by analyzing the problem, identifying and implementing solutions, and creating social change. [47]

The best of these partnerships bring people together, expand resources, focus on issues of community concern, and achieve better results than any single group could achieve alone. Partnerships offer many direct and indirect benefits[48] such as:

- ◆ Serving as effective and efficient vehicles for exchanging knowledge and ideas

- ◆ Demonstrating and developing community support or concern for issues

- ◆ Maximizing the power of individuals and groups through collective action

- ◆ Improving trust and communication among community agencies and sectors

- ◆ Mobilizing diverse talents, resources, and strategies

- ◆ Building strength and cohesiveness by connecting individuals and organizations

- ◆ Reducing the social acceptability of health-risk behaviors

- ◆ Changing community norms and standards

The pooling of resources, mobilization of talents, and use of diverse approaches that typify effective partnerships make them a logical cornerstone in any effort to end health disparities. Inequities in health have multiple causes and consequences that require complex solutions and actions from multiple disciplines and sectors (e.g., social services, health, housing, education, and law enforcement, among others). However, health and human service organizations often are limited in addressing such issues due to duplication of efforts, fragmentation of services, multicultural insensitivity, and unequal access to resources.

Through the sharing of human and material resources, finances, and time, partnerships provide a multifaceted approach to any issue. Such partnerships may even counter the declining trend in civic engagement and re-engage individuals and organizations to address local problems.[49] In fact, partnerships are appealing because they mirror the very principles of democracy that encourage their formation — principles such as civic participation, equality, tolerance, human rights, accountability, and transparency.[50] In short, local, state, tribal, regional, and national organizations must work collaboratively with the individuals, families, and communities that are affected by health disparities if these organizations hope to effect change.

Cultural and Linguistic Competency

Improving cultural and linguistic competency is necessary for achieving better health outcomes for racial and ethnic minorities and underserved populations. *Cultural competency* supports the view that health values, beliefs, practices, and behaviors are culturally bound.[51] Understanding how culture and health intersect fosters improved health outcomes. Many of the challenges encountered when integrating cultural competence into health care come from insufficient understanding of the role of culture in defining health.

Culture can be defined as a "set of shared attitudes, values, goals, and practices."[52] Culture influences a group's ways of thinking, feeling, and acting. Culture informs how a group perceives health, wellness, disease, health care, and prevention. As a concept, a definition, and a set of values, *cultural competency* was originally defined as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations."[53] Since then, service and support agencies and systems have adapted the definition to address their own vision, mission, and values.

Linguistic competency is less debated and more clearly understood by healthcare system administrators and providers. However, in practice, the focus has been more narrow than delineated by its definition, which is "the capacity of an organization and its personnel to communicate effectively and to convey information in a manner easily understood by diverse audiences, including persons of limited English proficiency (LEP), those who have low literacy skills or are not literate, and individuals with disabilities."[54] Most organizations recognize the need to provide translated materials and interpreters to LEP individuals and to individuals with disabilities. Rarely do organizations recognize the relationship of literacy to health literacy. Providing materials for individuals who have low literacy skills is also part of the framework for providing linguistically competent services.

Ensuring that LEP individuals receive services is based on federal law. Title VI of the Civil Rights Act of 1964 and its implementing regulations prohibit conduct that has a disproportionate adverse effect on LEP persons due to their race, color, or national origin. Thus policies and practices that adversely affect people with limited English proficiency may constitute national origin discrimination. The failure of recipients of federal financial assistance (often healthcare system administrators and providers) to take reasonable steps to provide LEP persons with a meaningful opportunity to participate in federally funded programs may constitute a violation of Title VI.[55]

Nondiscrimination

Virtually all hospitals — and most healthcare providers — are subject to federal civil rights laws.[55, 56, 57] These laws prohibit discrimination and ensure that federal funds are not used to support programs or activities that discriminate on the basis of race, color, national origin, disability, or age. For example, HHS implementing regulations for Title VI require that healthcare providers receiving federal funds (including Medicare, Medicaid, Children's Health Insurance Program [CHIP], grants from CDC, NIH, or any other HHS agency) may not engage in any of the following activities based on race, color, or national origin:

- ◆ Deny services, financial aid, or other benefits provided as a part of health or human service programs

- ◆ Provide a different service, financial aid, or other benefit, or provide them in a different manner from those provided to others under the program

- ◆ Segregate or separately treat individuals in any matter related to the receipt of any service, financial aid, or other benefit

In any of a number of their roles — e.g., as members of quality improvement teams, clinician-educators, community and patient advocates, or hospital board members — health and healthcare workers must be sensitive to any potential for civil rights violations. It is critical to be aware of and report concerns about compliance with federal civil rights laws. Everyone should have a commitment to report violations of the law, to protect the vulnerable, and to support access to quality health care for all people. In doing so, we can eliminate discrimination as a cause of health and healthcare disparities.

It is widely accepted that discrimination, racism, and bias directly and indirectly contribute to negative health outcomes and to health disparities.[58-63, 59, 66] The mechanism or magnitude of the connection between racism and health disparities has not yet been fully clarified.[59,60,61,63] Nevertheless, numerous studies associate real or perceived experiences of racism with increased risk for physical and psychological diseases.[59,60,63] For example, there may be associations with increased rates of hypertension, respiratory problems, chronic conditions, and poorer perceived physical health.[59,61,63,64,65] Acute or long-term exposure to racism may manifest as a stress response, which triggers harmful physiological and psychological pathways, as do other stress-causing experiences.[63]

> *"Of all the forms of injustice, inequality in health care is the most shocking and inhumane."*
>
> *– Dr. Martin Luther King, Jr.*

Many of the limitations on research that seek to establish and define the link between racism and poor health outcomes relate to the difficulties of measuring racism, ethnicity, and lifespan socioeconomic inequalities.[59, 63] The reality of inadequate data and gaps in knowledge on this subject highlight the need for solid, evidence-based studies on the connection between racism and health disparities — with the objective to determine how long-term exposure to bias affects health.

Racism can be categorized as follows:[60, 62]

◆ Institutionalized — "differential access to the goods, services, and opportunities of society by race"

◆ Personally-mediated — "prejudice and discrimination by individuals toward others"

◆ Internalized — "acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth"

The social movements of the 20th century resulted in significant reductions in discrimination and racism — and in major reductions in early death and the spread of disease. These changes were often interrelated. For example, systemic institutional changes such as the establishment of child labor laws; improved working and housing conditions; the civil rights movement; increased access to care for minorities; and anti-discrimination laws all indirectly or directly led to positive health outcomes, especially for those who had been marginalized in society.[67]

A pertinent illustration is the lack of trust in the medical establishment.[68, 69, 70] It is generally held that this phenomenon reflects an intergenerational awareness of past incidences of medical abuse and mistreatment of minority patients. Examples include segregated medical care; the abuses of the Tuskegee syphilis study of African American men conducted by the Public Health Service; questionable radiation studies among Alaskan Natives in the 1950s; coerced, unwitting, or underage sterilization among American Indian women in the 1960s and 1970s; high rates of sterilization of Hispanic women in New York City, California, and the Southwest; and use of Puerto Rican women during the 1950s as research subjects in early clinical trials of birth control pills.[71-79]

Public policies and personal patterns of behavior that were common in the past may still be reflected in some of our society's old operating patterns, laws, assumptions, and behaviors. For example, existing patterns of housing; location and quality of neighborhoods; bias in medical care access and delivery; the stress of real and perceived racism; and intergenerational internalization of stigma are all social determinants that contribute to health disparities.[63]

Achieving health equity requires cooperative, coordinated, and multifaceted solutions to improving determinants of health that affect various populations.[80] As described below, the mission and goals of the NPA and *National Stakeholder Strategy* aim to identify, support, and replicate such solutions.

Mission and Goals of the NPA and *National Stakeholder Strategy*

The mission of the NPA is to increase the effectiveness of programs that target the elimination of health disparities through the coordination of partners, leaders, and stakeholders committed to action. The *National Stakeholder Strategy*, one of three components of the NPA, was developed through a sequence of activities involving the collaboration of stakeholders from across the country. It was clear by the end of the sequence of activities used to develop the *National Stakeholder Strategy* that the following five goals were imperative:
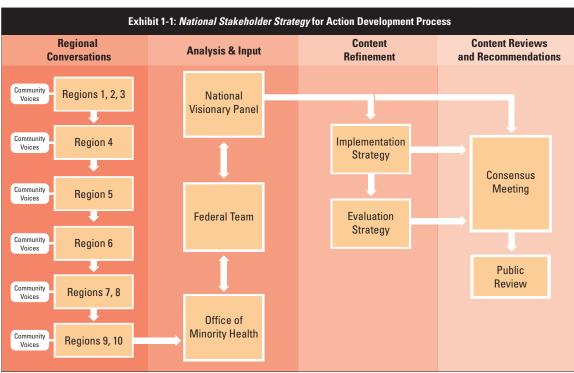
Goal 1: Awareness — *Increase awareness of the significance of health disparities, their impact on the nation, and the actions necessary to improve health outcomes for racial, ethnic, and underserved populations.*

Goal 2: Leadership — *Strengthen and broaden leadership for addressing health disparities at all levels.*

Goal 3: Health System and Life Experience — *Improve health and healthcare outcomes for racial, ethnic, and underserved populations.*

Goal 4: Cultural and Linguistic Competency — *Improve cultural and linguistic competency and the diversity of the health-related workforce.*

Goal 5: Data, Research, and Evaluation — *Improve data availability and coordination, utilization, and diffusion of research and evaluation outcomes.*

A detailed description of each goal, and the 20 strategies that support the five goals, is provided in Section 3 of this document.

PROCESS FOR DEVELOPING THE *NATIONAL STAKEHOLDER STRATEGY*

Community and Other Stakeholder Input

The process for developing the *National Stakeholder Strategy* was deliberate and began by obtaining the views of community leaders and other stakeholders. As outlined in Exhibit 1-1, the approach began with "Community Voices" meetings and "Regional Conversations" across the United States; continued on with analysis, input, and content refinement from community and additional stakeholders, experts, and representatives of federal agencies; was followed by an extended public review period and incorporation of public input into the *National Stakeholder Strategy*; and concluded with the finalization and dissemination of this document. This approach ensured that wide-ranging communities of stakeholders and diverse voices were heard and considered.

Exhibit 1-1: *National Stakeholder Strategy* for Action Development Process

*Regional Conversations included community-based representatives of African-American, Hispanic, Native American and Alaskan Native, Native Hawaiian and Pacific Islander, and Asian-American attendees at the Regional Conversations. In specific Regional Conversations, representatives from tribal, Caribbean, Pacific Islands, and academia also held meetings and/or provided input to the Regional Conversation outcomes. The Federal Team refers to the FIHET(Federal Interagency Health Equity Team).

Community Voices Meetings

The purpose of the Community Voices meetings was to draw on the expertise of individuals representing different populations to help inform the broader Regional Conversations (see below). It was important to bring together smaller groups that represented different communities to identify priorities and common issues. Participants were individuals representing specific constituencies including local communities, faith-based organizations, tribes, and geographic areas (e.g., U.S. island areas). In addition, participants also included representatives from state offices of minority health that were aligned with community missions to achieve health equity; and from universities and colleges that considered themselves supporters and data/information sources for their local communities.

"If we as a nation are to learn about creating an effective healthcare system for everybody, it is essential to hear the voices of everybody."
– Community Voices Meeting Participant

During the Community Voices meetings, participants emphasized that community involvement is necessary in creating innovative solutions to improve health outcomes. They also reported awareness of partnerships — among some academic institutions, health providers, and communities — which have played a critical role in promoting programs and solutions to address health disparities (specifically chronic disease disparities).

Regional Conversations

The Regional Conversations were designed to identify community-level priorities and develop community-inspired solutions. Six separate meetings were held in different parts of the country that included the 10 HHS regional areas (see Section 2 for a listing of HHS regional areas).

Invitations were extended to participants based upon extensive consultations with various sources including state public health and minority health officials; regional health administrators and minority health consultants; organizations representing different constituencies; and OMH partner organizations and grantees. Individuals were selected from one of six categories — community; tribal government (based on region) and tribal organizations; state government; health and healthcare systems; academic and research sectors; and the private sector (e.g., business community, employers, local and community foundations, etc.). To ensure diversity and generate community-oriented solutions, at least 40 percent of attendees were community leaders drawn from faith-based organizations, neighborhood coalitions, community-based organizations, and local government. Collectively, these conversations elicited input and fostered cooperation among a wide variety of stakeholders.

> "This Regional Conversation created a wonderful opportunity for each participant to have a voice."
> – Regional Meeting Participant

Insights and information derived from the Community Voices meetings were used as a springboard for discussion during the ensuing Regional Conversation. Each regional meeting included facilitated breakout sessions and also served as a venue for learning and open dialogue, collaborative conversations, and sharing of new ideas and insights. Participants were challenged to become a catalyst for change in their circles of influence.

Prior to each Regional Conversation, participants were asked to review several documents including profiles of health disparity initiatives and specific programs occurring in their region. They also reviewed fact sheets on health disparities and information on the importance of regional planning, building effective partnerships, and developing intrastate and interstate collaborations. Participants also were asked to consider questions such as the following before the meeting:

- ◆ What are the most pressing health disparities in your state or region? Which of these can you focus on collaboratively as a region?

- ◆ Are there any successful model programs or promising practices in your state that could work on a regional level?

- ◆ To eliminate health disparities in your region, what data or research would be useful in helping to develop a strategic action plan?

- ◆ How can you be more effective in sharing information on successes and barriers to eliminating health disparities in your region?

◆ What existing partnerships are successfully addressing health disparities in your state or region?

◆ Although societal factors (e.g., lack of insurance, economics, discrimination, lack of transportation) have an impact on health status, what local, state, and federal policies would have the greatest impact on eliminating health disparities?

◆ Are there programs or organizations in your state that have successfully developed a plan for strengthening local leadership?

> "The setting and structure of this meeting allowed for an informal atmosphere in which we were able to objectively look at our current programs and to be open to new ideas."
>
> – NPA Regional Meeting Participant

The Regional Conversations were foundational for advancing the NPA and developing the *National Stakeholder Strategy*. They also provided meeting participants an opportunity to increase their knowledge about health disparities as well as broaden the diversity of community involvement in identifying priorities, solutions, and barriers to improving the health status of racial and ethnic minority and other underserved populations (Exhibit 1-2 summarizes some of the issues identified by Regional Conversation participants). The conversations provided a venue for exchange of information, formation of new partnerships, and the development of targeted strategies for each region. From

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EXHIBIT 1 2: EXAMPLES OF ISSUES IDENTIFIED BY REGIONAL CONVERSATION PARTICIPANTS

Awareness about Health Disparities:
- Medical providers are not familiar with the prevalence of certain diseases among minority populations.
- The definition of "health" is often narrowly defined and lacks awareness that health disparities affect all populations.

Community Engagement and Capacity:
- Communities are not involved in how funding is applied.
- There is a "disconnect" between federal and state agencies when establishing priorities.
- Limited planning and funding are given to capacity building within communities.
- Grant writers are not experienced in writing for minority populations.

Access to Health Care and Quality of Care:
- Lack of preventive care — health care is more disease-management based
- Lack of information and self-guided disease management
- Lack or limited access to care — often non-existent; sometimes based on perceived ability to pay for services
- Mental health is not recognized or acknowledged within many cultures and populations

Cultural and Linguistic Competency:
- Lack of culturally competent care
- Lack of linguistically competent care
- Minorities are not adequately represented in healthcare professions and throughout the healthcare system.
- Lack of culturally competent education for providers
- Lack of respect or acknowledgment for culturally specific healing traditions

Data and Research:
- Small groups and subgroups are not included in data collection and sampling.
- Data are not shared among research institutions.
- Researchers and data collectors use tools of convenience and often will not travel into inner urban neighborhoods, to remote rural areas, or call cell phones (many people do not have landlines).

the outset, Regional Conversation participants identified "strengthening partnerships, enhancing capacity building initiatives, and improving access to care" as critical action steps for addressing health disparities.

Data Analysis, Input, and Content Refinement

A period of iterative analysis of data, input, and content refinement advanced the development of the *National Stakeholder Strategy*. This entire process is illustrated previously in Exhibit 1-1. Input from the Community Voices meetings and Regional Conversations was analyzed and organized, and then shared with community experts and federal representatives for further input and refinement. A federal team — the Federal Interagency Health Equity Team (FIHET) — provided sustained and continuing leadership for this process. The FIHET membership currently includes representatives from the federal departments of Health and Human Services, Agriculture, Commerce, Defense, Education, Housing and Urban Development, Justice, Labor, Transportation, Veterans Affairs, and Homeland Security, as well as from the Environmental Protection Agency.

A National Visionary Panel (NVP) was also convened to provide additional analysis and input. The panel represented a varied constituency of interests for eliminating health and healthcare disparities in the United States and was comprised of experts from community, public health, academic, healthcare, research, private sector, nongovernmental, and other national organizations and associations.

To begin the analysis process, the action step matrices prepared by participants from each Regional Conversation meeting were reviewed to identify the priorities that were common to all the regions. These were strategies for ending health and healthcare disparities that appeared repeatedly across regions. Ten *common* priority strategies emerged. A few regions identified *all* 10 common strategies as priorities for their constituencies; most regions only identified *some* of the common strategies as immediate priorities for their needs.

The 10 strategies common to all the regions were reviewed and refined by the FIHET and the NVP. The aim of the initial analysis of common strategies was to identify crosscutting strategies that could foster a common national reference point for shared action within and across regions. A common reference point for action also fosters efficient evaluation of outcomes.

The FIHET and the NVP identified an *additional 10 related strategies* that support and echo the 10 common strategies identified as priorities by Regional Conversation participants. FIHET and NVP representatives also contributed to linking the strategies to the five NPA goals. Thus, the *final 20 common strategies* provide a cohesive, comprehensive approach to ending health and healthcare disparities with broad applicability.

Meetings About Implementation and Evaluation of the National Stakeholder Strategy

Meetings with community practitioners and experts were also convened to begin exploring implementation and evaluation strategies for the *National Stakeholder Strategy*. These individuals were knowledgeable about a wide range of topics such as community collaboration, community engagement, multi-level support structures and processes, evaluation methods, and data analyses and reporting.

Reviews and Recommendations

The final stages of the development of the *National Stakeholder Strategy* involved input from a consensus meeting representing broad constituencies, an extended period of public review, and incorporation of public comments into the final strategy.

Consensus Meeting

OMH facilitated a meeting that brought together community leaders and other stakeholders to comment and vote on strategies, objectives, and measures. Seven expert panels presented on the strategies, objectives, and measures that had been developed throughout the *National Stakeholder Strategy* development process and provided recommendations for implementation and evaluation. Each panel was followed by a facilitated discussion where meeting participants could respond to the presentations and present additional priority objectives and measures that they believed would best support the NPA and *National Stakeholder Strategy*. At the end of each facilitated discussion, participants were asked to evaluate the information that was presented and discussed, and then vote for the strategies, objectives, and measures that they considered most aligned with the NPA and *National Stakeholder Strategy* goals.

Public Review

The draft *National Stakeholder Strategy* (identified as the *National Plan for Action* at that point in time) was posted online along with information requesting public comment. The process yielded a robust response from the public — approximately 2,200 comments were received, processed, and incorporated into the *National Stakeholder Strategy* wherever possible. Many comments provided information about the organizations submitting comments, health-related topics for inclusion in the *National Stakeholder Strategy*, general views about the *National Stakeholder Strategy*, and recommendations for specific additions and edits.

> "I feel this plan will bring forth true change, as a Community Leader I really feel that this will help us to build trust between our communities and healthcare industry."
> – Comment by Public Reviewer

SUMMARY

This section described the past, current, and future context for the *National Stakeholder Strategy* and the process by which it was developed. There is substantial evidence that supports the concerns about health disparities that were raised by community and other stakeholders who participated in the process that produced this strategy. Section 2 provides a detailed review of this evidence that confirms and identifies the wide range of health and healthcare disparities in this country. The evidence for health disparities provided in Section 2 lends context for the stakeholder-generated strategies and tools that are offered in Section 3 and which are the heart of the NPA.