February 17, 2011

To Whom It May Concern:

On behalf of the Association of Asian Pacific Community Health Organizations (AAPCHO) and the undersigned, we would like to acknowledge the Department of Health & Human Services for its plan to close the gap in health disparities facing Asian Americans, Native Hawaiians and other Pacific Islanders (AA&NHOPIs) and ensure that this population has equal access to all segments of DHHS, its programs and services.

AAPCHO is a national not-for-profit association of 27 community-based organizations dedicated to promoting advocacy, collaboration and leadership that improves the health status and access of medically underserved AA&NHOPIs in the U.S. its territories, and freely associated states. AAPCHO advocates for policies and programs that improve the provision of health care services that are community-driven, financially affordable, linguistically accessible and culturally appropriate.

AAPCHO's members are located in states with the highest population of AA&NHOPIs in the U.S. and in communities with high concentrations of medically underserved AA&NHOPIs. AAPCHO members, 20 of which are community health centers (CHCs), provide heath care services to over 400,000 patients annually. The majority of these medically underserved patients are uninsured, Limited English Proficient (LEP), and low-income. AAPCHO member CHCs are at the forefront of providing community-responsive, financially affordable and culturally and linguistically appropriate primary medical services to their patients in more than 15 languages.

Nationwide, AA&NHOPIs face multiple barriers that limit their ability to access health care services. Up to 35% of AA&NHOPIs live in linguistically isolated households (Census 2000), and are unable to access basic health care service since few services are offered in their respective languages. AA&NHOPIs are also more likely to live in poverty, with 10% (1.3 million) living below the poverty level, according to the U.S. Bureau of the Census. Reports also indicate that 21% of AA&NHOPIs (or 2.1 million) are uninsured. One of the most difficult challenges facing some AA&NHOPI populations, such as immigrant populations, is learning to navigate the health care system. These challenges include a lack of comprehensive insurance coverage and limited access to health information due to cultural and language barriers and social isolation. For many, the community health center, whose mission is to provide health care to all regardless of an individual's ability to pay for those services, is their *only* source of health care.

Community health centers and those serving primarily medically undeserved AA&NHOPI populations, face a unique set of challenges in providing care to their patient populations and subpopulations. Those challenges range from workforce development shortages to adequately prepping their organizational infrastructures to participate in Health Information Technology. Moreover, the medically underserved AA&NHOPI patients served by these providers have their own distinct health disparity areas, population characteristics, and barriers to care. Health disparity areas, such as hepatitis B, diabetes as well as certain cancers, continue to persist among many AA&NHOPI subpopulations. AA&NHOPIs have higher prevalence rates of tuberculosis and hepatitis B, than other racial ethnic groups. They are the only racial/ethnic group in which cancer is the leading cause of death, with higher cancer mortality rates among AA&NHOPIs than among other racial/ethnic groups. Despite these statistics, AA&NHOPIs are often portrayed as a "model minority". Existing health data on AA&NHOPIs are limited and often represent the group as a whole, masking the documented differences and disparities among the numerous AA&NHOPI subgroups.

While we believe DHHS' plan is in itself a thoughtful response that addresses the health and access issues facing AA&NHOPI populations, we hope the agency will consider the unique concerns and issues we raise on behalf of medically underserved AA&NHOPI patients and the community health centers that serve them. It is important that these two groups are *not* left behind in any national strategy that is developed to improve AA&NHOPI health. It is our hope that the submission of these comments and recommendations will lead to improved health and access to services for medically underserved AA&NHOPIs and a stronger safety net of providers that can continue to deliver quality health care to their patients, and is well-

positioned to move forward and capitalize on new health care reform developments and technologies.

Data Collection

As the nation moves forward with the implementation of Health Information Technology (HIT), many health care providers are rapidly attempting to ensure that their organizations are ready to capitalize on the benefits of this technology. CHCs are no different, and are evaluating their current infrastructures and determining how to integrate this technology. AAPCHO believes we must increase the capacity of CHCs to collect electronic data so we can improve overall research and data collection for underserved AA&NHOPI populations. There is currently a dearth of research and health data on the AA&NHOPI population as a whole. Moreover, data on underserved AA&NHOPIs is near non-existent. By building the capacity of CHCs to implement electronic data collection systems, we will help yield a more robust cache of AA&NHOPI disaggregated data. And in doing so, it will help give us a clearer, bigger picture of medically underserved AA&NHOPI subpopulation needs, and give us the data to justify the health disparities and health care needs of these population groups.

In order to achieve this goal we should create more federal and state funding opportunities (e.g. demonstration projects) that would enable CHCs to build its HIT capacity to collect data. Creating a national data registry and securing funding for such a project (either through federal or state agencies), would be another strategy that would allow AA&NHOPI-serving CHCs a central place to store electronic medical data on chronic diseases, enabling services/cultural and linguistic services, immigration, AA&NHOPI ethnicity, language, insurance, etc. A data repository of health data on AA&HOPI patients at CHCs currently does not exist. A final strategy would be to encourage HHS agencies to partner on this initiative. A benchmark that could be utilized for this goal would be the development of a national AA&NHOPI health center data registry. Establishing a registry would be a marked first step in tracking the overall health status of underserved AA&NHOPIs.

Just as there is a dearth of data on AA&NHOPI health issues, so is there an equally significant gap in research on AA&NHOPI populations. AAPCHO believes that through HHS' proposed plan there is an opportunity to change this trend, especially in the ever-growing popularity of Community-Based Participatory Research (CBPR), as well as the new Patient-Centered Outcomes Research (PCOR) methodology enhanced by the ACA. To do so, AAPCHO recommends that the capacity of AA&NHOPI communities to engage in PCOR and the organizations that participate in such research, be strengthened considerably. Engaging communities so they are able to participate and lead such community-based research efforts requires a multi-pronged approach.

AAPCHO first recommends that HHS work with lead national research agencies, such as the National Institutes of Health and the Agency for Healthcare Research and Quality to develop more funding, grant opportunities that enable AA&NHOPI communities to participate in PCOR. Grant opportunities that target AA&NHOPI communities are currently limited, and increasing these opportunities should help encourage more AA&NHOPI-specific research. Second, to ensure that more AA&NHOPIs participate in PCOR opportunities, HHS should work with federal grant-making agencies to ensure that AA&NHOPIs are included in grant and peer review committees. By increasing AA&NHOPI participation in grant and peer review committees, you will be allowing more AA&NHOPIs to become more familiar with the grant and peer review process. And lastly, HHS should work with health center networks that have an established relationship with AA&NHOPI communities, so it can better engage those communities and garner their participation in PCOR-related projects. It can be challenging to engage newer communities to participate in research, but by working with health center networks that have established relationships and trust with AA&NHOPI communities, these communities may be more effectively encouraged to participate in PCOR. A benchmark for this goal would be increased engagement and funding for AA&NHOPI community-led CBPR opportunities. Though we believe these are all smaller steps, we think each can go a long way in encouraging members of the AA&NHOPI community to participate and understand the importance of PCOR.

And lastly, the Patient Protection and Affordable Care Act of 2010 created the Patient Centered Outcome Research Institute (PCORI) as a non-profit organization charged with helping carry out research projects that provide quality, relevant evidence on how diseases, disorders, and other health conditions can

effectively and appropriately be prevented, diagnosed, treated, monitored, and managed. The Act calls on the appointment of new members to serve on a PCORI Board of Governors. There will also be a number of open positions on new committees (e.g. methodology committee) related to this body. In order to increase the capacity to conduct AA&NHOPI PCOR, AAPCHO recommends that HHS work with this entity and other federal partners to ensure that more AA&NHOPI community health centers and Community-Based Organizations (CBOs) have a voice within PCORI initiatives and strategies. By engaging CHCs and CBOs, we are ensuring that AA&NHOPI populations are not left out of future research and funding opportunities and that these populations do in fact benefit from this research. In addition, CHCs have health information technologies that can be leveraged to conduct PCOR research. A benchmark for this goal will be AA&NHOPI involvement in community stakeholder groups and PCOR committees, and priority-setting for grants and in peer review groups for funding opportunities.

Workforce

While the issue of workforce development and the shortage of medical professionals is a daunting problem that plagues the entire health care industry, the problem is especially acute for community health center providers. For community health center providers, who specialize in providing health care for underserved populations that is culturally and linguistically appropriate, it is critical to maintain not only a steady pipeline full of qualified doctors, nurses, physician's assistants, etc., but of professionals who are of the same culture or speak the same languages as the CHC's patients and who want to continue serving underserved patients. In order to ensure that medically underserved AA&NHOPIs continue to receive quality care and ensure that CHCs can continue to provide that care, a multi-faceted plan should be in place to address these shortages.

Though a goal does exist to address this workforce shortage issue, it currently falls under the umbrella of mental health and substance abuse. We believe similar workforce strategies and attempts to increase applications from AA&NHOPIs in the NIH and HRSA Loan Repayment Programs can be made more widespread and applied more broadly to other primary health care disciplines. CHCs and other primary care providers across the country would benefit from these adjustments.

With the impending use of HIT across the CHC network, there is also a need to prepare current health care providers with appropriate training to prepare them for the integration of HIT. To help organizations in this transition, a HIT Workforce Program that recruits and trains people to work and serve in underserved areas should be established. Creating such a program will help ensure that this new field and technology will address the development needs of underserved communities integrating HIT. Such a program will also help ensure that there is a viable HIT workforce that can be maintained. AAPCHO recommends that HHS and other federal agencies work with the National Health Information Technology Collaborative for the Underserved, which raises awareness of the benefits of and opportunities for workforce development and training in HIT. AAPCHO also recommends that community colleges that participate in AAPI-serving institutions program adopt existing HIT curriculums.

Lastly under this category, AAPCHO believes there should be a workforce recruitment and retention strategy specific to Native Hawaiians and Pacific Islanders, and one that is sensitive to the distinct needs of different regions, both in Hawaii and the Pacific jurisdictions. The workforce and health professional capacity between different islands and regions can differ widely, as do each region's/island's needs. For example, the more rural and less populated island of Lanai (which has few healthcare providers and also has faced challenges in retaining its providers) has notably different workforce needs than the island of Oahu, which is far more urban and populated. AAPCHO would recommend assessing the workforce needs within these areas, and devising focused, individual strategies and plans based on those assessments. There are significant populations of medically underserved Native Hawaiian and other Pacific Islanders living in Hawaii and the Pacific Jurisdictions. The health and access needs of these subpopulations are considerable, and should not fall below the radar within workforce shortage assessments. In addressing workforce needs, it is important to ensure that we are comprehensively canvassing and addressing the great need within those regions where medically underserved patients and providers exist.

Native Hawaiians and Pacific Islanders

Within the category of Native Hawaiians and Pacific Islanders, AAPCHO is pleased that HHS has

identified mapping the incidence of chronic disease among Native Hawaiians and Pacific Islanders as a priority. These subpopulations are disproportionately affected by certain diseases like diabetes and tuberculosis, to name a few. AAPCHO believes the agency could go one step further however and incorporate GIS mapping of elements that capture the "health access reality" of underserved AA&NHOPI populations. While mapping the incidence of chronic disease is a good starting point, we believe that mapping the proximity of these individuals to their closest community health center and/or facility that offers chronic disease management care would be most useful. Such maps would be a useful tool for community health centers and will be an important of moving forward solution-oriented, rather than problem-focused discussions.

Hepatitis **B**

AAPCHO is pleased that HHS recognized **Hepatitis B** as a persistent disparity area among AA&NHOPIs that requires continued diligence and attention. While this disparity issue is not unique to medically underserved AA&NHOPI patients, it is a significant disparity area that affects the whole AA&NHOPI community as well as the CHCs that serve them. Nationally, Asian Americans account for more than 50% of chronic hepatitis B virus cases. Laotians are the number one carriers of hepatitis B in the U.S. One in 10 AA&NHOPIs in the U.S. suffer from chronic hepatitis B. An estimated 65% of people chronically infected are unaware of their infection and at risk of transmitting the infection and of progressing to liver disease or developing liver cancer. AAPCHO recommends that greater screening efforts should be pervasive in all hepatitis B national strategies. Although hepatitis B continues to be a major health disparity, there is a safe and effective vaccine that can be used to close this gap. AAPCHO further recommends that vaccination be more strongly integrated into HHS' plan either as its own goal, or that "vaccinations" be explicitly included in each hepatitis B goal. We could drastically help reduce the morbidity and mortality of hepatitis B in the US if we ensure that vaccinations and screening are available and conducted.

AAPCHO also believes that you cannot begin to adequately address hepatitis B, unless you address liver cancer. Liver cancer is the third leading cause of cancer death among AA&NHOPIs. Within the U.S., Asian Americans are 6 to 13 times more likely to die from liver cancer than are Caucasians, with Vietnamese Americans 13x higher, Korean Americans 8x higher, and Chinese Americans 6x higher. Chronic hepatitis B is a leading cause of liver cancer, and one out of four chronic hepatitis B carriers will die of liver cancer. Because of these statistics, AAPCHO believes that liver cancer should also be included in an HHS' plan that addresses hepatitis B. We should aim to not only decrease the burden of hepatitis B virus infection, but we must also strive to decrease the burden of liver cancer. There should also be national education campaigns and community-based outreach that focuses on liver cancer, as many families are familiar with liver cancer deaths but are unaware of the connection of liver cancer to hepatitis B infection.

And finally, AAPCHO also believes that Perinatal HBV is a serious health issue among AA&NHOPIs that was omitted from the HHS plan. Perinatal HBV is not included within HHS' plan for hepatitis B, despite the fact that an estimated 1,000 babies are infected every year in the U.S. AAPCHO recommends that Elimination of Perinatal HBV be added as a separate goal, and that federal agencies such as the CDC and HRSA better coordinate their efforts to ensure that screening and vaccination is expanded under current HB perinatal case management programs. The CDC currently limits its coverage to prophylaxis for mothers and vaccination of all contacts within the mother's household. CMS can also play a role in this effort by implementing the perinatal hepatitis B screening quality endorsed by the National Quality Forum.

Cultural Competence and Language Access

AAPCHO also believes that any plan that addresses the needs of AA&NHOPIs must also stress the need for **Cultural Competence and Language Access**. Across AAPCHO's 27 members, some providers serve up to 99% Limited English Proficient patients. In 2008 more than half of AAPCHO's member patients were best served in a language other than English. The number of LEP patients served increased 134% between 2000-2008. Inadequate LEP information or information that is appropriate and sensitive to a patient's culture, often leads to delayed access to preventive and timely primary care services and increased utilization of ER services. We believe adequate support for interpreter services must remain a constant priority across all HHS-supported services and programs. We must strive to ensure that language access **is** accessible to all LEP individuals. AAPCHO's recommendation is that all DHHS goals and objectives

related to the provision of health care services include the integration of the national Culturally and Linguistically Appropriate Services (CLAS) standards for health care providers. The 14 standards, which comprise Culturally Competent Care, Language Access Services, and Organizational Supports for Cultural Competence, should be integrated throughout health care provider organizations and undertaken in partnership with the community that is being served. By utilizing the CLAS standards, we will help ensure that all health care providers are attempting to make their practices more culturally and linguistically accessible to their patients.

We thank you again for your thoughtful response in crafting the HHS Agency Plan for White House Initiative on Asian Americans and Pacific Islanders. We hope you will consider our recommendations as outlined above, as they were meant to ensure that the issues medically underserved AA&NHOPIs across the US and Pacific jurisdictions and the community health centers that serve them are represented in all initiatives and efforts that seek to improve the health of A&&NHOPIs overall.

Thank you for your time and consideration.

Sincerely,

Jeffrey Caballero, MPH Executive Director

AAPCHO (Association of Asian Pacific Community Health Organization)-Oakland, CA Aloha Care-Honolulu. HI Asian American Health Coalition/dba/HOPE Clinic-Houston, TX Asian Americans for Community Involvement-San Jose, CA Asian Center-Southeast Michigan-Southfield, MI Asian Community Alliance, Inc.-Cincinnati, OH Asian Health Services-Oakland, CA Asian Liver Center at Stanford University-Stanford, CA Asian Pacific American Legal Center-Los Angeles, CA Asian Pacific Health Care Venture -Los Angeles, CA Asian Pacific Health Foundation-San Diego, CA AsianWeek Foundation-San Francisco, CA B Free CEED (Nat'l Center of Excellence in the Elimination of Hepatitis B Disparities) Coalition-New York, NY California Hepatitis Alliance-Sacramento, CA Caring Ambassadors Program-Oregon City, OR Charles B. Wang Community Health Center-New York, NY Chinatown Service Center Community Health Center-Los Angeles, CA Community-University Health Care Center-Minneapolis, MN Family Health Center of Worcester-Worcester, MA Hep B Foundation-Doylestown, PA Hep B Free San Diego-San Diego, CA Hep B Free San Francisco-San Francisco, CA Hep B Free-Long Beach/South Bay-Long Beach, CA Hep B Free-Los Angeles-Los Angeles, CA Hep B Free-Orange County-Orange County, CA Hepatitis B Initiative of Washington, DC-Washington, DC Hepatitis Foundation International-Silver Spring, MD Immunization Action Coalition-St. Paul, MN International Community Health Services -Seattle, WA Kalihi-Palama Health Center-Honolulu, HI

Ko' olauloa Community Health & Wellness Center-Kahuku, HI Kokua Kalihi Valley Comprehensive Family Services-Honolulu, HI Kwajalein Atoll Community Health Center - Ebeye, MH Lowell Community Health Center-Lowell, MA Midwest Asian Health Association (MAHA)-Chicago, IL National Alliance to Nurture the Aged and the Youth-North Miami, FL National Taskforce Hepatitis B: Focus on Asian and Pacific Islander Americans-San Francisco, CA National Viral Hepatitis Roundtable-Rohnert Park, CA Neighborcare Health-Seattle, WA North East Medical Services-San Francisco, CA Operation Samahan-National City, CA Pacific Islands Primary Care Association-Honolulu, HI Papa Ola Lokahi-Honolulu, HI PTSO of Washington-Seattle, WA South Cove Community Health Center-Boston, MA The Bay Clinic, Inc.-*Hilo*, *HI* Waianae Coast Comprehensive Health Center-Waianae, HI Waimanalo Health Center-Waimanalo, HI West Hawaii Community Health Center-Kailua Kona, HI