<u>Summary of Recommendations for DHHS</u>
Updated for July 13, 2011 AA and NHPI Stakeholder Meeting

Prepared by: Asian & Pacific Islander American Health Forum, Asian Pacific American Labor Alliance, Asian and Pacific Islanders with Disabilities of California, Asian Pacific Partners for Empowerment Advocacy & Leadership, Association of Asian Pacific Community Health Organizations, Association Hawaiian Civic Clubs, National Asian Pacific American Families Against Substance Abuse, National Asian Pacific American Women's Forum, National Asian American Pacific Islander Mental Health Association, National Coalition for Asian Pacific Community Development, National Council of Asian & Pacific Islander Physicians, Native Hawaiian & Pacific Islander Alliance, Papa Ola Lokahi, and Southeast Asia Resource Action Center

1. Improve the collection, reporting and disaggregation of race, ethnicity and primary language data on Asian Americans, Native Hawaiians and Pacific Islanders.

<u>Problem</u>:

There is currently a dearth of research and health data on Asian Americans, Native Hawaiians and Pacific Islanders (AA and NHPIs). Moreover, data on underserved AA and NHPIs is near non-existent. While there have been improvements in the collection and reporting of data by federal agencies, including the 1997 revisions to the Office of Management and Budget's (OMB) standards for the collection, analysis, and reporting of racial and ethnic data in the United States, a number of federal and state agencies are out of compliance with the revised standards. For example, many health surveys still aggregate Native Hawaiians under an old outdated "API" ("Asian Pacific Islander") identifier. This does a tremendous disservice to Native Hawaiians and other ethnic subgroups because it masks health disparities affecting these populations and prevents our communities from providing a true picture of our health status.

We are pleased that HHS has released new draft standards for collecting and reporting data on race, ethnicity, sex, primary language and disability status pursuant to Section 4302 of the Patient Protection and Affordable Care Act (ACA). We hope the new standards promote a department-wide approach to addressing these gaps and inconsistencies to ensure that disaggregated race, ethnicity, primary language, sex and disability status data is collected, reported and analyzed throughout all HHS programs, activities and surveys.

In addition, the ACA bolsters the capacities of community health centers and low-resourced providers in communities of color to implement electronic data collection systems to help yield a more robust cache of AA and NHPI disaggregated data. Doing so will help give us a clearer, bigger picture of medically underserved AA and NHPI subpopulation needs, and give us the evidence to identify the health disparities and health care needs of these population groups.

<u>Solutions</u>:

- Adopt the recommendations from the Institute of Medicine's (IOM) 2009 report, *<u>Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement</u>*, on standardization of race, ethnicity and language data in the implementation of Sec. 4302 of the ACA. At a minimum, all HHS programs, activities and surveys must comply with the revised OMB standards. This includes, for example, the collection of alcohol, tobacco and other drug data for AA and NHPI populations in the Continental US, Hawaii and six Pacific Island Jurisdictions.

- Enforce and enhance complete reporting of data on Native Hawaiian and Pacific Islander health status nationally in accordance with the OMB revised standards. Federal agencies, state governments, and private foundations need to evaluate their data collecting, analyzing, and reporting standards to assure that they comply with OMB revised standards and, further, be able to correctly identify Native Hawaiian and Pacific Islander data as they may relate to their respective reporting requirements and/or studies.

- HHS should also engage in equal partnership with NHPI leaders to identify strategies to collect data on NHPI population groups, and work with these leaders in the analysis of this data. This process will help ensure the accurate portrayal of socio-demographic data and health profiles of NHPIs, increase HHS' ability to track progress and compare subpopulation groups (for use in the Healthy People 2020 objectives for instance), facilitate proper dissemination and utilization, as well as report back to NHPI communities.

2. **Increase the availability of culturally and linguistically appropriate services, and make investments in developing a culturally and linguistically appropriate workforce.**

<u>Problem</u>:

When health systems lack cultural and linguistic competence, they fail to meet standards of quality care. Asian Americans, Native Hawaiians and Pacific Islanders often face cultural and language barriers when seeking health care services, and are also underrepresented in many sectors of the professional and allied health care workforce. Native Hawaiians in particular have and continue to be underrepresented in health and allied-health professions.

There is a great need to ensure that culturally and linguistically appropriate services are provided in health care and health promotion programs. For example, alcohol, tobacco and other drug prevention, treatment and recovery services for AA and NHPI populations must be culturally competent and available in the Continental U.S., Hawaii and the six-Pacific Island Jurisdictions.

There are opportunities to address cultural and language access needs in the implementation of health reform, particularly through the health insurance exchanges. Since HHS will set the floor for how states design and structure their health insurance exchanges (HIE) and what services will be offered in HIE plans, it is important that HHS promulgate regulations that require a comprehensive package of services that include enabling services.

<u>Solutions</u>:

- To ensure compliance with the February 17, 2011 memo from the Department of Justice (DOJ) directing all federal agencies to review its commitment to Executive Order 13166, HHS must consider the needs of Limited English Proficient (LEP) individuals in the drafting of all ACA-related regulations, policies, procedures, and websites that are being developed and implemented, including plans participating in the HIE. Language services – including oral interpretation and written translation – should also be required in all new demonstration programs, payment systems, and models enacted as part of the ACA.

- Fund distance learning and telemedicine strategies for AA and NHPI communities to receive cultural competency training, technical assistance and other services through these technologies.

- Set aside at least 5% of the training fund at the Bureau of Health Professions at HRSA for AA and NHPI service providers. HHS should also dedicate federal funds for increasing and expanding Native Hawaiian health and allied-health workforce development. Besides the Native Hawaiian Health Scholarship Program, other federal initiatives such as the various health and allied-health professions loan repayment programs need to be expanded to include specific Native Hawaiian initiatives. The Department needs to actively recruit Native Hawaiians by offering summer internships and other types of learning experiences for Native Hawaiians.

- Support the development, testing, and utilization of effective culturally and linguistically appropriate health and socio-demographic survey tools to investigate underlining mechanisms of health differentials experienced by NHPI population groups.

3. Invest in prevention services and programs that reduce disparities in chronic diseases.

Problem:

Despite having higher rates of certain health conditions, many Asian American, Native Hawaiians and Pacific Islanders do not receive the recommended levels of prevention, counseling or care that they need. For example, Asian Americans are 6 to 13 times more likely to die from liver cancer than are Caucasians. Chronic hepatitis B is a leading cause of liver cancer, and one out of four chronic hepatitis B carriers will die of liver cancer. Thus, liver cancer and chronic hepatitis B should be included in any HHS plan that addresses health disparities. In addition, tobacco is the single most preventable cause of death and disease in the country, therefore integration of tobacco with other chronic disease and health issues is essential.

With the enactment of the ACA, we are pleased that the CDC and other HHS agencies are dedicated to reforming our health care system from a treatment model to a prevention model of care. As such, successful prevention programs such as tobacco control policy initiatives will result in the need for cessation services, particularly among those populations most impacted by tobacco and least able to access culturally appropriate cessation services.

Solutions:

- The planned national hepatitis B education campaigns and community-based outreach initiatives should incorporate liver cancer, as many families are familiar with liver cancer deaths but are unaware of the connection of liver cancer to hepatitis B infection. Additionally, HHS can restore availability of hepatitis B vaccine supply recently eliminated from the section 317 vaccines for our public programs and the safety net.

- Integrate tobacco cessation into the work of all chronic diseases. Ensure that comprehensive cessation services are reimbursable in all public and private health insurance plans and that funding for culturally and linguistically appropriate cessation services are provided.

- Provide funding for culturally tailored approaches to health promotion and policy initiatives (including the Community Transformation Grants) that are focused on specific ethnic/racial and LGBT populations both on the local and national level. Ensure that RFAs/FOAs are truly focused on these ethnic/racial/LGBT communities so that they can respond in an appropriate way.

4. Reduce disparities in access to care by making health care reform work for marginalized communities and adopting an integrated model of care.

Problem:

To truly fulfill the promise of health reform, HHS must also increase health care access and coverage for the most vulnerable populations including immigrants and underserved communities such as Native Hawaiians and Pacific Islanders. In addition, closing the gap in health care access means HHS must do its part to ensure that women and girls are able to access the full range of reproductive health care options.

It is also imperative that mental health and substance abuse be meaningfully included in discussions to reduce health disparities and implement health care reform. AAs and NHPIs are not immune to mental health and substance use disorder disparities and many suffer from alcoholism, problem gambling, tobacco use, depression, suicide, post-traumatic stress disorder and other serious mental health and substance abuse issues. Nearly 19 percent of AA and NHPI substance abuse treatment admissions were for stimulant abuse compared with 5 percent in the total treatment population (The DASIS Report: Asians and Pacific Islanders in Substance Abuse Treatment Admissions, 1999). People with serious mental health problems die 25 years earlier than the general population because of medical conditions that could have been treated had they received proper mental health care. An integrated model is needed to provide a holistic and culturally responsive approach that does not separate the mind and body.

One of the greatest challenges in providing mental health services and substance abuse treatment is the lack of appropriate resources in many communities. Proper use of technology can help close the gap by improving access to providers in both the mental health and substance abuse treatment arena. It is also important for HHS to play a role in improving efforts to train mental health and substance abuse treatment professionals on integrated care. Consumers are also a valuable and underutilized resource and should receive training and compensation as peer specialists. Physicians also need to be trained on how to work with AAs and NHPIs as the inappropriate prescription of psychotropic medications continues to be a major problem. The failure to provide proper care only exacerbates an already difficult situation where a person hesitates to seek services.

Solutions:

- HHS should include comprehensive sex education programs, teen pregnancy prevention programs, Title X family planning services, and abortion services as part of a comprehensive package of preventive health care services available for women. HHS should also stand against attacks on abortion coverage and access to reproductive health care for low-income women.

- Support provisions in the Affordable Care Act that include parity for mental health and substance abuse treatment services, improve the current mental health and substance use disorder workforce, and ensure that mental health and substance abuse treatment is included in the plans offered through the exchanges. Clarify the definition of "health care provider" to include mental health and substance abuse treatment professionals, psychiatric hospitals, behavioral and mental health clinics and substance abuse treatment facilities. HHS should also support efforts to develop, implement and provide supervision for an integrated approach, and ensure that resources are made available to include consumers as peer specialists.

- HHS must protect and assure the federal government's support for and commitment to Native Hawaiian health care as identified in H.R. 857 (which would provide 100% FMAP to Native Hawaiians) and the Native Hawaiian Health Care Improvement Act reauthorization; the ability for all

Native Hawaiians to access timely and appropriate health care regardless of their abilities to pay; and the ability of Native Hawaiians to administer and direct their own health care initiatives, including those providing traditional healing practices, behavioral health and health promotion practices, with federal support.

- Raise awareness about mental health and substance abuse problems and presentations in AANHPI communities, primary care physicians, and other community providers. Conduct community outreach to continue to de-stigmatize mental illness and substance abuse, and address family relations.

- Develop a pipeline for a diverse mental health workforce and substance abuse treatment professionals and ensure cultural competency trainings for providers. In addition, educate providers about medication adherence and differences in medication responses.

5. Engage Asian Americans, Native Hawaiians and Pacific Islanders as Stakeholders in HHS Outreach Efforts and Advisory Panels.

Problem:

While improvements in health systems can lead to better care and outcomes, community input and engagement can also play a major role in promoting health and reducing health disparities. Asian Americans, Native Hawaiians and Pacific Islanders are often the least represented in federal and state efforts to reduce health disparities. For example, Native Hawaiians have a special relationship with the federal government that dates back to the days of the monarchy when the kingdom had treaties with the United States, however few to none Native Hawaiians have ever been ever asked or appointed to sit on federal agency health advisory groups, committees, or commissions.

In order for policy change initiatives to be effective, it is also critical for HHS to make investments in community capacity building. Community capacity building can include community leadership development, community organizing and organizational development for Pacific Islander territories and jurisdictions, Native Hawaiians, Pacific Islanders and Asian Americans most impacted by health and health care disparities.

With health reform implementation efforts underway, it is imperative for HHS to engage community stakeholders in each stage of the reform process. For example, HHS has been successful in launching CuidadoDeSalud.gov, a Spanish version of healthcare.gov, and engaged Latino communities in a multi-city tour with senior White House officials. We hope HHS will dedicate similar resources and outreach strategies to engage AA and NHPI communities, and also make investments in building the capacity of community-based programs and initiatives.

Solutions:

- Include Native Hawaiians, Pacific Islanders and other underrepresented racial and ethnic groups on national federal advisory boards and commissions dealing with health care and research. Native Hawaiian and other underrepresented racial and ethnic groups health professionals need to be part of national health planning and health initiatives undertaken by federal agencies. HHS should also work with federal grant-making agencies to ensure that AA and NHPIs are included in grant and peer review committees.

- Protect and assure Native Hawaiians and Pacific Islanders' ability to have an open dialog with the federal government around areas of mutual concern and interest, including health care and the inclusion of NHPI representation in all bodies established under health care reform.
- Convene a separate NHPI Stakeholders meeting with HHS, to respectfully discuss these concerns and solutions, and to move cohesively and collectively onto the next steps.

6. Address program cuts and funding shortfalls to ensure the successful implementation of health care reform and other public programs.

Problem:

In today's challenging economic climate, we understand the need to reduce the national debt and deficit and put the country on a path towards fiscal sustainability. Meeting these aims means HHS must make smart investments to ensure the long-term health of our nation's families. Thus, it is important that HHS continue to support programs that are critical to Asian Americans, Native Hawaiians and Pacific Islanders during tough economic times, such as Medicaid and the Children's Health Insurance Program (CHIP). It is also critical that adequate funds are available to successfully implement key components of the ACA including prevention and investments in community-based programs and organizations.

Solutions:

- Protect Medicaid from any cuts. Medicaid matching funds are critical to state Medicaid programs that serve the most vulnerable. Medicaid is the single largest provider of health care and the single largest payer for mental health services. CMS should also avoid decreasing Medicaid DSH payment levels.

- Protect and target funding opportunities for community-based organizations that provide preventive services in Medically Underserved Areas (MUAs) and Medically Underserved Populations (MUPs).

7. Ensure compliance of existing anti-discrimination laws.

Problem:

Eleven years ago, in its decision in *Olmstead*, the U.S. Supreme Court held that Americans with disabilities have the right to live in the most integrated setting. Yet today, states are responding to budget shortfalls by drastically cutting home and community-based services. These draconian cuts are forcing seniors and people with disabilities into nursing facilities and other institutional settings because they do not have the services they need to remain independent. Seniors and people with disabilities overwhelmingly prefer to live in the community with supports rather than receive long-term assistance in a nursing facility or other institution. Unfortunately, under federal rules, the Medicaid system does not give people a choice and often requires that people go into a nursing facility or other institution to get the assistance they need.

Solutions:

- Accept, investigate and resolve individual and systemic complaints that document state policies and budget cuts that threaten the freedom of Americans with disabilities.

- Conduct regular, on-going compliance reviews of states for compliance with the *Olmstead* decision, and provide technical assistance to states to help them understand how they can voluntarily comply with the law. Develop specific benchmarks/criteria for assessing state compliance with the *Olmstead* decision, assess the states and publicly release this assessment on an annual basis.

- Work with the Department of Justice (DOJ) to develop "most integrated setting" criteria for determining when DOJ will step in and affirmatively enforce the *Olmstead* decision.

- Develop guidance with CMS for the states on the *Olmstead* decision that requires state Medicaid programs to comply with the "most integrated setting" requirement of the ADA, including a model *Olmstead* Plan that assures the freedom of Americans with disabilities who want to live in the most integrated setting. In addition, work with CMS to review state submissions for modifying their Medicaid State Plan and HCBS waiver services for the impact that these changes will have on the state's ability to comply with the *Olmstead*.

8. Develop and initiate health consultation policy for Native Hawaiians and Pacific Islanders in accordance with the Secretary's Consultation Policy for Native Americans and the UN Declaration on the Rights of Indigenous Peoples.

Problem:

Native Hawaiians, American Samoans, and Chamorro are indigenous Peoples of the United States and have been recognized as such in federal programs within DHHS for many years. (Please see appendix A for more background on the history of Native Hawaiian sovereignty.) As a result, these groups were afforded specific consultation in health policy under the Secretary of Health and Human Services' former Tribal Consultation Policy. Last year, this document was revised to include just American Indian and Alaska Native tribal governments.

On Wednesday, 6 July 2011, Governor Neil Abercrombie, State of Hawai`i signed into law S.B. 1520 – Hawai`i State Recognition of Native Hawaiians as the Indigenous People of Hawai`i.

Solution

- The Secretary must come forth with a document addressing health consultation policy and procedures for the other Native American Indigenous Peoples. This is consistent with the President's recent support of the UN Declaration of the Rights of Indigenous Peoples.

9. **Ensure inclusion of Asian Americans, Native Hawaiians and Pacific Islanders in human service programs at HHS:**

Problem:

Although the median income for Asian Americans is higher than the national median, the poverty rates are higher and incomes for some ethnic groups substantially lower than the national median. Poverty rates are especially high among Asian American, Native Hawaiian and Pacific Islander ethnic groups suffering from linguistic isolation. Community-based organizations serving low income AAs and NHPIs recognize that for individuals to go from welfare to self-sufficiency, they need a comprehensive support system, which includes livable wages, job creation, safe and affordable daycare, education, health and mental health care, transportation and other linguistic and culturally competent services.

A number of social and economic barriers can lock low-income AA and NHPIs into poverty. English language proficiency constrains employment options for many, often forcing immigrants and refugees into low-wage work with few benefits and little opportunity for advancement. Hundreds of community-based organizations serving low-income Asian Americans, Pacific Islander and Native Hawaiians benefit from the Community Economic Development Discretionary Grant Program, Assets for Independence, Office of Refugee Resettlement, and Community Services Block Grant. The people they serve rely on TANF, LIHEAP and Head Start programs in order to take care of their families.

When adapted to ethnic-specific needs, community-based organizations, community development corporations and mutual assistance associations can provide low-income AAPI communities with a comprehensive strategy to tackle barriers that lead to poverty. Community economic development corporations and social service organizations provide culturally and linguistically appropriate services, education and training to increase low-income persons' access to benefits and ability to attain financial stability. The flexibility of community economic development allows AA and NHPI communities to build affordable and senior housing while providing services for new immigrant communities, such as job training, small business development, ESL instruction, and child care, to build and sustain healthy communities.

Solutions:

- Ensure inclusion of Asian American, Native Hawaiian, and Pacific Islander community-based organizations for community and economic development and human services programs at HHS, including Head Start, LIHEAP, Office of Refugee Resettlement, Community Services Block Grants (CSBG), Social Services Block Grants (SSBG), the Office of Community Services' Community Economic Development Discretionary grants, the Job Opportunities for Low Income Individuals (JOLI) program, Fresh Foods Financing initiative and Assets for Independence program.
- Assess participation and establish a baseline of participation of community based organizations in HHS Office of Community Services programs and set improvement goals.
- Conduct outreach and information sessions about Office of Community Services community development programs and grants to community based organizations that serve large numbers of low income AAPIs in economically distressed areas.
- Assess adequacy and availability of translated materials about anti-poverty benefits and programs to meet the needs of LEP AA and NHPI communities.

Appendix A- Background on Native Hawaiians

The State of Hawai`i has a special political and legal relationship with, and has long enacted legislation to promote the welfare of, the Native Hawaiian people.

The United States, through Congress, exercised its constitutional authority to confirm a treaty between the United States and the government that represented the Native Hawaiian people, and from 1826 until 1893, the United States recognized the independence of the Kingdom of Hawai`i, extended full diplomatic recognition to the Hawaiian government, and entered into treaties and conventions with the Hawaiian monarchs to govern commerce and navigation in 1826, 1842, 1849, 1875, and 1887.

Pursuant to the Hawaiian Homes Commission Act, 1920 (42 Stat. 108, chapter 42), the United States set aside approximately 203,500 acres of land in trust to better address the conditions of Native Hawaiians in the federal territory that later became the State of Hawaii and in enacting the Hawaiian Homes Commission Act, 1920, Congress acknowledged the Native Hawaiian people as a native people of the United States, as evidenced by the committee report, which notes that Congress relied on the Indian affairs power and the War Powers, including the power to make peace.

In 1959, as part of the compact with the United States admitting Hawai`i into the Union, Congress delegated the authority and responsibility to administer the Hawaiian Homes Commission Act, 1920, lands in trust for Native Hawaiians and established a new public trust, commonly known as the ceded lands trust, for five purposes, one of which is the betterment of the conditions of Native Hawaiians, and Congress thereby reaffirmed its recognition of the Native Hawaiians as a distinctly native community with a direct lineal and historical succession to the aboriginal, indigenous people of Hawai`i. The public trust consists of lands, including submerged lands, natural resources, and the revenues derived from the lands; and the assets of this public trust have never been completely inventoried or segregated.

Native Hawaiians have continuously sought access to the ceded lands in order to establish and maintain native settlements and distinct native communities throughout the State;

- The Hawaiian home lands and other ceded lands provide important native land reserves and resources for the Native Hawaiian community to maintain the practice of Native Hawaiian culture, language, and traditions, and for the continuity, survival, and economic self-sufficiency of the Native Hawaiian people as a distinctly native political community;
- Native Hawaiians continue to maintain other distinctly native areas in Hawai`i, including native lands that date back to the ali'i and kuleana lands reserved under the Kingdom of Hawaii;
- Through the Sovereign Councils of Hawaiian Homelands Assembly and Native Hawaiian homestead associations, Native Hawaiian civic associations, charitable trusts established by the Native Hawaiian ali'i, nonprofit native service providers, and other community associations, the Native Hawaiian people have actively maintained native traditions and customary usages throughout the Native Hawaiian community, and the federal and state courts have continuously recognized the right of the Native Hawaiian people to engage in certain customary practices and usages on public lands;
- There is clear continuity between the aboriginal, indigenous, native people of the Kingdom of Hawaii and their successors, the Native Hawaiian people today;

Native Hawaiians have also given expression to their rights as native people to self-determination, self-governance, and economic self-sufficiency through the provision of governmental services to Native Hawaiians, including the provision of health care services, educational programs, employment and training programs, economic development assistance programs, children's services, conservation programs, fish and wildlife protection, agricultural programs, native language immersion programs, native language immersion schools from kindergarten through high school, college and master's degree programs in native language immersion instruction, and traditional justice programs; and by continuing their efforts to enhance Native Hawaiian self-determination and local control;

- Native Hawaiian people are actively engaged in Native Hawaiian cultural practices, traditional agricultural methods, fishing and subsistence practices, maintenance of cultural use areas and sacred sites, protection of burial sites, and the exercise of their traditional rights to gather medicinal plants and herbs, and food sources;
- The Native Hawaiian people wish to preserve, develop, and transmit to future generations of Native Hawaiians their lands and Native Hawaiian political and cultural identity in accordance with their traditions, beliefs, customs and practices, language, and social and political institutions; to control and manage their own lands, including ceded lands; and to achieve greater self-determination over their own affairs.

The United States has:

- Declared that the United States has a special political and legal relationship for the welfare of the native peoples of the United States, including Native Hawaiians;
- Identified Native Hawaiians as an indigenous, distinctly native people of the United States within the scope of its authority under the Constitution of the United States of America, and has enacted scores of statutes on their behalf; and
- Delegated broad authority to the State of Hawaii to administer some of the United States' responsibilities as they relate to the Native Hawaiian people and their lands.

The United States has continually recognized and reaffirmed that:

- Native Hawaiians have a direct genealogical, cultural, historic, and land-based connection to their forebears, the aboriginal, indigenous, native people who exercised original sovereignty over the Hawaiian Islands;
- Native Hawaiians have never relinquished their claims to sovereignty or their sovereign lands;
- The United States extends services to Native Hawaiians because of their unique status as the native people of a prior-sovereign nation with whom the United States has a special political and legal relationship; and
- The special relationship of American Indians, Alaska Natives, and Native Hawaiians to the United States arises out of their status as aboriginal, indigenous, native people of the United States.