

#### HEALTH EOUITY THROUGH ENHANCED DATA

# LEVERAGING COMMUNITY COALITIONS TO IMPROVE ASIAN AMERICAN, NATIVE HAWAIIAN, AND PACIFIC ISLANDER HEALTH DATA

The Health Equity through Enhanced Data (HEED) under the Office of Minority Health National Umbrella Cooperative Agreement (NUCA) is a project of the Asian & Pacific Islander American Health Forum.

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The Asian & Pacific Islander American Health Forum (APIAHF) is a health justice non-profit organization dedicated to improving the health and well-being of more than 17 million Asian Americans, Native Hawaiians, and Pacific Islanders living in the United States and its jurisdictions. We believe that all persons have the right to be healthy, the right to live in a thriving community, and the right to quality, affordable, and accessible health care.

For the past 29 years, APIAHF has worked with community advocates, public health leaders, and policymakers to generate policies, programs, and systems changes to improve the health of Asian American, Native Hawaiian, and Pacific Islander communities. Through our policy and advocacy efforts,

APIAHF was instrumental in the creation of the White House Initiative on Asian Americans and Pacific Islanders,

fought for the passage of the Patient Protection and Affordable Care Act, and continues to demand the inclusion of Asian Americans, Native Hawaiians, and Pacific Islanders in the collection and reporting of local, state, and national health data. APIAHF works with local and state-based CBO's in 20 states and territories who provide services and advocate for AA and/or NHPI communities.

#### **MISSION**

The Asian & Pacific Islander American Health Forum (APIAHF) influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian Americans, Native Hawaiians, and Pacific Islanders.

#### **VISION**

APIAHF envisions a world where all people share responsibility and take action to ensure healthy and vibrant communities for current and future generations.

#### **VALUES**

Our work derives from three core values:

**Respect** because we affirm the identity, rights, and dignity of all people.

**Fairness** in how people are treated by others and by institutions, including who participates in decision making processes.

**Equity** in power, opportunities, and resources to address obstacles hindering vulnerable communities and groups from living the healthiest lives.

# **TABLE OF CONTENTS**

- 4 Background and Overview
- 5 Part A. Evaluating Data Sources in Five States
- 10 Part B. Case Studies of Successful Community-Led Initiatives That Improved Data on AA and NHPI Health
- 24 Conclusions and Recommendations
- 25 References

### **BACKGROUND AND OVERVIEW**

According to the 2010 decennial Census, there are 18.2 million Asian Americans, Native Hawaiians, and Pacific Islanders in the United States, yet relatively little is known about the health and health access issues affecting these communities. The need to collect more baseline data on minority health to guide interventions and health promotion programs has been well established (Smedley et al., 2003)DC</pub-location><publisher>Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. The paucity of data on Asian American (AA) and Native Hawaiian and Pacific Islander (NHPI) health, particularly those disaggregated by ethnicity, is an important barrier to improving their health, as it hampers efforts to establish baseline of health and map progress towards improving it (Ghosh, 2010). Both AAs and NHPIs are highly diverse culturally, ethnically, and socioeconomically (Cook et al., 2011; Zhou and Gatewood, 2000). The proportions of foreign-born persons and those who have limited English proficiency (LEP) also vary across AA and NHPI ethnic groups (Cook 2011). Collecting and reporting data on these social determinants of health along with health data disaggregated by ethnicity is highly important (Gosh 2009; Islam 2010). Aggregated data representative of the entire AA or NHPI population are likely to obscure health disparities experienced by AA or NHPI subpopulations, as they are more likely to reflect the health status of larger ethnic groups (for example, Chinese and Filipinos), vastly underreporting greater health needs and disparities that may be experienced by smaller, socioeconomically more disadvantaged ethnic groups (such as Cambodians, Laotians, and Tongans).

The Asian & Pacific Islander American Health Forum (APIAHF) has made concerted efforts to improve data on AA and NHPI health it in recent years, beginning with the convening of the Health Brain Trust, a series of national meetings attended by researchers, government officials, and community advocates to build a national data agenda on AA and NHPI health (APIAHF, 2007, 2008, 2009). Echoing those documented in the literature (Ghosh, 2003; Ghosh, 2009; Islam et al., 2010), key challenges identified from the Health Brain Trust included small sample sizes that do not allow stable statistical estimates and the failure to disaggregate AAs and NHPIs by ethnicity in national health data, which masks greater health needs and disparities among smaller AA and NHPI ethnic groups. Strategies to address these issues were also formulated in these meetings, several of which guided APIAHF's subsequent work. This work includes the Health Equity through Enhanced Data (HEED) project we report here, which we conducted in collaboration with community partners in five states, Arizona, Georgia, New York, Ohio, and Texas.

This report covers our work in two key HEED components: 1) our review and assessment of currently-available state and local data sources in those five states to evaluate their strengths and limitations; and 2) a synthesis of five case studies our community partners conducted to document their work to improve state and local data on AA and NHPI health in their respective states.

#### PART A. EVALUATING DATA SOURCES IN FIVE STATES

#### **How We Identified Data Sources**

APIAHF conducted an extensive online literature review to identify AA and NHPI health and demographic data sources in the five states where the statewide community coalitions were located: Arizona, Georgia, New York, Ohio, and Texas. The inclusion criteria for data sources that were identified and reviewed included state- or local-level data sources by racial/ethnic categories that reported on: 1) health conditions and behaviors; 2) health care access and utilization; and/or 3) social determinants of health (e.g., income, education, and English language proficiency). In addition, we included national data sources to the extent that they included relevant state-level data.

To locate the data sources that met these inclusion criteria, APIAHF staff perused state- and local-level websites, mainly those of government agencies (including each county and state health department website of all five states) and academic or research institutions. We also used the Google search engine with various keyword search terms: "health," "health care," "healthcare," "demographic," "socioeconomic," "data," and "statistics," each combined with the names of each state, county, and top-ten largest cities within each of the five states. We also explored the websites of the AA- and/or NHPI-serving community organizations in these states. Our five community partners—Asian Pacific Community in Action (Arizona), the Center for Pan Asian Community Services (Georgia), the Coalition for Asian American Children and Families (New York), and Asian Services in Action, Inc. (Ohio), and HOPE Clinic (Texas)—also provided local knowledge of health-related data sources in their respective states and local areas, including those they had used for their state and local activities.

We identified 112 data sources that met the inclusion criteria. While most data sources provided state-level data, some included data on multiple geographic levels. Among all the data sources, 15% contained national-level data, 87% contained state-level data, and 29% contained county- or city-level data. Among the five states, Ohio (33%) had the largest number of data sources, followed by New York (28%), Arizona and Texas (both 20%), and lastly Georgia (13%).

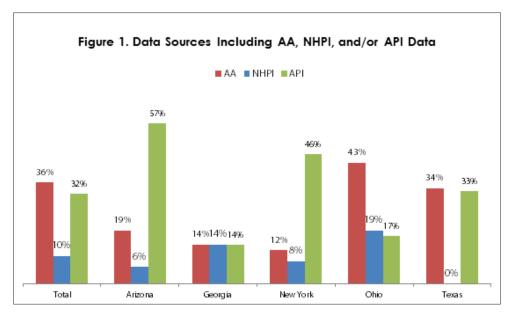
Nearly all of the data sources (91%) were online publications, with only a small set of data sources from online data query systems (8%) and conference presentations (1%). The distribution of data source types in each state mirrored this overall distribution. Most data sources were developed by government agencies (72%), followed by community-based organizations (17%) and academic or research institutions (11%).

# Seldom and Inconsistently Reported AA and NHPI Data

The ways in which AA and NHPI data were reported differed across data sources. Only 36% of the compiled data sources reported data for AAs and even fewer, 10%, reported data for NHPIs. Additionally, 32% combined the AA and NHPI racial groups using the outdated "Asian & Pacific Islander (API)" category, failing to comply with the 1997 Office of Management and Budget's 1997 Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity that require separate racial categories for AAs and NHPIs (Office of Management and Budget, 1997) (<a href="http://www.whitehouse.gov/omb/fedreg">http://www.whitehouse.gov/omb/fedreg</a> 1997 standards). Ohio had the highest percentage of data sources including AA-specific data (43%), while New York had the lowest (12%). Ohio also had the highest percentage reporting NHPI data (19%), while Texas reported no NHPI data at all. Arizona reported the highest percentage of data sources using API as an indicator (57%), and Georgia had the lowest (14%).

Most of the data sources did not report AA and/or NHPI ethnic-specific data (80%). While small proportions of data sources from Ohio (35%), Texas (22%), and New York (12%) reported such granular data, no data sources from Arizona and Georgia reported ethnic-specific data. Among data sources reporting ethnic-specific data, Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese (the

largest Asian ethnic groups in the U.S., according to the 2013 American Community Survey) were the most prominent granular ethnicities for which data were available. There were no data reported for any NHPI ethnic groups.



The appendix presents an overview of the data sources that included AA and/or NHPI data.

# **Limited Documentation on Methodologies**

A majority of data sources reporting AA, NHPI, or API data did not specify how race was defined—specifically, whether the "alone" (i.e., single race) or "in combination with other race" category was used. Only 34% of data sources specified how race data were collected for AAs, 33% for NHPIs, and 8% for APIs. This is an important omission given that multiracial populations are growing fast among AAs and NHPIs, consisting of 15% of AAs and 56% of NHPIs, according to the 2010 Census. Multiracial individuals often experience greater social and cultural challenges (such as questions about their racial identity) including dual race identity stressors that may put them at higher health risks than their single-race counterparts (Sakai et al., 2010).

Just 10% of all data sources reported what languages the surveys were conducted in, and only select Texas data sources reported conducting the surveys in AA languages (i.e., Chinese, Korean, and Vietnamese). No data sources reported conducting the surveys in NHPI languages.

Only 28% of data sources reported the total sample size of the dataset. Among the five states, Arizona (38%) had the highest percentage of data sources including information about the sample sizes, followed by Ohio (26%) and New York (19%); Georgia (7%) and Texas (6%) had the lowest percentages of data sources reporting the sample sizes. Among data sources that included total sample sizes, a very small number included AA and NHPI sample sizes. The small number of data sources reporting sample sizes may be because most data sources reviewed were overwhelmingly online publications whose target audience was intended for a broader general audience and not for researchers, thus containing findings that were easier to understand with little information on methodologies.

# **Paucity of Health and Demographic Indicators**

As Table 1 shows, data sources from the five states reported on a variety of health and demographic indicators. Nearly all national data sources included these data disaggregated by race, including by AAs and NHPIs. Most data sources from Arizona, New York, and Ohio also disaggregated data by race, mostly for AAs and not often for NHPIs. Texas data sources occasionally included health and demographic data for AAs, and Georgia rarely included data for AAs. No data sources from Texas and Georgia reported health and demographic data for NHPIs.

The vast majority of data sources included health outcomes (89%). The most frequently reported among them were chronic conditions (62%) such as cancer (46%), heart disease (26%), and diabetes (25%). A little more than half of all data sources reported on health behaviors (51%), including alcohol or tobacco use (30%), weight (25%), and physical activity (15%). Information about health care access and utilization was also available in 42% of data sources. Also included were infectious diseases (34%) and general health status (19%). Some data sources reported additional health outcomes including maternal and child health (30%), oral health (10%), and disabilities.

Table 1. Health and Health Care Topics Reported for the Five States

Health Topic	Percent of Total Data Sources
General health status	19%
Chronic conditions or diseases	62%
Cancer	46%
Heart disease	26%
Diabetes	25%
Mental health	19%
Stroke	13%
Lung disease	5%
Arthritis	1%
Asthma	1%
Infectious diseases	34%
HIV/AIDS	26%
Sexually transmitted diseases	16%
Hepatitis	13%
Health care access and utilization	42%
Health insurance coverage	30%
Usual source of care	25%
Preventive care	18%
Emergency care	10%
Health behaviors	51%
Alcohol or tobacco use	30%
Weight	25%
Physical activity	15%
Nutrition	13%
Violence	13%
Illicit drug use	10%
Other	41%
Maternal/child health	30%
Disability	10%
Oral health	10%
Mortality	4%

As Table 2 indicates, the percentages of data sources that reported on key social determinants of health were relatively low. Educational attainment (37%) and income level (36%) were reported in only about one in three data sources, and those that did report on key social determinants of health related to immigrant health, such as language use (13%), citizenship status (12%), and English proficiency (10%), were even lower.

**Table 2. Demographic Indicators Reported for the Five States** 

Demographic Indicator	Percent of Total Data Sources
Age	68%
Gender	62%
Educational attainment	37%
Income level	36%
Poverty status	21%
Place of birth	17%
Employment	13%
Language use	13%
Citizenship	12%
English proficiency	10%

# PART B. CASE STUDIES OF SUCCESSFUL COMMUNITY-LED INITIATIVES THAT IMPROVED DATA ON AA AND NHPI HEALTH

The community initiatives reported in these five case studies were conducted by community-led coalitions which included community-based organizations (CBOs), state and local public health departments, academic researchers, and other stakeholders in Arizona, Georgia, New York, Ohio, and Texas.

These five coalitions led an array of initiatives to improve state or local data in the geographic areas they are located. The objectives of these initiatives included: passing state and local legislation to establish the legal framework for the standardization of data collection and reporting, including standards for granular ethnic categories (New York); collecting and reporting primary data, both quantitative and qualitative, in order to increase data to identify AA and NHPI health issues in the geographic areas they served (Georgia, Ohio, and Texas); and compiling existing AA and NHPI data in high impact publications by leveraging local expertise to demonstrate the health and health care needs of the communities they serve (Arizona). In most cases, the data thus collected or compiled and reported were used strategically to promote the health of their constituents, for example, to raise awareness of health issues affecting AA and NHPI and/or to advocate for policies or programs to address these issues.

Community coalitions allow pooling and mobilization of resources and diverse approaches to develop widespread public support for issues or actions to address unmet needs (Butterfoss and Francisco, 2004). Community coalitions have proliferated since the 1990's to promote the health of disadvantaged populations largely by preventing disease and health risk behaviors and improving access to health care (Butterfoss, 2007). With the growing recognition that policies that allocate resources and set courses of action are often the underlying causes of health- enhancing or damaging conditions, policy change has become an important focus of coalition work in some communities (Freudenberg and Tsui, 2014). While coalition work is not novel, the coalitions featured in these case studies were unique in that they coordinated and led campaigns to improve health data, which is conventionally considered to be within the purview of academic researchers or government data collection agencies. To achieve these goals, these community coalitions used innovative strategies.

Below we describe the experiences of these coalitions. How coalition partners worked together to implement successful community initiatives to improve data and, in most cases, to use data to address health disparities impacting their constituents is the central focus of these case studies. Their experiences offer lessons on how communities might engage and lead initiatives to improving data on the health of AAs, NHPIs and other small populations. As the intended use of data might be somewhat different for CBOs than for researchers, their experiences also point to the ways in which community-initiated research might be conducted in the future.

# **Community Coalitions and Memberships**

Coalitions are embedded in communities, and as a result, contextual factors—such as trust between groups, politics and administrative history of collaboration, geography, and community readiness—can have a significant impact on coalitions (Butterfoss et al., 2006; Kegler et al., 2010). Community readiness and a prior history of collaboration, associated with the collective experience of working together through APIAHF's national Health Through Action (HTA) initiative, might be among the key contextual factors that facilitated the work of the five coalitions featured in this report. HTA was a multi-year (2006-2011) national capacity-building initiative funded by the W.K. Kellogg Foundation and coordinated by APIAHF that involved eighteen community partners in fifteen states, most of which led coalitions. HTA went far beyond the scope of conventional capacity-building centering on organizational development and financial sustainability (Alexander et al., 2010) by making research

training and technical assistance and policy advocacy high priorities. HTA also helped enhance the community partners' understanding of the critical role data and research play in community education, policy advocacy, and other interventions to promote health equity. All of the lead agencies in the community coalitions featured in this report participated in HTA.

Although the circumstances surrounding the birth of these coalitions somewhat varied, all five coalitions cultivated collaborative relationships with diverse organizational and individual members in their respective states prior to or in conjunction with the launch of their respective HEED initiatives reported here. Most of the organizational members of the coalitions served primarily AA communities, but the coalitions also worked with other individuals or entities, utilizing their skills and expertise or support base to implement their initiatives.

Coalition for Asian American Children & Families (CACF) was founded in 1986 by a group of proactive social service providers who were concerned that private and public health, education, and human service institutions in New York City were ill-equipped to serve the growing number of AAs and immigrant families. The majority of its member organizations were social service providers working with the full spectrum of the AA (including East Asian, South Asian, Southeast Asian) and NHPI communities. CACF's other key partners were advocates working with other communities of color and other disadvantaged populations such as lesbian, gay, bisexual and transgender (LGBT) and disability communities. In its initiative featured in this report, CACF also worked with elected officials of districts with high or growing proportions of AAs, as well as academic researchers investigating AA health issues.

Reaching Asian Americans through Innovative and Supportive Engagement (RAISE) based in Cleveland, Ohio grew out of a partnership built by Asian Services in Action, Inc. (ASIA), the lead agency. ASIA's partners included smaller AA and ethnic, voluntary, cultural and faith-based organizations working to address various health issues including domestic violence, type 2 diabetes, and breast and cervical cancer prevention that recognized the value of working together to address common concerns faced by each ethnic community. While most of the organizational members of RAISE in Ohio were associations and language schools based in Asian ethnic communities, the coalition also worked with refugee resettlement organizations serving refugees from Burma and Nepal, as well as other parts of the world such as Africa, and a local community development corporation. Though not a formal member, the Cuyahoga County Board of Health also worked closely RAISE, playing an essential role in conducting a local AA health survey.

Georgia Asian Pacific Islander Community Coalition (GAAPICC) based in Atlanta, Georgia was established in November 2005 by the Center for Pan Asian Community Services (CPACS), the lead agency, to meet and discuss community concerns and learn from one another's experiences. The mission articulated by GAAPICC in 2005 was to improve the overall well-being of AAs and NHPIs by bringing the diverse AA and NHPI communities in Atlanta together. GAAPICC includes over 25 organizations and individuals.

Asian American Health Coalition (AAHC) in Texas was founded in 1994 by AA CBOs and voluntary associations with a vision of eliminating health disparities in the AA community in the Greater Houston area in a culturally and linguistically competent way. AAHC established the HOPE Clinic in 2002 to serve the ethnically-diverse AA populations in the southwest Houston area. In 2007, AAHC founded the Houston Asian American Health Collaborative (HAAHC) as a project committee entrusted with policy advocacy to work with organizations and institutions outside the AA communities including government agencies (such as city, county, and state health departments), coalitions based in other racial and ethnic communities (such as African American Health Coalition, Hispanic Health Coalition, and Native American Health Coalition), and elected officials (e.g., Texas District Representatives).

Members of Health Through Action Arizona (HTAA) had served on the advisory board for the lead agency, Asian Pacific Community in Action (APCA), and formally founded this coalition in 2006 to support AA community partnerships. HTAA was a coalition of organizations and individuals representing AA communities such as Chinese, Filipino and South Asian (as well as pan-ethnic organizations like Asian Chamber of Commerce); state and county health departments; health plans and providers; a local private foundation; and academic researchers. Individual members of the coalition included health practitioners working for a pharmaceutical company and professional associations such as Leukemia Lymphoma Society and American Society of Pediatrics Arizona Chapter.

# Improving State and Local Data On AA and NHPI Health: Coalition Objectives and Community Contexts

The objectives of the five coalitions with regard to improving data on AA and NHPI health somewhat differed, largely reflecting the local social and economic contexts and the capacity of the lead agencies and their key partners. Still, the main thrust of all five data initiatives came from the communities' recognition that existing data collection and reporting efforts (or the lack thereof) are inadequate to document and monitor the health and health care needs of diverse AA and NHPI communities, and therefore hampered government and community efforts to address them. Community advocates also recognized that priorities in government resource allocation to community programs are driven by population data.

CACF took an upstream approach to establish a legal framework to improve data on AAs and NHPIs collected in New York State. The coalition set a goal to pass state and local legislation that would mandate standards for the collection and reporting of demographic data by state and local government agencies in New York State. Key components of the standards included the use of 18 AA and 4 NHPI ethnic categories for data disaggregation, as well as making health data publicly available at regular intervals. The goal of passing legislation was set with the recognition that priorities in the allocation of government resources were largely driven by data, that the existing data collection regime was ill-equipped to ensure equitable distribution of resources to prioritize the needs of small, underserved communities, and that a new legal framework was necessary to institute far-reaching, systemic changes in the ways in which data were collected and reported as a critical first step in addressing health disparities disproportionately affecting these communities.

RAISE in Ohio aimed to collect primary data that would help identify the health needs and health disparities issues affecting local AA communities. What triggered this work was a 2011 county health report that ASIA, Inc. the lead agency, perceived to be an inaccurate representation of the health needs of AAs. ASIA, Inc. believed that the low level of community responses to the county health survey contributed to the underreporting of health issues in AA communities. ASIA also determined that the paucity of culturally and linguistically appropriate data collection tools may have hindered AA community participation in the survey. RAISE's initiative revolved around addressing these issues.

Similarly, the key issue perceived by CPACS and other GAAPICC coalition partners was the lack of data to shed light on the health and health access needs of Georgia's growing AA communities. Collecting data on AAs, as well as on a particularly vulnerable subgroup in the AA community with greater health and health access needs (i.e., individuals with disabilities and their caregivers) became the key objectives of this coalition. In the case of CPACS and GAAPICC, state government's initiatives and resources provided were the initial impetus for their work. It was the 2009 resolution of the Georgia General Assembly that led to the Georgia Senate Study Committee on Georgia Racial Health Disparities for Asian and Pacific Islander Americans, which subsequently commissioned CPACS to conduct a comprehensive study of AA and NHPI health issues in Georgia. Funding provided by the Georgia Governor's Council of Developmental Disabilities supported CPACS's disabilities study. Like ASIA and RAISE in Ohio, CPACS and other GAAPICC partners also saw that limited English proficiency

of many AA community members posed a significant barrier for AA community participation in health data collection. CPACS thus developed and administered surveys and conducted focus groups and interviews, using three Asian languages, Korean, Vietnamese, and Chinese (Mandarin), in addition to English used in the focus groups with Asian Indians.

The objective of APCA and other HTAA coalition partners was to address the dearth of reliable health data on AAs and NHPIs in Arizona by compiling available data in a "Data Book." The idea for this project was initially proposed by Asian Pacific American Studies faculty at Arizona State University who had produced a compendium of articles covering a variety of issues affecting communities of color (including a volume devoted to AAs and NHPIs). Like the community coalitions in other states, APCA saw the strategic value in producing a high-impact publication that would become the evidence base for advocating for progressive policies and robust programs for AA and NHPI communities. Like the other lead agencies of the community coalitions, APCA also viewed the dearth of publicly available data on AAs and NHPIs in Arizona as a barrier that limited funding and programs to serve these communities.

For AAHC, collecting data on AA and NHPI health was, to a large extent, a means to enhance its main goal of reducing the cancer burden in AA and NHPI communities of Houston and other parts of Texas. Prioritizing cancer as a critical health issue, the coalition saw the need to collect data as the evidence base for cancer prevention work to collectively address the cancer burden and disparities in these communities.

# **United Around Common Goals: Coalition Strategies**

The coalitions engaged in a variety of activities to achieve their objectives stated above. While their strategies somewhat varied, understandable given the diverse objectives and community contexts, there are considerable commonalities among them. Chief among them are: cultivating and leveraging a broad-based network; engaging government and/or research partners with expertise or capacity critical for the successful implementation of the initiative; crafting and communicating progressive messages tailored to the circumstances of coalition members and other key partners to make their campaign relevant to them; and, perhaps most importantly, strong leadership with a clear vision that effectively deployed strategies and mobilized partners to achieve said objectives.

All of these components were in place in the "Invisible No More" campaign led by CACF in New York in 2012. In this campaign, CACF brought together a broad-based network of community-based organizations and advocates, academic researchers, and elected officials. They included: CBOs that provided services to AA and NHPI communities; organizations and advocates representing disadvantaged communities (such as communities of color and the LGBT and disability communities) that also perceived similar needs for data improvements as a basis for promoting changes that would benefit their constituents; academic researchers who investigated AA health disparities; and elected officials in districts with high proportions or growing numbers of AAs. Finely-crafted messages delivered in a series of briefings and meetings CACF held were critical in successfully forging broad consensus on the need to establish a legal framework to improve data. While "data equity" was central to this messaging, specific messages were tailored to the specific missions, circumstances and needs of the various partners. For example, the key message used to engage elected officials in the campaign was that sound data would help them serve their constituents better through equitable and efficient allocation of government resources and increased transparency and accountability of government's action. By mobilizing its member organizations and other key allies in its campaign, CACF was able to secure sign-ons from elected officials for the proposed bills. Functional division of labor among some key partners in this campaign is also worth noting. Since the key objective of the campaign involved new legislation, CACF worked closely with elected officials including members of the State Assembly, State Senate, and New York City Council who introduced the bills. Academic researchers lent to the

campaign their expertise on best practices and recommendations for AA and NHPI data collection and reporting, particularly data disaggregation, which informed the content of the bill.

To collect primary data to improve understanding of the issues affecting local AA communities in Ohio, RAISE also brought together diverse community health stakeholders. Central among them were potential or prospective end users of the data collected to address community needs. For example, RAISE sought technical assistance by the Cuyahoga County Board of Health in developing a community health assessment survey for AA communities. RAISE also collaborated with the St. Clair Superior Development Corporation, a local non-profit organization working to revitalize inner-city areas, to conduct a detailed, door-to-door survey about the built environment in the AA community.

An important focus of RAISE's work was to ensure that the data collection tools were culturally and linguistically appropriate and contextually-relevant for local AA communities. In developing the community health assessment survey working with the County Board of Health, for example, ASIA, Inc. utilized existing survey instruments developed by Centers for Disease Control and Prevention (CDC) and the Health Improvement Partnership Cuyahoga (HIP-C), the largest community health coalition in the county, while adding culturally-appropriate items such as ethnic food items and physical activities rooted in ethnic culture. Another key role RAISE played in these projects was to mobilize its network to get the message out to communities about the survey and its importance for improving AA health in order to increase the community response rate. In order to rally the RAISE coalition partners behind this work, ASIA, Inc. spread the message that the data collected would inform the county's future work to improve AA community health by helping to identify and prioritize pressing needs and then to evaluate the impact of the work to address them. Such messaging was effective in mobilizing coalition members in efforts to raise awareness and increase community participation in the surveys. ASIA, Inc.'s messaging also accentuated the community ownership of these projects, communicating to its partners that they were key players in the process, not merely data collection staff. As ASIA, Inc. reported, this message helped build trust on the part of community partners.

GAAPICC's initiative in Georgia also involved primary data collection, conducted with the support of public entities with the capacity to use the data to implement programs to address the needs of underserved communities. One of the key projects implemented by CPACS and other GAAPICC partners was the first statewide needs assessment for AAs with developmental disabilities and their caregivers in Georgia, funded by the Georgia Governor's Council of Developmental Disabilities. Similar to ASIA, CPACS also leveraged its network, primarily GAAPICC's member organizations and faith-based organizations, to recruit community participants for focus groups and interviews with caregivers, conducted in-language as needed. In developing and implementing these projects, CPACS worked closely with researchers at Georgia State University. CPACS reported key findings and articulated policy recommendations in a white paper, a vehicle CPACS deemed more practical than trying to assemble or meet with policymakers for in-person presentations. Target audiences included community members, funders, researchers, teachers, government agencies, and policymakers. To raise awareness of disability issues and to argue for increased supportive services for the AA disability community, GAAPICC made a series of presentations, in English and Asian ethnic languages, to developmental disabilities professionals (including teachers, service providers, and therapists) and policymakers to raise awareness of disability issues and advocate for increased supportive services for the disability community. They also mounted a community educational campaign to dispel cultural myths within AA communities about individuals with disabilities and to increase awareness of the hardships AAs with developmental disabilities and their caregivers experienced.

In Arizona, even with academic researchers as key partners, an important priority for HTAA was to create a community-owned document of their issues by leveraging local expertise and other resources. While existing relationships were leveraged to rally coalition partners, also critical was HTAA's presentation of the Data Book project as an important opportunity to highlight important

health issues and available resources within the community in an evidence base for progressive policies beneficial to its constituents in Arizona. With resources contributed by a number of coalition members and other supporters, the "Data Book" project turned out to be a truly collaborative community affair. In addition to local researchers and practitioners who contributed to writing articles on health topics, the coalition secured significant resources from community members to cover the design, photographic services, and printing of the report.

In the comprehensive community needs assessments and focus groups AAHC conducted in Texas, the coalition identified chronic diseases, particularly cancer, as the highest-priority health issue. Through HOPE Clinic, the clinic they established, AAHC also collected information on the barriers to accessing health services community members experienced, using comprehensive intake forms, surveys, and evaluation forms for each event. Dissemination of the research findings was an important focus of AAHC's work in Houston. They raised awareness of health disparities affecting AA and NHPI communities by using social media and local media, hosting town halls and forums, holding conferences, presenting in meetings, and making congressional visits. HOPE Clinic crafted its core message around AAHC's mission of providing high-quality health care to its constituents in a culturally and linguistically appropriate manner, which was instrumental in uniting coalition partners around a common goal.

# **Outcomes and Accomplishments**

CACF successfully raised state-wide awareness of the need to improve data collection and reporting by government agencies in New York State. The State Assembly passed the bill (A9792), but the State Senate did not vote the senate version of the bill (\$7503) out of committee in the 2012 legislative session. Although the state bills were not enacted, the work to push for similar legislative frameworks continued, which was a testament to the increased community capacity and maturity for policy advocacy on data equity. These efforts included the introduction of Intro 937, a municipal ordinance in New York City that would have mandated the use of granular Asian ethnic categories, primary languages spoken, and country of origin/place of birth in data collection, as well as a revised version of the state bills (A1186a/S2348a) to mirror the proposed municipal ordinance. These legislations were not enacted.

RAISE's work increased the awareness of the need to improve data on AA health in Ohio. The Cuyahoga County Board of Health, for example, became aware for the first time of the need to disaggregate data on these communities by ethnicity. As ASIA, Inc. and other members of RAISE had envisioned, the data collected were indeed used to improve the conditions of the local AA community. For example, key findings of the survey AsiaTown Master Plan Committee conducted in collaboration with St. Clair Superior Development Corporation were used to demonstrate to elected officials the need to improve the built environment of the local Asian enclave in order to promote physical activity among its primarily Asian American residents. The data initiatives also elevated the profile of ASIA, Inc. on the state and national levels. In 2014, ASIA was asked to serve as a member of the county-wide health initiative, led by the county board of health, working to improve the health of all county residents. ASIA's executive director was also appointed to serve as a commissioner on President Obama's Advisory Commission on AAPIs, and has provided expertise to improving federal data collection standards on AAs and NHPIs.

Key accomplishments for HTAA in Arizona included raising the awareness of AA health issues through the publication and dissemination of its Data Book. Entitled "State of Asian Americans and Pacific Islanders in Arizona, Volume 2: Health Risks, Disparities, and Community Responses," HTAA's Data Book was unveiled at a symposium hosted by HTAA that engaged community members and activists in a lively discussion of the issues covered and policies proposed in the publication. The Data Book also became an important resource for public and private entities, such as the state and county health

department and ACLU, to improve their understanding of AA and NHPI health issues.

CPACS and its partners in Georgia successfully raised awareness of the hardships experienced by the AA disability community. GAAPICC worked to disseminate the findings of the needs assessment to a wide range of stakeholders including state and local health departments, the Governor's Council on Developmental Disabilities, and professionals working with individuals with developmental disabilities (such as teachers, service providers, therapists, specialists, and lawyers). The coalition also pushed for culturally and linguistically appropriate services for the AA disability community, which resulted in the funding CPACS secured to provide such services. GAAPICC also was able to develop care-group programs to help caregivers actively support and learn from one another.

Due to its initiative to conduct research on AA health and to disseminate key findings from this project to advocate for more resources for their constituents, AAHC in Texas successfully secured additional private and public funding to expand cancer screening activities and education efforts and to expand the city's community health center system to better serve AA communities. In 2012, HOPE Clinic became a federally-qualified health center, greatly expanding its capacity to serve low-income AAs and NHPIs and other communities of color. Working with over 29 different community partners, HOPE Clinic now provides high-quality health care and promotes preventative care in over 14 different languages.

# Lessons Learned: Facilitators, Barriers, and Best Practices

These five case studies demonstrate how community organizations can build and leverage broad-based coalitions to effectively improve data on small populations. Their experiences are unique in that they staged campaigns to improve health data, which is conventionally considered to be within the purview of academic researchers or government data collection agencies. They also demonstrate that community organizations with intimate knowledge of community contexts (such as local cultural and socioeconomic conditions, key organizations and other stakeholders that are potential allies, and the local and state legislative environments) can be integral to community coalition work to build an evidence base for identifying and addressing health issues affecting community members.

While the strategies that the five coalitions used varied to a certain degree, there are significant commonalities in the factors that led to their success. They include: cultivating and leveraging a broad-based multi-sector network, engaging partners with expertise or capacity critical for the successful implementation of the data initiative; crafting clear and tailored messages to mobilize coalition members and other key partners around common goals; and, perhaps most importantly, strong grassroots leadership with a clear vision that effectively deployed these and other strategies to achieve said objectives. In addition, there were barriers these coalitions encountered such as limited resources, varying degrees of community readiness among AA communities, difficulties with effectively engaging small communities, and the lack of strong relationships with state and local agencies with the capacity to effect changes as informed by improved data, some of which the coalitions successfully addressed.

#### **Facilitators**

#### Leadership

Leadership—defined as the skills of the leaders in guiding the coalition toward the accomplishment of its goals and cultivating commitment to the coalition from members, their organizations, and their members—is among the most critical factors for successful coalition work (Kegler et al., 1998). Perhaps because of the nature of the objectives set by the coalitions that involved improved data collection and reporting, largely unconventional for community coalitions, strong leadership of the lead

agencies may have been even more critical in advancing their respective data initiatives than in more conventional coalition work. To a certain degree, the lead agency of each coalition may have acquired their leader role because of the key role they played in founding the coalition.

Community contextual factors can influence coalition activities and their successes, which include history of collaboration, demographics, local norms and values, and community readiness (Butterfoss et al., 1993; Butterfoss et al., 2006; Kegler et al., 2010). Readiness of the lead agencies was critical in carrying out these initiatives to effectively improve data. In some cases, the initial ideas for the community initiatives were proposed by external partners or other entities—for example, academic researchers (HTAA), elected officials (CACF), and other government offices (CPACS)—but the ability to seize such opportunities to launch initiatives to improve the conditions of their communities is a testament to the strong leadership and far-sighted vision of the lead agencies.

How such readiness of the lead agencies came about is also worth noting. To a large extent, the readiness of the lead agencies and their partners may have been due, at least in part, to the intentional capacity building efforts made by APIAHF in the aforementioned HTA program funded by a prominent private philanthropic foundation, the W.K. Kellogg Foundation. With its strong focus on research and data, HTA may have raised community awareness of inadequate data resources and the lack of culturally and linguistically appropriate data collection practices involving AAs, NHPIs, and other small populations, and inspired them to collect and improve data on their communities. The leadership roles the lead agencies played in their respective coalitions in HTA (which supported coalition work) may also have prepared them to effectively guide their partners in the initiatives reported here.

Notably, the very capacity of APIAHF, a national organization, to provide the capacity building training and technical assistance to support the growth of the community coalitions in improving data on AA and NHPI communities was supported by private and public entities. In addition to HTA, APIAHF leveraged funds from the CDC Capacity Building Program (2005-2011) to build its own capacity in the areas of policy development, research, and program management and evaluation. This was essential to move forward the national agenda for increased and more useful data on AA and NHPI health and to support the research capacity building of HTA grantees in their respective states. The support of the U.S. Department of Health and Human Services Office of Minority Health, under a National Umbrella Cooperative Agreement for the current HEED project, has also enabled APIAHF and its HEED partners to document and disseminate best practices and successful models of collaboration from these case studies to promote similar efforts in other communities nationwide. These experiences suggest that building and utilizing community capacity to improve state and local data might need to be purposefully nurtured and promoted with private and public resources.

As discussed below, the lead agencies in the five coalitions helped bring about other critical components, such as the building of broad-based networks, developing messaging, and learning from prior campaigns to develop key pieces of their respective initiatives.

#### **Broad-based Networks**

A coalition's membership is widely regarded as its primary asset (Butterfoss 1993; Wandersman 1997). Cultivating and mobilizing broad-based networks, including both formal organizational and individual members and external partners, was critical in the successful implementation of the community initiatives. As indicated above, networks of all five coalitions went beyond AA and NHPI CBOs to include organizations and coalitions based in other communities and mainstream institutions such as state and local public health departments, elected offices, and academic institutions, or individuals working for them. Leveraging the expertise and skills of mainstream partners to strategically deploy them where needed was also essential. For example, given that data-related work is likely to require specialized research skills, enlisting academic researchers (in the cases of CACF, APCA, and CPACS) or

government agencies (ASIA and HAAHC) with such skills was integral to these community initiatives. Coalition work to pass legislation, by nature, required the involvement of elected officials to craft and introduce them (CACF).

In some cases, the lead agency shared leadership roles with non-community partners whose expertise or capacity was essential to the successful implementation of the initiative. In such cases, the lead agencies led efforts to enlist community members and organizations in other tasks needed to successfully achieve their objectives, while key partners with more technical skills (for example, academic researchers or county board of health) performed research-related tasks that required them. For example, in HTAA, leadership roles were shared between the lead agency and academic partners. One researcher became a co-editor of the Data Book (working with APCA's then-executive director who also served as the co-editor), while APCA devoted staff time to orchestrating the entire project, enlisting local experts (such as health practitioners) in writing articles to be included in the Data Book and securing financial or in-kind donations from a variety of CBOs and individual community members to ensure that the publication was informative, accurate, and aesthetically pleasing.

As the HEED partners found, it was vital to get diverse stakeholders to embrace the initiative from the beginning and keep them engaged. Making the initiative relevant for each of the key stakeholders, in part through messaging, was an effective way to do so, which we discuss below in detail.

# Messaging

As noted above, the coalitions' objective to improve data was unconventional for community-based coalitions. Finely-crafted messaging was critical to coalescing coalition members and other key partners around this seemingly unconventional goal. The messaging developed by these coalitions had some common elements. One was to invoke universal values espoused in a democratic society, such as fairness and equity. For example, the overarching message CACF used was that sound data was a matter of inclusion and equity. The name of the campaign, "Invisible No More," already implied that the paucity of data on AAs and other small populations makes them invisible, that is to say, not matter (with the implication that small communities were treated unfairly). Thus articulated, these universal values helped inspire many organizations representing small and underserved populations, well beyond AA and NHPI communities, to actively participate in the campaign. They also helped enlist elected officials conditioned to embrace and promote such values. Though somewhat more subtle, such values were implied in the messages of other coalitions as well. For example, ASIA, Inc., CPACS, and HTAA all maintained that better data would help ensure more equitable resource allocation which, in turn, create more programs to serve small populations (such as AAs and NHPIs) or the segments in those populations that may particularly experience hardship.

Making the specific initiative or project relevant for each of the coalition partners in more practical terms was also critical to effectively mobilizing them. Messaging by ASIA, Inc. communicated to other community partners, for example, largely centered on how the data collected would be used to better serve the community by documenting, quantifying and prioritizing community needs. CACF made a strong case to elected officials that improved data would make resource allocation more efficient and save costs (a plausibly convincing argument in an era of government deficits). From the outset, APCA's message was that the Data Book was needed to advocate for policies to benefit the community. CPACS/GAAPICC also made a strong case that the white paper developed would be used to address the issues critically affecting AA community members with disabilities and their caregivers. To AAHC, its mission to provide high-quality health care to its constituents in a culturally- and linguistically-appropriate manner in itself became a core message that helped unite coalition partners. With the hopes of increasing access to care for the diverse Asian community in the Houston area, the partners eagerly collaborated to share resources.

#### **Learning from Prior Campaigns in Other Communities**

Even with the resources the extensive multi-sector networks were able to leverage, there were cases in which the network fell short of securing all the resources needed to successfully implement a campaign that involved highly-technical expertise (such as writing and introducing legislation). To fill this gap, CACF and its partners researched prior, similar campaigns in other jurisdictions. CACF analyzed similar state legislation including California's data disaggregation bill (AB1088) and Oregon's Partner of Quality Care Community Stakeholder Process, as well as the federal data collection standards laid out in the Affordable Care Act's Section 4302. CACF staff also learned from advocates and legislative staff that had played key roles in these legislative campaigns about their key messaging, cost-benefit analysis, and stakeholder engagement process. Not only was such information essential in fine-tuning the campaign, the successful passage and enactment of similar legislation in other jurisdictions helped to convince their coalition partners that they were addressing issues universal to small populations, well beyond their local communities or state, and that such a campaign could indeed succeed.

ASIA/RAISE found it essential to have access to research tools that could be adapted for their use with local AA communities. In their case, the Community Health Assessment and Group Evaluation (CHANGE) tool developed by the CDC and the community health assessment tool developed by the county turned out to be valuable. At the same time, resource sharing was mutually beneficial to both community and non-community partners. The importance of having in-language surveys in working with residents with limited English proficiency became a key lesson to the county board of health, which may guide their future work in working with such populations.

CPACS/GAAPICC used lessons learned from their own prior experiences. One of their key strategies (one that involves the publication of the white paper) was informed by the lesson they learned in their own past experience with scheduling in-person meetings with policymakers. CPACS found that the white paper indeed was a highly effective vehicle of disseminating findings to policymakers to advocate for programs for the disability community.

#### **Barriers**

#### **Limited Resources**

As stated above, the membership of the coalition is its key asset. On the flip side, coalitions are also often limited to the resources and capacity the coalition members can leverage. Along those lines, one lesson APCA and its partners learned was the importance of identifying early on the right skill sets (or the lack thereof) available within the network. For example, in writing the Data Book, the topics covered were limited to the range of expertise of the local practitioners, and some topics (for example, child development, immigrant detention, and incarceration) thus were left out. Interpreting and translation services are another type of resource needed to implement the initiatives in linguisticallydiverse AA communities. The majority of AAs in the U.S. are foreign-born, many of whom have limited English proficiency (LEP), which posed challenges for coalition partners in hosting multi-cultural community dialogue, especially given the paucity of bilingual coalition members who could serve as interpreters. For this reason, APCA's Data Book was developed mostly by English speakers, and its dissemination was also limited to English speakers.

AAHC also reported the challenges involved in producing educational materials in all the different languages used in local communities because hiring professional translators would be prohibitively expensive for a community coalition. AAHC also found it challenging to work with small and emerging communities (for example, Burmese refugees) that had low reading literacy (in both English and their native language) and low health literacy, as well as a different cultural framework for viewing health and treatment of disease. Working in those communities required the help of insiders who speak their

languages. These may be issues many organizations or coalitions that serve AAs and NHPIs of diverse linguistic backgrounds may experience. Conducting surveys and focus groups in-language is a way to address these issues. To a large extent, these barriers might be addressed by continuing to build the coalition's capacity, purposefully seeking out and enlisting bilingual members from small ethnic communities who can facilitate effective communication with their co-ethnic members with both LEP and low literacy.

As ASIA found, relying on coalition members who were volunteers posed a challenge for community coalitions and its ability to create long-term sustainability of coalition work to continually collect data on community health and disseminate key findings to advocate for their communities. AAHC discovered that fewer resources during tough economic times put strains on coalition work and limited growth of the coalition due to fewer resources available for travel, networking, and convening events. Similarly, as ASIA discovered, limited proficiency in technology (such as familiarity with statistical software) may be another barrier community coalitions face. As stated above, these challenges may be overcome by continuing to build the capacity of the coalition to secure such expertise or capacity.

## **Challenges in Affecting Policy Changes**

After publishing their respective publications, both APCA and CPACS experienced challenges in promoting changes consistent with their findings. CACF experienced challenges in building strong relationships with state and local agencies that would implement the data collection bills in the event they were enacted. As APCA found, bringing about policy changes would require a broader set of allies with different skills from all the sectors currently working within and in alliance with the existing community coalition to advance local policies that integrate health and wellness as foundational principles. Building new relationship with decision makers will be critical to their next steps to influence and shape policies.

# **A Varying Degree of Community Readiness**

One of the key challenges AAHC experienced was the varying degrees of community capacity and readiness among AA community groups in the Houston area. For example, most partners tended to focus on their specific ethnic constituents, rather than the Asian population as a whole, when they conducted cancer education. Engaging diverse ethnic communities was a challenge to the coalition working to address pan-Asian issues. The varying degree of readiness led some partners, particularly those that were more established, to bear greater workloads than others. Such disparities within the coalition could potentially alienate some members and exhaust others. A framework in which more established partners can help build the capacity of smaller ones, potentially supported by public and private foundations, might be promoted.

# Perceptions of "Small" AA Populations

Some coalitions found that mainstream perceptions of "small" sizes of AA and NHPI populations undermined their ability to advocate for their communities. This perception is not far-fetched given the relatively small sizes of AA and NHPI populations in many states. The AA communities in Cleveland, Ohio, for example, made up just 2% of the population, and the perception that the AA community was small became an obstacle in securing resources (ASIA/RAISE). A strong case may need to be continuously made that AA and NHPI communities are highly diverse, with some ethnic (especially small) communities facing greater needs, and that the needs of all underserved populations, large or small, need to be addressed in government and community programs to achieve racial equity.

#### **Best Practices and Successful Models of Collaboration**

The experiences of all five coalitions featured in this report represent best practices for community coalition work to improve data on small populations. Each of them made the best use of available resources and/or found creative solutions to overcome the limitations imposed by scarce resources. Each of these best practices offers lessons for communities with similar demographic profiles on the strategies they might use to improve data to effectively demonstrate the conditions that critically affect them.

Taking advantage of New York City's relatively large AA population and institutional infrastructure (such as the high number of CBOs serving AA and other underserved communities, as well as elected officials representing jurisdictions where AAs resided in large numbers or were growing in numbers), CACF worked to institute systematic changes that would improve data on AA, NHPI and other small communities for many years to come. Working in states such as Georgia and Texas where AA populations were still small, but larger than in many other states, GAAPICC and AAHC worked to collect primary data on the health of their communities. These initiatives were exceptional, given that they took place outside of the states with the largest AA populations such as California and New York. In Ohio, a state where the AA population is even smaller than Georgia and Texas, the efforts by ASIA and its coalition partners to initiate projects to administer multiple culturally-tailored, Asian in-language surveys were truly remarkable. APCA's experience in Arizona to compile data gleaned from the existing literature offers lessons for small AA communities without the support of large AA communities and the infrastructure they allow.

All the facilitating factors listed above, such as strong and visionary leadership, broad-based networks, and messaging were present in the experiences of these five coalitions, which future similar state campaigns might replicate to achieve successful outcomes. Additionally, the intention to use data collected or compiled to produce tangible outcomes that can benefit AA and NHPI communities is another key facilitating factor. In this regard, purposeful dissemination of key findings to actively promote needed policy and community changes also makes the campaigns meaningful. Additionally, most of these coalitions made concerted efforts to raise state and local awareness of AA and NHPI health issues and health care needs to advocate for more resources. These efforts include developing and disseminating AA and NHPI data products (GAAPICC and HTAA), often the first step to address those needs.

Two broad successful models of collaboration emerge from the experiences of these coalitions, defined largely by the relationship between community and non-community partners and how the latter were engaged in community coalition initiatives. These models may guide future work of community coalitions to advocate for changes for their constituents.

One successful model involved partnerships with state and local governments. This model is a form of community-based participatory research (CBPR) that effectively integrates research and action and has been articulated previously (Cook 2008). Armed with scientific expertise and access to resources and government decision-makers, government agencies may be in a unique position to freely investigate and promote action to better serve underserved communities. Some case studies featured in this report (GAAPICC, RAISE, and CACF) show that government agencies in those states contributed their expertise and staff resources in unique and diverse ways. In supporting RAISE, members of the Cuyahoga county board of health helped develop community health assessments tools and compiled and analyzed AA community health survey data. The Georgia State legislature and executive offices passed resolutions and allocated funding to collect data on AA health. Elected officials in New York City and State worked with CACF to write, introduce, and pass state bills aimed to establish the legislative infrastructure that would systematically improve data collection and reporting on small populations.

The second model involved working with academic researchers. The community-academic

collaboration is a conventional CBPR model reported in a number of prior publications in which academic researchers provide research expertise and community partners offer contextually-relevant recruitment strategies, access to underserved populations, and community perspectives on research problems investigated or interpretation of findings (Israel et al., 2003; Israel et al., 1998; Minkler and Wallerstein, 2003). The model of community-academic collaboration manifested in some of the case studies featured in this report (mainly involving HTAA and GAAPICC) somewhat differs from this conventional model in the sense that the lead agency and other community partners were firmly focused on how the findings from the collaborative project will be used to produce tangible outcomes for their communities to implement action-oriented initiatives.

Both models of partnerships we identify in which community partners play an integral role have the great potential to inform policies and other interventions that will improve the health of disadvantaged communities, as these models are conducive to leveraging human and economic resources made available by academic and government partners to address issues critical affecting communities.

# **CONCLUSIONS AND RECOMMENDATIONS**

Findings from these case studies suggest that community organizations can play a leading role in addressing existing limitations with the collection, analysis and reporting of AA and NHPI data at the state- and local-levels. Community coalitions can help prioritize and address community needs and effectively facilitate community participation in research on AA and NHPI health in order to generate actionable knowledge to address those needs. To promote such work, we recommend the following:

<u>Problem</u>: Existing state and local data on AA and NHPI health do not adequately demonstrate the diverse health and health care needs of disaggregated AA and NHPI subgroups.

<u>Solution</u>: To ensure quality data, AA and NHPI data disaggregated by ethnicity should be collected and reported to reveal the distinct differences within the AA and NHPI populations and greater needs for some subgroups.

<u>Problem</u>: Research studies on community health often lack community participation and relevance to community issues.

<u>Solution</u>: Community data initiatives need to be promoted to ensure all are counted and reached. More broadly, community-led efforts to investigate their own issues and to produce actionable knowledge should be promoted, and public and private funding need to be provided to legitimize and support such efforts.

<u>Problem</u>: Limited awareness and data on AA and NHPI health among state and local policymakers.

<u>Solution</u>: Public and private partnerships can improve policymakers' understanding of community conditions and lead to meaningful action. Such partnerships should be promoted to facilitate multi-sectoral data collaborations to build and expand the evidence base for policy and community efforts to improve AA and NHPI health.

#### **REFERENCES**

Alexander, J. A., Christianson, J. B., Hearld, L. R., Hurley, R. and Scanlon, D. P. (2010) Challenges of Capacity Building in Multisector Community Health Alliances. *Health Education & Behavior* **37**, 645-664.

APIAHF (2007) Proceedings of the Health Brain Trust on Data and Research: Improving the Health & Well-Being of Asian Americans, Native Hawaiians & Pacific Islanders, Washington, D.C., 2007.

APIAHF (2008) Proceedings of the 2nd Health Brain Trust on Data and Research: Strengthening the Involvement of Asian Americans, Native Hawaiians and Pacific Islanders in Community-Based Participatory Research, Houston, TX, 2008.

APIAHF (2009) Proceedings of the 3rd Health Brain Trust on Data & Research: Utilize Data from Local Evaluations. San Francisco: Asian & Pacific Islander American Health Forum. Retrieved from Atlanta, GA, 2009.

Butterfoss, F. and Francisco, V. T. (2004) Evaluating Community Partnerships and Coalitions with Practitioners in Mind. *Health Promotion Practice* **5**, 108-114.

Butterfoss, F. D. (2007) Coalitions and Partnerships in Community Health. Jossey-Bass, San Francisco, CA.

Butterfoss, F. D., Goodman, R. M. and Wandersman, A. (1993) Community coalitions for prevention and health promotion. *Health Educ Res* **8**, 315-30.

Butterfoss, F. D., Lachance, L. L. and Orians, C. E. (2006) Building allies coalitions: Why formation matters. *Health Promot Pract* **7**, 23S-33S.

Cook, W. K., Chung, C. and Tseng, W. (2011) Demographic and Socioeconomic Profiles of Asian Americans, Native Hawaiians, and Pacific Islanders. Asian & Pacific Islander American Health Forum, San Francisco, CA & Washington, D.C.

Freudenberg, N. and Tsui, E. (2014) Evidence, power, and policy change in community-based participatory research. *Am J Public Health* **104**, 11-4.

Ghosh, C. (2003) Healthy People 2010 and Asian Americans/Pacific Islanders: defining a baseline of information. *Am J Public Health* **93**, 2093-8.

Ghosh, C. (2009) Asian American Health Research: Baseline Data and Funding. In *Asian American Communities and Health*, Vol. 73-103, Islam, N. S., Trinh-Shevrin, C. and Rey, M. J. eds. Jossey-Bass, San Francisco.

Ghosh, C. (2010) Asian American Health Research. In *Asian American Communities and Health: Context, Research, Policy, and Action*, Trinh-Shevrin, C., Islam, N. S. and Rey, M. J. eds, pp. 73-103. Jossey-Bass, San Francisco.

Islam, N. S., Khan, S., Kwon, S., Jong, D., Ro, M. and Trinh-Shevrin, C. (2010) Methodological Issues in the Collection, Analysis, and Reporting of Granular Data in Asian American Populations: Historical Challenges and Potential Solutions. *Journal of Health Care for the Poor and Underserved* **21**, 1354-1381.

Israel, B. A., Schultz, A. J., Parker, E. A., Becker, A. B., Allen, A. J. and Guzman, J. R. (2003) Critical issues in developing and following community based participatory research principles. In *Community-Based Participatory Research for Health*, Minkler, M. and Wallerstein, N. eds, pp. 53-76. Jossey-Bass, San Francisco, CA.

Israel, B. A., Schulz, A. J., Parker, E. A. and Becker, A. B. (1998) Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health* **19**, 173-202.

Kegler, M. C., Rigler, J. and Honeycutt, S. (2010) How does community context influence coalitions in the formation stage? a multiple case study based on the Community Coalition Action Theory. *Bmc Public Health* **10**.

Kegler, M. C., Steckler, A., McLeroy, K. and Malek, S. H. (1998) Factors that contribute to effective community health promotion coalitions: A study of 10 project ASSIST coalitions in North Carolina. *Health Education & Behavior* **25**, 338-353.

Minkler, M. and Wallerstein, N. (2003) Introduction to community based participatory research. In *Community-Based Participatory Research for Health*, pp. 3-26. Jossey-Bass, San Francisco, CA.

Sakai, J. T., Wang, C. and Price, R. K. (2010) Substance use and dependence among Native Hawaiians, Other Pacific Islanders, and Asian ethnic groups in the United States: contrasting multiple-race and single-race prevalence rates from a national survey. *J Ethn Subst Abuse* **9**, 173-85.

Smedley, B., Smith, A. and Nelson, A. (2003) *Unequal treatment: confronting racial and ethnic disparities in healthcare*. Institute of Medicine, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Washington, DC.

Zhou, M. and Gatewood, J. (2000) *Contemporary Asian America: A Multidisciplinary Reader.* . New York University Press, New York, NY.









