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ABOUT APIAHF

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.
BACKGROUND

In 1985, the federal government issued its first report on minority health entitled Report on Black and Minority Health. The report, authored by then Secretary of Health and Human Services, Margaret Heckler, was groundbreaking in its recognition of disparities in key health outcomes between Whites and other minority groups. Yet, the Heckler Report concluded that Asian Americans, Native Hawaiians and Pacific Islanders (AAs and NHPIs) were healthier than other minorities despite the “paucity of data” on these populations. Asian American-serving health professionals, service providers, public health officials, and community leaders from all over the country gathered in New York to challenge the report’s characterization of AA and NHPI health, and to discuss the real health concerns of diverse and fast-growing AA and NHPI communities. The gathering, known as the Asian American Health Forum, served as a platform for health advocates to identify gaps in AA and NHPI research, develop recommendations and advance strategies for addressing the dearth of AA and NHPI health data. The event also laid the groundwork for the formation of a national organization known as the Asian & Pacific Islander American Health Forum (APIAHF). APIAHF, and many of its community-based partner organizations, would be at the forefront of data equity and data advocacy efforts for decades to come.

Data equity for AAs and NHPIs encompasses many components, such as improved data collection, analysis, and reporting at the federal, state, and local levels; better quality in-language administration and cultural adaptation of surveys; comprehensive collection and disaggregation of AA and NHPI ethnic group data; sufficient samples for reportable estimates; and oversampling of smaller ethnic groups. Data disaggregation is critical to develop a better understanding of the varying impacts of socioeconomic conditions and health disparities among AA and NHPI ethnic groups. This in turn can improve the development, implementation, and focus of programs and policies for AA and NHPI communities that are variably impacted by conditions, diseases, and other health issues.

Data advocacy encompasses the wide range of actions communities take in order to achieve data equity. Data advocacy can include: comment letters, legislative visits, meetings with department of health staff and/or university researchers, rallies, educational convenings, legislative advocacy, and administrative advocacy.

RWJF Data Equity Project

In 2015, APIAHF received funding from the Robert Wood Johnson Foundation (RWJF) to implement the Data Equity Project. This project sought to address: (1) the underutilization of national health data and (2) the limited efforts by federal and state agencies to promote higher quality data collection, analysis, reporting, and dissemination of AA and NHPI health data. APIAHF partnered with six AA and NHPI-serving community-based organizations (CBOs) in the promotion of public-private partnerships with state/local data collection agencies and entities.

This report highlights promising practices for advancing data equity gleaned from the review of APIAHF’s national efforts and the experiences of APIAHF’s six Data Equity Project partners. The report also offers policy recommendations to support adoption of public-private partnerships for improved data equity. The funding for this RWJF Data Equity Project was utilized to convene and cultivate a learning community of six CBOs to exchange strategies in overcoming challenges and communicating
benefits of data disaggregation; to share encouraging practices in improving health data collection, reporting, and dissemination for AAs and NHPIs; and to document and disseminate these strategies and practices. A majority of the data equity work of APIAHF’s partners preceded the RWJF Data Equity Project, and those local legislative advocacy efforts were supported by the respective CBOs’ budgets and grants. None of the legislative advocacy work mentioned in this report was supported financially by APIAHF’s RWJF project. The local legislative advocacy work began in 2012 for partners in California, New York, and Oregon prior to APIAHF’s receipt of RWJF funding for this data equity project.

Why Is Data Disaggregation Important for AA and NHPI Communities?

The Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) community is the fastest growing racial group in the country, growing over four times as rapidly as the total U.S. population and expected to double to over 47 million by 2060. AAs and NHPIs are comprised of over 80 ethnic and cultural groups who speak over 100 languages/dialects. Although AAs and NHPIs share geographic and cultural commonalities, there are unique social, educational and economic differences associated with different AA and NHPI ethnicities.

Given the rich diversity of ethnic groups, it is important to improve the current data collection and reporting practices, which often groups—or “aggregates”—AA and NHPI subgroup data into a single monolithic group. Data aggregation is problematic because it masks disparities among smaller and often underserved AA and NHPI communities and paints a misleading picture of AAs and NHPIs as healthy and economically secure—a characterization commonly known as the “model minority myth.” Moreover, some agencies fail to report on AAs and NHPIs in their data publications. Instead, data on AAs and NHPIs are suppressed or are categorized simply as “Asian,” “API,” “AAPI,” or “other.”

Data collection, analysis, and disaggregation are integral components in properly identifying, monitoring, and addressing social service needs for the growing and diverse AA and NHPI communities. Disaggregation and public reporting will help to ensure that agencies deliver vital services to their clients, base service delivery on information that accurately captures the diversity of demographics and service needs in the population, and help develop vital programs in a timely and efficient manner. Data collection categories and methodologies should also be standardized to allow for cross-tabulation and data analysis across data sets.

Disaggregation can also help federal, national, state, and local governments make more informed decisions about funding allocations. Disaggregated data provides the evidence base needed to accurately identify the service needs of underserved populations. Accurate data on the diverse AA and NHPI community will effectively dispel the model minority myth and provide a better understanding of the real challenges facing the country’s fastest growing group.
APIAHF’S HISTORY OF NATIONAL DATA EQUITY EFFORTS

Over its 30-year history, APIAHF has prioritized data disaggregation and data equity to help improve the health and well-being of AAs and NHPIs. APIAHF leveraged numerous public-private partnerships with key federal partners and agencies such as the U.S. Census Bureau and the Department of Health and Human Services (DHHS). Within DHHS, APIAHF worked with the Office of Minority Health (OMH), Health Resources and Services Administration (HRSA), National Center for Health Statistics (NCHS), and Centers for Disease Control and Prevention (CDC) to focus on data improvements for AAs and NHPIs. In 1989, APIAHF engaged key data champions from federal agencies, researchers, clinician leaders, and community groups, and established the National Research Advisory Committee (NRAC). The purpose of the NRAC was to strategize on improving the data for AA and NHPI health, especially in federal data sets. APIAHF’s NRAC greatly benefited from the advice, and later, active participation of Dorothy Rice, former NCHS director. Her guidance and engagement with APIAHF in addressing the data gaps on AA and NHPI health in 1988 initiated an active, longstanding partnership with NCHS to address data issues.

In 1990, the NRAC’s ideas stimulated efforts to improve AA and NHPI data through two legislative bills: the Asian & Pacific Islander Health Improvement Act (HR 4992), and the Disadvantaged Minority Health Improvement Act (HR 5702). NRAC also led key improvements to public health statistics such as modifying forms to acknowledge AAs and NHPIs as independent race categories rather than “other,” implementing more granular collection of race and ethnicity categories, coding and reporting on AAs and NHPIs in the National Health Interview Survey (NHIS), and financing special studies to augment information from population health surveys. These and other national data equity initiatives helped influence the Office of Management and Budget (OMB) to revise its federal data standards on race and ethnicity in 1997. Notably, the revised standards separated the existing “Asian Pacific Islander” category into “Asian Americans” and “Native Hawaiians and Other Pacific Islanders.”

Since then, there have been continued improvements to further AA and NHPI health data led by NCHS, the Social Security Administration, and other federal agencies and health advocacy organizations. In 2008, APIAHF submitted comments and recommendations to NCHS to disaggregate AA and NHPI data in the National Health and Nutrition Examination Survey (NHANES). This led to NCHS’ first effort to oversample AAs in its 2011-2014 cycle of NHANES, which has continued in its 2015-2018 cycle. APIAHF collaborated with NCHS by providing input in the outreach and recruitment of AA community-based organizations (CBOs) and communities to participate in the survey, translating NHANES materials into Asian languages, and identifying local interpreters. The 2011-2014 NHANES oversample of AAs offered an important opportunity to better understand childhood overweight and obesity among AA children using a nationally representative sample. This private-public partnership allowed APIAHF to conduct a data analysis of NHANES and the California Health Interview Survey (CHIS). APIAHF found that risk factors for childhood overweight and obesity include being Filipino or Southeast Asian, being male, and being a preteen (ages 9-12).

2. HR 4992, the Asian & Pacific Islander Health Improvement Act of 1990, was introduced by Representative Norman Mineta, but not enacted, and HR5702, the Disadvantaged Minority Health Improvement Act of 1990, introduced by Representative Henry Waxman, which authorized and appropriated federal dollars to advance the provisions of HR 4992. These included allocating to APIAHF via an NCHS contract to disburse grants for AA and NHPI health studies; and directing NCHS to collect health-related data on “Asian Pacific Islanders” specific to single racial population and subpopulations.
3. Age 9-12 risk factor based on NHANES analysis only.
APIAHF’s partnership with federal agencies also extended beyond population health surveys. Pursuant to Section 4302 of the Affordable Care Act (ACA), APIAHF worked closely with OMH to develop and implement new national data collection standards for race, ethnicity, sex, primary language, and disability status. APIAHF staff attended stakeholder meetings, submitted comment letters and organized colleague organizations to ensure the standards were as robust as possible. APIAHF was one of only two organizations invited to speak on the telephonic briefing organized by DHHS to announce the public release of the new standards in 2011, which include for the first time the collection of seven AA and four NHPI subgroups.

DATA ADVOCACY STRATEGIES

APIAHF’s partnerships with federal agencies proved effective and helped shape the policy and practice of disaggregated data collection, analysis and reporting on the national level. At the core of the partnerships were strong relationships with key decision-makers that were leveraged at strategic points in time. In addition, APIAHF’s model for successful public-private partnerships included:

- Identifying and nominating individuals to serve on federal advisory committees, peer review boards and other committees that influence data collection, survey (re)design and publication.
- Inviting federal partners to join community-based research/data advisory groups.
- Advocating for increased funding for key statistical agencies such as the National Center for Health Statistics.
- Assisting federal agencies disseminate health studies, reports, and journal articles on AA and NHPI populations.
- Developing model guidance for translation and interpretation of surveys.
- Responding to requests for comments from the federal register.

Variations of these strategies proved applicable to the data advocacy efforts of CBOs on the state and local levels, as evidenced below.

LOCAL AA AND NHPI DATA EQUITY EFFORTS

Over the years, APIAHF increasingly provided technical assistance to community-based organizations seeking to advance similar data disaggregation requirements on the state and local governments. Through the Data Equity Project, APIAHF worked with a group of six AA and NHPI CBOs that had previously participated in a capacity-building program also led by APIAHF. (See Appendix A for a profile of each organization.) Beginning in 2015, APIAHF served as the lead organization of the Data Equity Project and provided technical assistance and oversight to the six partner CBOs based in Arizona, California, Illinois, New York, Oregon, and Utah. APIAHF created a learning community to foster peer-to-peer discussion of strategies, challenges, and successes amongst the partners. The CBO partners engaged in data disaggregation and advocacy efforts, some successful and others still underway, and shared lessons from their experiences with each other. The learning community fostered an exchange of policy language, messaging, and advocacy strategies that helped the CBOs
strengthen their partnerships with state and local agencies for improved data collection and analysis. Several of the Data Equity Project CBO partners played key roles in helping to enact data equity legislation in their states and working in coalitions of diverse stakeholders to effect systemic changes to advance health equity. Specifically, the CBOs successfully leveraged their partnerships through the following strategies:

1. Identify champions to clearly and vocally support data equity efforts
2. Garner support from public and private sector partners
3. Collaborate and partner with public agencies on health reports
4. Tailor and adapt successful models
5. Engage and mobilize impacted communities

These approaches are described in more detail in the following section of the report.

**PROMISING PRACTICES IN LEVERAGING PUBLIC-PRIVATE PARTNERSHIPS FOR DATA EQUITY**

A promising practice is an action, program, or process that leads to an effective and productive result in a situation. These promising practices were identified through key informant interviews with the Data Equity Project partners, briefing conference calls with data advocates, and previously funded data development efforts of APIAHF.

1. **Identify Champions to Clearly and Vocally Support Data Equity Efforts**

Federal, state, and city officials, researchers, and community leaders have been central figures in the effort to advance health data equity for AAs and NHPIs. These key champions often offered not only their support but also leveraged their leadership roles and responsibilities to promote public awareness, garner additional support or streamline the process to achieving the desired outcome.

APIAHF and the Data Equity Project partners engaged several known champions in the data equity movement. These engagements included in-person meetings, teleconferences, email communication, and inviting these champions to participate as convening speakers and join data equity advisory groups. At the national level, APIAHF has worked with a number of key federal champions, including Dorothy Rice and Dr. Ed Sondik, former NCHS directors; Dr. Samuel Lin, former Assistant U.S. Surgeon General and Deputy Assistant Secretary for Health, DHHS; Betty Lee Hawks, formerly with the Federal Office of Minority Health (OMH); and Dr. Jane Lin-Fu, formerly with the Health Resources and Services Administration (HRSA). Ms. Rice served as the NCHS Director in the 1980s during the period of the Heckler Report and the establishment of the Office of Minority Health. She understood the value of disaggregated data as a critical tool for monitoring and addressing health disparities. In the late 1980s, she left NCHS and returned to California to serve as a professor at the UCSF Institute for Health & Aging. In 1989, APIAHF staff member Ninez Ponce contacted Ms. Rice at UCSF and sought guidance on how to develop a national strategy to advance data disaggregation. With Ms. Rice’s guidance and connections, APIAHF was able to connect with P. Doug Williams, NCHS Acting Associate Director for Data Standards, and Edward Hunter, NCHS Associate Director of Planning, Budget, and Legislation, to
join the APIAHF National Research Advisory Committee and help develop a national strategy to advance the first AA and NHPI data disaggregation initiatives in Congress, at federal agencies, and with federal datasets.

Dr. Ed Sondik, Director of NCHS in the 2000s and the first part of the 2010s, was also seminal in leading efforts to advance data equity within NCHS. Under Dr. Sondik’s leadership, NCHS revised two of its national health surveys to collect disaggregated AA and NHPI subgroups for the first time in the agency’s history. NCHS oversampled Asians for the first time for NHIS in 2006 and NHANES in 2011, and implemented an NHIS oversample of NHPIs in 2014. These oversampling efforts are critical to the monitoring and surveillance of health disparities within AA and NHPI subgroups, particularly for AAs.

Betty Lee Hawks was another key federal partner within HHS in the early years of OMH. Ms. Hawks recognized the need to document the health issues facing AAs and NHPIs. As a result, she educated the agency of the impact of health issues such as cancer, women’s health, and cultural competency on AA and NHPI communities, and worked with external advocates such as APIAHF and the Association of Asian Pacific Community Health Organizations on administrative policy within OMH and HHS to support more AA and NHPI health programs at the national, state, and community levels. Another NRAC member was Dr. Jane Lin-Fu, formerly with HRSA, documented the health hazards of lead poisoning in children. She was one of the first authors who documented the issues of AA and NHPI health disparities and published one of the first seminal journal articles in the late 1980s about the model minority myth, a major gap in AA and NHPI health data, and the need for more data evidence and data disaggregation to fully understand the health issues facing AAs and NHPIs. These champions were instrumental in addressing data gaps and stimulating improvements in data collection, analyses, and reporting on AA and NHPI health.

APIAHF’s Data Equity Project partners also found state and local data equity champions among legislators, researchers, epidemiologists, and community advocates. In Utah, diabetes afflicts nearly half of the state’s Tongan population. If the current growth trend of the disease continues, one in three adults will have diabetes by 2050 in the state. Thus, the National Tongan American Society (NTAS) approached the Utah Department of Health’s (UDOH) diabetes department to seek help in reducing diabetes prevalence within the NHPI community. In 2003, the year NTAS initiated its diabetes reduction efforts, there was a paucity of diabetes data for NHPIs, forcing advocates to rely on anecdotal evidence. After hearing from local NHPI community members about a UDOH staff person who had provided basic health education materials on diabetes, NTAS’ Executive Director walked into the UDOH office without an appointment and asked to meet this particular staff person. The two shared anecdotes of the devastating impact of diabetes on local NHPIs and discussed a federal grant opportunity to address diabetes among NHPIs. UDOH provided technical assistance with NTAS’ grant application, and the organization successfully received the grant. This set the tone for years of ongoing collaboration between UDOH and NTAS. Today, NTAS has four grants from UDOH focused on chronic diseases, cancer, and maternal/child health in the NHPI community.

The Invisible No More campaign was launched in 2012, when former New York Assembly Member Grace Meng contacted the Coalition of Asian American Children & Families (CACF) to be the lead community partner for a state disaggregated data bill. CACF worked closely with Assembly Member Meng to identify a potential state senate sponsor, which was Senator Diane Savino. This state bill secured support from the community but did not get voted out of committees in the state legislative session. In the same year, New York City (NYC) Council Member Daniel Dromm refined the state bill
and worked with CACF to introduce a similar bill at the city level. This bill would amend the NYC charter to ensure that City agencies utilize a standard approach to data collection, disaggregation, and reporting out on AAs and NHPIs.

2. Garner Support from Public and Private Sector Partners

APIAHF’s CBO partners found it helpful to engage and build relationships with different sectors, such as local and state agencies (i.e. health departments and government operations divisions), legislators, universities, and allied CBOs. These partnerships supported the active engagement of community stakeholders from public and private sectors, and increased their capacity to address systemic problems by drawing on their individual and collective resources. Public-private partnerships can wield more power than one organization or even a group of similar organizations.

In New York, CACF involved over 50 partners, including City Council members and staff, the Mayor’s Office for Immigrant Affairs, Assembly members, health department staff, research partners, and local and national organizations in their data equity efforts. In lieu of framing their data equity efforts solely on AA and NHPI communities, CACF broadened their partnerships to engage other like-minded social justice entities, such as other communities of color, LGBT, multi-racial, and disability groups. The support and buy-in of these allies for the Invisible No More campaign has helped to elevate concerns for improvements in data collection. NYC Council Member Daniel Dromm is also the key sponsor for an LGBT bill on gender identity and sexual orientation. Through ongoing discussions, community advocates are determining ways to leverage the larger banner of the need for NYC to push forward on data improvements to better reflect the diversity of the city’s residents.

5 No RWJF funding was used to fund CACF’s legislative efforts.

CACF press conference at New York City Hall, February 9, 2016
In California, Empowering Pacific Islander Communities (EPIC) cultivated partnerships and relationships with state and national organizations, state legislators, and universities in support of a state data equity bill, AB 1088, which was passed in 2011. EPIC worked with Assemblymember Mike Eng and bill co-sponsors Asian Americans Advancing Justice - Los Angeles, Asian Americans for Civil Rights and Equality, and Asian & Pacific Islander California Action Network. EPIC utilized their network of CBOs throughout California to raise awareness about the importance of collecting disaggregated data on AA and NHPI communities and garner support from state legislators. EPIC developed factsheets in English and Pacific Islander languages to explain the importance of the bill and how it helps the NHPI community. Through its engagement efforts with NHPI community members, EPIC submitted 60 letters of support, provided testimony, and used social media and communications to raise awareness of AB 1088.

In Illinois, Asian Health Coalition (AHC) entered into a formal partnership with the University of Chicago to form the Center for Asian Health Equity (CAHE) in 2015. CAHE represents a major commitment by the University of Chicago to close the gaps in Asian American health data by engaging research scientists to conduct innovative research and ongoing monitoring of socioeconomic, racial/ethnic, and other social determinants of health and access to health care.

In September 2015, AHC hosted a leadership convening to strengthen relationships between AA community leaders and leadership from the Chicago Department of Public Health, Illinois Department of Public Health (DPH), and University of Chicago Medicine. The theme for the event was “The Collective Impact – Filling Gaps, Aligning Resources, and Propelling Progress.” Over 25 community leaders representing AA and NHPI CBOs, community health clinics, and faith-based organizations attended the convening. Panelists provided background information and status updates on health data equity issues, including current efforts to advance health equity, existing models of community engagement for agencies and institutions to include AA participation, and improving current surveillance systems to better collect AA health data.

The event raised several data gaps and challenges, such as:

1. There are inconsistent definitions of AAs and the aggregate classification of AAs raises questions about the comparability of data. Some data on AAs only include one or two subgroups, and such subgroups may be overrepresented due to which groups live in the place where sampling occurred.

2. There is a lack of or inconsistent reporting of race and ethnicity data in Illinois and Chicago disease registries, health plans, and hospitals. Accurate reporting of race and ethnicity data in these settings is important both for enhancing patient care and for providing valuable estimates of disease prevalence and health outcomes in particular populations. The issue of reporting of AA race and AA subgroup data within these settings is understudied.

3. There is limited data collection in Asian languages. In Illinois, there is no state-sponsored data collection effort where survey administration is consistently conducted in a language other than English or Spanish. Nearly 65% of the AAs and NHPIs in Illinois and Chicago are foreign-born and there are high levels of limited English proficiency (LEP) and linguistic isolation experienced by many low-income AA and NHPI communities.

4. There is an undersampling of AAs or ethnic subgroups in Illinois surveys, which often precludes the inclusion of AAs in the final analyses.

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6 No RWJF funding was used to fund EPIC’s legislative efforts. RWJF funding supported EPIC’s participation in sharing their strategies and approaches in leveraging public-private partnerships for data equity with RWJF Data Equity Project partners.
While still in the early stages of its collaboration with its public partners, AHC’s active engagement has already increased the visibility and consideration of AA and NHPI disparities and the data equity challenges among some of the state’s most influential decision makers.

3. Collaborate and Partner with Public Agencies on Health Reports

Some of the CBOs involved with the Data Equity Project worked closely with public institutions such as county and state health departments and universities to issue reports focused on AA and NHPI health. These reports were often the first of their kind, and provided groundbreaking health data and research on specific AA and NHPI populations at the local or state levels. The reports demonstrated the value of disaggregated health data, and the impact of public-private partnerships on the field of health disparities literature. The partnerships formed through the report development process also created additional opportunities for the CBOs to advance their health equity work.

Asian Pacific American Network of Oregon (APANO) worked closely with the Multnomah County Health Department in Oregon on a county-specific Pacific Islander Health Disparity Supplement report. APANO and Pacific Islander (PI) partners requested that this type of report be conducted annually, and tailored to other communities of color. APANO also recommended that the county create a permanent, PI health equity staff position and invest in a community leadership program to build capacity of PI community to be directly engaged in data analysis and program development. The County Health Department responded by funding and hiring a policy & community liaison focused on Pacific Islanders in their Health Equity Initiative in 2015.
In 2011, Asian Pacific Community in Action (APCA) and their coalition of multi-sector partners from CBOs, universities, state Department of Public Health, and health providers developed a data book called the *State of Asian Americans and Pacific Islanders in Arizona, Volume 2: Health Risks, Disparities, and Community Responses*. This data book became an important resource for various public and private entities. Recommendations from this book helped APCA to successfully secure resources to address healthy eating and active living needs among the AA and NHPI community. More recently, APCA worked with non-profit agencies, such as Asian Americans Advancing Justice, to help promote the Western Advancing Justice demographic report. In addition, APCA worked with the White House Initiative on AAPIs to promote their roundtable regarding data disaggregation and data equity in Phoenix in July 2015.

In Utah, UDOH partnered with NTAS to include NHPIs in key state health reports, such as the Utah Pacific Islanders 2011 report. NTAS has also increased UDOH’s ability to survey the NHPI community. NTAS helped to design and pilot test a health survey, translate the survey instrument into Tongan, recruit interviewers, and promote participation in key informant interviews and surveys. This was the first survey project UDOH had completed in a language other than English or Spanish.

### 4. Tailor and Adapt Successful Models

When APIAHF began conversations with NCHS about conducting a NHANES Asian oversample, APIAHF asked about the challenges and successes of similar NHANES oversamples with African Americans and Hispanics. NHANES shared their experiences and approaches with those oversamples, which included lessons learned about the critical role of early community engagement. As a result, APIAHF dedicated a significant amount of time engaging with national and local AA CBOs to support NCHS’ community outreach and recruitment efforts of AA survey participants. APIAHF’s experience with AA and NHPI outreach also informed its efforts to work with NCHS to ensure culturally and linguistically appropriate survey development, implementation and reporting. For example, APIAHF advised NCHS on how to address variations among AA subgroups and languages in conducting the oversample within the AA community.

Similarly, the Data Equity Project partners adapted lessons learned from existing federal and state models to respond to questions and challenges about their efforts. For example, state legislators
wanted to know if similar data equity bills had been passed in other states. By sharing the challenges, successes, processes, and sample legislative language, the partner organizations built not only their reputation and relationship with the legislators, but also legislative support and champions. The learning community formed through the Data Equity Project provided a forum for this exchange of ideas and best practices. For example, CACF in New York conferred with the Data Equity Project partners in Oregon (Asian Pacific American Network of Oregon) and California (Emerging Pacific Islander Communities), whose states had successfully enacted data disaggregation bills, to refine its strategies and develop key messages. AHC learned about data collection standards in other states before beginning their research on their own states practices. The background knowledge and lessons learned from their Data Equity Project colleagues continues to inform AHC’s efforts to address the barriers departments of health face in improving AA health data. In short, the best practices and models shared within the Data Equity Project’s learning community helped the CBO partners create an effective “launching pad” for their data advocacy efforts.

5. Engage and mobilize impacted communities

In order to advance data equity, all of APIAHF’s partners found it important to create a groundswell of community support. Legislators, government administrators, and other decision-makers involved in shaping data collection, analysis, and reporting efforts often did not consider taking steps to improve data for AA and NHPI communities until they felt there was broad endorsement and buy-in from community members.

In 2013, APANO advocates and partners convened community listening circles and provided testimonies prior to HB 2134 passing. APANO and their coalition partners were also active in the rulemaking process after passage of HB 2134, the nation’s leading state standards on race, ethnicity, language and disability data in health and human services. APANO served on the joint Race, Ethnicity, Language and Disability (REAL+D) Steering Committee, which is charged with implementation oversight and legislative report backs on the law. APANO and other community members contribute to REAL+D analysis and assessment project by conducting a detailed assessment and impact analysis of the changes that will be required across Department of Human Services and Oregon Health Authority to support the implementation of HB 2134 and the related Oregon REAL+D data collection standards. The outcome of the in-depth analysis will include a detailed business case and recommended implementation strategies for REAL+D data standards compliance. HB 2134 rules established through the Oregon Health Authority and Department of Human Services have begun to trigger changes to over 60 state databases and collection practices. They have also started to reshape county and contractor data collection.

CACF’s coalition mobilized a broad-based network of organizations that served AAs, NHPIs, and other communities of color, as well as LGBT and disability communities and academic researchers who had worked with elected officials to introduce previous state data equity bills. Its broad coalition efforts ensured that CACF’s messages and public education efforts would reach multiple audiences. CACF’s data campaign “Invisible No More” raised state-wide awareness of the need to improve data collection and reporting by government agencies and led to current efforts to push for the enactment of similar legislation on the local level.

EPIC worked with State Assembly member Mike Eng and local and national organizations to help pass AB 1088 in 2011. While AB 1088 passed to collect disaggregated data from the Department of Fairness and Housing and Department of Industrial Relations, the community advocated to collect
disaggregated AA and NHPI data in other departments focused on health and education. National groups such as Southeast Asia Resource Center (SEARAC) and EPIC worked with the Assemblyman Rob Bonta to introduce AB 176 in 2015. While AB 176 passed both houses of the California legislature, the Governor of California vetoed the bill. In response, SEARAC, EPIC and APIAHF mobilized their networks. Over 600 organizations and individuals in 27 states signed a response letter to the Governor expressing deep disappointment in the veto action. SEARAC, EPIC, APIAHF, and other organizations are continuing these collaborations to mobilize support for AB 1726, a new iteration of AB 176 introduced in 2016. Their efforts include communications components such as media placements, story collection, press conferences, rallies, petitions, and social media campaigns.

Recently, the Chicago DPH released its Healthy Chicago 2.0 report outlined DPH’s health improvement plan and priorities for 2016-2020, which included childhood obesity as a priority area, however race/ethnicity data was only available for Hispanic, Non-Hispanic Black, Non-Hispanic White and Non-Hispanic Other. Similar to the Heckler Report published 30 years earlier, DPH’s report revealed very little about Asian Americans.

DPH is scheduling a series of listening sessions and town halls to share the improvement plan presented in the report and is working with AHC to schedule one of these sessions with Asian community members. AHC plans to gather community members to respond to the plan, and develop collaborative strategies to address the paucity of AA data presented. These could include translation of future health surveys, providing assistance in survey participation, and supporting survey development.
POLICY RECOMMENDATIONS TO SUPPORT PUBLIC-PRIVATE PARTNERSHIPS

The Data Equity Project yielded several successful strategies for leveraging public-private partnerships from the perspective of CBOs. Policymakers can also play a role in supporting these partnerships to help advance data disaggregation and data equity efforts.

- **Policymakers should utilize multiple strategies to build partnerships with community-based organizations.** APIAHF partner organizations have demonstrated successful ways to partner with policymakers at the local and state level to advance data equity. CBOs are trusted voices in their communities because they are part of the communities they serve and understand their unique needs. CBOs serve as a bridge to the community, and policymakers can use partnerships with CBOs to educate the community about the benefits of data equity policy changes and specific legislation and to garner community support and engagement around these issues. Policymakers can also work with CBOs to help design and disseminate surveys to the community to get their feedback on community needs and the best ways to access and use data to benefit the community. Policymakers should create opportunities for CBOs to share their expertise in engaging and connecting with communities. As APIAHF CBO partners have shown, they can help to encourage survey participation and community feedback. CBOs can also serve in facilitating partnerships between policymakers and communities to increase awareness and foster discussion about how to address health equity through better collection of data.

- **State and local agencies should update data collection, analysis and reporting practices to collect relevant data on growing and emerging populations, including those within the AA and NHPI community.** As communities continue to become more diverse, it is important that data collection systems and practices change to accurately capture data and identify unique needs within sub-populations of communities. CBOs can help state and local agencies improve their data collection, analysis, and reporting practices to better understand the diversity of the communities they serve.

- **Policymakers should involve CBOs in an advisory capacity to assist with implementation of data equity legislation and policy changes.** CBOs can serve on advisory boards or committees to provide technical assistance and feedback from the community to help with the implementation of new data collection and reporting standards. When CBOs are closely involved in implementation, they can represent the community voice and ensure effective and timely implementation.

- **Data should be comprehensive and accessible to the community.** Data is only as good as its availability to users. Once disaggregated data has been collected, it should be made accessible and understandable to communities so community-based researchers, CBOs, and others can effectively use the data to identify health inequities and needs of the community. If numbers are too small for some subgroups, state and local agencies should provide clear explanations and justification for why that data cannot be reported.
LOOKING AHEAD

Public-private partnerships and data champions are vitally needed at all levels to advance data equity. On a national level, the respective AA and NHPI oversamples with NHANES and NHIS are making immense national impacts in describing and examining health equity. At state and local levels, several AA and NHPI CBOs have been successful in changing data collection and reporting standards to more accurately capture disparities within the growing AA and NHPI population. In doing so, they are improving data equity not only for AAs and NHPIs, but also for other underserved communities.

It is important to tie local and state efforts to a larger national movement. Successes and challenges in other parts of the country can be leveraged for justification of why data legislation should move forward or why growing AA and NHPI communities need to be represented in state health reports. Collaborations and structured learning cohorts between national, state and local data advocacy organization such as the RWJF Data Equity Project can help advance successful data disaggregation and data equity initiatives across the country. For example, the New York partner applied best practices from California’s and Oregon’s experiences to successfully introduce state and municipal data equity legislation in New York City. Other partners in Illinois and Utah have expressed interest in proposing comparable data equity bills and gained insightful mentorship from their data equity partners from California, New York and Oregon.

As the numbers of AA and NHPI community are growing and expected to double to over 47 million by 2060, the momentum for data equity is growing. More communities are demanding better public reporting of health disparities and population data, and advocates are successfully making the case to policy makers for more robust data standards. Partnerships between private organizations and public entities will be essential to finding the solutions needed to address these growing needs. Accurate data on the diverse AA and NHPI community will effectively dispel the model minority myth and provide a better understanding of the real challenges facing the country’s fastest growing group.
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APPENDIX A: DATA EQUITY PROJECT PARTNER PROFILES

Asian Health Coalition (AHC) in Chicago, Illinois

Background

Asian Health Coalition’s (AHC’s) mission is to improve the health and well-being of Asian Americans (AAs) in Illinois through advocacy, technical assistance, education, and community-based research. The agency was founded as the “Asian Health Coalition of Illinois” in 1996. AHC gained visibility in the AA and NHPI community in 1999 for its annual health conferences and health screening fairs targeting low-income, limited-English proficient clients in Chicago. AHC has streamlined its focus to building strong and innovative health promotion programs in AA communities throughout the metropolitan Chicago area.

Work Conducted Prior to RWJF Data Equity Project

In 2015, AHC entered into a formal partnership with the University of Chicago, to form the Center for Asian Health Equity (CAHE). CAHE represents a major commitment by the University of Chicago to address needs that go well beyond the traditional service role of an academic medical center, with a strong focus on closing the gaps in AA health data by engaging research scientists to conduct innovative descriptive, explanatory and methodological research and ongoing monitoring of socioeconomic, racial/ethnic and other social determinants of health and access to health care.

Work Conducted Under RWJF Data Equity Project

Besides working on programs focused on chronic diseases, communicable diseases, mental health and substance abuse, AHC has experience in research and data. For this data equity project, AHC has built and leveraged key public and private partnerships that put them in a stronger position to advocate for and facilitate data equity for AAs and NHPIs in our state. Specifically AHC has:

1. Met with Chicago Department of Public Health’s (DPH’s) new Health Commissioner, Dr. Julie Morita, who is the first AA to hold this post to discuss strengthening CDPH’s efforts with the AA community.
2. Met with Illinois DPH’s new Director, Dr. Nirav Shah, who is also the first AA to hold this post, to discuss health disparities and needs among the AA population.
3. Joined the Cook County Department of Public Health’s Community Health Advisory Committee, which aims to improve public health using a health equity lens and participated in the Cook County DPH’s WePlan community assessment as a community partner.
4. Met with Illinois State Representative Greg Harris in order to explore the feasibility of introducing a data disaggregation bill in 2016 or 2017.
5. Participated in the State Health Improvement Planning Coordination Council to develop the 5-Year State Health Improvement Plan.
6. Reviewing the creation of an AA community health data registry with the University of Chicago that will capture de-identifiable key data indicators and demographic information by ethnic subgroup.
In September 2015, AHC hosted a convening for AA CBO leaders to meet with leadership from the Chicago Department of Public Health, Illinois DPH and University of Chicago Medicine. The theme for the event was entitled “The Collective Impact – Filling Gaps, Aligning Resources, Propelling Progress” and was attended by 25 community leaders and included conversations health data equity for AAs in Chicago.

For more information on Asian Health Coalition, please visit: http://www.asianhealth.org/
Asian Pacific American Network of Oregon (APANO) in Portland, Oregon

Background

Asian Pacific American Network of Oregon (APANO) is a statewide, grassroots organization, uniting Asians and Pacific Islanders (APIs) to achieve social justice. APANO uses their collective strengths to advance equity through empowering, organizing and advocating with API communities. APANO focuses on the key areas as of community organizing, policy advocacy, civic engagement, leadership development, community development and culture work.

Work Conducted Prior to RWJF Data Equity Project

In 2009, APANO took a leadership role in the Oregon People of Color Health Equity Collaborative, focusing on data equity, cultural competency, and resourcing and professionalizing bilingual/bicultural community health workers. In 2012, APANO’s research identified the data disparities, impacts and cost to AANHPI communities, developed a statewide coalition for data equity, leading to the legislative concept that would become Oregon House Bill 2134. HB 2134 was signed into law by the Governor, and APANO and partners established the nation’s leading state standard for race, ethnicity, language and disability standard for health and human services. APANO advocates and partners were active in the rule making process, and subsequently serve on the joint Race, Ethnicity, Language and Disability (REAL+D) Steering Committee with implementation oversight and legislative report backs. HB 2134 rules established through the Oregon Health Authority and Department of Human services are triggering changes to over 60 state databases and collection practices, and reshaping county and contractor data collection. APANO continues to work with four counties in the Metro Portland region to adopt these standards at the local levels.

The REAL+D Steering Committee conducted a comprehensive review of databases to assess the gaps in current data collection. For example, while 87% of Oregon Health Authority databases collect race/ethnicity, there is wide variance in standard categories and none utilize the HB 2134 standard. In 2015, APANO and partners helped secure an additional $650,000 from the legislature to continue to move forward full implementation of HB 2134 standards APANO continues to ensure that emerging AA and NHPI groups are included, and the HB 2134 legislation requires a review of the standard every two years. Currently the standard includes 12 distinct AA and NHPI categories that account for over 90% of AAs and NHPIs in Oregon, making the “other Asian” and “other PI” categories more meaningful.

Work conducted under RWJF Data Equity Project

APANO worked closely with the Multnomah County Health Department on a county-specific Pacific Islander (PI) Health Disparity Supplement report. APANO and Pacific Islander partners requested that this type of report be conducted annually and for other communities of color. APANO recommended that this county create a permanent, PI health equity staff position and invest in a community leadership program to build the data analysis and program development capacity of PI community. The County responded by funding and hiring the new PI specific policy analyst position in 2015. APANO continues to work with the county to host future Data Equity Summit. APANO is starting to analyze data from the special one-time Medicaid BRFSS that includes a race oversample plus a logic question for disaggregation of AA and NHPI and is working on a new BRFSS data collection pilot using Respondent Driven Sampling.

For more information on Asian Pacific American Network of Oregon, please visit: http://www.apano.org/
Asian Pacific Communities in Action (APCA) in Phoenix, Arizona

Background

The mission of the Asian Pacific Community in Action is to improve the health and well-being of the Asian Pacific Islander community in Maricopa County through empowerment, health promotion, and disease prevention. APCA’s programs have focused on chronic diseases prevention, education, and linking to screenings, oral health, language access, ACA outreach and enrollment, civic engagement, and data development and advocacy.

Work Conducted Prior to RWJF Data Equity Project

APCA has focused on data equity since 2006. With the state health department, APCA would advocate for inclusion of AA and NHPI data in health reports. APCA had been asked by state health department to be involved in their state community profiles but unfortunately did not have the financial resources to do so. APCA has worked with non-profit agencies, such as AAAJ, to help promote Western Advancing Justice demographic report. In addition, APCA worked with the White House Initiative on AAPIs to promote their roundtable regarding data disaggregation and data equity in Phoenix in July 2015.

APCA also led a coalition effort to publish a Data Book in 2008 compiling available data on AA and NHPI health to create an evidence base for progressive health policies and programs for AA and NHPI communities in Arizona. While working closely with Arizona State University faculty, APCA aimed to create a community-owned document of community health issues and resources. APCA enlisted local health practitioners to write articles on various health topics and pooled community resources to cover the design and printing of the report. Previous resources were unveiled at a symposium hosted by APCA that engaged community leaders and activists in lively discussions of the issues covered and policies proposed in the publication. The Data Book became an important resource for various public and private entities such as the state and county health departments and the American Civil Liberties Union.

Work Conducted Under RWJF Data Equity Project

APCA participated in the state’s health disparities roundtable and focused on cross-cultural and health equity issues. APCA also became an active member of a health equity roundtable and an established city commission focused on health disparities. APCA received a Dataquest Foundation grant and served as the lead agency and working with core group partners who serve low-income, historically undeserved, linguistically isolated communities in Maricopa and Pima County, and looks forward to seeing the data collected used to improve oral healthcare in Arizona.

For more information on Asian Pacific Community in Action, please visit: http://apcaaz.org/
Coalition for Asian American Children & Families (CACF) in New York, New York

Background

The Coalition for Asian American Children and Families is the nation’s only pan-Asian children’s advocacy organization, aims to improve the health and well-being of Asian Pacific American children and families in New York City. CACF challenges stereotypes of Asian Pacific Americans as a "model minority" and advocates on behalf of underserved families in our community, especially immigrants struggling with poverty and limited English skills. CACF promotes better policies, funding, and services for East Asian, South Asian, Southeast Asian, and Pacific Islander children, youth, and families.

Work Conducted Prior to RWJF Data Equity Project

Recognizing that the existing data collection infrastructure in New York State was inadequate to guarantee equitable distribution of resources to AA, NHPI, and other small populations, CACF launched a state-wide campaign in 2012 on the need for improved data disaggregation. The “Invisible No More” campaign set a goal to pass state and local legislation requiring the standardization of data, advocating, for the use of 19 AA and 4 NHPI ethnic categories, collection of primary language and country of origin, as well as the scheduled release of publicly-available health data. CACF’s coalition mobilized a broad-based network of organizations that served AAs, NHPIs, and other communities of color, as well as LGBT and disability communities and academic researchers. Although these bills were not enacted, the campaign raised state-wide awareness of the need to improve data collection and reporting by government agencies and led to current efforts to push for similar state and local legislation.

CACF worked closely with the New York City Council on Int. No. 251, a bill that would amend the NYC charter to ensure that City agencies utilize a standard approach to data collection, disaggregation, and reporting of AAs and NHPIs. Basic demographic information on AAs and NHPIs had been collected in NYC, but CACF urged NYC Council to collect more detailed data about the communities' needs in order to provide those who need help the most. Int. No. 251 was modeled after ACA Section 4302 and included questions on primary language. Over 100 groups from AA, NHPI and other communities signed on to support CACF’s data equity efforts. The bill also inspired Int. No. 551, a bill to collect multiracial categories and Int. No. 552, a bill to collect gender identity, sexual orientation, and mandate trainings for city agencies on best practices for administering surveys and intake forms for the LGBTQ community.

Work Conducted Concurrently During RWJF Data Equity Project

A hearing took place on May 2015 to provide an opportunity for the public to voice their feedback on the three proposed bills. CACF held a press conference in early February 2016 along with their colleagues serving the LGBT and mixed race communities to call on the NYC City Council Speaker to take action on 3 data bills. Although there is tremendous support with over 41 city councilmembers signing on out of 51 and negotiations between the City Administration, agencies and the bill sponsors have been ongoing and overall positive, there is a hold up on pushing this forward due to competing priorities by City leaders. Many AA and NHPI partners continue to support CACF’s data advocacy and equity efforts.
No RWJF funds were used to support CACF’s legislative advocacy efforts. RWJF funding supported CACF’s participation in sharing strategies and approaches for leveraging public-private partnerships for data equity with RWJF Data Equity Project partners.

For more information on Coalition for Asian American Children & Families, please visit: http://cacf.org/
Empowering Pacific Islander Communities (EPIC) in Southern California

Background

Empowering Pacific Islander Communities’ mission is to promote social justice by engaging NHPI communities through culturally relevant advocacy, research, and development. EPIC’s project areas have focused on leadership development, educational equity, ACA outreach and enrollment, civic engagement, and data development and advocacy. Native Hawaiians and Pacific Islanders (NHPIs) are rarely represented in racial and ethnic data collected and reported by federal and state agencies, which often use the outdated and overly broad “Asian Pacific Islander” category. EPIC advocates for data that accurately reflects NHPI diversity so that disparities across key socioeconomic characteristics can be identified and addressed.

Work Conducted Prior to RWJF Data Equity Project

EPIC worked with state (Asian Americans Advancing Justice Los Angeles/AAAJ-LA, API Caucus, AACRE, and CPEHN) and national organizations (APIAHF, APPEAL, CAPACD) on state and national health advocacy issues. EPIC worked with AAAJ-LA and local Southern California legislators who introduced Assembly Bill 1088 (AB 1088), which would ensure that state-collected health, social services, labor and civil rights data is disaggregated into AA and NHPI ethnic groups and also made publicly accessible. When it was introduced, AB 1088 also would have required the state Departments of Public Health and Health Care Services to collect expanded demographic data. But because of budget restrictions, the bill was shaved down to two agencies that would incur only minor costs. AB 1088 would require the Department of Industrial Relations and the Department of Fair Employment and Housing, to collect the same ethnic data as the U.S. Census, by adding eight Asian and two NHPI ethnic groups. In addition, AB 1088 would require data on AA and NHPI ethnic groups to be posted online and easily accessible, although currently, that data is challenging to find. EPIC was able to get over 60 letters from the community to support the bill. AB 1088 was assigned by the Governor in 2011, required two state agencies to collect employment, housing and economic data for disaggregated AA and NHPI ethnic groups.

Work Conducted Concurrently During RWJF Data Equity Project

In 2015, the Accounting for Health and Education in API Demographics Act (AHEAD Act) AB 176 was introduced by data champion Assembly member Rob Bonita. The AHEAD Act would have required the California Department of Public Health and the higher education institution administrations of the California Community Colleges, California State University, and the University of California to collect demographic data to disaggregate different ethnic origins and make the data publicly available for specified AA and NHPI subpopulations that include but are not limited to 16 AA and 5 NHPI groups. AB 176 passed unanimously in the state Senate and drew just one dissenting vote in the Assembly. In October 2015, California’s Governor vetoed the bill.

EPIC, along with Southeast Asian Resource Action Center (SEARAC) and APIAHF mobilized 500 AA and NHPI individuals and 100 CBOs from 27 states to respond to this veto by signing-on to a letter. In November 2015, SEARAC, EPIC and APIAHF worked with EPIC to meet with the Senior Advisor to the Governor to discuss future data disaggregation efforts. The Governor’s office shared an openness to considering another iteration of the data disaggregation bill, and in January 2016, AB 1726 was introduced. AB 1726 would require the updating of the reporting categories for future decennial censuses. The bill would require, on or after July 1, 2017, the State Department of Public Health and Health Care Services to collect demographic data to disaggregate the following AA and NHPI ethnic groups for future decennial censuses:

- Asian American
- Pacific Islander
- Native Hawaiian
- Other AA and NHPI communities

AB 1726 was vetoed by the Governor in 2017.
Health, the State Department of Health Care Services, the Board of Governors of the California Community Colleges, the Trustees of the California State University, and the Regents of the University of California to use the additional separate collection categories and other tabulations for specified AA and NHPI groups.

No RWJF funds were used to support EPIC’s legislative advocacy efforts. RWJF funding supported EPIC’s participation in sharing strategies and approaches for leveraging public-private partnerships for data equity with RWJF Data Equity Project partners.

For more information on Empowering Pacific Islander Communities, please visit: http://empoweredpi.org/
National Tongan American Society (NTAS) in Salt Lake City, Utah

Background

The mission of the National Tongan American Society is to advocate for, and empower all Tongan-Americans and other Pacific Islanders through programs and referrals that promote health, youth development, education and artistic, and ethnic and cultural preservation. NTAS seeks to fulfill its mission to create and maintain programs that meet the needs of the Tongan-American community, their families, and their friends. In addition, it seeks to encourage the Tongan “ʻofa faka-kāinga” (extended-family love and care) that crosses ethnicity, national origins, gender, and religious boundaries. NTAS’ programs have focused on chronic diseases prevention, education, and linking to screenings, healthy eating active living, ACA outreach and enrollment, civic engagement, language access, research, and data development and advocacy.

Work Conducted Prior to RWJF Data Equity Project

NTAS has had a relationship with the Utah Department of Health (UDOH) since 2003. NTAS approached the state’s diabetes department at UDOH to forge relationships and seek help in addressing diabetes in the NHPI community. UDOH offered assistance to NTAS in writing a diabetes-focused grant application, which NTAS received. This effort marked the beginning of a continued effective partnership with UDOH on diabetes outreach and education to NHPIs. NTAS successfully advocated to UDOH to have NHPIs as its own category on surveys and specifically for tracking infant mortality data. NTAS is represented on advisory committees on some key NHPI health reports. In addition, because NTAS is a small non-profit organization, it lacked the expertise in data collection and analysis and was fortunate to have UDOH’s assistance in collecting NHPI-specific data.

NTAS leveraged this public-private partnership and collaborated on multiple health reports focused on NHPIs and major health issues, such as diabetes, infant mortality, and obesity. More recently, NTAS has been approached by several departments in UDOH to work with them such as cancer, maternal child health, obesity, other chronic diseases, and Office of Health Disparities. NTAS created its own survey to look at health behaviors and perceptions of health among adults and youth. UDOH helped to develop the survey with NTAS to make sure was cultural relevant. NTAS collected 600 surveys and shared its own data with UDOH.

Work Conducted Under RWJF Data Equity Project

NTAS has identified additional opportunities to improve data equity through collaboration. NTAS will partner with UDOH’s Office of Health Disparities to create a mental health survey since currently there is no disaggregated data on NHPI mental health and NTAS has identified an NHPI researcher to help with this effort. An additional prospect includes working with key policy makers and agencies to address inequities in the treatment of NHPIs, likely associated with a high rate of school-to-prison pipeline of juvenile and other issues in NHPI and other students of color. This could entail gathering data for NHPI populations and ensuring that necessary culturally competent trainings are completed by school administrators, teachers, school research officers, police officers, etc. when working with NHPIs and other students of color, race, ethnicity and gender.

NTAS has strong public-private partnerships with the University of Utah. This is demonstrated by NTAS securing a community wellness coach grant with the university and along with other communities of color. Due to this funding, NTAS hired a coach to lead women’s health and coordinate this research
grant. NTAS continues to leverage these partnerships to facilitate engagement of NHPI communities in data collection, translation, survey development, implementation, and dissemination and to ensure that NHPIs are included in health reports and initiatives at the forefront and not as an afterthought.

For more information on National Tongan American Society, please visit: https://www.facebook.com/TheNTAS