

Health Equity through Enhanced Data

HEALTH THROUGH ACTION ARIZONA

BACKGROUND

In the state of Arizona there are limited publicly available data on Asian American, Pacific Islander, and Native Hawaiian (AA and NHPI) health risks and challenges. This limitation has a negative impact on community health programs and funding priorities. Without accurate local data, public health interventions rely on anecdotes and nationally collected data for the design, implementation and evaluation of programs. While this approach can lead to innovative programming and contribute to lessons learned, the dearth of reliable information also means that many health issues in the community remain unknown or lack the evidence base to be adequately addressed or funded.

As an AA and NHPI health-serving organization, Asian Pacific Community in Action (APCA) and the Health Through Action Arizona (HTAA) Coalition decided to fill this information gap by drawing upon expertise within the local community to raise awareness about emerging health issues or unique challenges, unmasking the disproportionate risks facing certain language/cultural communities, and highlighting the different programs and agencies working to improve the health and well-being of AAs and NHPIs in Arizona. The hope was that researchers and activists in the local community would use the information gathered to further investigate particular topics or develop robust programs and policies in response to community issues.

While these goals seemed daunting in the beginning, APCA had built upon the work of Health Through Action Arizona (HTAAZ) that was formed with partners and allies from various sectors of the community that came together for various health related initiatives. This includes fulfilling the goals of what became known as the “data book” project, which became *State of Asian Americans and Pacific Islanders in Arizona, Volume 2: Health Risks, Disparities, and Community Responses*.

COALITIONS

HTAA was formed by APCA as part of a national effort, in part, to elevate the capacity of health and human service organizations to do policy and advocacy work. The coalition formed by re-engaging a previously formed advisory board to APCA that was made up of local community members, representatives of AANHPI community organizations, researchers, and health practitioners. While AANHPI communities in Arizona have a long history of working together in coalitions for diverse causes, HTAA was the first to assemble a group of allies for the purpose of improving policies and systems to benefit community health. For example, the AAPI Coalition of Arizona was made up of community members that collaborated with Arizona State University (ASU) to publish the first book about AANHPIs in Arizona. Some of these same individuals and representatives also participated in the Health through Action Arizona (HTAA) coalition when it was formed in 2008. Hence, under the umbrella of HTAA, there were individuals who understood the importance of uplifting local community voices and issues and who had an interest in telling the story of AANHPI health. Through this mutual understanding among individuals and organizational allies, including the state health department, a committee of the HTAA coalition set out to identify practitioners working in the allied health professions that could write about timely health issues in the local communities. As it were, the general outline of topics in the book were initially intended to form the inclusion criteria for who would be invited to contribute an article to the publication, and the early outline included topics in infectious disease, chronic disease, mental and social health, community advocacy and service. However, because the coalition embraces a core value and commitment to build and tap local community assets, the expertise in the community is ultimately what drove the book’s final

topic areas. However, it was recognized that several topics were missing because of a dearth of local and/or academic voices; neither housing, economic disparity, or criminal justice issues in AA and NHPI communities were addressed in this volume. Interestingly, topics were presented by community experts that were not broadly known about or considered in the early planning stages but were subsequently included. These included such topics as h. Pylori infection among refugees, mental health issues among AA and NHPI college students who experience discrimination, and the limitations of language access services for victims of domestic violence. All the topic areas and suggested focus of each article was primarily driven by the authors' content expertise. Because they were experts in their fields, it was natural that the final publication reflected the concerns and ideas of the health and health care workforce in Arizona.

The contributing authors that emerged were made up of experts contributing to the practice and study of health and health care, including practitioners, researchers, and advocates who were tapped by HTAA members. In many cases, teams of researchers and/or practitioners collaborated to bring together a variety of information sources for one article. For example, two coalition members representing the State Health Department and the Arizona State University College of Nursing and Health Innovation collaborated on an article detailing the cancer disparities in AA and NHPI communities compared to other racial and ethnic populations. The authors in turn contributed to the book's policy recommendations recognizing the importance of early detection of cancer, smoking cessation, adherence to a traditional Asian diet high in fruits and vegetables. Another article on hepatitis B reinforced the notion that the burden of hepatitis B infection was very real in Arizona and made recommendations for preventing and treating hepatitis B infection. These data and information along with each authors' recommendations lay the foundation for CBOs to advocate for public health policies and programs in AANHPI communities.

An editorial decision was made to include photographs of local community residents who worked in the health-related professions. Several photographs were of nurses from the Korean Nurses Association and the Philippine Nurses Association. Other participants were volunteers in the community or nominated by a community member as a champion for health. In addition to featuring local champions, the rich photography and book layout were an opportunity to create visibility of APCA and the Health Through Action Arizona coalition as advocates for AA and NHPI community health. Award-winning photographer Nick Oza donated his time to taking hundreds of photographs and selecting the most fitting images. Fritz Communications allied with the coalition and donated time to the graphic design and art direction of the story. Finally, the partnership also stretched to reach allies in local companies, like Arizona Public Works, that supported the work in a number of ways, including donating the costs of printing and packaging, offering advice on ways to disseminate and discuss the achievements of the book, and creating venues and dialogue space to bring the data story to diverse audiences, as it was intended.

STRATEGIES

The data book was meant to tell a story about the community despite the national narrative of Arizona in the after-math of SB 1070, a law that many people in Arizona believed to be a state-sanctioned racial profiling law that would damage community health and public safety concerns. The real consequences of past and present policies like SB 1070 and other anti-immigrant policies become masked by political maneuvers that often occupy front page news. While the vocal outrage against SB 1070-type laws is present and necessary, less vocal responses are also important. In communities all around Arizona, the silent protests against the root causes of policies like SB 0170 were, and have usually, manifested as public safety and health concerns, unchecked and untreated diabetes and cancer, delayed care, and fewer opportunities for good nutrition, fear, domestic violence, and navigating an in-accessible health care system for the poor. Because of these untold stories, the data book project became the opportunity to tap local experts on a breadth of topics that would support overarching policy recommendations and changes to protect the health and well-being of the local community. The

recommendations were synthesized from the authors and editors of the volume and serve as a testable model for community-informed policy-making.

By tapping local expertise and working through partnerships, APCA also believed that the project advanced the HTAA mission to promote active local leadership by telling a truer story of AA and NHPI health. The credibility of locally sourced health information can only be measured according to community standards and community peers. Many authors provided sources for the data they provided and offered opportunities to delve deeper into any topic. In this way, the book was also provocative: one goal was to help stimulate the academic discourse on AA and NHPI health risks and challenges, creating the evidence base to appropriately address community health. In this sense, the priority was to create a community-owned written record of community issues and targeted initiatives and resources that together would provide the necessary evidence and building blocks to advance the coalition goals of impacting local policies. The local movements highlighted in the book included the Arizona South Asians for Safe Families (ASAFSF) domestic violence hotline, a local volunteer-driven organization that works specifically to improve cultural and linguistic access to victim services. In 2008, following the U.S. and global economic collapse, the volunteers who staff the hotline reported a significant uptick in the number of calls they received. Although the surge in victim reports also coincided with Arizona's anti-immigrant policies, it became clear that ASAFSF was a trusted community partner that worked in partnership with a broad spectrum of organizations to advocate for great cultural and linguistic competence in victims services.

Subsequent to the passage of SB1070, ACPA and coalition partners launched a community information Know Your Rights campaign. The campaign goals were to increase community awareness about people's rights to receive services in their primary language and to create the demand on providers to ensure these rights are protected and fulfilled.

OUTCOMES AND ACCOMPLISHMENTS

The completed Volume 2, *State of Asian Americans and Pacific Americans in Arizona: Health Risks, Challenges and Community Responses*, was finished as Arizona was deep in the aftermath of SB 1070, an anti-immigrant contentious piece of Arizona legislative history that has in large part been struck down by the U.S. Supreme Court. The volume was unveiled at the Health Through Advocacy Symposium hosted by HTAA and preceded by an artists' reception of the community portraits. The symposium engaged thought leaders and activists in the community on issues and policies embedded in the data book. The Executive Director of the American Civil Liberties Union of Arizona (ACLU-AZ) at the time presented on the unnecessary shackling of immigrant women in immigration detention. Another speaker spoke on the local need to advocate for midwives that provide invaluable services to women of color. Others spoke on issues like reproductive rights and refugee/asylee women. This allowed us to engage in deep conversation about the important efforts in the community to address unjust policies and practices while working to protect the rights of AAs and NHPs. It also provided a forum for community allies, like the State and County Departments of Health and ACLU-AZ, to develop a baseline understanding of AANHPI health. As the issues become more visible to mainstream partners, there comes an opportunity to tackle some seemingly intractable problems with a community of allies that understands the complexity of addressing health from a systems and policy point of view.

Often, the lack of reliable data prevents advocates from speaking out against anti-immigrant policies. The vacuum left by the lack of data also means that advocates are less equipped to fight against the myths perpetuated about the communities that eventually result in damaging racial stereotypes, like the Model Minority Myth. Likewise, as we have seen with reproductive health laws recently, the data gap allows politicians to use our communities as political tools to create more harm. The volume has since served as a guidepost for discussing community needs and recommended policies, as well as a reference for community health issues when few other sources exist.

Aside from the specific health knowledge that was generated through the data book project, key policy recommendations were also included. The recommendations published at the time still hold in the current post-Obamacare world and were designed to inform policies at all levels of public health and health care delivery by informing policy-makers that it is important to assess the health needs of distinct AA and NHPI groups in a way that nurtures meaningful access in health care. The following two policy recommendations focus on data advocacy and cultural/linguistic access:

1. Realize the diversity of the AANHPIs and advocate for policies that recognize the varying health risks of different AAPI ethnic communities. For instance, maternal and child outcomes for AAPI women vary greatly by ethnicity among other social and cultural factors; public health policies ought to utilize reliable data on AAPI health when crafting legislation or public programs.
2. Champion language access by ensuring that all people regardless of what language they speak deserve full access to information about their health care needs in order to make better-informed decisions.

In the months after publication, Coalition partners disseminated copies of the data book through their networks. APCA was invited to present the data book findings to the City of Phoenix diversity groups, to Arizona Department of Health Services, nursing students, funders, and local foundations, decision makers, health providers and advocates. Coalition members and agency staff continue to give talks about the book's recommendations, and/or specific issues treated in the many articles. Beyond raising awareness in the local community, the data book also presented data that has been useful in applying for funding and in setting priorities for future health programs. The Strategies to Research and Implement the Vision of Health Equity (STRIVE) Project, a local initiative funded by Centers for Disease Control and Prevention (CDC), drew upon the recommendation advocating for an adherence to traditional Asian diets that incorporate a variety of food sources and preparation techniques that promote healthy nutrition.

CHALLENGES

While the data book was being compiled, not all important topics could be covered due to the absence of local experts who could write about them. Many topics were therefore left out (e.g. developmental disabilities and substance use) and some topics required field interviews with local advocates, community members and key health professionals. Domestic violence, for example, is an issue that affects a large proportion of AA and NHPI families, but the surprising lack of data and statistics needed to address the root causes in a culturally responsive way prompted the author to design and implement a data-gathering project that was entirely driven by local community data. While this approach took an extraordinary effort and provided a much needed local perspective on domestic violence, it became clear that gaps in data are not currently being filled in a way that substantially informs programs committed to ending domestic violence and that the data is not readily available and/or accessible. Often, program funding sources require there to be readily available data and statistics to support a grant application or respond to a request for proposal, for example. At times, community documents like this publication are one of few sources of disaggregated data.

Another challenge that emerged after the book was produced was finding the forums where the AA and NHPI community could engage in dialogue about the issues in the book. It is important to note that the book was published in English only, while 72 percent of the community are foreign born and a growing number speak limited English. At the time neither APCA nor Coalition partners were well-equipped to host multi-lingual community dialogue. In the future it will be imperative to ensure that community dialogue does occur in multilingual settings so that all people may participate in shaping the story of the AA and NHPI community in Arizona.

LESSONS LEARNED

Developing a discussion guide to train and assist community facilitators on leading community dialogue would have been a useful tool to accompany the data book. While some of the content in the book involved technical topics, the dialogue around health risks, challenges, and policy considerations can be scaled to engage communities.

Finally, this particular collaboration could have benefited from engaging a more inclusive community of AA and NHPI and other partners. After publication, it became clear that more work was needed to advocate for better data for all AA and NHPI populations. This task would require a broader set of allies from all sectors working within and in alliance with communities to advance local policies that integrate health and wellness as foundational principles. Community health centers and municipalities, for instance, have a responsibility to integrate culturally competent health in all policies that guide patient care or provide services and resources to city residents. Likewise, community-based organizations have a duty to ensure that residents are equipped to navigate all the steps needed to secure healthy futures. Upcoming editions of the data book could also make meaningful contributions to AA and NHPI health by focusing on cross-cultural health issues and community responses as a way to stimulate and advance conversations and health-supporting policies in Arizona from a pan-cultural informed viewpoint.