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HEALTH

What a Difference a Data Set and Advocacy Make for AAPI Health

Ninez A. Ponce

The year 1976 was pivotal in the use of data for evidence-based health policy making in the United States. In 1976, the new U.S. Department of Health and Human Services put forth the “Proposed Rule” whereby area-level data on poverty rates, the share of elderly population, the infant mortality rate, and the density of primary care physicians translated from mere data points to a vivid picture of a population’s “need.” These indicators shed light on areas in which federal monies could make a difference. With this proposed rule, building the United States’ landscape of safety-net clinics ostensibly resulted in meeting the needs of the most vulnerable populations.

Thirty-five years later, particularly with the changing demographics of the United States, the Proposed Rule now requires updating, and new data sets and studies, primed by advocacy, can inform this reform. Rosy Chang Weir, Stacy Lavilla, Winston Tseng, Luella J. Penserga, Hui Song, Sherry M. Hirota, Jeffrey B. Caballero, and Won Kim Cook argue that the omission of indicators on the population’s need for language services systematically neglects to acknowledge the established disadvantage of Limited English Proficient (LEP) Asian Americans and Pacific Islanders (AAPIs) and other LEP immigrant groups in accessing timely and appropriate healthcare. In their article, Weir and her colleagues from the Association of Asian Pacific Community Health Organizations (AAPCHO) and co-authors from Asian Health Services, the Asian and Pacific Islander American Health Forum, the Alameda Health Consortium, and the University of California, Berkeley present a strong case that the LEP measure indicates need, that measures are available from public data sets, specifically the American Community Survey (ACS), and the measure is effective in detecting medically underserved areas (MUAs) that AAPCHO—a national association representing community health centers serving AAPIs—currently serves.

Absent of an LEP indicator, the Proposed Rule could systematically exclude MUAs in which medically underserved AAPIs reside.

Reforming measures with new data sets not available thirty-five years ago such as the ACS, and state data sets such as the California Health Interview Survey would authentically detect the needs of vulnerable AAPI populations. Further, federally funded national data sets that existed thirty-five years ago, such as the National Health Interview Survey and the National Health and Nutrition Examination Survey, have recently embarked on conducting their surveys in some Asian languages and oversampling for some Asian ethnic groups. Banking on an evidence base built from good data is especially critical today, as funding cuts threaten to limit community health centers or exclude funding for interventions for the AAPI population because of unmeasured, and therefore unheralded, health needs.

Weir and colleagues are in good company in this issue with contributions by researchers and advocates sharing the successful experience in building a local data set for designing interventions and program evaluation (Beverly J. Gor and Lovell A. Jones), documenting the state of data needed to fight childhood obesity in AAPI populations (Shao-Chee Sim), and in moving forward a national data development and policy agenda for AAPIs as health-care reform mandated by the 2010 Affordable Care Act becomes implemented in 2014 (Winston Tseng, Priscilla Huang, and Won Kim Cook). It is clear from these articles that data sets and data advocacy is more mature than it was thirty-five years ago, but in the words of Tseng, Huang, and Cook, "Core issues about lack of data persist."

The article by Gor and Jones is a "lessons learned" article, which would be instructive for all local areas hoping to build local data sets depicting the health needs of AAPIs that national/federal data sets fail to capture. Gor and Jones suggest that the lack of data could be overcome with support from policy makers, committed academic partnerships, and genuine engagement of the community. To this end, they describe a 2003 community-academic collaboration that produced a telephone survey to document the cancer needs of Chinese and Vietnamese in Houston, a city that ranks fifteenth in metropolitan areas in the United States for having an Asian American population, in a state that ranks fourth in the nation for having the largest Asian American population. This

data has led to advocacy for health care access and language services, evaluation studies on cancer education, and a tool to design interventions that raise health literacy and empowerment.

In contrast to the local data success in Houston, Sim's article about the lack of data and childhood obesity in AAPIs is sobering: only 20 out of 18,014 or 0.11% of articles on childhood obesity are about AAPIs. Sim's suggestions for building the evidence base include targeting community prevalence studies, community needs assessments, risk factor studies, and program evaluations. But importantly, Sim points out that the generation of these studies require a research infrastructure focusing on fighting childhood obesity—an infrastructure perhaps that we have seen most prominently in the AAPI cancer prevention community—for example, through the two National Cancer Institute-funded Community Network Projects, the National Center for the Reduction of Asian American Cancer Health Disparities through Cancer Awareness, Research and Training, and Weaving an Islander Network for Cancer Awareness, Research and Training. The local survey that Gor and Jones describe also had a cancer-prevention focus and was supported by the Center for Research on Minority Health at the M.D. Anderson Cancer Center. To effectively fight childhood obesity through data and research, Sim entreats the need for funding to train and mentor junior researchers and the need to create a national clearinghouse to compile research literature and evidence-based practices for AAPIs.

Finally, Tseng, Huang, and Cook evaluate the provision of Section 4302 of the Affordable Care Act (ACA) in collecting race, ethnicity, and language data to reduce health disparities. But because Section 4302 is vaguely worded, Tseng, Huang, and Cook put teeth to the provisions by specific recommendations to make the ACA more responsive to the AAPI population. For example, they suggest implementing the 2009 Institute of Medicine recommendations on standardizing the collection of race, ethnicity, and language data; that national surveys, health care providers, and health programs collect data at the point of care and enrollment; and that health surveys should be translated based on the community's need. Resonant in their recommendations as with all the other companion articles, is the engagement of communities in the design, planning, and implementation and dissemination of data on race, ethnicity, and language.

Each of the four articles provides unique factual lessons on the health policy arena—federal and local—that affects AAPIs in the United States. All promulgate a shared message: better data sets and relentless advocacy make a policy difference. Funding helps, but a shared vision, and the academic-community-legislator collaborations that have built and continue to mount the evidence base in the service of meeting AAPI health needs, has certainly come a long way since 1976. Now we know how to achieve better data, and the AAPI community has the organizational acumen to put forth these recommendations with a unified voice.

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