Health care equity long overdue for Asians, Pacific Islanders

BY JOSEPH SANTOS-LYONS AND VICTORIA DEMCHAK
CONTRIBUTING COLUMNISTS

Joseph Santos-Lyons is the Executive Director and Victoria Demchak the Policy Coordinator with the Asian Pacific American Network of Oregon

I learned early that the question, "How are you?" could become profound. Elders would look into my eyes and ask me in such a way that I felt not only a deep connection, but had to answer in the most holistic way possible.

We bring this spirit of holistic acceptance into our community organizing at APANO, the Asian Pacific American Network of Oregon. In our story collection, forums and workshops, we've uncovered authentic and uncomfortable feelings about accessing health care. Our communities have difficulty receiving quality care: When our mother sits at home, suffers and procrastinates seeing her doctor because it feels awful to be treated like a child, when our grandfather strains to understand his grandson's struggle to translate complex medical jargon, when our auntie whimpers in pain because her cancer was caught too late, we stand up and take notice.

During this time of "Obamacare" and health reform, the stories of our communities ground our efforts for health equity. Cultural competency for health professionals and uniform race, ethnic and language data collection are two core strategies that would improve health care in our communities: for our mothers, grandfathers and aunties. Cultural competency recognizes that a holistic acceptance about culture can improve how we provide health care. That recognition informs every aspect of health care from diagnosis, doctor-patient communication and treatment. Paired with better data collection, we could improve our health outcomes and better target care to the diverse groups that make up Oregon. And in this time of limited resources, both strategies will save money longterm.

But right now, any progress we make is limited when we don't know who our health system serves.

I sat down at the table with officials from the big health institutions in our region – OHSU, Providence, Kaiser, etc. – to give input into their required community health assessment. These executives saw that there was a big jump in the number of Asians and Pacific Islanders in one area, and were curious about how best to serve this community. We agreed that you can't just hire someone who speaks Asian, or Pacific Islander, so to speak. We needed to know the language needs and cultural backgrounds of the community in order to best serve the community.

Like many of our health professionals, Dr. Connie K. Y. Nguyen-Truong recognizes that culture and language affect our health. As a nurse and scientist, Connie seeks to understand the conditions facing the Vietnamese communities she serves. Yet too often, for the communities of color she serves, there is little research that she can review in order to make the best decisions to care for adults, older adults and families she sees. This makes it extraordinarily difficult to address the real health disparities she sees every day.

But it's not just Asian and Pacific Islander communities. Our African and African-American communities suffer from these as well, and in some of the same ways. Dahabolul Khadija Fai of the African Women's Coalition knows that one of the biggest health issues facing Africans is institutional ignorance: "When you don't recognize Africans' ethnicity or country of origin, you pretty much deny everything these people are." And Khadija knows that there's a similar result in the African community as in the Asian community, because "we don't know what are the African issues in the health field because there is no data that says this is what Africans experience."

We know that all communities are hurt by poor data collection practices that fail to collect uniform demographic information. This makes our communities, particularly communities of color, immigrants and refugees, invisible. This information masks many disparities in health, education and employment and is a barrier to developing solutions.

Because of our diversity, Asians and Pacific Islanders (API) are particularly hurt by practices that group us into a single category in public health reporting and data tracking: The reality is, the 215,000 API in Oregon come from 60 unique ethnic origins and speak over 100 different languages. APIs experience huge barriers in achieving good health with higher rates of heart disease, diabetes and certain types of cancer that differ from white and other communities of color.

Over a decade ago, the Oregon Governor's 2000 Racial and Ethnic Health Task Force began to realize these hurtful gaps in the data and declared that to overcome health disparities, we would have to update race, ethnicity, and language data collection systems. They would have to be comprehensive and consistent across the state. But 13 years is a long wait.

So we acted. And we did not act alone.

We created our own coalition to overcome the challenge of bringing invisible communities to light in Oregon. We built on our long-term relationships with the Coalition of Communities of Color, Racial Equity Report Card, and the Healthy Oregon Partners for Equity (HOPE) Coalition. Our allies from other communities of color came together as the Oregon Health Equity Alliance (OHEA). Together, we identified improved data collection as one of the keys to unlocking the box of disparities facing Oregon.

And we decided on our feasible solution by creating Oregon House Bill 2134 to establish new uniform racial, ethnic, language and developmental disability data collection practices for the Oregon Health Authority (OHA) and Department of Human Services (DHS). This legislation accomplishes our goals: accountability to our communities with regular public reports, a stakeholder advisory group, and ensuring data collection standards are updated every other year to keep up with population change and national best practices.

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But sponsoring legislation is new for us at APANO and we needed to learn more. We started with where Oregon Health Authority was in its data collection, and built on their health equity goals and policies. We built a coalition with more than 45 organizations in Cover Oregon, the new health insurance exchange. And we benefited from the Northwest Health Foundation's communications training and polling to develop a clear and disciplined message on effective and affordable health equity.

Our coalition clarified roles, authority and process early, and was our base to reach out and learn what advocates and health providers needed, while our allies at Disability Rights Oregon and SEIU made sure this legislation went beyond race to uncover disparities for folks who experience developmental disabilities.

Without our allies, starting with individuals like Dr. Nguyen-Truong, we could not have communicated the importance of our work and achieved our results. At APANO, and Oregon's health advocacy community, we are proud of our work to share this project with partners and find receptivity in new places. We hope to continue our momentum from our 55-0 vote on the House floor as we move into the Senate and beyond.

Between our work with data and cultural competency, we hope our aunties and uncles can understand their doctor, and that they will be treated with respect and dignity. Health professionals have power, the power to diagnose and decide treatments. Cultural competency is about taking responsibility to use both power and knowledge with an awareness of Oregon's diverse cultures to deliver quality health care.

Executive Director Rev. Joseph Santos-Lyons is a Chinese-American cultural organizer, minister, and musician. Born in Portland, adopted and raised in Clackamas County, Joseph has worked for democracy, human rights and systemic change that addresses the root causes of inequities for 25 years in Oregon, Colorado, Massachusetts and the Philippines. Currently he serves as staff for the Asian Pacific American Network of Oregon.

Victoria Demchak grew up in Portland and worked in cooperative groceries and planning in New York state for several years. She earned her bachelors in English and economics at University of Oregon, and a masters in city planning at Cornell University. She now works with APANO researching health equity.

Coalition of Communities of Color

Formed in 2001, the Coalition of Communities of Color (CCC) is an alliance of culturally specific community-based organizations with representatives from six communities of color: African, African American, Asian and Pacific Islander, Latino, Native American and Slavic. Representation on the CCC is determined by individual communities, and all decisions are based on consensus.

APANO
Asian Pacific American Network of Oregon

The Asian Pacific American Network of Oregon is a community organization with over 2,000 constituents that works to advance racial equity in public policy.