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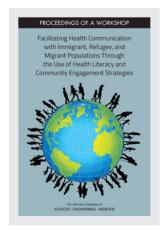
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Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literacy and Community Engagement Strategies Proceedings of a Workshop

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Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literacy and Community Engagement Strategies

PROCEEDINGS OF A WORKSHOP

Joe Alper, Rapporteur

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

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This Proceedings of a Workshop was reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the National Academies of Sciences, Engineering, and Medicine in making each published proceedings as sound as possible and to ensure that it meets the institutional standards for quality, objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this proceedings:

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Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings nor did they see the final draft before its release. The review of this proceedings was overseen by Georges Benjamin, American Public Health Association. He was responsible for making certain that an independent examination of this proceedings was carried out in accordance with standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the rapporteur and the National Academies.



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### Acronyms and Abbreviations

AAPCHO Association of Asian Pacific Community Health

Organizations

ACA Patient Protection and Affordable Care Act

CDC Centers for Disease Control and Prevention

EHR electronic health record

ESL English as a second language

GUIA Guides for Understanding Information and Access

IDNYC New York City identification card program

PRAPARE Protocol for Responding to and Assessing Patient Assets,

Risks, and Experiences

PTSD posttraumatic stress disorder



1

### Introduction<sup>1</sup>

The increasingly diverse ethnic composition of the United States population has created a profound and ongoing demographic shift, and public health and health care organizations face many challenges as they move to address and adapt to this change. In addition, said Bernard Rosof, chief executive officer of the Quality in Healthcare Advisory Group, in his introductory remarks to this workshop, the current political climate has created tremendous uncertainty about what the future holds for a strong, vibrant, multicultural United States, making it more difficult and vital to provide needed public health services to everyone living in this country.

To better understand how the public health and health care communities can meet the challenges of serving an increasingly diverse population, the Roundtable on Health Literacy created an ad hoc committee<sup>2</sup> to plan and conduct a public workshop on facilitating health communication with immigrant, refugee, and migrant populations through the use of health

<sup>&</sup>lt;sup>1</sup> This section is based on the presentation by Bernard Rosof, chief executive officer of the Quality in Healthcare Advisory Group, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

<sup>&</sup>lt;sup>2</sup> The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop was prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

#### 2

#### BOX 1-1 Statement of Task

An ad hoc committee will plan and conduct a 1-day public workshop that will feature invited presentations and discussion on facilitating health communication related to immigrant, refugee, and migrant populations through the use of health literate approaches. The workshop may include presentations and discussion of issues related to cultural competence, language access, and understanding of the U.S. health care system. The committee will define the specific topics to be addressed, develop the agenda, select and invite speakers and other participants, and moderate the discussions. A brief proceedings of a workshop will be produced in addition to a proceedings of a workshop by a designated rapporteur in accordance with institutional guidelines.

literate approaches<sup>3</sup> (see Box 1-1). The goal of the workshop, explained Rosof, was to identify approaches that will enable organizations that serve these ethnically and culturally diverse populations in a manner that allows all members of these communities to obtain, process, and understand basic health information and the services needed to make appropriate health and personal decisions.

"The wide variety of language and cultures and the lack of understanding of how to effectively use public health and health care services make it imperative that health literacy approaches be used to align health system demands with individual skills, individual abilities, and individual knowledge," said Rosof. Health literate approaches, he added, will provide linguistically and culturally appropriate materials and services, which in turn will contribute to better care coordination, adherence to care plans, contribute to person and family-centered care, and to achieving the quadruple aim of providing better care, improving the health of the community and the population, making care affordable, and creating joy in practice.

#### ORGANIZATION OF THE PROCEEDINGS

An independent planning committee organized this workshop in accordance with the procedures of the National Academies of Sciences, Engineering, and Medicine. (See Appendix A for the workshop agenda.) The

<sup>&</sup>lt;sup>3</sup> Health literate approaches provide culturally and linguistically appropriate information in a manner that facilitates understanding and using that information to make informed health decisions.

INTRODUCTION 3

planning committee's members were Gem Daus, Jennifer Dillaha, Alicia Fernandez, Megan Rooney, Bernard Rosof, Umair Shah, Alina Shaw, and Winston Wong. This publication summarizes the workshop's presentations and discussions, and it highlights important lessons, practical strategies, and opportunities for using the principles of health literacy<sup>4</sup> to facilitate health communication with immigrant, refugee, and migrant populations. Chapter 2 recounts a moderated discussion on the challenges immigrant, refugee, and migrant populations in the United States face regarding health and accessing health care, and Chapter 3 continues that discussion with examples of how various organizations are providing care to members of those populations. Chapter 4 considers the interplay between health literacy and outreach efforts in immigrant, refugee, and migrant communities, and Chapter 5 provides some examples of health literacy principles being applied to communication with immigrants, refugees, and migrants. Chapter 6 discusses where future efforts might focus.

In accordance with the policies of the National Academies, the workshop did not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants. In addition, the organizing committee's role was limited to planning the workshop. The Proceedings of a Workshop was prepared by the workshop rapporteur as a factual summary of what occurred at the workshop.

<sup>&</sup>lt;sup>4</sup> The following principles of health literacy, articulated by the Centers for Disease Control and Prevention for use in public health, are also applicable to health care. They include (1) "Ensure public health information and services are appropriate and easy to understand and use; (2) Involve representatives from your target audience in planning, implementing, disseminating, and evaluating health information and services; (3) Develop key partnerships to help facilitate change, influence behavior, and generate interest in health literacy; and (4) Support changes to improve public health professional health literacy skills." See https://www.cdc.gov/healthliteracy/training/page1619.html (accessed June 5, 2017). Additional discussion can be found in a paper by Parker and Jacobson (2014) at https://nam.edu/perspectives-2014-health-literacy-principles-guidance-for-making-information-understandable-useful-and-navigable (accessed June 5, 2017).



2

## Issues and Challenges in Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations<sup>1</sup>

The workshop opened with a moderated panel discussion on issues and challenges to facilitating health communication with immigrant, refugee, and migrant populations. Moderator Alicia Fernandez, professor of clinical medicine at the University of California, San Francisco, began the discussion by asking each of the three panelists—Paul Geltman, medical director for ambulatory care services at Franciscan Children's Hospital; Jeffrey B. Caballero, executive director of the Association of Asian Pacific Community Health Organizations (AAPCHO); and Henry R. Perea, former member of the County of Fresno Board of Supervisors—to describe the work they do with these populations and identify some of the biggest challenges and opportunities.

Geltman explained that he has worked with refugee and immigrant communities for his entire career, including in his current position as medical director of the Massachusetts statewide health screening program for all refugees entering the country from overseas and in his prior position with the Cambridge (Massachusetts) Health Alliance, where his patients included individuals from some 50 countries and a variety of socioeconomic and ethnic backgrounds. In response to a prompt from Fernandez to define a refugee, Geltman said that refugee is a defined visa category that includes

<sup>&</sup>lt;sup>1</sup> This chapter is based on a panel discussion involving Paul Geltman, medical director of ambulatory care services at the University of California, San Francisco; Jeffrey B. Caballero, executive director of the Association of Asian Pacific Community Health Organizations; Henry R. Perea, former member of the County of Fresno Board of Supervisors; and moderator Alicia Fernandez, professor of clinical medicine at the University of California, San Francisco.

similar individuals such as those seeking political asylum and temporary protected status, victims of trafficking, and Amerasians from Southeast Asia, among others. Before reaching U.S. shores, he noted, most refugees go through a health screening program that is overseen by the Centers for Disease Control and Prevention (CDC) and implemented by the International Organization for Migration.

Most states now have a defined public health system for conducting additional health screens once refugees enter the United States, and they offer, via a network of community organizations, housing services, English language instruction, and job placement services, he said. While health screening is a public health function, it can serve as what Geltman called "an excellent bridge for primary care." Financial supports for health care through automatic Medicaid enrollment of refugees typically end after 8 months, added Geltman, though coverage now lasts for 1 year in states that accepted Medicaid expansion under the Patient Protection and Affordable Care Act (ACA). Refugees are also exempt from the 1998 welfare restrictions that apply to other documented immigrant groups. These restrictions, Geltman explained, require a 10-year work history to receive public benefits.

As a final note to his introductory comments, Geltman said that depending on the state, "the vagaries of health insurance come into play for those who do not meet the typical categorical eligibility requirements for Medicaid." As an example, when the Lost Boys of Sudan came to the United States in 2001, many of them lost their health care benefits after their immediate eligibility period ended. "They lost their health insurance and that effectively shut them out from care even though they were refugees here in the country with proper documentation," said Geltman.

Next, Caballero explained that AAPCHO is a national association representing 35 community-based organizations in 12 states serving more than 750,000 patients annually who are predominantly Asian Americans, Native Hawaiians, and Pacific Islanders. Of the 35 AAPCHO organizations, 30 are federally qualified health centers, and they serve as the safety net provider, particularly for Asian American and Pacific Islander populations in the communities they serve. Caballero noted that 77 percent of the patients served by AAPCHO organizations are within 100 percent of the federal poverty level and 92 percent are within 200 percent of the poverty level. At some AAPCHO health centers, the percentage of patients who have limited English proficiency can reach 98 percent. Chinese is the predominant primary language at many of the centers, but language diversity can be large. Oakland Asian Health Services, for example, provides services in 14 languages, while the AAPCHO health center in Seattle and King County (Washington) provides services in 42 languages.

Caballero noted that his primary function is to advocate on behalf

of these community health centers as part of an overall effort to raise awareness about health disparities in these communities and to promote cultural competency and language access resources. Over the past 4 years, AAPCHO has partnered with the Asian American Health Forum and Action for Health Justice, a network of national and 70 community-based organizations in 22 states, to help in the health insurance enrollment process. This effort, he said, touched some 1 million lives and enrolled individuals who speak more than a dozen different languages. More recently, however, he and his colleagues have been responding to the anti-immigrant fears in their communities. "We have spent significant resources nationally and with many other organizations responding to these fears," said Caballero.

AAPCHO has been collaborating with a number of national partners, including the Oregon Primary Care Association and the National Association of Community Centers, on a tool—the Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)—to assess social determinants of health in these communities. The partners have piloted PRAPARE over the past 3 years. The goal is to be able to integrate this needs assessment into electronic health records (EHRs) so that organizations across cities, states, and even at the national level can begin aggregating data to better understand the needs of immigrant, refugee, and migrant populations in their communities.

As an introduction to his comments, Perea noted that he has taught at a university, been a police officer, a school board member, a medical center human resources director for 30 years, a member of the Fresno city council, and for the past 12 years a member of the County of Fresno Board of Supervisors. Those experiences, he explained, prepared him for the political activism he was now going to embark on in the next phase of his life. He then recounted how an issue arose in Fresno County when the ACA came into being. Prior to that time, Perea said, Fresno County paid approximately \$20 million annually to the local privatized health system to provide health care for everyone in the county, including undocumented individuals. However, the ACA created a gap in specialty care, particularly for undocumented individuals.

At the time, said Perea, the county received a \$5 million grant from the state of California that it needed to use or return to the state. Each of five county supervisors had a different idea on how to spend the money, and his idea was to use it to address that coverage gap. "You can imagine the debate we had for over a year in trying to move that money," said Perea. In the end, Perea's son, who represented Fresno County in the California legislature, proposed legislation requiring counties and cities to spend the money on health care for undocumented individuals. The bill passed, and after another six months of arguing and an election that changed the Board of Supervisors' composition, the county board decided to spend that money

to address this coverage gap. He acknowledged that this is a short-term solution, since the money will run out eventually, but it points to the progress that communities can make when they engage in political advocacy.

#### CHALLENGES DEALING WITH THE HEALTH CARE SYSTEM

After noting that immigrant, refugee, and migrant populations have different legal status that affects their access to health care, Fernandez asked the panelists to speak about the common challenges the health care system faces in providing care for these populations. Geltman replied that language proficiency and limited health literacy are major challenges for providing appropriate care. Even those individuals who come from countries where English is a second language, such as Nigeria or Sierra Leone, have limited English proficiency, he explained. Community supports and social networks play a critical role in providing health care and other needed services to these individuals, he said. In fact, he added, using friends and families as interpreters, something that is normally discouraged, can be a critical factor in overcoming limited English proficiency and delivering appropriate care to individuals in these populations.

Caballero explained that many of the health care centers his organization represents do not ask individuals if they were born outside of the country or about their country of origin. "Based on the best legal counsel that we have received thus far, there are some protections for the health records, but if ICE [Immigration and Customs Enforcement] agents come with a subpoena you have no choice but to provide the health records." One effect has been that many health care organizations are considering mechanisms to systematically disenroll people to make sure that the names of potential enforcement targets are no longer in their systems. This activity, in turn, creates the challenge of how to reach out to these communities to deliver health care without creating more panic, he said. One approach the health centers are taking, and with which their clinicians feel comfortable, is to collect preferred language, race, and ethnicity information, which can serve as a proxy for the "foreign-born question."

For the past 12 years, Caballero said, AAPCHO has been trying to standardize the delivery of what it calls care-enabling services and to categorize these services and their relevance to patient outcomes in immigrant, refugee, and migrant communities. These non-clinical services include eligibility counseling, enrollment support, case management, transportation, and language services. This work has played an important role in creating the PRAPARE needs assessment tool, Caballero said. In the past, these enabling services functioned as a proxy for social determinants of health. Going forward, this new tool will serve as a more direct measure of those social determinants and help the health centers determine which of its

enabling services are having the biggest impact on these social determinants and on the effectiveness of the clinical services they deliver to these populations. "We are also trying to demonstrate that with the combination of monitoring and quality improvement we can help reduce the total overall cost of care," said Caballero.

A major difference between the refugee and undocumented populations, said Perea, is that the former can legally receive services, while the latter cannot. What he has seen, though, is that there are many people who begrudge spending tax dollars on providing members of either group with health care. One change he has noticed is how the increase in diversity in the immigrant population in Fresno County has affected care delivery. "In the last few years, we have had discussions about cultural competency and how to deal with the differences in the Hmong community versus the Hispanic community versus the growing Ukrainian community," said Perea. Fresno County's health system is trying to deal with this diversity by hiring people with different religious and cultural perspectives to be part of health teams and by employing some unusual strategies, such as establishing community gardens.

Community engagement, he said, plays a critical role in helping the health system—and the political bodies that provide funds to the health system—better understand the care needs of these different populations. He noted the importance of setting aside the emotions of the immigration issue and looking at the need to care for these populations in terms of basic economics. In Fresno County, for example, agriculture is a \$7 billion industry, and the local agriculture industry now admits officially that 90 percent of its workforce is undocumented. Without a healthy workforce, that industry would suffer, as would the American hospitality and construction industries, said Perea.

Returning to the subject Caballero raised regarding increased immigration enforcement, Fernandez noted that Zuckerberg San Francisco General and the San Francisco Department of Public Health, in response to changes in immigration policy, have started a "You are safe here" campaign featuring prominent posters placed throughout the hospital and its affiliated clinics. In addition, the parent of every child in the San Francisco Unified School District received a postcard promoting this idea. Also, all 300 community-based organizations with a city services contract received "You are safe here" materials to distribute to their clients. She also said that a huge issue for clinicians, and particularly pediatricians, is that social history matters when it comes to delivering care, and the issue of whether to document immigration status and social history in patient charts has become a concern. "The advice that we are giving people is to ask only when you have a need-to-know, meaning when it completely affects the medical care,

not as part of the general background and not to chart that," Fernandez explained.

However, she added, "in this climate of fear, we have found that hospital and health care systems that receive federal funding are required now to ask questions about race, ethnicity, and preferred language in order to get prime dollars." In many places, she said, staff is pushing back against this requirement. Geltman noted that he believes that an immigrant's legal status is very important to know about because it is tied to the social supports, services, and other benefits for which that individual is eligible. While asking about legal status is important, he agreed that writing it down in the patient's chart should no longer be done. He added that the only time to ask about a person's immigration status is when there is an existing trusted relationship between the clinician and the community. In his case, he had become the go-to pediatrician for a large evangelical Brazilian church in one of the communities he served. "They all knew me and were reassured to come to me and I could ask them these questions in a way that was not threatening," said Geltman.

In today's climate, he added, even those who have legal immigration status are living with a sense of uncertainty about their future in the country, a situation that reminds him of the days after the September 11, 2001, attacks. He also pointed out that refugees in particular go through extreme vetting that is far more rigorous than the screening other immigrants have to go through to legally come to the United States. In addition, many of these refugees now belong to smaller groups and so are not coming into large preexisting communities that can help them get settled and secure needed services, he said.

#### **BUILDING TRUSTED RELATIONSHIPS**

Federal funding is available to establish what are called mutual assistance associations, which Geltman explained are small community agencies designed to support local refugee populations. It is important, he said, for clinicians and public health practitioners to establish relationships with those associations as one means for creating a trusted bond with the communities they serve. Another way to build such a bond, said Caballero, is to include community advocates on health centers' patient-majority boards and to create patient leadership councils that include representatives of all ages from the local community. The AAPCHO health centers, he said, have been engaging these leadership councils for more than a decade, and in today's political climate these councils have become increasingly important players in helping the health centers remain connected with and trusted by the communities they serve. The key point here, said Caballero, is that these trusted relationships were cultivated before they were needed.

Another important role for these councils, he added, is in designing culturally competent programs.

Perea touched on this issue by recounting a recent dinner he was invited to over the holidays by a group of influential and well-respected Muslim doctors. At this dinner, which was served by a Syrian refugee family that had completed the 18-month extreme vetting process, the doctors noted that when it came to clinicians, nobody in the community had qualms about being seen by a Muslim doctor. Yet in the community, their children were being picked on at school and their wives were being criticized at the grocery store. Perea's response was to recommend that these experienced clinicians need to "hold hands" with community organizations representing the other ethnic and cultural groups and create a political power to counter those kinds of behaviors. "We have to push back," said Perea. He also noted that immigrant, refugee, and migrant populations, whether they are documented or not, have a tremendous economic power that they need to harness. As a final thought, he said that health care providers and community organizations need to get out of their silos and work together to counter current anti-immigrant sentiment and actions. "If we stay in our silos, they pick us off. If we come together, we have strength," he said.

Caballero agreed with Perea and noted that AAPCHO's member organizations have been conducting active civic engagement campaigns that include voter turnout efforts. Early evaluations of these efforts show that voter turnout has increased 20 to 40 percent in some of the areas served by these health centers. He added that while there are undocumented immigrants in the Asia and Pacific Islander community, this same community largely comprises citizens who are eligible to vote, though one not engaged by any particular political party.

#### THE ROLE OF HEALTH LITERACY

From his work with the Somali community in Massachusetts, Geltman learned that the relationships among culture, English proficiency, and health literacy are complex. For example, in a study he conducted on oral health, there were some aspects in which health literacy played some role and others for which health literacy had no bearing on outcomes. The extent to which health literacy matters, he said, has much to do with social capital and community supports. "There are ways to get around low health literacy when working with communities or individual patients," he said. Somalis, for example, generally have good oral health status that derives in part from their Islamic faith and the cleansing rituals they engage in before praying. "Understanding these undercurrents and that the community can support people without having literacy skills becomes an important factor in effectively engaging and providing care to those communities," said Geltman.

This last comment prompted Caballero to note how literacy and English proficiency has played a role in enrollment efforts conducted by AAPCHO's health centers. While Massachusetts's health exchange offers multilingual computer enrollment forms, an AAPCHO member health center has to hire staff every year to help the 35,000 clients who do not speak English or Spanish, particularly for patients who feel more comfortable speaking Chinese or Vietnamese. AAPCHO health centers have also found much of enrollment materials' language too complex. As a community network, the AAPCHO health centers worked among community partners and their community panels to develop a glossary of the 100 most frequently used enrollment terms and concepts in an additional 10 languages. These are now posted online, though he noted that the federal government would not endorse these glossaries because they did not use the federally approved—and too complex—terms.

#### **DISCUSSION**

Bernard Rosof began the discussion period by noting that the comments from the panelists reminded him of something Martin Luther King, Jr., said, which was "If I cannot do great things, I can do small things in a great way." That prompted Ruth Parker, professor of medicine, pediatrics, and public health at Emory University School of Medicine, to ask the panelists for examples of the strategies, practices, and approaches that can work and that can get lost in the overwhelming burden of the issues confronting these populations.

Geltman responded that he had hoped to apply something he learned from a health literacy conference presentation by a pediatrician from a Kaiser Permanente facility in North Carolina that served a predominantly low-literacy and low-income African-American and Latino population. This pediatrician, Geltman recounted, had concluded that she needed to provide written materials with basic, bulleted take-home messages with no more than three to five key points. After hearing this presentation, Geltman returned to Massachusetts and broke down the standard information contained in dense American Academy of Pediatric information sheets into simple bulleted lists for his patients, who came from 50-some countries and a variety of ethnic and religious backgrounds. However, when he gave these new information sheets to families whose first language was not English, they did not like them. "They actually loved the American Academy of Pediatrics forms because of the density of information," Geltman explained. Even though the language was too complicated for them, these families wanted the information and they wanted it in writing.

The solution, he said, was too add back more information from the American Academy of Pediatrics forms while retaining the easy-to-read for-

mat, with big fonts and bulleted lists. "It worked and we got great feedback on them," said Geltman. "Even if people could not read them themselves, they had friends and families who could read them for them." He noted that he had 15 5- to 7-page bulleted documents translated into Brazilian Portuguese, Spanish, and Haitian Creole, the most common languages in his clinic, thanks to a \$20,000 grant from the Cambridge Health Alliance. His clinic, however, could not afford to translate them into other languages. "The desire for information is universal regardless of people's literacy levels and you have to find a way to provide it to people," he said, adding that "this was a local solution for us in Massachusetts, and it may not work in other communities. You have to figure out what your needs are in your community and a way to deliver it to them effectively."

Catina O'Leary, president and chief executive officer of Health Literacy Media, asked Caballero to comment on the proxies that his organization and its health centers have developed to replace asking a patient if they are foreign born. He replied that preferred language, race, and ethnicity combined is a more accepted or appropriate proxy than collecting undocumented status, which is what the health centers used to ask about in the 1990s.

Earnestine Willis, the Kellner Professor in Pediatrics at the Medical College of Wisconsin, asked Geltman if he has found anything that works with regard to overcoming the fear and mistrust common among marginalized populations. Geltman replied that he has been fortunate to work for the past 11 years in Cambridge, Massachusetts, where the community is sensitive to these issues and tries to go out of its way to include groups that are marginalized elsewhere. He also noted Massachusetts, like the rest of New England, has centralized its public health services at the state level and contracts with nonprofit community health centers to provide many of these services. These nonprofit community health centers, such as the Cambridge City Hospital where he worked, have developed good relationships with their communities through their clinic-level patient advisory boards and other outreach efforts that come down from their boards of directors and permeate institutional structures. In addition, he said, the people who work at these health centers are committed to having these kinds of relationships. "They attract the type of person to work there who wants to be engaged in the community and get involved," said Geltman. In Boston, he noted, there are not many private medical practitioners, in part because of the trusted role of the community health centers that formed in the late 1960s and early 1970s. The result is that in the Greater Boston and eastern Massachusetts region, people know that these institutions support them. "We get to that level of trust," he said.

Perea remarked that he believes that the majority of people in the United States "think the way we do." In his opinion, a small number of

people are dominating the discussion today and creating the fear that these communities are experiencing. If the majority does not remain silent, good things can happen. One lesson he learned in his time as an elected official was that he and his colleagues operate on a three-legged stool model. One leg is a thorough understanding of an issue gained from talking to the experts. The second leg is community input, with the media serving as the third leg. Understanding this concept and getting all three legs of the stool working together will, he said, lead to more successes than failures and provide cover when taking necessary steps that do not please the small but vocal minority.

Robert Logan, communications research scientist at the National Library of Medicine, pointed out that while immigration enforcement is not unique to the current federal administration, the tone of the conversation has changed. Moving on, he said a previous roundtable workshop featured several speakers who made a compelling argument that the most effective way to deliver indigent care in the United States and to help marginalized populations is to have a health care system that combines medical care and social welfare care. Caballero responded that one of the biggest strengths of the PRAPARE<sup>2</sup> social determinants tool is that it will provide health systems with a systematic way of identifying the social needs prevalent in their patient populations. This, in turn, will enable them to prioritize which social factors are more common among their most expensive or complex patients and either develop the services to address those factors themselves, or build community partnerships to provide those services, in combination with the health services they already provide for those patients.

Jennifer Dillaha, medical director for immunizations and medical advisor for health literacy and communication at the Arkansas Department of Health, noted that Arkansas has a large population of migrant Pacific Islanders who are in the country legally but not eligible for Medicaid and are having difficulty navigating health care and obtaining needed care. Her observation is that the faith-based community of these Pacific Islanders could be important partners for bridging the health literacy and access to care gaps, but that her state has found it difficult to connect to that faith-based community. She asked Caballero if he had any ideas on how to make that connection. He replied that his recommendation was to develop relationships with the community groups that serve the communities of interest and through those relationships learn which strategies and approaches would be most effective.

Geltman then recounted how he and his colleagues spoke to the imam of a local mosque serving the Somali community to have him encourage his congregation to include toothbrushing as part of the pre-prayer ablu-

<sup>&</sup>lt;sup>2</sup> See http://www.nachc.org/research-and-data/prapare (accessed June 5, 2017).

tions, an approach he called social marketing using a faith-based approach. In terms of being a best practice, he said his research has shown there is a great role for faith-based organizations. However, he added that he is "not a big fan of just saying this community goes to church or temple or the mosque and therefore we should use that for a public health agenda. There is no evidence to suggest that that is going to be better than any other approach unless you have a specific targeted practice that you are trying to promote and have access to that community in a very culturally appropriate manner."

Laurie Francis, senior director of clinical operations and quality at the Oregon Primary Care Association, first reminded the workshop that the federally qualified health centers started as centers of community health focused on social and economic issues. She then asked the panelists for their ideas on how an increased understanding of social and economic drivers of health and well-being, obtained using tools such as PRAPARE, can help communities align their voices and increase their power to produce change. Geltman recommended an approach developed by a group now called the Right Question Institute<sup>3</sup> that helps people become empowered to advocate for themselves. He first encountered this group when it was working to empower parents to advocate for their children with regard to improving Boston's schools. He has since worked with this group to apply their strategy around parent activism and advocacy in a health care setting in a similar manner to the way the health literacy community has developed the Ask Me 3 approach. That approach encourages patients and families to ask three specific questions of their providers to better understand their health conditions and what they need to do to stay healthy. What these approaches come down to, said Geltman, is that they teach people how to advocate for themselves even if they lack literacy skills.

<sup>&</sup>lt;sup>3</sup> See http://rightquestion.org (accessed August 11, 2017).



3

# Accessing and Using Health Care Services

The workshop's second panel session focused on the theme of access and featured four presentations on approaches for improving access to and use of health care services for immigrant, refugee, and migrant populations. Nick Nelson, director of the Human Rights Clinic and associate program director of the internal medicine program at Highland Hospital in Oakland, California, spoke about delivering trauma-informed care and what practitioners need to think about and be aware of when interacting with immigrants, refugees, and migrants. Julia Liou, director of program planning and development at Asian Health Services and manager of the California Healthy Nail Salon Collaborative, described one innovative access point for reaching newly arrived populations. Jesús Quiñones, Guides for Understanding Information and Access (GUIA) program coordinator at Casa de Salud in St. Louis, Missouri, discussed approaches to establishing trust as the first step to bringing immigrants, refugees, and migrants into the health care system. Kari LaScala, health communications specialist with Wisconsin Health Literacy, gave the final presentation in this session on workshops her organization developed to help refugees and immigrants understand how to use their medications properly. An open discussion followed the presentations.

## DELIVERING TRAUMA-INFORMED CARE TO IMMIGRANTS, REFUGEES, AND MIGRANTS<sup>1</sup>

Nelson began his presentation by noting that there have been at least three observational studies in urban and coastal primary care clinics demonstrating that the prevalence of torture among all people born outside of the United States, including those from developed countries, is between 4 and 10 percent (Crosby et al., 2006; Eisenman et al., 2000; Hexom et al., 2012). He believes that the prevalence of torture in the populations this workshop is considering is considerably higher, as is the prevalence of less stringently defined forms of abuse and trauma, such as domestic violence, socioeconomic and ethnic persecution, and migration trauma.

Nelson illustrated the various aspects of the physical health, mental health, and socioeconomic and legal issues relevant specifically to the immigrant, refugee, and migrant populations with stories of some of the patients he and his colleagues have seen in their human rights clinic. The first story he told was of two young men who escaped forced military conscription in Eritrea, fled through Sudan to the Arabian Peninsula, and stowed away on freighters, one to Ecuador, the other to Brazil. These two men then walked from their respective landing points to Oakland, California, even though neither could read the Roman alphabet—their native language was Tigrinya—let alone speak English, Spanish, or Portuguese. In terms of their physical health, having been born and raised in Eritrea put them at risk of having HIV/AIDS, tuberculosis, and intestinal parasitic diseases such as schistosomiasis, while their treks from the Latin American tropics increased their risk of having other health issues. "The array of risks that people become exposed to is so diverse that even the CDC [Centers for Disease Control and Prevention] guidelines do not really cover them," said Nelson, referring to the typical refugee health screening programs of the sort that Paul Geltman mentioned in the first panel discussion.

One clinical story illustrating how important it is to consider place of birth and think outside of the CDC guidelines involved a Vietnamese immigrant who had been a U.S. resident for some 20 years when he was hospitalized. This man had developed a primary brain tumor, and his oncologist had treated him with combination chemotherapy that included immunosuppressant drugs. When he came to the hospital, he was suffering from a fulminant multi-system illness characterized by renal failure, respiratory failure, and what Nelson called a bizarre rash. Test results revealed that parasitic worms, which had been living asymptomatically in the man's

<sup>&</sup>lt;sup>1</sup> This section is based on the presentation by Nick Nelson, director of the Human Rights Clinic and associate program director of the internal medicine program at Highland Hospital in Oakland, California, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

colon, had disseminated throughout his body when he was immunosuppressed. "He died of this illness," said Nelson, "but this could have been prevented with a simple stool examination or blood test when he arrived or at any time during the years he had been in the United States."

Recently, Nelson's hospital saw an outbreak of trichinosis, a disease he had never seen in his practice, in members of an extended social network. One family in this network had purchased a feral piglet on eBay, raised it in their backyard, and cooked it—incompletely—for a New Year's celebration. "Both by virtue of in-country exposure and cultural practices once people are here, there are medical issues we need to be aware of," said Nelson.

Mental health is another aspect of care that Nelson said he has learned about through his work in the human rights clinic. In medicine, he explained, there are various diseases such as tuberculosis and syphilis that are called great imitators because they present with symptoms that are easily confused with other illnesses. "Trauma is the great imitator in psychiatry," he said. "Trauma can present with symptoms that are primarily anxiety, symptoms that are primarily depression or frank psychosis, and a huge variety of presentations rooted in the individual idiosyncrasies and in the cultures of the individuals in whom they develop."

As an extreme example of this, Nelson told the story of a middle-aged information technology professional who had arrived from Yemen and had refugee status. This man came to the hospital complaining of precipitous weight loss over the preceding 2 months, symptoms that immediately raised concerns that the man had metastatic cancer. A \$500,000 battery of tests, including endoscopy of his upper and lower gastrointestinal tract, found no trace of cancer or any other problem. Several months later, he returned to the hospital with the same complaint, and another \$500,000 of clinical tests again revealed nothing. Several clinic visits later, someone in primary care asked him specifically if he had ever been tortured, and it turned out that 2 months prior to his initial visit to the clinic he had gone back to Yemen to prosecute a dispute with the government over some land his family owned. "They had imprisoned him and tortured him in ways that are too horrible for me to describe in mixed company, or just any company really," said Nelson, "All of what he was experiencing represented the psychological residue of that torture."

As an internist, Nelson said he has had a difficult time learning and understanding the socioeconomic aspect of the traumas his patients have experienced. "For me, the medical and psychiatric issues are pretty straightforward because as a physician, especially one who works in a county hospital, I am used to the fact that the prevalence of medical and psychiatric disease are differentially distributed in ways that systematically afflict people who are on the wrong end of power hierarchies, whether it is because you are part of an ethnic group or you are poor or whatever,"

said Nelson. "The intricacies of how that plays out in terms of access to services, to housing, to social support, have been a real eye opener for me over the years."

In Oakland, for example, there are vibrant indigenous Guatemalan and Eritrean communities, and if someone from one of those two groups arrives in Oakland, there will be people who speak their language and who can help with assistance finding housing, employment, and other services. "But I think every urban community in the United States has people who came here under enormous pressure, possibly even because of a threat to their lives, and ended up in places where they do not have that kind of community and do not have access to services."

Recently, Nelson examined a woman from Guinea who had the classic signs of female genital mutilation, which typically results in the San Francisco asylum court granting asylum, he explained. However, in this case the woman had married a South African who had abused her sexually and physically for 10 years in South Africa, which complicated the situation. Ultimately, however, the court did grant her asylum thanks to the efforts of her immigration lawyer, but until that happened she was not eligible for any support. "This poor lady mainly speaks French and has no contacts in the East Bay. During the coldest winter of the last 5 years, she was supporting herself exclusively with part time and totally unguaranteed work in an unheated African hair braiding salon, where she slept on the floor at night," said Nelson. "Obviously, it was much worse for her than it was for me, but I felt terrible because here I am a doctor in a county hospital who has some kind of social justice mission and I am trying to marshal the resources that I usually have for patients like this, in terms of social workers and therapists, but the main barrier was that she was an asylum seeker in process and was just not eligible for anything."

Fortunately, he added, this story ended well, but that is not always the case, particularly when these individuals are seen by primary care clinicians who do not have training or specific experience to imagine the extent of what immigrants, refugees, and migrants have to contend with in their daily lives. In that regard, perhaps the most important thing a clinician can do is be curious and ask people about their experiences. Nelson noted one study (Shannon et al., 2012) in which refugees were asked to identify the single greatest barrier to them divulging the history of their traumas. By a large majority, the refugees responded that the clinician had never asked.

The final story Nelson recounted spoke to the new set of difficulties that immigrants, refugees, and migrants face today. An undocumented Mexican woman with poorly controlled diabetes who he had been taking care of for many years came to urgent care three months ago with chest pain and changes in her electrocardiogram suggesting she might be having a heart attack. The Spanish-speaking resident who saw her called Nelson

because she refused to go to the emergency department for fear she would be arrested by Immigration and Customs Enforcement and deported, just as her son had been many years ago. Nelson told the resident to tell her from him that she would not be arrested and that she needed to be seen in the emergency department. However, when he arrived in the emergency department 2 hours later to see how she was doing, she was not there and he has been unable to contact her since then.

"We as clinicians have to be aware of those issues and find sensitive ways to inquire about them," said Nelson. "One of the reasons that this discussion today is so helpful is because we have brought together people who know a great deal more than I do and have better ideas about how we might approach those difficult and sensitive issues without re-traumatizing or scaring people." As a final thought, he added that he believes it vital to recognize how current changes in federal policy toward migrants, refugees, and asylum seekers affects the clinical encounter. "We all face an increasingly weighty burden of proof, which I think was discussed eloquently in the last panel, to demonstrate to these people that we are on their side, and we have a grave responsibility to advocate on their behalf."

## INNOVATIVE ACCESS POINTS CUSTOMIZED FOR NEWLY ARRIVED POPULATIONS<sup>2</sup>

In 2015, a *New York Times* article highlighted the health issues that nail salon workers experience because of their exposure to potentially toxic chemicals in nail care products. Liou explained that the reporter for this story spent a week at Asian Health Services to understand the issues confronting nail salon workers, who on average handle known carcinogens and reproductive toxicants such as benzene, bi-n-butyl phthalate, formaldehyde, glycol ethers, methylene chloride, and toluene on a daily basis for 8 to 10 hours per day. "For Asian Health Services, we are most concerned about the workers because of the cumulative and chronic exposures to these products that they handle so frequently," said Liou.

Asian Health Services, said Liou, serves more than 27,000 clients in Alameda County (California) who speak 12 different Asian languages. She and her colleagues became aware of the occupational health problems facing Vietnamese nail salon workers when one of her organization's community health workers, who was conducting outreach and education about diabetes, met one nail salon employee who kept complaining about how

<sup>&</sup>lt;sup>2</sup> This section is based on the presentation by Julia Liou, director of program planning and development at Asian Health Services and manager of the California Healthy Nail Salon Collaborative, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

she was having a hard time breathing while she was working and about a chronic rash she had developed. In relatively short order, more than 100 nail salon workers had reported similar stories, with some complaining about miscarriages or reporting they had developed breast cancer. "There were so many stories, not just one or two," said Liou.

Talking with her clinical colleagues, she realized that they had been seeing patients who worked in the nail salon industry with similar complaints and pregnant workers who were concerned about the possible harm their babies could suffer from chemical exposure. "We started noting that this was an epidemic happening within this community that tended to be overlooked," said Liou.

When the Asian Health Services team began looking into the issue, they found a study conducted among Vietnamese nail salon workers in Boston (Roelofs et al., 2008) that identified a constellation of acute health problems, such as asthma, headaches, and contact dermatitis plaguing these women. Another study of Vietnamese manicurists in California (Quach et al., 2015) found that these women were at greater risk of pregnancy complications, including gestational diabetes and placenta previa. They also heard concerns among nail salon workers about cancer, though there are no studies that have documented an increase in cancer rates in this population that totals at least 400,000 people nationwide.

Liou noted that some 58 percent of nail salon workers are of Asian descent, with the vast majority being female immigrants with limited English proficiency. Many of these workers, she added, are distrustful of the government because of their home country experiences. The average yearly income of a nail worker is less than \$23,000.

Asian Health Services' mission is to provide services to and be advocates for its community. "That means we are responsive to the issues we see in our patient population and we want to address health, not just within the clinic, but also looking at the social determinants of health," Liou explained. This issue, however, is complex because the chemicals in nail products are there legally, and there is no independent third party that reviews these products for safety before they reach the consumer, she said. In addition, there is a paucity of research available on this particular population, and little had been done around outreach and education within this community.

She and her colleagues decided to start small, convening a gathering of six people. They secured seed funding from The California Endowment and the Women's Foundation to hold an all-day meeting in 2005 on how to address the issue of nail salon worker health and safety. From this starting point, they established a research advisory committee to bring together researchers who were interested in studying this problem. They also formed policy and outreach working groups and a nail salon worker and owner

advisory group. Today, the California Healthy Nail Salon Collaborative includes more than 20 organizations statewide. It collaborates with experts in industrial hygiene and chemistry to think through some of the issues related to salon worker health and safety. Recognizing that the majority of nail salon workers have less than a high school education, the Collaborative has created educational materials written at a fourth-grade literacy level and rich with pictures and visuals. The Collaborative also formed focus groups to identify tips for workers that they could realistically use in their workplaces, such as wearing gloves to avoid dermal absorption of chemicals. "We have also worked with our partners and trained them on these topics so they could do these trainings as well," said Liou.

One interesting finding from the focus groups was that the workers were interested more in learning how to speak English better than they were about their health. Another issue that arose was a concern about ergonomic health, so Liou and her partners created quick tips, for example how to avoid wrist pain. The Collaborative created cards for the workers with phrases they could use with their clients when their backs or wrists started hurting, such as "Excuse me, I need to stretch quickly. I have been in this position a long time," and "Can I put this pillow under your wrist? This will help me see your hand better."

The primary concern of business owners was avoiding fines, not health. "Unfortunately, a lot of health messaging was not getting through," said Liou. What she and her colleagues realized, she said, was that they had to start with the basics, such as teaching them about the State Board of Cosmetology and its regulations and appeals processes. "We had to do that first before we could even get through to talk about health," said Liou. "That was an important lesson for us."

Those discussions, she said, helped build trust within that community, which then enabled Liou and her collaborators to conduct trainings, increase awareness and knowledge, and start thinking about how to change behavior and move people to take action. Through their trainings, they identified people who seemed committed to change and developed a leadership program for those individuals. They developed a curriculum that includes topics such as how to get people to share their stories in a safe space, how to take notes and report findings, and how to hold meetings away from work. "We started to see that folks were actually beginning to develop some leadership skills and feel a little more empowered," said Liou.

Once they started building leadership in the community, the next step was to create a model for change that would include some solutions to address some of the social determinant factors that the workers might not necessarily control. To create the model, they held community meetings and asked workers and owners, most of whom also work in the nail salons, to comment on possible solutions. The idea of banning certain chemicals,

for example, was not favored because of the fear that doing so would hurt business. This led to the idea of rewarding salons that were doing right by their workers and to the creation of the Healthy Nail Salon Program (see Figure 3-1). The Collaborative worked with its policy members to identify champions in the San Francisco area and identify what defines a healthy workplace in a nail salon. "We were able to define a healthy nail salon as one that uses safer products that are available, uses ventilation, is able to train all of the workers, and has owners who invest in healthy and safe workplace practices," said Liou. In 2009, the San Francisco Board of Supervisors unanimously approved the Nail Salon Recognition Program ordinance.

At that point, said Liou, the Collaborative realized it had a model and infrastructure by which nail salons could adopt the recommended solutions and salon workers could implement the health tips. Since then, they have identified additional partners who have replicated the Healthy Nail



FIGURE 3-1 Promotional material for the Healthy Nail Salon Program. SOURCE: Healthy Nail Salon Program as presented by Julia Liou at Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literate Approaches: A Workshop on March 15, 2017.

Salon Program in four other cities and counties in California. Replication was important, she noted, because it created champions in the state legislature who could talk about nail salon worker safety. Replication also got the attention of the media. "We were able to tell the story of many of the workers and owners who did this," said Liou. "We now have 143 Healthy Nail Salons throughout the state." An early evaluation of San Francisco's program (Garcia et al., 2015), funded by the U.S. Environmental Protection Agency, found that workers in Healthy Nail Salons had reduced chemical exposures and increased knowledge of healthy workplace practices. The California legislature has since passed the Healthy Nail Salon Bill to extend this program statewide, and the Collaborative is working with microloan partners to provide funds to nail salons in the state that want to become Healthy Nail Salons. Liou noted in closing that she is working with people in New York to build out the model and include labor rights as well. "We recognize this is an issue in addition to health that falls within the social determinants of health realm," said Liou.

## ESTABLISHING TRUST TO BRING INDIVIDUALS INTO PRIMARY CARE<sup>3</sup>

Casa de Salud—House of Health in Spanish—is a 501(c)(3) nonprofit health care organization that aims to provide high-quality medical and mental health services for the immigrant and refugee population in the St. Louis metropolitan area, which includes some 30 counties in Illinois and Missouri, explained Quiñones. A staff of 20 and about 60 volunteer providers conduct between 400 and 500 examinations per month and, in 2015, saw more than 2,100 patients. Knowing that it cannot provide all of the health care services its clients need, Casa de Salud works to facilitate access to the region's health care infrastructure, coordinate referrals, conduct patient advocacy and navigation, and provide guidance about financial assistance and health education.

Casa de Salud's main partner has been St. Louis University, which donated a building to the organization and allowed it to renovate it. Originally, the organization was founded to meet the needs of the Hispanic and Latino community, but as Quiñones explained, he and his colleagues realized quickly that there are many foreign-born communities in the St. Louis metropolitan area. "We have the International Institute of St. Louis, which is responsible for bringing immigrants and refugees to the city," he said.

The GUIA Program that Quiñones oversees is a social work and case

<sup>&</sup>lt;sup>3</sup> This section is based on the presentation by Jesús Quiñones, GUIA program coordinator at Casa de Salud in St. Louis, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

management program that assists Casa de Salud's clinical program. "We operate in a case management model that aims to facilitate access to the health care infrastructure, both at the systems level and the patient level," he said, noting the importance of being part of systems-level processes in addition to the political process. "My supervisors, our president, and I focus on systems-level access by building relationships with health care organizations in the St. Louis area. This is done to ensure that there are referral pathways that we can use for our patients and also to overcome the unique barriers that our population faces resulting from their lack of access to public assistance programs," said Quiñones. Some 70 volunteer providers—physicians, internal medicine providers, specialty care providers, mental health providers, nutritionists, and dieticians—provide services contingent on their ability to make time. "When we are unable to meet a patient's needs, we refer them externally," said Quiñones.

Case managers, acting as community health workers, provide patient-level access, which includes referral coordination or appointment setting and evidence-based education on chronic illness management. The GUIA Program has an appointment reminder system that uses whatever means are necessary to reach its clients, and it coordinates a home visit program to address chronic illnesses, primarily diabetes and hypertension, that includes three home visits over 6 months and monthly calls between visits. During each home visit, the case manager, acting as a community health worker, provides chronic illness education, and a volunteer nurse assesses the client's health and administers specific interventions. The goal of the home visit program is to empower patients using a patient-centered model, said Quiñones.

Quiñones said his program has developed its own tools, using published studies as a guide, to measure program efficacy, both so that it can report to its funders and to determine if any interventions are not working. For example, Casa de Salud developed its own diabetes curriculum when it found that its clinics were not using existing written materials consistently. "We wanted to be consistent across all levels of the clinic and we wanted the curriculum to be accessible to low literacy and low numeracy patients." The new evidence-based, culturally competent program is delivered verbally, with patient understanding assessed using teach-back methods. For example, instead of the existing example of a healthy meal that included pictures of mashed potatoes, chicken, and salad, Casa de Salud's diagram has beans and rice. Another tool the diabetes curriculum uses is a set of what he called "glucose wands" instead of showing them pictures of what arteries look like in a diabetic and non-diabetic patient. The wands contain beads representing red blood cells. One wand contains a viscous fluid, the other a less-viscous liquid, and clients can easily see the difference in the way the beads can move in the two wands.

With regard to evaluation, the program uses a teach-back tool administered on the first and last visit and a simple self-efficacy scoring tool. At one time, the program also included a 24-hour diet and physical activity recall instrument used by dieticians and nutritionists, but this was not the best tool for this population. Quiñones explained that since some of their clients are in the food service industry, home visits are usually scheduled for Monday, which is a common day off in that industry. The problem was that in many of the communities Casa de Salud serves, Sunday is a day of church parties, so the results of the diet and physical activity recall activity were providing a skewed picture of dietary and physical activity behaviors. "That was a lesson we learned recently," he said.

As part of its trust-building activities, Casa de Salud does not ask clients specifically about their insurance or documentation status. "We simply do not ask," said Quiñones. He noted that all nonprofit health care organizations in the St. Louis region need to have community benefit programs, which includes financial assistance processes. "Our case managers have extensive experience guiding patients through that process, which is extremely lengthy," he explained. Another way in which Casa de Salud has been able to build the community's trust in it and the health care system at large is to assist them in accessing all aspects of the health care system, including specialist and other forms of care. "You cannot just tell them to go see a neurologist, because they do not know where to go," said Quiñones, "and when they go they may face discrimination. Having someone assist them in the continuum of care has really helped to establish trust."

In closing, he noted that in 2016, the GUIA Program sent 1,322 referrals outside of Casa de Salud, and 6 case managers were able to schedule 1,500 appointments in primary and specialty care. "We really do think that a trusting relationship with the case manager is what is driving these interventions," said Quiñones.

## LET'S TALK ABOUT MEDICINES: WORKSHOPS FOR REFUGEES AND IMMIGRANTS<sup>4</sup>

The goals of the Let's Talk About Medicines project, explained LaScala, was to help refugees and immigrants gain a better understanding of how to more safely and effectively use their medications and develop a comfort level around asking questions of their doctors and pharmacists. This 2-year project, she added, was a spinoff from a similar project Wisconsin Health Literacy had developed for seniors, and it features 20 workshops each year.

<sup>&</sup>lt;sup>4</sup> This section is based on the presentation by Kari LaScala, health communications specialist with Wisconsin Health Literacy, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

During the first year, project staff facilitated workshops for refugees and immigrants in the community, while staff from the sponsoring community organization observed the workshop. "For sustainability purposes, they are now implementing the workshops themselves in year two," said LaScala. The 90-minute workshops include interpreters and translations when needed. The goal is to have 15 to 30 participants per workshop, with each participant receiving a pillbox. LaScala and her colleagues conducted preworkshop and 60-day post-workshop assessments.

When Wisconsin Health Literacy staff was developing the workshops for seniors, they spoke with doctors and pharmacists to identify trouble spots that served as the main workshop topics. The workshop topics include

- The main parts of a medication label,
- Dosage instructions: determining how much medicine to take and when,
- Basic storage techniques,
- Strategies to remember to take medications, and
- The importance of asking the pharmacist questions.

While the topics remained the same for the refugee and immigrant workshop, LaScala and her colleagues modified the content based on feedback from community health educators at Wisconsin's refugee organizations. For example, the workshop for seniors includes a discussion about when not to take certain over-the-counter medications with prescription medicines. This was extended in the refugee and immigrant workshop to include herbal preparations and other cures from their home countries. The refugee and immigrant workshop also includes a discussion about the differences between a pharmacist and doctor and what happens at a pharmacy. "Some of the refugees, depending on where people are from, might have gotten their medicines directly at the doctor's office and not had to go to a pharmacy. Other times, they could just go to a market," LaScala explained. "Often, they are not aware that to get a prescription medicine you first have to see a doctor, who writes the prescription, and then go to the pharmacy to get it." The workshops also featured sample medications so that the participants could see, for example, what an inhaler looks like and how to measure a liquid medication.

There were many challenges to delivering this content to refugees and immigrants, particularly around language and interpretation. "We had interpreters at our workshops and that works out great, especially if it is just one language or two languages and two interpreters," said LaScala. "But we did have one workshop where we had six different languages and six different interpreters. I left with a little bit of a headache after that workshop." Among the languages spoken by attendees at the first year

of workshops were Arabic, Burmese, French, Hmong, Somali, Spanish, Swahili, and the Sgaw dialect of Karen (a language spoken by people from Myanmar and neighboring parts of Thailand).

Written translations were also problematic with some of the less common languages, she noted. At first the idea was to rely solely on interpreters and not have any written materials at all. However, the health educators at the refugee organizations said it would be helpful to have any kind of translations, so LaScala worked with those organizations to identify either a staff member or a community member who could be trusted to translate materials into the less common languages. In one case, the individual translating materials into Karen had to handwrite the translation because there was no keyboard she could use that would produce the right symbols. In another instance, the pre- and post-workshop questionnaires for Arabic speakers had to be adjusted to reflect the fact that Arabic is read from right to left.

Working with English language learners was also a challenge given that there were usually people at the workshops with different levels of English proficiency. When the workshops were held in conjunction with an English class, the tutors or even other attendees were often helpful. The diverse background and culture of the participants also presented challenges. Some people, for example, had been in refugee camps for years, while others were coming in as immigrants. Education and literacy levels varied widely, too, as did the experiences participants had with doctors and pharmacists in their countries of origin. The important points for dealing with the fact that every participant is different, said LaScala, is to be prepared for this diversity and to encourage workshop participants to ask questions.

Working with the 13 sponsoring community organizations was not without problems, said LaScala, though she called them "phenomenal partners." Some of the organizations were reluctant to renew their participation in the second year given the time and effort involved in recruiting participants and organizing the workshops, the difficulty in predicting the number and language of the participants at a given workshop, and the challenge of conducting the 60-day post-workshop surveys. At least one of the partner organizations told her that they have to prioritize what they are able to do today given the current climate around refugees and immigrants. She did note, though, that she has been able to locate replacements for those organizations that were not onboard for the second year of the project.

From the questionnaires LaScala and her colleagues learned to keep explanations as simple as possible, to allow for questions along the way, and to keep the workshops interactive. Remaining flexible was important, as was remembering that a simple smile and a hello go a long way. She noted that as the participants became more comfortable in the workshops, they began asking questions and having fun. "These are serious topics, and

some of these people are suffering or have come from serious trauma or tough backgrounds," said LaScala. "Just to have fun in the workshop is a really nice way to go."

As a final thought, LaScala stressed that this work is important. She recounted a story from one of the one workshops. After the workshop, one of the refugee medical liaisons told her that a client she was seeing had multiple medications to manage. The liaison asked him if he could handle doing so and he said that he could because he had just attended the workshop and had his pillbox to help him organize his medications. "That was great to hear," said LaScala. She also noted that she is working with a pharmacist in Milwaukee to create a video to provide tips on how pharmacists can communicate better with refugees and immigrants in their communities.

#### **DISCUSSION**

Earnestine Willis asked Quiñones if some of his program's volunteers were legal experts, and he replied that the program used to hold a onceper-month law clinic in partnership with St. Louis University that brought a law firm to the health clinic to screen patients for legal assistance problems. However, the clinic recently ended that program because many of its patients reported that it was a waste of time to see someone who would tell them what they needed to do, and then tell them that they had to go see someone else to take care of their problem. "It was putting up an additional barrier," said Quiñones. Now, the clinic recommends that its patients go directly to one of the legal assistance organizations in the St. Louis area. Still, there are significant barriers, he added. "For example, most law firms or legal assistance places, you have to call and no one picks up—it is more like leave a message and someone will call you back in English," he explained. "Very few organizations have bilingual options. That is our experience."

Robert Logan commented that the panelists had all spoken eloquently about person-to-person, person-to-group, and group-to-group efforts. He wondered if social media or other types of media have been helpful to any of their projects. Liou responded that using ethnic media was helpful, in part because simply posting a small advertisement gave the program legitimacy in the eyes of a salon's employees and owner. Ethnic media also served as a useful conduit for messaging to the community at large. She and her colleagues also held press conferences for the ethnic and mainstream media to capitalize on the local champions they had developed relationships with and to get the message out to the broader community about the importance of worker health.

Quiñones said that when Casa de Salud was founded, the majority of outreach was done at health fairs and via word of mouth. For the past 4 years the organization has not had an outreach person on staff. "The majority of our patient referrals are done by friends and family, which is something unique to our Hispanic and Latino community," he said. However, Casa de Salud is having trouble with outreach to other foreign-born communities in the St. Louis region, so the organization has redeveloped its website and Facebook page so that people can request an appointment directly from those locations.

LaScala said her program does not usually promote its workshops using social media because the sponsoring community organizations have better ways of reaching the people who would benefit from the workshops. Nelson noted that he used to worry about using social media to bring more clients into his clinic because hospital administration might question how busy the clinic was if it had to resort to advertising to drive traffic. Now Nelson said his concern is that using social media would create a repository of information about individuals that might put them at risk with regard to immigration enforcement. "I do not know what to do at this point," he said.

Alicia Fernandez commented that the community organizing that Liou and her colleagues at Asian Health Services has done is unique, noting that even progressive institutions such as San Francisco General have not been able to duplicate the type of work Liou's organization has accomplished. She asked Liou if she could speak about how her position is funded, how her program is funded, and how Asian Health Services sees her work as fitting into their strategic vision. Liou replied that Asian Health Services has always seen advocacy as a key piece of its mission, so there is a commitment to this particular issue because of its advocacy component. Financial support comes from foundation grants and federal education and training funds, and she noted, there is leadership commitment at the highest levels to her program.

Bernard Rosof asked Liou if she has worked with anyone outside of San Francisco. She replied that she has been in touch with a coalition in Seattle and King County, but that coalition is working from a regulatory agency model. She is also aware of smaller groups outside of San Francisco that are working on something similar.

Ruth Parker asked Nelson if the term human rights clinic helps or hurts the core mission of providing health care services. Nelson said the only time it causes an issue is when he is asked to testify as an expert witness at immigration hearings. Some government attorneys, he said, will claim he is partisan because he works at a human rights clinic. The fact is, he said, the name of the clinic puts it in harmony with its national organization, Physicians for Human Rights, which provides forensic evaluations through a volunteer network. "The way they would put it, and the way I put it, is the fact that I work in an emergency room does not make me partisan in

diagnosing pneumonia," said Nelson. "I diagnose people with pneumonia when they have pneumonia. If someone is a traumatized refugee, I diagnose their PTSD [posttraumatic stress disorder]. If they do not have PTSD, I do not diagnose it."

Parker then asked all of the panelists if they had any specific requests for the roundtable with regard to specific areas for engagement or action. Nelson responded that it is his sense that clinicians need more and broader education, even at the level of medical school and residency, about the issues he raised as far as talking to their foreign-born patients about torture and other traumas they may have experienced. He also said that the types of programs that the other three panelists discussed were excellent examples of how to respect an individual's background, culture, and language skills. "I would love to have my residents rotate through all of these programs," he said.

Liou wondered if the roundtable could help spread the word about a tool her team has developed for clinicians that aims to help them identify patients who work in the nail salon industry and then provide tips to protect their health. Quiñones said that there is currently little conversation regarding integration of physical and mental health for immigrants and refugees, and he thought a more detailed discussion on that topic and on funding opportunities for nonprofits would be useful.

Michael Villaire, chief executive officer at the Institute for Healthcare Advancement, commented that trust and engagement have to occur before addressing health literacy and asked the panelists to talk about the challenges of earning trust and engaging immigrant, refugee, and migrant communities. Quiñones replied that his organization does this in part through its advocacy activities, particularly with regard to getting medically necessary services for its patients who do not have access to public assistance programs and therefore do not have insurance.

Liou said that she and her colleagues had to step back and think about where nail salon workers and owners are coming from with regard to their fears that wearing masks and gloves will scare off their customers and put them out of business. Her approach was to hold workshops and make them fun. These workshops were not framed as health workshops, but rather as community gatherings, she explained. In one instance, her program held a Lunar New Year celebration and then started infusing some ideas about health. They also held community forums at which workers and owners could express their concerns. She noted that her program has also been building relationships with other trusted community and social services organizations.

Community organizations are where LaScala starts establishing trust. "They know they can trust us to get workshop materials to them on time, that we will respond to their questions, that we will work together to

develop a great workshop because the refugees and immigrants already have a trusted relationship with them," she explained. She said that she can feel trust building between the community and her program over the course of a single workshop, fostered by the openness with which workshops are run and the freedom of the community members to ask questions and share their stories. Nelson agreed that partnering and working with community organizations is key and that his clinic would not survive otherwise. "We take forensic referrals and referrals for complicated, traumatized, medically complex, decompensated PTSD patients," said Nelson, who added that the only reason these individuals will come to his clinic is because a trusted staff member at a community organization referred them. "The community organizations are where the magic happens for us," said Nelson. The interpreters at Highland Hospital, who serve a dual role as cultural ambassadors, also play a major role in building trust with the community, he added.

Umair Shah, executive director at Harris County Public Health in Houston, Texas, remarked that the refugee health clinics run by the county health department often double as de facto community centers and provide the opportunity to engage the community in ways that go beyond providing health care. Nelson responded that he, in fact, had a meeting later today to figure out how to do just that with Highland Hospital's refugee clinic, which is a separate entity from his clinic that serves asylum seekers. He commended the community organizations whose primary mission is to do legal advocacy for acting as de facto community centers that also provide case management services and psychological services. "These places serve as vital nuclei for those communities," said Nelson.

Imelda Plascencia, health policy outreach manager with the Latino Coalition for a Healthy California, asked how the threat of increased immigration enforcement has affected use of services and enrollment at Nelson's clinic, noting that her organization has heard many stories of people intentionally disenrolling from health clinics. Nelson said that the federally qualified health centers in the region and the University of California, San Francisco, have done a good job developing clear policies about who is allowed where in a facility and which areas are restricted, and in training staff about how to respond to incursions by immigration enforcement officials. LaScala said that given the current circumstances, refugee organizations are having to prioritize what they can work on with regard to the most important needs of the communities they serve.

Liou said Asian Health Services has been developing policies around the issue of private space in its clinics and training staff about how managers can respond when dealing with an immigration enforcement official. She said her organization has had patients who want to disenroll from Medi-Cal even when not warranted and is trying to encourage patients to get the services they need. It is also developing a role-play for its provid-

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ers to help them answer their patients' questions. Quiñones said that as of January 2, 2017, Casa de Salud's policy is to cooperate fully with agents in accordance with the law. "We already have a policy in place and staff has been trained," he said.

4

## Health Literacy Considerations for Outreach

The first panel of the workshop's afternoon session discussed four areas: using health literacy concepts to teach English, messaging for disaster and emergency preparedness, outreach to uninsured foreignborn populations, and strategies for identifying and working with trusted advisors and decision makers. All mentioned their challenges with health literacy and ensuring they are able to fully capture their targeted populations. Maricel Santos, associate professor of English at San Francisco State University, discussed teaching English to non-native speakers using health and health literacy concepts. Justine Kozo, chief of the office of border health at the San Diego Health and Human Services Agency, spoke about the challenges of messaging for disasters and emergency preparedness. Rishi Sood, director of policy and immigration initiatives at the New York City Department of Health and Mental Hygiene, described outreach efforts to uninsured foreign-born populations in New York City. Mimi Kiser, program director for the interfaith health program at the Rollins School of Public Health at Emory University, gave the final presentation on strategies for identifying and working with trusted advisors and decision makers. An open discussion followed the presentations.

## TEACHING ENGLISH USING HEALTH CONCEPTS AND HEALTH LITERACY<sup>1</sup>

Santos began her presentation with two takeaway messages. The first was that the adult literacy world and public health need to be spending more time in each other's worlds. The second was that the goal is not to make things simple, but to make them understood. A teacher telling a class that his or her goal was to make things simple would not motivate learners to return, but telling students that his or her goal is to find out how that day's lessons would intersect to the learners' needs starts a conversation that is likely to continue. Santos, who spends the bulk of her time training teachers, said that many of her graduate students are interested in connecting English language education with the outside world, and a large part of her funding is associated with workforce training grants. She noted that she and her colleagues have been discussing how to address both workforce development and health literacy education to empower immigrant communities.

Santos then told a story to illustrate how English as a second language (ESL) teachers can introduce health concepts into English instruction (Santos et al., 2011). The story starts with a statement about posole: You don't ever think about vegetables because you never ate enough meat in your country. You think that the best and most delicious thing is to prepare a very delicious posole. From this story, the ESL teacher can bring in themes and start a discussion around child nutrition, changing diets in immigrant families, and how to preserve home traditions in a new country. Using what is known as a "re-storying" approach to collaborative interpretation of texts, the teacher asks the students to describe what the story says about vegetables and to interpret why the writer talks about posole and why the writer talks about meat in the last two sentences. Finally, the students reflect on how this story reminds them of their own stories and talks about who should hear those stories.

In one class, this story triggered a disagreement between two Spanish-speaking students about whether or not the posole has vegetables in it, with one student arguing that beans are a vegetable, and the other disagreeing with her. What was important, said Santos, is that one beginning adult ESL learner understood the story well enough to disagree with it and that she and another student were expressing, in English, a reaction to the story. "Imagine that dynamic in a clinical encounter," said Santos. One thing that happened in this conversation is that the two women eventually started interspersing Spanish into the conversation, a phenomenon that linguists

<sup>&</sup>lt;sup>1</sup> This section is based on the presentation by Maricel Santos, associate professor of English at San Francisco State University, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

call translanguaging. The implications of this for health literacy among immigrants and refugee communities is that it should be thought of as a multimodal, multilingual competence. "If you look at what is going on in classrooms where people are developing this competence, you do not see it demonstrated in English only," said Santos. "This has an important implication for how we assess the development of health literacy and its outcomes if we are only able to do it largely in English."

She then recounted a story about when she first met the late Archie Willard, a leading figure in adult literacy who founded VALUEUSA, a national adult learner leadership organization. She was giving a talk to a group of adult learners and the subject was supposed to be on reading and how it connected to health. Willard pulled her aside and told her that the students are going to start telling their life stories and he predicted that her impulse was going to stop the discussion to get the students back on track but that she needed to resist. His point, she said, was that learners, in order to become leaders, need uninterrupted opportunities to tell their life story. "To gain a voice as a health literate person in this world requires opportunities not only to tell your story, it's actually better framed as the right to impose listening onto others," said Santos. (This characterization of health literacy competence as reflective in one's ability to "impose listening on others" builds on the work of Bonny Norton [language education] and Pierre Bourdieu [sociology] [Norton, 2013].) "That has such important implications for patient engagement, but also in classrooms where we try to do a very active job of allowing ourselves to listen as best we can despite the comprehensibility of an accent and despite the fact that this person does not have the right vocabulary."

Another important concept that comes up in the posole story, she said, is that learners need opportunities to ask questions, even risky ones, and this is particularly true in the context of a clinical encounter. The health literacy community knows this, and it also understands that English proficiency does not equal success (Gee, 2014).

To apply health literacy in adult ESL classrooms, Santos suggested using real-life stories to develop language lessons of high interest to learners and to use learner stories as texts. Classroom talk can serve as health literacy in action, and health literacy talk can serve as identity work. ESL classrooms, she noted, are good places to discuss health issues because they are viewed as safe places to get advice, ask questions, and analyze information. They can also provide access to hard-to-reach communities and links to existing social networks within marginalized communities (Santos et al., 2014).

Santos listed a number of keys to unlocking health literacy competencies of adult ESL learners. These included focusing on message abundancy (Gibbons, 2003); scaffolding, or breaking up learning into chunks and

providing a tool or structure with each chunk (Walqui, 2006); emphasizing oral interaction around texts (Bigelow and Tarone, 2004); harnessing the power of embodied language (Whiteside, 2008); emphasizing interaction and transaction (Whiteside, 2008); and honoring the lived experience in the classroom. She also said that teacher training and health educator training programs need to be speaking to each other more often and need to be incentivized to do so. "We are both very siloed because we have our own licensing expectations with very little connection," said Santos.

She also called for new thinking about health literacy credentialing. "There are no certificates when an adult ESL learner completes 3 years of ESL and is actually better at health care navigation," she said. One model may be efforts in the adult education system (e.g., corrections education, work-based education) that aim to provide a continuous sequence of adult education and reward intermediate milestones with a credential or certificate. "I wish we had something like that in adult education for health literacy because it would enable us to not only demonstrate linguistic outcomes—do they have better vocabularies—but also that they have better self-advocacy skills," said Santos. Credentialing is particularly valuable for learners at the beginning levels of literacy learning, for whom there are often no formal ways to reward progress. While adult education is good at that kind of assessment, she said, it lacks the connection to public health to translate assessment into the health care context.

To close her presentation, Santos returned to the idea of learner leadership. "Where are the adult learners in our conversations?" she asked. She noted that community organizing is one place where the dynamic preserves a place at the table for the least proficient to be heard. As a final thought, she called on those in attendance to identify at least three or four adult education programs that they would call to start making the connection between adult ESL instruction and health literacy.

#### MESSAGING FOR DISASTERS AND EMERGENCY PREPAREDNESS<sup>2</sup>

Every day in San Diego approximately 75,000 northbound crossings occur, said Kozo, and roughly 32 percent of the city's population is Latino. In addition, San Diego is a major resettlement destination, accommodating some 3,500 refugees annually. As a result, more than 100 languages are spoken in the city. Kozo noted that a recent report found that some 400,000 individuals report speaking a language other than English at home, speak English less than very well, and are not prepared for emergencies such as

<sup>&</sup>lt;sup>2</sup> This section is based on the presentation by Justine Kozo, chief of the office of border health at the San Diego Health and Human Services Agency, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

the huge wildfires in 2007 and 2014 that led to the evacuation of more than 500,000 people.

The language diversity in San Diego creates a number of challenges with regard to messaging and emergency management, said Kozo. A study conducted by California State University at San Marcos on the experience of agricultural workers during those wildfires found that people were too terrified to come out of their homes when they received evacuation orders from law enforcement. "They were so terrified, for a number of reasons you can imagine, that many people just shut their blinds and prayed," she said. Another study conducted in the aftermath of a 2011 24-hour black-out across San Diego County found that families in refugee communities sent their children to schools, which were closed, because they had no idea about what was happening.

Incidents such as these produced a great deal of public criticism about how San Diego County responds to these emergencies in terms of helping people in isolated communities. As a result, explained Kozo, the directors of public health and the office of emergency services got together and started an initiative under the auspices of the Live Well San Diego vision to create communities resilient to disaster and emergencies. The Office of Emergency services looked into translation software options that could be disseminated via the county's reverse 911 system. "We looked into that and there is no system you can trust," said Kozo. "When you are sending out lifesaving information such as 'You need to evacuate your home' or 'You need to boil your water, it is not safe to consume,' you cannot rely on Google Translate or any other computerized software to translate that information correctly."

Starting in 2012, the county began the process of planning a large community forum to bring together representatives from the top six languages other than English spoken in San Diego, which included Arabic, Chinese, Filipino, Korean, Spanish, and Vietnamese. Representatives from several refugee organizations pointed out that while smaller in number, refugee communities are more vulnerable and have fewer resources, so the list was expanded to included members of the Somali and Karen communities. At the first all-day meeting, directors of community-based organizations came along with a client, colleague, or patient from their communities. This meeting featured a keynote speaker from ECHO, an organization based in Minnesota that focuses on health communication, and eight focus groups, each professionally facilitated with simultaneous interpretation in all eight languages. The focus groups were asked the specific questions:

- During an emergency, where do you get your information?
- Who do you turn to, and who do you trust?
- Do you have a landline at home?

- What media does your community have access to?
- If you received some information from the county government, how would you respond?
- What is your level of trust with government?

Perhaps the key finding from this exercise was that during emergencies or when people are in need, they turn to one another for support and information. "Social networks are everything," said Kozo. Another finding was that a community's youth are a trusted source of information because younger members of the community tend to be bilingual, assimilate quicker, and they are more savvy with social media so they have quicker access to information. Schools were noted as a trusted source of information, as was the Red Cross. All eight focus groups listed various faith-based organizations in their communities, as well as media when available, as additional trusted information sources. Kozo explained that while the Latino population in San Diego has access to several local Spanish language news and radio stations, the Somali and Karen communities do not have access to the equivalent.

Another finding was that the level of English proficiency varies across these communities. The Korean and Karen communities reported very high levels of literacy, while the Somali and Latino communities reported lower levels. Also in some languages there are multiple dialects within communities. "We were told that there are 80 different dialects within the Filipino Tagalog language," said Kozo. Yet despite these challenges, information travels quickly through these communities via word of mouth.

A key finding for Kozo and her colleagues was the varying degrees of trust in government. "Many groups said they flat out have mistrust [of the] government because of their experiences in their home countries," she said. "Some groups said if they received a letter in the mail that had a government logo, that they might just simply toss it in the trash." In fact, out of the eight groups, the Filipino group was the only one that recognized the county seal. Schools were the one exception to the mistrust of government.

The focus groups recommended using existing social networks to disseminate information at times of emergency. One of the best ways of doing that, said Kozo, is to use phone trees and partner relays. What this means, she said, is that her agency has worked to create partnerships with trusted community-based organizations and rely on those organizations to disseminate updated, accurate, and vetted information. "You have to engage with these partners ahead of time, and then they share that information with their clients in various languages or however they disseminate information," she said.

In addition to holding one-on-one meetings with community-based agencies, she and her colleagues have been conducting trainings three times

per year that bring together community-based agencies serving refugee, immigrant, and newly arrived communities. "We train them on topics that are of interest to them related to public health and emergency preparedness," said Kozo. Her agency has also conducted drills with an online, two-way communication platform it uses, called ReadySanDiego, as part of its partner relay. The county also uses this platform to disseminate pertinent public health information, such as on Zika. Currently, her agency has more than 300 partners.

Unfortunately, said Kozo, the communication drills her agency held in 2015 and 2016 had low participation, and the feedback was that the communication platform is clunky, requires a password that partners forget, is not searchable on Google, and does not come with a mobile app. As a result, Kozo's team is exploring new communications platforms and hopes to have a new system in place by the summer of 2017.

In terms of what this program asks of its partners, Kozo said they need to join the partner relay, designate someone within the organization to be the point person, and to share pertinent information during emergencies. What the program offers in return is updated, vetted, trusted, and timely information during emergencies, as well as regular communication on pertinent health topics and trainings three times per year on important public health and emergency information. The program also provides a direct phone line and email address that allows the partner relay liaison to contact the county's emergency operations center.

So far, the program has conducted 10 trainings among refugees on subjects including wildfire prevention and childhood lead poisoning. Law enforcement has spoken about what to expect during an evacuation. A training scheduled for May 2017 will focus specifically on the refugee community.

#### OUTREACH TO UNINSURED FOREIGN-BORN POPULATIONS<sup>3</sup>

Though the percentage of people uninsured in New York State and New York City has dropped to historic lows since the passage of the Patient Protection and Affordable Care Act (ACA), the uninsured rate among noncitizens and the undocumented population remains high, said Sood. He explained that the undocumented population in New York City represents approximately 1 in 16 residents, and two-thirds of that population, or 345,000 people, lacks coverage as of 2013. In addition, approximately

<sup>&</sup>lt;sup>3</sup> This section is based on the presentation by Rishi Sood, director of policy and immigration initiatives at the New York City Department of Health and Mental Hygiene, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

245,000 undocumented and uninsured adults aged 19 and older live in households with income under 200 percent of the federal poverty level as of 2013. In New York State, he added, all children regardless of immigration status are eligible for health insurance.

In 2014, New York City Mayor Bill de Blasio launched a taskforce to identify ways to improve health care access for the more than 3 million foreign-born residents of the city, with a specific focus on those left behind by the ACA. The centerpiece recommendation borrowed heavily from models in California, including Healthy San Francisco, My Health LA, and the Health Program of Alameda County, as well as the My Health model in Harris County, Texas, and models from Massachusetts and Nevada. "Everyone does it slightly differently, but through months of conversation we documented what was done around the country and determined it was time for New York City to launch what we call a direct access health care program," said Sood. This program, ActionHealthNYC, builds on the city's robust public hospital system, which includes 11 public hospitals and dozens of other facilities, and dozens of community health centers, many of which are federally qualified health centers, he explained.

The benefits of the direct access model, said Sood, begin with the enrollment process, which is tied to other city programs such as New York City's municipal identification card (IDNYC). Enrollees in the program choose a primary care home that provides coordinated care with consistent fees. In addition, this program pays providers to deliver remote care coordination, rather than care management provided solely within the walls of a particular health facility. At the time of the workshop, ActionHealthNYC was in the midst of a 1-year demonstration phase, with the goal of enrolling 2,400 people from the Lower East Side and Chinatown neighborhoods of Manhattan; the Jackson Heights, Corona, and Elmhurst neighborhoods in Queens; and the Sunset Park and Borough Park neighborhoods of Brooklyn.

ActionHealthNYC partnered with six community-based organizations in the demonstration neighborhoods to reach its target populations. It also used paid advertising and generated 41 earned media hits in its 5 months since the program was announced on March 10, 2016. In addition, the program mailed notices to IDNYC participants and Emergency Medicaid recipients in the demonstration neighborhoods and worked with allied organizations to spread the word. Sood noted that the network of health facilities involved in the demonstration includes many that lie outside of the target neighborhoods because people often get health care services near their place of employment or where they know they will receive care in the language that they speak rather than where they live. Enrollment in the program began May 2, 2016, and ended August 13, 2016, with clinical services starting on July 1, 2016. Sood noted that people could make appointments through the city's 311 system, though it had to stop the 311

system from accepting appointments 10 days before the enrollment period ended because of a large spike in enrollment thanks to the mailings. "A good problem to have, but not something you really wanted to run into," said Sood. Though the program prepared health education materials in 13 languages, Sood said the participants in the demonstration speak 32 different languages and come from 77 countries. Enrollees live in 139 zip codes in every borough of the city.

In the final moments of his presentation, Sood spoke about the challenges of reaching ActionHealthNYC's target population, which turned out to be harder than expected. "How hard can it be to reach 1 percent of a particular population to provide a health care program that charges no quarterly or monthly fees, only point-of-service fees?" asked Sood. "The truth is, it was much more complicated than we thought." In the end, only one-third of the enrollees came through the community-based partners. Another one-third were walk-ins who found out about the program through word of mouth or an advertisement, and the remaining one-third came in through the 311 system. "What that tells us is that the varied approach was important and that we cannot just send out letters, we cannot just work with community-based groups, and we cannot just rely on word of mouth," said Sood.

Another important lesson from the enrollment process was that although people distinguish between federal and local government, local government is still government and partnering with trusted community-based organizations is more important than ever given the distrust of governments among the target population, said Sood. "We should not understate the political climate," he said. "I did some of the enrollments myself at a number of our sites and the questions that we heard most often were from people asking how we were going to protect their information." This study, he explained, had institutional review board approval and he and his team are taking every precaution to protect the participants' information. Nevertheless, he said, some people thought the risk was still too high and declined participation in the program.

## PARTNERSHIPS IN BUILDING TRUSTED COMMUNITY NETWORKS<sup>4</sup>

In 2009, Kiser and her colleagues at Emory University began a project to build and mobilize capacity within networks of faith-based and com-

<sup>&</sup>lt;sup>4</sup> This section is based on the presentation by Mimi Kiser, program director for the interfaith health program at the Rollins School of Public Health at Emory University, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

munity organizations at 10 sites around the country. These organizations had established links with public health, and the goal was to extend their reach to vulnerable, at-risk, and minority populations in order to improve influenza vaccine outreach and uptake. The 10 sites included in this project were a subset of those that were part of a leadership development program that the Centers for Disease Control and Prevention (CDC) funded, called the Institute for Public Health and Faith Collaborations. Kiser's team had trained 78 teams of religious and public health leaders in 24 states to collaborate on eliminating health disparities for the CDC-funded program. During the H1N1 outbreak of 2009, the U.S. Department of Health and Human Services' Faith-Based and Neighborhood Partnerships program, which knew of this network, thought that tapping into the resources and community capacity of these sites might be an expedient way to deliver H1N1 services to some of the priority populations, she explained.

Understanding the nature of these partners is important, said Kiser. Five are large faith-based health systems that, because of their faith-based mission, have a strong commitment in their community outreach programs to build strong institutional relationships with the faith-based community in their catchment areas. Kiser noted that the partners in this project included the Arkansas Department of Health; a small faith-based organization that conducts large-scale health promotions and disease prevention activities in underserved communities in Detroit; the Buddhist Tzu Chi Foundation in Los Angeles; a federally qualified health center in Lowell, Massachusetts, that works with refugee and immigrant communities; a small nonprofit organization in Pennsylvania that serves a rural community; and large faith-based health systems in Chicago, Memphis, Minnesota, and New York City.

The project's accomplishments, said Kiser, are measured in the number of people vaccinated across the 10 sites and the number of vaccination events the partners have held. She noted that along with vaccinations, the sites conduct education outreach and engagement with partners. Some sites, she added, have adopted the Arkansas Department of Health's influenza prevention workshop approach. One site has an academic partner who conducted qualitative research on trust with religious leaders and used the findings to build some educational outreach tools. Minnesota's site, on behalf of the state health department, conducted interviews on emergency communication with community leaders and as a result conducted outreach using e-newsletters, radio, family nurses, and faith-based organizations.

One partner in Minnesota, Fairview Health Services, had a CDC Epidemic Intelligence Service officer who helped develop a survey to administer at its vaccination clinics to learn about people's attitudes and decisions about vaccination. Administered to between 1,600 and 2,800 people per year since the 2011-2012 influenza season, this survey showed that people

TABLE 4-1 Results of Surveys on Attitudes and Behaviors Regarding Influenza Vaccination

	2011-2012	2012-2013	2013-2014	2014-2015	2015-2016
No health insurance	55.5%	45.2%	40.9%	30.4%	32%
No regular doctor	19.2%	15.1%	13%	13.6%	13%
Shots provided free	65.8%	51%	48%	49.6%	52%
Trusted place/setting	42.5%	28.3%	26%	24.9%	26%
Convenience	16.3%	19.6%	22.2%	46.1%	46%
Interpreters	23%	12.1%	13.6%	9.1%	12%

SOURCE: Emory Interfaith Health Program as presented by Mimi Kiser at Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literate Approaches: A Workshop on March 15, 2017.

come to the clinics because they have no health insurance, the shots are free, the clinic is a trusted place, and it is convenient, among other reasons (see Table 4-1).

Kiser and her collaborators conducted a modified Delphi technique to identify some of the key practices associated with the successes the programs were having in reaching their focus populations. This analysis identified 14 practices organized in four core drivers—having a faith mission, inclusivity, trust in their communities, and compassion-driving flexibility—and five associated processes (see Figure 4-1). According to Kiser, these processes—marrying stories with data, keeping relationships and presence paramount, building and maintaining trust, developing enduring collaborations, and identifying trusted leaders—are the day-to-day work that contribute to program success. Supporting the core drivers and five processes are five enduring infrastructure capacities: leadership that anchors the work, volunteers on the ground, a circle of core partners, network connections, and multisectoral collaborations. Kiser and her collaborators partnered with the Association of State and Territorial Health Officials to build a toolkit based on this framework.<sup>5</sup>

One model Kiser highlighted was that of the Buddhist Tzu Chi Medical Foundation, which she characterized as being light on bureaucracy and able to respond rapidly in a way that her public health partners were often not able to do. This organization, which serves a large portion of the Asian population in Los Angeles, sets up clinics to provide health services at migrant farm worker camps early in the morning, before the workers

 $<sup>^5</sup>$  See http://ihpemory.org/ihp-programs/public-health-and-faith-community-partnerships (accessed May 5, 2017).

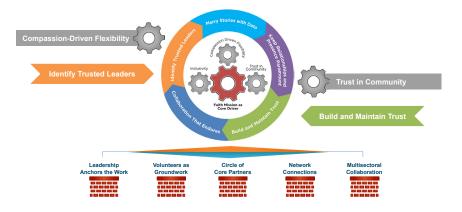


FIGURE 4-1 Model practices framework.

SOURCE: Emory Interfaith Health Program as presented by Mimi Kiser at Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literate Approaches: A Workshop on March 15, 2017.

have to be in the fields, or late in the evening when the workers return to camp. They follow the same pattern at homeless shelters. They also provide services at cultural celebration venues, said Kiser.

She also discussed the Lowell (Massachusetts) Community Health Center, a federally qualified health center with a long history of responding to the needs of immigrant communities, particularly the Cambodian refugee community and most recently African immigrants. To deliver services to the Cambodian community, the Lowell center partnered with a local Buddhist center and built a mediation room in the health center itself. To service the African immigrant community, the Lowell center has established a strong outreach relationship with a network of African churches. Kiser noted that this organization has been intentional about hiring staff who represent the ethnicity and culture of those they serve, and it has developed a large community health worker program. "They have adapted that to work and build relationships and connectivity to these different ethnic populations through the faith-based and community organizations," said Kiser.

In Chicago, two organizations with a long-standing partnership—faith-based Advocate Health Care system and the University of Illinois at Chicago's Neighborhood Initiative—formed the Center for Faith and Community Health Transformation. The center capitalizes on the partnership's unique communication capacity from an extensive network of faith-based and other like-minded partners with whom it has built trusted relationships. In one case, the center worked with the Council of Islamic Organizations

#### **Diverse Ethnicities Diverse Religious Traditions** African American Bosnian Buddhist Caucasian Muslim Iragis Native American • Africans Hindu Hispanic Ghanaian Catholic Burmese Nigerian Lutheran Vietnamese Cameroonian · Presbyterian Somali · Evangelical Free Cambodian Kenyans · Christian Reformed Laotian Chinese South Asians Episcopal Baptist Methodist UCC/UUA

FIGURE 4-2 Ethnicities and religious traditions served by the Minnesota Immunization Network Initiative.

NOTE: UCC/UUA = United Church of Christ/Unitarian Universalist Association of Congregations.

SOURCE: Emory Interfaith Health Program as presented by Mimi Kiser at Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literate Approaches: A Workshop on March 15, 2017.

of Greater Chicago to develop a flu prevention method framed by the commitments and theological perspectives of the Islamic faith tradition. This method was disseminated through a newsletter that reached more than 9,000 readers. These collaborators also created a website with 2-minute videos of religious leaders providing encouraging words out of that faith tradition around promoting flu prevention and flu shots. These videos are in Arabic, Chin, Haitian Creole, and Hispanic.<sup>6</sup>

In Minnesota, Fairview Health Services partnered with the Minnesota Department of Health and a network of core partners who together reach a diverse set of ethnic immigrants in settings such as churches, mosques, a Hindu temple, a Sikh temple, a Buddhist monastery and temple, a Burmese Baptist church, the local Tibetan Foundation, a Somali mall, a Hmong flea market, homeless shelters, English as a second language centers, child care centers, food pantries, and the Mexican Consulate (see Figure 4-2). Together, these partners hold large-scale vaccination events, and Kiser characterized them as the "go-to vaccine sites for many of those populations." The partners only hold these vaccination clinics when invited by the

<sup>&</sup>lt;sup>6</sup> The videos are available at http://www.faithhealthtransformation.org/resources-and-toolkits/health-topics/flu-prevention-and-immunization-resources/diverse-spiritual-leaders-encourage-flu-prevention (accessed June 14, 2017).

host sites. "That relationship is really nurtured and respected," said Kiser. Trained volunteers staff the clinics, which are held at hours convenient to the particular population. Most of the clinics have an extensive network of translators on hand.

Kiser concluded by noting that these programs all deliver trusted and accessible messages outside of the health care system through trusted networks and relations. In every case, the partners have a flexible and adaptive organizational capacity that enables them to quickly deliver messages in a relevant language and with relevant cultural meaning. Most communities, said Kiser, have leaders and organizations who have the relationships and commitments that can leverage connections and social capital for the well-being and health of all. "It is very rewarding to see what these community networks and leaders have been able to build over time in their communities, and I'm honored to be working with them and sharing their work with you here," said Kiser, ending her remarks.

#### **DISCUSSION**

Robert Logan began the discussion by noting that libraries become trusted places and safe havens after disasters without any outreach. He asked the panelists to comment on the potential to integrate libraries in their work. Sood did not know if any of the outreach efforts in his program included libraries, but he acknowledged that they should. "When I talk about the outreach efforts of the program, I usually mention churches and temples and other places of worship, but point well taken," said Sood. "I can say that at the least my team will take that into account as we move forward." Kozo also thanked Logan for that suggestion and said she would reach out to libraries directly when she returned to San Diego. "I'm excited to take this back to my team," she said.

Santos replied that she does not work directly with libraries in her work, but she said adult education has a strong hold in libraries. She also said that librarians tend to be ahead of the curve on media literacy and the tools that are available, and that expertise could play an important role in mapping networks. She did note that in rural areas, libraries are often mobile and not someplace a person can walk into whenever they want. She also pointed out that librarians in San Francisco and the Bay Area are important health literacy intermediaries. Umair Shah said that in Harris County (Texas), public health already works with the library system and is looking at co-locating public health services and libraries to enable joint programming.

Shah then asked the panelists to talk about any impacts that today's resource-constrained environment has had on the importance of partnerships and working with diverse groups outside of the silos of public health

and health care. Sood said that such partnerships are quite important in New York City. For example, he noted that the Mayor's Office of Immigrant Affairs has a partnership with the city health, education, and social services departments to align messages that then go to the public through community-based organizations. Kiser said that she has seen the reduction in dollars make it difficult for agencies to spend time on forming partnerships given that funds for outreach activities are often the first ones cut as budgets tighten. "I think it is a fairly resource-intensive activity," she said. Where she has seen success is when larger faith-based health systems have reached out to the faith community to bring it alongside public health.

Santos said there are certain populations for which additional resources are needed to make a difference, such as adult learners with limited years of schooling and adolescents who have "maxed out" of high school but are too young to enter the adult education system. "There are these populations that deserve more individualized attention and are going to need innovation," she said. As an example, she cited a recently published paper by the Open Door Collective which spotlights four different health literacy projects and all have some funding from the Workforce Investment Act or from a health insurance foundation that decided to invest in adult literacy professional development. These projects were able to integrate the health component into a program that would meet the learning needs of their learner community and the needs of their funders.

Bernard Rosof asked Sood about his experience working with the large not-for-profit health systems in New York City that have an obligation under the ACA to be involved in the type of work described during this session. Sood replied that from the health department perspective, it is sometimes easier to work with the public hospital system than with private health systems. The long-term goal of his program is to work with private hospitals in addition to public hospitals. Kiser added that in all of her years working to link public health with the faith community, New York City public health has always had a devoted staff member working with the faith community and taking that role seriously.

Laurie Francis commented about the need to move care outside of the health care system in order to maximize the effectiveness of constrained resources for improving health. Working with community partners would be one way of spreading resources. She then asked Santos if she could speak more about her concept of the right to impose listening. Santos said that this idea comes from Bonny Norton, an identity theorist who would say to stop treating health literacy as a set of reading and writing skills and instead look at it as a change in identity. "When you gain new practices,

<sup>&</sup>lt;sup>7</sup> See paper at http://www.opendoorcollective.org/adult-basic-education-and-community-health-center-partnerships.html (accessed August 11, 2017).

new navigation skills, new competencies, you change who you are able to interact with," said Santos. In her view, health literacy is a means of increasing social participation, which suggests there are theories and models from the social participation field to bring to bear on the challenges of improving health literacy. It also suggests to her that the adult education system needs to be a partner of the health care system so that the classroom rather than the 11-minute clinical encounter becomes a place for working on health literacy.

Willis asked Sood if ActionHealthNYC was incorporating mental and oral health in its agenda, and Sood replied that that the seven federally qualified health centers and two public hospitals in its pilot program do offer mental health services and New York City's ThriveNYC program aims to improve mental health for all New Yorkers. He noted that some of the federally qualified health centers are seeing people who are physically healthy and enrolled in the program strictly for behavioral health services. Oral and dental services are covered and are available at half of the program's primary care homes. Clients of the other health centers are free to go to another site to get dental care.

Kozo said her program recognizes the extreme importance of mental health, especially when dealing with refugee and migrant communities who have experienced trauma in their home countries, on the journeys to the United States, and even in this country. She did note that it was only recently that mental health was raised as a topic of interest at one of the program's trainings, but once it came up it became a huge discussion point. As a result, the May/June training session will include a presentation on available mental health resources in the community. Kiser added that some of the organizations she works with have started asking for suicide prevention education and are starting to receive training in mental health first aid.

Rosof then asked if any of the programs were addressing autism. Kozo replied that there is always a focus on autism at the annual binational health month that is held every October. This program is put on by the University of California, Berkeley, Health Initiative of the Americas and all Mexican consulates in the United States. While this is not connected to her program in emergency preparedness, it is an important issue to the Latino community in San Diego. Santos noted that adult education programs based in unified school districts are helping families who fear deportation get their child's individualized education program together in case they have to leave suddenly.

Kozo added that public health uses the partner relay system during non-emergency times to share helpful resources with the community, and these resources have included information on mental health. It has not been used to push out resources on autism, learning disabilities, or developmental disabilities, but she said she will do that. Julia Ackley, the health literacy program manager at Sutter Health, said that in a previous role she worked for Help Me Grow, a national network that does care coordination for children through age 5 with developmental delays including autism. This organization, she said, does extraordinary work partnering with pediatricians to create a health literate, multilingual, trauma-informed care approach to support families. These families, in turn, serve as advisory members for organizations and could be good partners for the type of programs discussed at this workshop, particularly given the shortage of resources available for children with mental health issues.

Santos noted the importance of having discussions among content experts and teachers when thinking about how to address hard health topics such as gestational diabetes, a program she is currently developing. "People may not know how to engage in talk about gestational diabetes even though they are interested in it," she said. Teachers, though, are good at looking at the "on ramps" that create meaningful opportunities for learners to talk to each other and engage in a topic.

She also responded to a question from Ackley about how a large health care organization such as hers can partner with adult education programs by noting that most adult education programs are registered with an organization called the Outreach and Technical Assistance Program for Adult Educators. This organization has an online directory that can be searched by zip code, which is typically how she finds programs with which to work. However, she added, it helps to have a faculty member to be a community partner, so she suggested going to a nearby university and finding its office of civic and community engagement. "Those folks have the infrastructure to bridge build for you," said Santos. Many universities also have a service learning component that requires students to do service work in the community. "Then you have a cadre of individuals who are in training who might be able to work for you," she said. Adult English as a second language teachers are also good sources of ideas on issues that arise in a community. "That is how I found out about lead poisoning in Salinas," she said. Santos then noted that there is a need for a crowdsourcing portal to identify good ideas and share them.

Wilma Alvarado-Little, principal and founder of Alvarado-Little Consulting, asked the panel if their programs had made any allowances for the deaf and hard-of-hearing communities, especially those for whom American Sign Language is not their primary or preferred language. Kozo said that San Diego County's communication relay has a technology in place for alerting both the hearing and visually impaired communities.

<sup>&</sup>lt;sup>8</sup> See http://www.otan.us (accessed May 5, 2017).



5

# Application of Health Literacy to Communication with Immigrants, Refugees, and Migrants<sup>1</sup>

The following discussion focuses on communication with immigrants, refugees, and migrant workers. It also reflects challenges to practitioner's competencies in serving the health and non-health needs of these populations and other mechanisms for establishing open channels of communication with these populations. To provide some context for her remarks, Megan Rooney, director of program development at Health Literacy Media, said there are 42.4 million immigrants in the United States, representing approximately 13 percent of the U.S. population. There are also some 3 million refugees, or approximately 1 percent of the U.S. population, according to figures she obtained from the Migration Policy Institute and Pew Research. She then explained that she intended in her talk to frame the strategies for applying health literacy to communications with immigrants, migrants, and refugees in a way that addresses the unique mental health challenges, experiences of trauma, and different levels of stress. The strategies will also focus on helping these individuals build a sense of trust and a sense of control in their lives. This sense of control has been lost for so many of these people because they have had to either flee for their lives or make the choice to leave their homes to better their lives and their family's lives.

She also noted that she sees trauma and deeper levels of stress as residing on a continuum. "You see refugees who have experienced torture on

<sup>&</sup>lt;sup>1</sup> This section is based on the presentation by Megan Rooney, director of program development at Health Literacy Media, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

the end of deep experiences of trauma and then you have some migrant workers who have made the choice to come to the U.S., as well as many immigrants who have also made a choice and who are happy to be here," said Rooney. "Nevertheless, they have all experienced separation from family, the need to navigate an extremely complex system, language barriers, and many are away from their support systems when they first get here."

Culture, said Rooney, informs many aspects of health, including what people are willing to talk about, who they are willing to talk with, what they are willing to disclose, and what words they use. "This can affect a wide variety of communication skills, from which family member you choose to talk to when you have a whole family in your room or your office, what food you suggest people eat, and how you break bad news," she said. "All of these have implications based on people's cultural beliefs." What is important in this context, she added, is for clinicians to be aware of their own cultural beliefs and have an openness about how those beliefs might influence how they interact with their patients.

One topic that Rooney has not heard discussed often in the health literacy field is that of structural competency. Structural competency recognizes the often invisible structural-level determinants, biases, inequities, and blind spots that shape people's definitions of health long before the clinical encounter. Structural competency, she explained, represents a broad view of health and incorporates social determinants with culture and focuses clinical care on reducing inequalities at the neighborhood, institutional, and policy levels.

To illustrate the importance of using words for messaging that people in the community use and understand, Rooney recounted some instructional materials Health Literacy Media was developing to explain clinical trials to adult learners. When testing some of these materials with an adult learner class and explaining the concepts, she talked about a research study of breast cancer medications and showed a graph to help explain the results. In the ensuing discussion, people in the class kept talking about how the patients who did not respond well in this clinical trial did so because they did not go to their classes or because the teacher did not describe things well enough. Rooney said she was baffled by these comments until she realized that she had been using the words "research study" to mean clinical trial, but the people in her class associated the word "study" with passing and failing a class. "I thought the words 'research study' were really simple," she said. "This experience taught us the importance of talking with people and understanding that the words we think are simple are not all of the time."

As another example of how good intentions do not always translate into good messages, Rooney told a story about how she wanted to issue a press release and include a quote from someone at the local hospital system about the importance of getting a primary care provider. While everyone involved in this messaging campaign thought this was a good message, her colleagues at the hospital system told her that it was a bad idea to include a quote from the hospital. Their explanation was that many people in this community could not afford care from a primary care provider associated with the hospital. What would be appropriate, they told her, was to get a quote from someone working at the local free health clinic. The lesson here, said Rooney, was about the importance of working with local health systems and gaining a deep understanding of their communities and their relationships with those communities. "Until you get deep into it, you do not understand those kind of nuances," said Rooney.

Commenting on Justine Kozo's use of partner relays, Rooney noted the importance of involving community organizations to get key messages from schools or the government to the individuals who need that information and increase the chances they will pay attention to that information. She also reiterated the lesson from Kozo's experience that the communication platform matters in that it needs to be simple, easy to use, and not require a password-protected login.

Regarding culturally informed organizations, Rooney said one main feature is that they offer ongoing trainings for staff on cultural humility, cultural awareness, and trauma-informed care. She noted that several speakers at the workshop described training clinics for staff on how to handle and talk with their patients about immigration issues. Another important feature of a culturally informed organization is that it works to ensure its workforce reflects the cultural mix of the population, as well as offering translation and interpretation services. A third critical feature is that such organizations offer services adapted to the specific needs of the client population. For example, a clinic that serves a Latino migrant worker community would offer after-hours appointments, allow family or larger groups into clinic visits, and perhaps use fotonovellas or videos instead of word-heavy written materials. Such a clinic would also factor current fears about immigration enforcement into the approaches it uses to assure its community that it is a safe place for them to come and receive care. Evaluating treatment outcomes by racial, ethnic, and language groups is also important to determine whether strategies are improving outcomes. "This allows for adjustments as needed for certain populations," said Rooney.

Commenting on important messages she had heard throughout the day, Rooney stressed the need of culturally informed organizations to build connections with local political leadership, which Henry Perea discussed in his presentation. The success of the Healthy Nail Salon Collaborative in getting the state legislature to pass a bill to better protect nail salon workers demonstrates the value of working with the political system. Along the same lines, an overarching theme from the day was the importance of

committing to engaging communities by building trusted relationships in the community through leadership councils, patient advisory boards, and community outreach committees. Such engagement is crucial for truly understanding a community's needs and informing program development. True community engagement also involves activities that fall outside of the narrow definition of health care services, such as building and organizing a community garden and holding events with the primary mission of having fun and making them interactive.

Rooney reiterated Kari LaScala's point that a simple smile can go a long way toward building trust and making someone feel safe. "I cannot emphasize that enough," said Rooney. "These are individuals who are up against an intimidating system every day. They come in to yet another office for yet another conversation that they could potentially not understand, so to see a warm, smiling face can make the tension just completely drop out of their faces and their wall goes down." Another way to build trust, Jesús Quiñones mentioned, is to guide patients through every step of the health care system and to provide services such as counseling, enrollment support, case management for referrals, financial assistance, and transportation assistance. Rooney said her experience working with refugees has been that the only way they can navigate the system is if someone is there with them. "Expecting someone to find an address and get on a bus does not work with many of them," she said.

Engaging non-traditional providers, such as shamans, can help build trust with certain communities, as can garnering social capital and understanding and using people's social networks to engage and care for them. Another strategy for lowering barriers to care for immigrant, migrant, and refugee communities is for health systems to be parsimonious about the information they collect and chart about their clients, particularly information on social history or immigration status. Rooney also noted the importance of creating a welcoming physical environment, of talking to patients and not just handing out written information, and of using easy-to-understand tools such as glucose wands and culturally relevant food plates.

One source of information she has found helpful when working with a new group of refugees is the Cultural Orientation Resource Center, which has a series of country- and culture-specific cultural backgrounders.<sup>2</sup> The Centers for Disease Control and Prevention,<sup>3</sup> Refugee Health Vancouver,<sup>4</sup> and Harborview Medical Center's EthnoMed website<sup>5</sup> are other sources

<sup>&</sup>lt;sup>2</sup> See http://www.culturalorientation.net/learning/backgrounders (accessed May 5, 2017).

<sup>&</sup>lt;sup>3</sup> See https://www.cdc.gov/immigrantrefugeehealth/profiles/index.html (accessed May 5, 2017).

<sup>&</sup>lt;sup>4</sup> See http://refugeehealth.ca (accessed May 5, 2017).

<sup>&</sup>lt;sup>5</sup> See https://ethnomed.org/culture (accessed May 5, 2017).

of information on immigrant, migrant, and refugee cultures that health systems should find useful, said Rooney.

Referring to Nick Nelson's presentation on trauma-informed care, Rooney provided a definition to make sure everyone understood this concept. A trauma-informed approach to care, she said, perceives trauma not simply as a past event, but as a formative one that may be contributing to the client's current state or circumstances. "To be trauma-informed is to understand clients and their symptoms in the context of their life experiences and cultures with an appreciation that some symptoms may represent efforts at coping," said Rooney. She added that trauma-informed care represents a shift from focusing on what is wrong at the particular clinical encounter with an individual to one that considers what happened in the past that brought a patient to that clinical encounter. "It recognizes trauma as an ongoing factor," she said, noting that up to 35 percent of refugees have experienced torture in their countries of origin. Beyond torture, immigrants, refugees, and migrants have experienced a loss of extended family and social networks. Many have also experienced difficult journeys to the United States and spent time in refugee camps, which she said are dangerous places, and in detention centers.

Rooney said she valued Nelson's comments that providers can have a humble, solicitous curiosity about their patients and that one of the biggest barriers to divulging social history is that the clinician never asked. She said that Nelson told her after his talk that he has a behavioral specialist in the room whenever he is taking a social history so that he has someone with a trained ear who can capture relevant information that he can use to build a care plan. She also seconded his call for medical education to incorporate trauma-informed care, noting that social workers and psychologists receive such training.

To her, training on trauma-informed care should include the following strategies:

- Creating a sense of safety in a predictable environment, something done routinely in mental health care. This includes communicating clearly about clinic locations and hours; building clean, orderly, calming spaces; developing clear policies on how to report abuse; setting aside quiet "time-out" spaces for patients who become agitated; and respecting client privacy and modesty. Clinics should also decide whether having visible security personnel is comforting or distressing to patients, and whether it is culturally appropriate to separate males and females.
- Being trustworthy and building a trusting relationship.

- Emphasizing and encouraging client choice to help patients have more control over their environment and life.
- Collaborating and taking a patient-centered approach that treats
  patients as the experts regarding their own health. This would
  include helping patients set goals and evaluate the services they
  receive.
- Empowering patients to understand how their past experiences might be informing what they are feeling physically and mentally and to help them focus on wellness instead of illness.

Addressing the subject of trauma-informed interpretation, Rooney said that the law requires having a qualified interpreter trained in medical interpretation available at no cost to the patient. By law, children and families may not interpret unless this is an immediate threat to the patient's safety and no qualified interpreters are available. In emergencies, Rooney has relied on an interpreter hotline as a last resort. Trauma-informed interpretation, she said, places an additional requirement that the interpreter acts as a cultural ambassador who contributes to a sense of safety and trust during the clinical encounter. In smaller communities, clients and interpreters may know each other, so it is important that the interpreters receive training on the need for strict confidentiality because stigma can be an important factor in a patient being reluctant to talk about past events.

When working with an interpreter, Rooney said it is important to learn the client's preferences and brief the interpreter before the clinical visit. Gender, for example, can be an issue, and her practice, for example, is to have an interpreter of the same gender as the patient whenever possible. Getting the same interpreter for every encounter with a given patient, particularly when mental health is an issue, is key, said Rooney, because it helps build an alliance that fosters trust and safety. Scheduling extra time is important because it often necessary to repeat messages through the interpreter and use methods such as teach-back to ensure the patient understands those messages. In addition, there needs to be time to introduce the interpreter and patient to one another and allow them to interact as part of the trust-building process.

Rooney recommended sitting in a triangle or circle during the clinical encounter so that everyone can see each other and for the clinician to look at the patient, not the interpreter, when speaking to the patient. She also recommended keeping sentences short, avoiding jargon, paying attention to body language, and to be prepared to redirect the conversation when necessary. Once the visit is over, clinicians should check in with the interpreter to hear any comments they may have and what they may have found confusing or distressing. As a final thought on this subject, she said that clinicians should be aware of what she called vicarious trauma. "Some interpreters

have also been through traumatic experiences, so it is nice to debrief the interpreter and check in to make sure that they are okay afterwards," said Rooney.

She noted several sources for obtaining translated health materials, including the National Library of Medicine,<sup>6</sup> EthnoMed,<sup>7</sup> and Health Information Translations,<sup>8</sup> and she stressed the particular importance of applying health literacy principles when working with immigrants, refugees, and migrants. While it may be obvious to use simple words, it is less obvious that even simple words may not translate as intended into another language or culture. The key concept, said Rooney, is to communicate in a way one's audience can understand the first time they read or hear it. She also recommended that providers focus on the three most important points they want to cover in a patient encounter and to prioritize need-to-know information over nice-to-know information. For example, for a patient with asthma, how to use an inhaler or avoid situations that might trigger an asthma attack would be need-to-know information. Telling the patient how many people in the United States have asthma would be nice-to-know information.

Teach-back, in addition to being a core health literacy principle, can also help patients have a great sense of control over their lives, said Rooney. "The fact that their provider wants to hear from them and wants to hear their opinion is just showing that they are valued and that their opinion matters," she explained. Teach-back can also help the provider remain aware of language barriers that could prevent someone from understanding or explaining a concept, and it can provide an opportunity to gauge a patient's cognitive ability and stress level. Providers should also remember to speak slowly, maintain a friendly tone of voice and a smile, and respect cultural norms around handshakes and hugs at the end of a clinical encounter. "All of this is to create a better kind of empathic, trusting relationship between provider and patient," said Rooney in closing.

<sup>&</sup>lt;sup>6</sup> See https://healthreach.nlm.nih.gov (accessed May 5, 2017).

<sup>&</sup>lt;sup>7</sup> See http://ethnomed.org/patient-education (accessed May 5, 2017).

<sup>&</sup>lt;sup>8</sup> See https://www.healthinfotranslations.org (accessed May 5, 2017).



6

### Where Do We Go from Here?<sup>1</sup>

Suzanne Bakken moderated the final panel discussion of the day that explored how the health care field can move forward and communicate about health with immigrants, refugees, and migrants. The panelists were Anthony Iton, senior vice president for healthy communities at The California Endowment; Clifford Coleman, assistant professor of family medicine at the Oregon Health & Science University; Iyanrick John, senior policy strategist at the Asian and Pacific Islander American Health Forum; and Hugo Morales, executive director and co-founder of Radio Bilingüe.

Bakken began the discussion by asking the panelists for their ideas on the key things that health practitioners need to know about communicating with immigrants, refugees, and migrants. Coleman, a family physician, began by noting that this workshop would have been unnecessary if health care providers were providing clear communication as the default. In his opinion, the gap between the level at which health information is presented and the level that these populations can understand is so large that addressing this problem requires looking at everything health professionals do, the way they work, and the way they craft and present messages. As a result, there is no quick answer to this problem, he said, but the first thing that has

<sup>&</sup>lt;sup>1</sup> This section is based on the comments by Anthony Iton, senior vice president for healthy communities at The California Endowment; Clifford Coleman, assistant professor of family medicine at the Oregon Health & Science University; Iyanrick John, senior policy strategist at the Asian and Pacific Islander American Health Forum; and Hugo Morales, executive director and co-founder of Radio Bilingüe, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

to happen is for the health care community to open its eyes and be aware of the problem. All health care professionals, he said, need broad-based awareness raising, and he suggested that if advocacy communities were to take on this task, it would create a real potential to improve lives through changes in communication practices.

John replied by first explaining that the nonprofit Asian and Pacific Islander American Health Forum is a national health policy and advocacy organization that works directly with community-based organizations nationwide. "We see ourselves as an intermediary," said John. "We try to bring the experiences and voices that we hear from the community to the federal government and engage in advocacy to address the issues these communities are facing on the ground." For example, his organization has been pointing out the challenges that the Asian and Pacific Islander community has faced enrolling in health insurance marketplaces because of limited English proficiency and lack of knowledge about insurance among immigrants. Both he and Coleman then noted the importance of trust and engagement as the first step in health literacy.

### WHAT SYSTEMIC CHANGES ARE NEEDED?

Bakken then asked the panelists to comment on any systemic changes they feel are needed to improve communication with immigrants, refugees, and migrants. Iton responded by first explaining that The California Endowment is in the midst of a 10-year, \$1 billion initiative, called Building Healthy Communities, to address health disparities in 14 low-income California communities populated disproportionately by recent immigrants, refugees, and first- and second-generation residents of the United States. The initiative's one caveat is that it is not spending any money on health care itself. Rather, it focuses entirely on the social determinants of health. In his opinion, Bakken's question assumes that the health care system needs people to be more health literate in order for the health care system to do what the health care system wants to do to people. He argues the opposite, which is that communities have a good sense of what they need to be healthy, and what they need is for the health care system, the education system, the criminal justice system, and the land use system to cooperate in facilitating their access to health protective services. "It may be that some of these systems are not as literate as they ought to be about the needs of these populations," said Iton.

With respect to the 14 communities his program works with, building trust and agency, both at the community and individual level, is an important strategy for enabling people to feel they have some control over the things that are happening to them on a day-to-day basis. "Most of what we recognize as the root cause of chronic disease is a sense of allostasis or

allostatic load, where people feel chronically stressed out and lacking control or lacking access to critical resources that they need to be able to pursue healthy lives," said Iton. This approach, he explains, focuses on allowing people to tell the stories of how they got to where they are today and hear the stories of others in their community who are also trying to navigate in their foreign, and often new, environment. Even for people who have been in the United States for multiple generations, the institutions they come in contact with can still be foreign. "They use acronyms and they have their preferred ways of communicating to people. They have eligibility criteria that you either meet or you do not meet, and if you do not meet them, then you are basically turned away and told that you are not worthy or deserving or sick enough yet," said Iton. Allowing people to see that others are in the same situation as they are, even if they speak a different language or come from a different culture, is critical, he said, to facilitating a sense of belonging and value, that their perspectives and experiences matter. "We are trying to help some of the institutions that we work with to appreciate that aspect of storytelling as a way of facilitating trust between institutions and populations," he said.

Morales, who said he emigrated from Oaxaca, Mexico, when he was 9 years old and grew up as a farm worker before going to college, explained that the nonprofit community radio network he founded to facilitate communication among Spanish-speaking immigrant, refugee, and migrant populations, owns and operates 12 full-power FM stations in Arizona, California, Colorado, New Mexico, and south Texas. One message that he heard several times during the workshop, and one he wanted to reiterate, was not to underestimate the anti-immigrant sentiments that exist today. In his opinion, the focus should be on helping immigrants build their own institutions and support authentic community media opportunities, two activities The California Endowment's initiative is enabling.

"We should be building capacity to address the integration of immigrants through local and regional collaboratives of service providers, immigrant advocates, and legal services," said Morales. Capacity building, he added, should include creating a positive culture within the immigrant community that includes a positive culture on health drawn from the positive elements of traditional immigrant cultures. In his opinion, capacity building should support traditional arts, immigrant native languages, and multilingualism, all of which are important for the mental health of individuals, families, and communities. In communities with low literacy levels, it is particularly important to identify trusted immigrant messengers. "Even though their formal education may be very low—they may be illiterate—but they may be the most trusted person or leader in their community," said Morales.

John explained that the community-based organizations he works with

are not community health centers. Rather, they are smaller communitybased organizations that provide a variety of different types of services to the Asian and Pacific Islander population across the country. For example, he works with small organizations serving the community of immigrants from the Marshall Islands in Arkansas and from Tonga in Salt Lake City. These organizations provide services such as job placement, help with small business issues, and financial literacy, not just health care services. A major project his organization undertook was to create the Action for Health Justice Network, which Jeffrey Caballero discussed in his presentation, to assist those with limited English proficiency to enroll in Patient Protection and Affordable Care Act (ACA) coverage. "Through that experience, we really saw how the in-person assistance from these community-based organizations was key to helping people enroll in coverage," said John. When it comes to finding partners, he follows the slogan, "where people live, work, play, and pray," to identify the organizations who are trusted sources of information in the community. Going forward, he said, it will be important to find partners that can provide financial and logistical support for these small, community-based organizations. His organization, for example, provides grant writing training to help them build their capacities and grow.

Currently, many of the activities his organization and other community-based organizations engage in, such as the development of the glossary of health insurance terms Caballero mentioned, have no adequate financial support and depend on volunteers. The glossaries, for example, depended on an intensive community review process to ensure they were user-friendly and understandable. In his opinion, one way to support these community-based organizations would be to integrate them into the health care delivery system as a means of providing these types of services to these communities.

Coleman said that while raising awareness is an important first step along a pathway to changing the way health information is presented, shared, and made actionable by health care providers, the research evidence is "bleak in terms of our ability to change people's behavior once they are out in practice." His institution has conducted a series of studies trying to figure out how to teach its medical students and residents to be the agents of change and do the right thing regarding health literate communication once they get out into practice. Unfortunately, he said, the results of these efforts have shown that an increased awareness and changed attitudes toward communicating better do not necessarily translate into more health-literate communications with their patients because they see the way their preceptors and faculty talk to patients and they slip right into those older practices.

Given these results, Coleman is taking a different approach, which is to teach his students four core habits they will demonstrate consistently even when they think no one is looking. These habits include building relationships by spending 30 seconds of their time sitting down with patients, engaging them, making eye contact, speaking slowly, and getting the computer out of way. "We are teaching our students that 30 seconds of time, of undivided attention, sets up a successful visit," said Coleman. The second habit the students develop is to set an agenda to find out what truly concerns the individual in front of them rather than focusing on the first complaint they hear. "Studies show that about 50 percent of the time, the average patient walking into a primary care office will not mention their main concern first, but will mention something else," he explained.

The third habit he is trying to instill from the beginning of his students' education is to use plain language in spite of the pressure students feel to use "medicalese," the new language they are learning and that many other faculty members expect them to use. This is an emerging area of inquiry, he said, and one he and some of his colleagues believe will prove useful. The fourth habit is to use teach-back to check understanding. "Teaching these four core habits is going to be our attempt at changing the system from the learner up," said Coleman. The goal, he added in response to a question from Iton, is to demonstrate to faculty that the communication style engendered by these habits produces higher quality care.

### WHO SHOULD BE AT THE TABLE?

When Bakken asked the panelists to discuss who needs to be included in change efforts and how to entice them to participate, Iton responded that changing outcomes requires changing the power dynamics in the interactions between institutions and communities. In his experience, "the status quo is the product of a power dynamic that needs to be disrupted," he said. "The way you disrupt that is to develop meaningful incentives and meaningful accountability measures." The California Endowment, he said, supports community health by helping communities develop the power to challenge institutions and hold them accountable. His simple answer to Bakken's question, then, is to develop meaningful incentives for institutions to behave in a way that correlates with higher quality outcomes and accountability measures to "hold these institutions' feet to the fire." Faculty access to bonus pools, he suggested, could require meeting certain thresholds in terms of their communication skills. Morales agreed and said the client base needs to be included in developing accountability measures and assessing outcomes. He noted, though, that it is important to do so in partnership with community-serving institutions that are both able and willing to participate and predisposed to collaboration.

Since cost is going to be a major driver of efforts to better integrate community-based organizations into the health care system, John suggested that health economists need to be at the table. "We know that we can get better culturally and linguistically appropriate care when we involve community-based organizations in helping the limited English proficient and immigrants navigate the health care system, but what does that mean, in terms of cost savings? If we can show that evidence, would insurers and others be more willing to kind of engage in these partnerships?" asked John.

Coleman also agreed that incentivizing "good behavior" is the approach most likely to work, and he cited The Joint Commission's incentive programs for creating change where change was difficult. "I think The Joint Commission could do a good job, for example, of holding institutions to the Culturally and Linguistically Appropriate Services standards," said Coleman. In the same way, he suggested that certifying organizations, such as the one that oversees the U.S. Medical Licensing Examination, could incorporate these types of standards into their testing and certifying programs. "I think there is some interest in that area, but there are many competing demands," he said.

#### WHAT RESOURCES ARE NEEDED?

When Bakken asked about the types of resources needed to make some of these changes, Coleman replied, "the easiest answer is money, but the more important one is will." Going back to his first comments about the importance of raising awareness, he noted that this workshop highlighted many good examples of approaches and programs that work. The next step, he said, should be to raise awareness of these programs and tap into the will of those organizations who see the value of these approaches and of applying health literacy as a tool to improve outcomes for these populations. In his view, health literacy is like a handle that fits on any machine. "Whatever your problem is that you want to fix, you can take health literacy and apply it to that issue. You can generate improvements that way," said Coleman. The problem, he added, is that not enough people realize how broadly useful health literacy can be.

Morales agreed that will is important, as is the kind of education the nation provides to its citizens. In his opinion, the nation should invest in bilingual education as a means of creating a workforce that communicates better. A more diverse faculty at our nation's universities and colleges would help, too.

### **DISCUSSION**

Alicia Fernandez began the open discussion period by noting that even in San Francisco, a sanctuary city where both the mayor and city council have issued statements supporting immigrants and undocumented individuals, there is a crisis of fear. Though she acknowledged that it is still unclear as to whether there have been more anti-immigrant raids than there were prior to the new federal administration taking office, she is hearing more anecdotal reports of immigrants being apprehended and of families living in fear and not seeking medical care or in some cases even not sending their children to school. Given this situation, she asked the panelists if their organizations had discussed this situation and if they had come up with ideas for combating this crisis of fear. Iton said that The California Endowment is a health foundation that gives money to support building healthy communities. In this current climate, however, The California Endowment decided to provide funds to defend the rights of people to remain in the United States. Its mechanism for doing so is its \$25 million Fight for All Fund, which has the following basic elements:

- Defend the ACA and other pieces of national policy that protect immigrants, including the Deferred Action for Childhood Arrivals and Deferred Action for Parents of Americans programs.
- Work directly with threatened populations, including Muslim communities, undocumented individuals, the transgender community, groups such as Black Lives Matter that are pushing against the militarization of the police, and to some extent women in rural areas needing reproductive health services. This effort provides lawyers, advocates, and works to protect various forms of sanctuary.
- Advocate to support local policies within California that create equity and opportunity for highly vulnerable populations.
- Be proactive about recognizing that California has a different narrative than much of the rest of the country, one of inclusion that recognizes that human capital cannot be wasted if the nation is to thrive in the 21st century.

"We recognize there is a movement afoot in California that needs to be bolstered, one of environmental justice, climate justice, social justice in general, and health equity," said Iton. "There are a number of different efforts that are happening around this state that need to be brought together around a narrative of California's future that is taking us into the 21st century by utilizing all of our assets and investing in all of us." He noted, however, that at a recent meeting he attended with representatives from other foundations, there was a discussion about how many of the programs that support the desired changes are on the chopping block, prompting a general feeling of despair. He asked his fellow foundation representative to multiply that despair by a factor of 100 and know that is what people living in immigrant, refugee, and migrant communities are feeling every day. "That has profound direct health impacts on cortisol and

stress levels. It can change people's physiology, change their genetic expression," said Iton. "All of this is happening right now because of policy or in many cases in the absence of policy in the face of abject need. We have to be attentive to that."

Morales, whose organization has received some of those California Endowment funds, referred to his earlier comment about the need to empower the immigrant community. Toward that end, he and his colleagues are getting families to form support networks in their communities and teaching them how to stand up for their rights. He noted that not all members of the Latino community are poor, and it needs to come together and exercise its economic and political clout. As an example, he recounted how the president of the American Academy of Pediatrics was a recent guest on one of his network's radio shows. He told about his recent visit to one of the detention centers for refugees from Latin America and described a warehouse scene in which the lights are never turned off and in which children age 5 and older are kept separate from their parents. He also described how these children, who would ordinarily be playing and enjoying themselves, were just sitting still, motionless. "This is the power of the media," said Morales. "This is a voice that probably half a million Latinos are hearing. These are the kind of stories that need to get out and hopefully will get into the mainstream media."

Coleman, expanding on the issue of fear, noted there are 40 million Americans who are afraid of losing their health care. In Oregon, where Medicaid expansion brought the state's uninsured rate down to 5 percent, he is seeing patients daily who are afraid they will not be able to see him anymore. "I just want to make sure we are thinking broadly," said Coleman.

Changing the subject, Jennifer Dillaha said that she and Michael Villaire held a webinar for the California Immunization Coalition on health literacy and cultural competency. In preparing for this webinar, she reviewed the literature on immunizations and cultural competency and was struck by one study showing that the highest rates of immunization correlated with whether staff in the health department demonstrated cultural humility. "I think of cultural humility as being the mirror image of cultural competency, where cultural competency is for the people you are working with and cultural humility is your understanding of your own culture and its impact on your interactions," said Dillaha. She asked Rooney and the rest of the panelists if they could comment on any efforts at training for cultural humility. Rooney said that cultural humility is important because it is difficult, if not impossible, to truly understand everything about another person's culture. "To me, humility is a piece of any type of cultural training or discussions you are having. I think we should all be culturally sensitive, aware, and humble," said Rooney. She said there are many trainings that stress being

aware of that fact and to be open and sensitive to what people are hearing from their patients.

Coleman, responding from his perspective as an educator, said that when asking students questions related to cultural humility or egalitarian values, they all espouse the same altruistic, affirming attitudes and opinion. In practice, though, implicit bias gets in the way and these same students do not follow through in their actions. "We don't talk much about cultural competency because it does not get us anywhere," said Coleman. His institution's approach was to focus on culturally responsive care by developing a curriculum that invests heavily in having students understand, recognize, and own their implicit bias using the implicit association test<sup>2</sup> developed at Harvard University. This validated, online tool measures differences in response times to differences in pictures, and it gets quickly to what a person has learned over time and where they have opinions that may not be willing or able to recognize explicitly, he said.

Lindsey Robinson, 13th District Trustee for the American Dental Association, commented on the efforts going on around the country to integrate oral health into overall health and she asked the panelists is they knew of community-level efforts along those lines. Morales replied that many immigrant cultures dismiss dental care because it is not part of their routine or culture. He, for example, did not see a dentist until he was 34 years old and needed treatment for an infection, even though he had access to free dental coverage when he was in college and graduate school. Access may be an issue, he said, but awareness is the bigger problem for many cultures and he suggested turning to ethnic media to reach these populations and inform them about what dental care means to their overall health.

The final question of the day came from Ruth Parker, who asked the panelists if they had any suggestions for the roundtable specific to health literacy. In his response, John wondered if the roundtable could serve as a clearinghouse of best practices from different parts of the countries. He also suggested that the roundtable should connect with organizations such as his that work with large networks of community-based organizations as a way of sharing health literacy best practices more broadly.

Iton replied that questions about health literacy presume the relationship between institutions and individuals is based on the institutions being experts and individuals as "waiting supplicants to have knowledge disgorged into their beaks." In his opinion, that frame reinforces community disempowerment. "There has to be a resetting of the assumption that the problem is that a community is not literate and instead think about how literate these institutions are regarding the real needs of communities and

 $<sup>^2</sup>$  The test can be found at https://implicit.harvard.edu/implicit/takeatest.html (accessed June 5, 2017).

the real expertise of communities," said Iton. His hope was that the roundtable could help reset that dynamic so that communities can help institutions understand how illiterate the institutions are regarding the needs of community members.

Coleman said he agreed with Iton wholeheartedly. He then added that the way the U.S. health profession educational environment feels to him right now is that it will take the rest of his career, if not forever, to move institutions to change the way they train professionals on how to talk and listen to their patients. In his opinion, the way to create the demand to make change happen more quickly is to influence organizing bodies and accrediting agencies, and he said he believes that the roundtable, if anybody, has the potential to exert that type of influence.

Bernard Rosof concluded the workshop by noting that he and several colleagues published a paper that appeared online in January 2017 (Egener et al., 2017) on the responsibility of academic and other health care organizations to maintain professionalism in their communities, with community partnerships being one of the four pillars to meet those responsibilities. Given the discussions of the day, and particularly those highlighting the fear in which immigrant, refugee, and migrant communities are experiencing today, Rosof said this responsibility is even more relevant. In his opinion, the roundtable needs to be more timely, comprehensive, and responsive to community needs. "It is not that we have not been before, but this to me seems more urgent and powerful," said Rosof in closing.

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## Appendix A

## Workshop Agenda

Facilitating Health Communication with Immigrant, Refugee, and Migrant Populations Through the Use of Health Literate Approaches: A Workshop

> March 15, 2017 East Bay Community Foundation Oakland, CA

8:30-8:45 Welcome, Introduction, and Workshop Overview Bernard Rosof, M.D., MACP

8:45-9:45 Panel: Issues and Challenges

Moderator: Alicia Fernandez, M.D., Professor of Clinical Medicine, University of California, San Francisco Panelists:

- Paul Geltman, M.D., M.P.H., Medical Director of Ambulatory Care Services, Franciscan Children's Hospital
- Jeffrey B. Caballero, M.P.H., Executive Director, Association of Asian Pacific Community Health Organizations
- Henry R. Perea, M.P.A., Former Member Board of Supervisors, County of Fresno

9:45-10:15 Discussion

10:15-10:30 BREAK

74	FACILITATING HEALTH COMMUNICATION
10:30-11:35	Panel Accessing and Using Health Care Services
10:30-10:35	Introduction of Panel Speakers
10:35-10:50	Delivering Trauma-Informed Care Nick Nelson, M.D., Highland Hospital Human Rights Clinic
10:50-11:05	Establishing Trust to Bring Individuals into Primary Care Jesús E. Quiñones, Guides for Understanding Information and Access Program Coordinator, Casa de Salud
11:05-11:20	Innovative Access Points Customized for Newly Arrived Populations Julia Liou, M.P.H., Asian Health Services, Healthy Nail Salon Collaborative
11:20-11:35	Medicines: Workshops for Refugees and Immigrants Kari LaScala, J.D., Health Communication Specialist, Wisconsin Health Literacy
11:35-12:00	Discussion
12:00-1:30	LUNCH
1:30-2:35	Panel: Health Literacy Considerations for Outreach
1:30-1:35	Introduction of Panel Speakers
1:35-1:50	Language Access: Using Health Concepts and Health Literacy in the Teaching of English Maricel Santos, Ed.D., Associate Professor, San Francisco State University
1:50-2:05	Messaging for Disasters and Emergency Preparedness Justine Kozo, M.P.H., Chief, Office of Border Health, San Diego Health and Human Services Agency
2:05-2:20	Outreach to Uninsured Foreign-Born Populations Rishi Sood, M.P.H., Director of Policy and Immigrant Initiatives New York City Department of Health and Mental Hygiene

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2:20-2:35	Strategies for Identifying and Working with Trusted Advisors/Decision Makers Mimi Kiser, D.Min., M.P.H., RN, Program Director, Interfaith Health Program, Rollins School of Public Health
2:35-3:15	Discussion
3:15-3:30	BREAK
3:30-4:00	Application of Health Literacy to Communication with Immigrants, Refugees, and Migrants Megan Rooney, M.S.W., M.Ed., Director of Program Development, Health Literacy Media
4:00-5:00	<ul> <li>Panel: A Moderated Discussion: Where Do We Go from Here?</li> <li>Moderator: Suzanne Bakken, RN, Ph.D., Professor of Biomedical Informatics, Columbia University</li> <li>Panelists: <ul> <li>Anthony Iton, M.D., J.D., M.P.H., Senior Vice President for Healthy Communities, The California Endowment</li> <li>Liliana Osorio, Deputy Director of Health Initiative of the Americas, University of California, Berkeley, School of Public Health</li> <li>Clifford Coleman, M.D., M.P.H., Assistant Professor of Family Medicine, Oregon Health &amp; Science University</li> <li>Iyanrick John, J.D., M.P.H., Senior Policy Strategist, Asian and Pacific Islander American Health Forum</li> <li>Hugo Morales, J.D., Executive Director and Co-Founder, Radio Bilingüe</li> </ul> </li> </ul>
5:00-5:30	Discussion
5:30	Closing Remarks and Adjourn



## Appendix B

# Biographical Sketches of Moderators, Speakers, and Panelists

Suzanne Bakken, RN, Ph.D., is the Alumni Professor of Nursing and Professor of Biomedical Informatics at Columbia University. Following doctoral study in nursing at the University of California, San Francisco, she completed a National Library of Medicine postdoctoral fellowship in Medical Informatics at Stanford University. The goal of Dr. Bakken's program of research is to promote health and reduce health disparities in underserved populations through the application of innovative informatics methods. A major focus of her current grant portfolio is visualization of healthcare data for community members, patients, clinicians, and community-based organizations. Dr. Bakken currently directs the Center for Evidence-based Practice in the Underserved and the Reducing Health Disparities Through Informatics (RHeaDI) predoctoral and postdoctoral training program; both funded by the National Institute of Nursing Research (NINR). She also served as Principal Investigator of the Agency for Healthcare Research and Quality-funded Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) and its follow-up study, WICER 4 U, which is focused on promoting the use of WICER infrastructure through stakeholder engagement. She has also received funding from the National Cancer Institute, National Library of Medicine, and the Health Resources and Services Administration. Dr. Bakken has published more than 200 peer-reviewed papers. In 2010, she received the Pathfinder Award from the Friends of the National Institute of Nursing Research. She is an elected fellow of The New York Academy of Medicine, American Academy of Nursing, American College of Medical Informatics, and a member of the National Academy of Medicine.

Jeffrey B. Caballero, M.P.H., is the Association of Asian Pacific Community Health Organizations' (AAPCHO's) Executive Director and has been with the organization since 1993. In this capacity, Mr. Caballero advocates for programs and policies that increase access to high-quality, comprehensive community health care services that are culturally and linguistically appropriate. He has overall authority for all AAPCHO programs, finances, and operations and serves as chief spokesperson for the organization. Mr. Caballero participates on numerous national committees that address issues affecting Asian Americans, Native Hawaiians, and other Pacific Islanders, such as tuberculosis, hepatitis B, diabetes, and cancer. His work experience encompasses a variety of fields, from grassroots organizing and health education to bone marrow transplant and primary health care. He has played leading roles in the development of several national plans to reduce health disparities, including Eliminating Hepatitis B in Asian Pacific Islander Communities, Utilization of Health Information Technology to Eliminate Health Disparities, and Development of Patient Centered Medical Homes. Recently, Mr. Caballero was a featured speaker on the topic of health care reform at the 2009 California Hepatitis Alliance meeting and also spoke at the U.S. Department of Health and Human Services Office of Minority Health's 2009 World Hepatitis Day in Washington, DC. In addition to his work for AAPCHO, Mr. Caballero now serves as Vice-Chair of the National Viral Hepatitis Roundtable, Board-Elect of the American Diabetes Association and is a member of the National Diabetes Education Program's executive committee. Mr. Caballero received his bachelor's degree in Biochemistry/Cell Biology from the University of California, San Diego, and his Master's of Public Health from the University of California, Los Angeles.

Clifford Coleman, M.D., M.P.H., is a national expert in the field of health literacy. His research and teaching focuses on improving health literacy and clear communication training for health care professionals. In 2010 he was the principle investigator on a national consensus study to identify a comprehensive set of health literacy educational competencies for health care professionals. Dr. Coleman is a practicing physician and faculty member at the Oregon Health & Science University (OHSU) School of Medicine, where he is responsible for the curriculum on health communication, professionalism, and ethics. At OHSU in 2014, he developed and implemented the first known health professions curriculum which integrates health literacy teaching as a running thread throughout the pre-clinical training years. Other interests include improving medical education for culturally responsive care. Dr. Coleman is an Assistant Professor in the Department of Family Medicine at OHSU, where his clinical interests include health care for medically complex individuals and underserved populations. He has a

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bachelor's degree in psychology from Dartmouth College, and a Doctorate of Medicine from Stanford University. He completed a dual residency in Family Medicine and Public Health & Preventive Medicine at OHSU, with a Master's of Public Health from Portland State University in 2004. Dr. Coleman was born in Oregon, and identifies as biracial: African American and white.

Alicia Fernandez, M.D., is a professor of clinical medicine at the University of California, San Francisco, and an attending physician in the General Medical Clinic and the Medical Wards at San Francisco General Hospital. Her research primarily focuses on health and health care disparities, and she is particularly interested in vulnerable populations, Latino health, immigrant health, and language barriers. In addition to her research and clinical practice at San Francisco General Hospital, she does a great deal of mentoring for students, residents, fellows, and faculty. She has received several honors and awards, including the Arnold P. Gold Professorship for Humanism in Medicine. She has served as an advisor to the Robert Wood Johnson Foundation, The California Endowment, the National Quality Forum, The Commonwealth Fund, the American Medical Association, the American Board of Internal Medicine, and other organizations on projects focused on health care disparities, Latino health, and limited English proficiency populations. She was a standing member of the Agency for Healthcare Research and Quality Health Care Quality and Effectiveness study section (2006-2010) and is currently a member of the National Institutes of Heath's Health Services Organization and Delivery study section.

Paul Geltman, M.D., M.P.H., has more than 25 years of experience as a physician. Over that time, he has become a nationally recognized public health expert on immigrant and refugee issues. He is the long-standing medical director for refugee and immigrant health in the Division of Global Populations and Infectious Disease Prevention at the Massachusetts Department of Public Health. Dr. Geltman has worked in clinical, policy, and public health settings with refugee populations resettled in Massachusetts as well as in Rwanda. He practices primary care pediatrics and serves as medical director and vice president for ambulatory care services at Franciscan Children's in Brighton, Massachusetts. Dr. Geltman is a graduate of Princeton University and received his M.D. and M.P.H. degrees from the George Washington University School of Medicine and Health Sciences. After his pediatric residency at the Floating Hospital for Children in Boston, he completed a postdoctoral academic fellowship in child advocacy and community pediatrics, with a focus on immigrant and refugee children, at Boston Medical Center (then Boston City Hospital). His academic work has produced wide-ranging publications including the most extensive report on lead poisoning among refugee children in the United States and a ground-breaking, nationwide study of the functional and behavioral health status of the unaccompanied refugee minors known commonly as the "Lost Boys" of Sudan. Most recently he has concluded a major research grant from the National Institute of Dental and Craniofacial Research that supported the largest study ever conducted of the relationships among health literacy, English language skills, acculturation, and health status of a U.S. refugee population.

Anthony Iton, M.D., J.D., M.P.H., is senior vice president for healthy communities at The California Endowment. In the fall of 2009, he began to oversee the organization's 10-year, multimillion-dollar statewide commitment to advance policies and forge partnerships to build healthy communities and a healthy California. Dr. Iton serves on the board of directors of the Public Health Institute, the Public Health Trust, the Prevention Institute, and Jobs For The Future. In the past, he has served as both the director and County Health Officer for the Alameda County Public Health Department. In that role, he oversaw the creation of an innovative public health practice designed to eliminate health disparities by tackling the root causes of poor health that limit quality of life and lifespan in many of California's lowincome communities. He has worked as an HIV disability rights attorney at the Berkeley Community Law Center, a health care policy analyst with Consumers Union West Coast Regional Office, and as a physician and advocate for the homeless at the San Francisco Public Health Department. Dr. Iton's primary focus includes health of disadvantaged populations and the contributions of race, class, wealth, education, geography, and employment to health status. His awards include the Champion of Children Award from the United Way and the National Association of City and County Health Officials Award of Excellence for the use of information technology in public health. In February 2010, Dr. Iton was recognized by the California Legislative Black Caucus with the Black History Month Legends Award and presented on the floor of the California State Assembly with a resolution memorializing his life's work and achievements.

Iyanrick John, J.D., M.P.H., is the senior policy strategist for the Asian & Pacific Islander American Health Forum (APIAHF), a national health justice organization focused on improving the health and well-being of Asian Americans, Native Hawaiians, and Pacific Islanders living in the United States and its territories. He assists with APIAHF's health policy and advocacy efforts on issues related to health care access, language barriers, the collection and reporting of disaggregated data, and other health equity initiatives. He also helps to guide the intermediate and long-term policy and program strategy for the organization. Prior to working at APIAHF,

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Mr. John worked as a policy analyst for the Maryland Office of Minority Health and Health Disparities at the Department of Health and Mental Hygiene and as a research consultant for the Loma Linda University School of Public Health in southern California. Mr. John holds a J.D. from the University of Maryland School of Law, an M.P.H. in Epidemiology from the Loma Linda University School of Public Health, and a B.S. in Biology from Washington Adventist University in Takoma Park, Maryland.

Mimi Kiser, D.Min., M.P.H., RN, has been with the Interfaith Health Program (IHP) since 1993, after a first career as a community health nurse. She cut her teeth in faith and health working with Dr. Tom Droege at The Carter Center in the early years of Atlanta Interfaith Health taking on the responsibility of coordinating program planning and evaluation using a participatory approach. For 5 years she worked with Dr. David Hilton, facilitating Training for Transformation workshops in health ministry and public health settings. Dr. Kiser has taught "Health as Social Justice" and "Faith and Health: Transforming Communities" for Emory public health, nursing, and theology graduate students for a number of years. She is currently chair of Emory's Religion and Health Collaborative Academic Programs Working Group. Through her leadership, IHP and Emory's new collaborative are contributing innovative education and training models to the faith and health movement. IHP was supported by the Centers for Disease Control and Prevention, most recently directing the Institute for Public Health and Faith Collaborations. The Institute has ignited the work of 78 collaboratives in 24 states aimed at the elimination of health disparities. Dr. Kiser has contributed nationally to building the capacity of health groups to form collaborative relationships with the faith community, specifically through networks such as the American Public Health Association's Caucus on Public Health and the Faith Community, the Coalition for Healthier Cities and Communities' Faith Action Team, and the Health Ministries Association. Her on-the-ground work took on new dimensions when she took on part time work from 1996 to 2001 as coordinator of Parish Health Ministry for St. Luke's Episcopal Church. She is currently chair of Emory's Religion and Health Collaborative Academic Programs Working Group. Through her leadership, IHP and Emory's new collaborative are contributing innovative education and training models to the faith and health movement. Dr. Kiser earned her doctorate in ministry in Faith and the Health of Communities at Wesley Seminary in Washington, DC.

Justine Kozo, M.P.H., serves as the Office of Border Health Chief for the County of San Diego, Health and Human Services Agency, where she facilitates collaborative activities among organizations working in the California/Baja California border region. In her role, she participates on numer-

ous projects ranging from health education to research, encompassing a broad range of topics from emergency preparedness to infectious disease prevention. One of Ms. Kozo's main projects involves working with the Office of Emergency Services and other County departments on an effort to improve communication with limited English proficient populations during public health emergencies and natural disasters. Prior to working for the County of San Diego, Ms. Kozo worked at the University of California, San Diego, and San Diego State University for 8 years in various public health roles, including managing community-based, binational (San Diego-Tijuana) research studies. She earned her master's degree in public health with an emphasis in health promotion, from San Diego State University in 2006. Ms. Kozo has co-authored several manuscripts addressing topics including HIV research in the San Diego-Tijuana border region and border health in general.

Kari LaScala, J.D., is a health communications specialist with Wisconsin Health Literacy (WHL), a division of Wisconsin Literacy, Inc. WHL plays an instrumental role in planning, writing, testing, implementing, and managing health literacy interventions for various at-risk populations in Wisconsin. While practicing law in Chicago, much of her work was focused on helping at-risk populations; specifically, she worked at a domestic violence clinic representing low-income victims of domestic violence in protective orders and divorces against their abusers. Prior to joining WHL, she worked at the Waunakee Public Library where she organized and implemented a majority of the programming for adult patrons. As a freelance writer, she also penned articles for the *Waunakee Tribune* and other local newspapers. Ms. LaScala holds a B.A. in journalism and psychology from Northern Illinois University and a J.D. from Northern Illinois University College of Law.

Julia Liou, M.P.H., is the director of program planning and development at Asian Health Services (AHS). Ms. Liou oversees fundraising, program planning, grants, and manages various community projects. She co-founded and manages the California Healthy Nail Salon Collaborative, a statewide coalition effort to address the health and safety issues nail salon employees and community members face in their work environment.

Hugo Morales, J.D., is the executive director and co-founder of Radio Bilingüe, the National Latino Public Radio network. In 1976, Mr. Morales and an all-volunteer staff of farmworkers, teachers, students, and artists founded Radio Bilingüe, which, on July 4, 1980, began broadcasting over the entire San Joaquin Valley, California. At the time, Mr. Morales, a graduate of Harvard College and Harvard Law School, was an adjunct lecturer of La Raza Studies at California State University, Fresno. Ever since then,

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Mr. Morales has been executive director of Radio Bilingüe and a pioneer and advocate for bilingual and minority-controlled public media throughout the country. Radio Bilingüe is now a national satellite community radio service in Spanish, English, Triqui, and Mixteco that serves Latino radio audiences throughout the United States and Mexico, with live 24/7 streaming service online. It has its headquarters in Fresno, regional offices in Salinas and El Centro, and national production studios in Oakland, California. Radio Bilingüe has 15 FM radio stations (113 full power FM stations and 2 FM repeaters): 8 in California, 3 in New Mexico, 1 in Colorado, and 1 in Arizona. Radio Bilingüe is the recognized Spanish-language radio service for the public radio system in the United States. It serves more than half a million listeners with Linea Abierta, its pioneering daily Spanish-language national talk show, Noticiero Latino, its independently produced news service, and its rainbow of Spanish-language traditional folk music for its national Latino audiences broadcast on its 24-hour satellite programming service used by affiliates throughout the country. The entire 24-hour daily operation is totally devoted to public service. Mr. Morales is a Mixtec Indian from Oaxaca, Mexico. At the age of 9, his family immigrated to Sonoma County, California, where he grew up in a migrant labor camp. After attending public schools and serving as his high school student body president, he graduated from Harvard College and Harvard Law School in 1972 and 1975, respectively. In 1994, Mr. Morales became the first resident of the San Joaquin Valley to be a recipient of a MacArthur Foundation Fellowship. In 1999, the Corporation for Public Broadcasting honored him with the Edward R. Murrow Award, public radio's highest distinction. In 2006, Mr. Morales received the Cultural Freedom Prize from the Lannan Foundation, established "to recognize people whose extraordinary and courageous work celebrates the human right to freedom of imagination, inquiry, and expression." Mr. Morales is fluently bilingual in English and Spanish and is a student of French and Portuguese.

Nick Nelson, M.D., studied Classics and Religion at Reed College and Wadham College before attending medical school at St. George's Hospital in London. He undertook postgraduate training in Internal Medicine at Highland Hospital in Oakland, California, where he served as an intern, resident, and chief resident before joining the faculty in 2012. Since that time he has directed the Highland Hospital Human Rights Clinic (HRC), which serves asylum seekers and refugees residing in Alameda County. The HRC has grown from a single doctor in 2012 to include two general internists, a doctor of psychology, and two nurse practitioners. The clinic has a dual mission: to provide trauma-informed primary care for victims of torture and other forms of abuse residing in Alameda County; and to document human rights abuses through forensic medical and psychologi-

cal evaluations for people seeking asylum in the United States. Since 2012, HRC clinicians have performed more than 150 forensic evaluations and testified on behalf of asylum seekers in many cases before Federal Immigration Courts. The clinic's service to traumatized refugees was recognized in 2015 when it won an Exemplary Health Partner award from the International Rescue Committee. In addition to directing the HRC, Dr. Nelson also serves as an associate program director in Highland's Internal Medicine Residency Program.

Liliana Osorio is the deputy director of the Health Initiative of the Americas (HIA) at the School of Public Health, University of California, Berkeley. Since joining HIA in 2002, Ms. Osorio has led and collaborated in several projects, including the coordination of the annual Binational Health Week, one of the largest mobilization efforts in the Americas to improve the wellbeing of Latino immigrants. Other projects include the Binational Policy Forum on Migration and Public Health, the Summer Institute on Migration and Global Health, the Research Program in Migration and Health, and the Binational Promotores Program. She has managed several statewide campaigns targeting Spanish-speaking Latinos, including the "H1N1 Influenza Outreach and Education Campaign to Reach the Hard-to-Reach Latinos in California" and a 2-year campaign to educate and refer Latinos to enroll in health insurance through California Covered. Ms. Osorio is the editor of four editions of the English-Spanish Dictionary of Health Related Terms. She has also collaborated in the development of several other publications, including educational manuals for community health workers and fact sheets on migrant health issues. Ms. Osorio received her bachelor's degree in social communication and journalism in Colombia, and currently is pursuing a Master of Public Health at San Diego State University.

Henry R. Perea, M.P.A., graduated from Fresno State University with a bachelor's degree in Criminology and received his master's degree in public administration with a Healthcare Specialization from the University of Southern California. In his elected official capacity Henry served on the Fresno County Office of Education Board of Trustees, Fresno City Council, and Fresno County Board of Supervisors representing District 3 where he completed his last term in January 2017. In his professional career he served as a human resources director at a level 1 trauma hospital and burn center for the Valley and as director of classified personnel at two local school districts. Mr. Perea's public service has been focused on improving the quality of life for Fresno County residents. A few of those public service highlights include establishing a Youth Psychiatric Treatment Center; expanding mental health programs; improving services to be culturally competent; designating \$5 million to provide health care for Fresno

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County's undocumented residents; building the Lighthouse for Children and child development center; and spearheading the effort to reduce infant mortality rates in Fresno County by establishing a partnership with Fresno State University, First 5 Fresno, and Fresno County Public Health, Social Services and Children's Mental Health.

Iesús E. Quiñones was born in Mayagüez, Puerto Rico, where he obtained a college preparatory education that enabled and facilitated his move to St. Louis, Missouri, in 2010. He obtained his Bachelors of Science in Psychology and Neuroscience from Saint Louis University in 2013. During his undergraduate career, Mr. Quiñones worked as a research assistant with the Department of Psychology and as a Program Coordinator Assistant with the Department of Anatomy of the School of Medicine. Additionally, he was the principal investigator of a study titled Attitudes Towards Substance Use for his senior capstone thesis. Mr. Quiñones began working in the healthcare setting in early 2012 at Casa de Salud, a nonprofit health care clinic that provides high-quality medical and mental health services to the immigrant and refugee communities in St. Louis Metropolitan Region. Beginning with Casa as a front desk receptionist in 2012, Mr. Quiñones greeted patients at their check in and helped everyone feel welcomed. His excellent performance and passion for working on behalf of its patients led to his promotion as Referral Coordinator, where he assisted patients in scheduling external referral appointments and providing support during their transition to care outside of Casa. In 2015, he was named the Guides for Understanding Information and Access program coordinator and facilitated the restructuring of the program into a goal-oriented case management model. Mr. Quiñones sits on the St. Louis Regional Health Commission's and Washington University in St. Louis' Institute of Clinical and Translational Sciences Community Advisory Boards.

Megan Rooney, M.S.W., M.Ed., is the director of program development at Health Literacy Media. Her accomplishments at Health Literacy Media include developing a Plain Language program informed by an evidence-based writing practice for readers with limited literacy, training clear communication skills to more than 400 health care providers, and securing more than 200 health communication projects from an international pharmaceutical company. Ms. Rooney has served as a Mental Health Therapist for the International Rescue Committee, where she provided culturally aware, trauma-informed, and linguistically accessible mental health care to international survivors of human rights abuses, as well as developed an evaluation program to assess client satisfaction and mental health progress. In addition, Ms. Rooney has worked as an English as a second language (ESL) instructor at the International Institute of Saint Louis, where she

integrated health literacy tenets into a curriculum designed to help students navigate the U.S. health care system. Ms. Rooney's bibliography includes having co-authored articles published in outlets such as the Multi-Regional Clinical Trials Center at Harvard, the *Journal of Health Communication*, and the journal of *Health Communication* & *Behavior*. In 2016, Ms. Rooney received her Master's of Social Work with a Health Concentration at the University of California, Berkeley. Ms. Rooney also holds a Master of Education from The University of Texas at Austin in health communication with concentrations in stress and psychoneuroimmunology.

Maricel G. Santos, Ed.D., is an associate professor of English at San Francisco State University, where she teaches in the M.A. in TESOL (Teaching English to Speakers of Other Languages) Program. Her teaching and research areas include socio-cognitive dimensions of L2 acquisition, health literacy, immigrant literacies, and teacher identity formation. From 2008-2013, she was a research fellow funded by a grant from the National Institutes of Health, Research Infrastructure in Minority Institutions (RIMI) program. Her health literacy research explores ways that adult English as a second language (ESL) participation serves as a health-protective factor in immigrant communities. In collaboration with the University of California, San Francisco, she is studying the effects of peer support networks and innovative curricula on health literacy outcomes among beginning-level adult ESL learners.

Rishi Sood, M.P.H., is director of policy and immigrant initiatives in the Bureau of Primary Care Access and Planning at the New York City (NYC) Department of Health and Mental Hygiene. In this role he oversees policy analysis related to health reform and works on various initiatives to improve access to quality primary care for NYC residents. He is program director of ActionHealthNYC, NYC's new health care access program for uninsured residents, recommended to the NYC mayor by a task force Mr. Sood co-chaired. Mr. Sood earned a master's degree in public health and an undergraduate degree in medical anthropology from Case Western Reserve University. He is currently pursuing a doctoral degree in public health leadership at the University of Illinois at Chicago.