

Southeast Asian American Comments on the State Health Innovation Plan

On November 12th leaders and community members from 3 Southeast Asian American communities met with Mark Schaefer, Michael Michaud and other members of their team to discuss the State Health Innovation Plan. The meeting was attended by Theanvy Kuocho, the Executive Director of Khmer Health Advocates, Howard Phengsomphone, the Executive Director of the Lao Association of Connecticut, Nighi Le, the Executive Director of the Connecticut Coalition of Mutual Assistance Associations, Richard Miller, MD, the Medical Director of Khmer Health Advocates, Mary Scully, Clinical Director and Director of Programs for Khmer Health Advocates, Thomas Buckley MPH, Reg. Ph., Charles Caley, Pharm.D. of the UCONN School of Pharmacy, Julie Wagner, Ph.D. from the UCONN Medical Center and 20 members of the Southeast Asian community.

Background on this Group

Southeast Asian refugees arrived in Connecticut in the late 1970's, 1980's. By definition, refugees are survivors of extreme trauma having experienced war, torture and genocide and granted resettlement in a country other than their home country on the basis of a well-founded fear of persecution. Their status on arrival is that of permanent resident. Today, there are at least 25,000 Southeast Asians living in every county in Connecticut with Hartford (7000), Fairfield(6000) and New Haven(4000) having the largest numbers.

Refugees are resettled for reasons of compassion, diplomacy and politics and are under the care of the Federal Office of Refugee Resettlement for the first 5 years of entry into the US. ORR provides funding for some Mutual Assistance Associations which focuses primarily on employment and supportive services for employment. MAA's have been very involved in providing medical and social service interpretation, translating, transportation and other support services. The Vietnamese Association and the Lao Association are the primary source of these services for their communities and have operated continuously for over 30 years.

Khmer Health Advocates which was founded in 1982 as a Mutual Assistance Association focused services entirely on health care and became the national Cambodian American health organization. In 1984, KHA began a torture treatment program which is essentially a medical home for victims of torture. KHA is a founding member of the National Consortium of Torture Treatment Program, one of 33 torture treatment centers in the United States and has continuously offered these services for more than 30 years. In addition, KHA operates programs for health promotion and development and was funded by the National Diabetes Education Program to develop community based resources for Cambodians on a national level as well as being named a Center of Excellence for Ending Disparities in Health by the CDC REACHUS Program (Racial and Ethnic Approaches to Community Health)

This group is offering the following comments on the State Health Innovation Plan based on the November 12th meeting and a thorough reading of the written report

Comments

The Southeast Asian American Community in Connecticut would like to express our gratitude to Governor Malloy, Lieutenant Governor Wyman and the members of the Steering committee for the extraordinary effort and thoughtfulness in developing the State Health Innovation Plan.

The following comments are based on our experiences caring for a community with special needs:

Addressing health disparities.

1. Khmer Health Advocates applauds the SHIP commitment to health equity, consumer empowerment and community based programs. The plan shows a real understanding of the issues and outlines a clear strategy for making care equitable
2. The "whole person centered care" model proposed is essential, practical and doable. However the wording on page 42 reverts back to a "practice centered model" when it states that providers must take "*reasonable steps to ensure meaningful access to care that is culturally and linguistically appropriate for patient populations and individuals*" Likewise the footnote on page 38 relieves AMH's of the obligation of providing "person centered care" based on 4 factors that include numbers of LEP's in a practice, frequency of services, nature of the importance of the services and resources available. This footnote which we believe comes from Federal guidelines is practice centered and muddies the waters in terms of accountability.

A person who does not receive care that meets their language needs is not receiving care. A person who does not receive care that is culturally appropriate is not accessing comprehensive health care. Exceptions to the mandate to provide "person centered care" create a disparity in care. Our communities have had extensive experience with these guidelines and know they are used to avoid accountability. Solutions are possible but will not be developed if there is a perceived way to avoid an issue that is complex and difficult.

Data Collection and Accountable Care

1. Managing risk is essential to a health care program and it is vital that data will be collected for special populations. It is interesting to note that on page 25, Asians are not even included in the State's data. Page 43 however clearly describes plans to address "sub-populations" which we understand to mean ethnicities within a specific group. Cambodians for example have a rate of depression and PTSD ten times that of other Asian and the general population.
2. Accountable care requires that data is collected and analyzed in a linguistically and culturally appropriate manner. This is an extraordinarily difficult achievement but absolutely necessary for equitable care. The plan should assure early adaptation of mechanisms and tools that assure that Limited English speaking persons are evaluated using meaningful measures.
3. Literacy is a major consideration in many communities and mechanisms for addressing this are achievable through the use of "spoken format" tools.

4. Evidence-based care must include special consideration of populations with clusters of conditions that are specific to their ethnicity and trauma experiences. The statement of "incorporating clinical recommendations for disparity populations as available" is again soft language which does not mandate equal care for all. Whether or not this language is supported by the Office of the Health Advocate does not change the fact that it will be considered a loop hole by many providers and will necessarily divert limited community based resources from service delivery to advocacy and support of civil rights interventions.

Health Care Delivery Mechanisms

5. The section on helping Providers achieve the AMH accreditation describes the need for flexibility for the development of medical home. The torture treatment model is based on behavioral health medical home and across the nations medical homes have been certified that are led by APRNs and Pharmacists. Connecticut should nurture the development of homes that can address the needs of special populations. This might mean the development of medical or behavioral homes that are led by nurses or pharmacists with close partnerships with primary physicians rather than the other way around. Under the current plan a primary care physician would oversee an average of 1300 patients. Khmer Health Advocates data suggests that the average high risk torture victim requires 40 hours of specialized care when delivered by cross cultural teams. This time is expected to increase by 40% when delivered by staff unfamiliar with treating Limited English Speaking persons with special needs. It is highly likely that practices will avoid seeing these high risk patients or provide a level of care that is "less than" others.
6. The group welcomes the inclusion of a plan for populations with special needs. While the description in the plan focuses on the integration of health and mental health, we hope that it will also allow for subsets of the population who have clusters of conditions that are not widely understood by mainstream providers and that require complex integration and coordination using risk assessment tools developed for that population.

Community based Public Health

1. Health Enhancement Communities can be successful if as is stated on page 51 they are "community driven". It should be noted however that many new communities that have great need do not have the human or material resources necessary for advocating on behalf of their community. The more traumatized the community the less likely they are to be able to participate in the development of programs unless they are given support to do so. Outreach and financial support is necessary to achieving equity in this area. The long term outcome of an outreach effort can be financially important to the plan.

For example, based on state numbers for the cost of high risk Medicaid, patients, the Cambodian community in Connecticut which numbers about 4,000 people has at least 1000 members who have 3 or more chronic conditions including a serious mental health disorder and

have a health care cost of \$33,000,000 per year. These numbers certainly justify an investment in public health prevention services.

2. Certified Community –Based Practice Support Entity is again a shift in focus from “person centered care” to practice centered. A Certified Community-based” Person” Support Entity available to Practices would keep the focus on the needs of the community member rather than the providers. “Person Centered care” is difficult, tedious and time consuming but there is mounting evidence that it can improve outcomes and reduce costs. The language needs to be clear as it directs the priority actions.

The SEA community applauds this important part of the SHIP plan and the plan for implementation. For special needs populations this part of the plan holds potential for improved outcomes and great cost savings especially in the areas of use of emergency rooms and hospital readmissions. For this reason, the plan should consider funding the certification process to assure that community based organizations can participate early in the planning process to assure that they can participate fully. It is often difficult for community leaders in high risk communities with limited human resources to decide if they are going to help a community member access care or if they are going to attend a planning meeting.

3. The SEA community welcomes an expansion of DPH programs into the communities and into community partnerships. For many communities there is little or no prevalence data available but there is community concern that chronic disease is occurring more often and at an earlier age than the general population, eg. new data from a RAND corporation Study done in California provides the first prevalence data for the Cambodian community in the area of diabetes. It shows that Cambodians 35 and over have a rate of diabetes of 29% more than twice the general population. In addition 19% are pre-diabetic. Prevention programs that target younger Cambodians can potentially reduce this escalating rate.

Falls Prevention Programs highlights the need for great attention to Medication Therapy Management. While this service is usually associated with treatment, it is an important component of prevention that can be successfully delivered to special populations through specially trained cross cultural teams. The use of teams greatly reduces the cost and improves delivery of these services.

Community Engagement

Throughout the document, SHIP describes a process for community engagement on a consumer and organizational level. While it is vital to assess risk in individual patients, it is also vital to assess risk in communities. In communities that have experienced war, torture and genocide as well as resettlement human and material resources vary and often are extremely limited. Likewise “new communities in the

United States" have vastly different resources than other minority communities that have been in the country for a long time.

Since the passage of the Personal Responsibility and Work Opportunity Act of 1996, there has been considerable misunderstanding of the status of refugees. Until that time, the Office of Refugee Resettlement funded many projects for communities but immediately afterwards. They restricted support to the first 5 years in the United States. In the initial bill all permanent residents were slated to lose all Federal support one year after the passage of the bill. That was changed by Congress before enactment and permanent legal residents continued to have access to the same programs as naturalized citizens. This has not changed. Most Southeast Asians in Connecticut arrived as refugee and have legal status.

The loss of Federal funding was not made up for with state funding and SEA community based organizations struggle to sustain themselves. Community leaders must often choose between providing service and participating in systems change. Many also require more time for translation of language and cultural concepts. These issues must be considered when seeking to involve these communities in consumer group, advisory boards or expert panels. Taken participation will feed inequities.

Incentives for outcomes

1. A study done by the Connecticut Pharmacists Association and the UCONN School of Pharmacy with a sample of Cambodian survivors showed that greater involvement in their own care reduced symptoms of depression. Many refugee populations have had very positive experiences with health care in the refugee camps where many served as medics, outreach workers, community health workers and in technical positions. All refugees were responsible for maintaining their own medical records.

Poor outcome are not the product of a lack of incentives but rather a lack of health literacy. In refugee communities rather than fund incentives, there should be funding for programs that address social isolation which has been directly linked to early mortality.

Workforce development

Cross cultural teams offer the best potential for each member of the team working at the top of their license or certification. There are three components to maximizing the effectiveness of these teams that include (1) training (2) experience (3) electronic support and care management systems.

Community based organizations can play a major role in the development of each and should be included in the process. The UCONN School of Pharmacy and the Urban Service Tract Program have

already developed experiential programs with the SEA community. Training in the use of electronic programs, spoken format tools and assessments must occur for all team members.

Health Information Technology

While the plan promotes important use of electronic record keeping systems, data sharing and care management systems, the concept of telemedicine is lagging behind the resources that are currently available.

The State needs to pass laws that allow for patients to be seen remotely using secured videoconferencing. Although the use of videoconferencing for psychiatry has been proven to be safe and effective, there is no mechanism for providers to be paid for those services. The KHA torture treatment community has successfully used telemedicine to reach patients across the state for assessments, medication therapy management (MTM), patient monitoring and the delivery of therapy. This has extended the reach of specialists while greatly reducing the cost.

Telemedicine could also enable the state to access resources for care that are in other states and even in the home country of the patient greatly improving the potential for health equity. E.g. Health promotion or monitoring via the Internet.

The group has concern that because of language, their communities will not have equal access to some of the new tools for improving care. There is no process described for how Limited English Speaking patients will have access to patient portals. Also how will new monitoring tools be made available to these people?

CHWs trained to use technology are vital and will greatly increase the ability to the new health care system to conduct screening of patients for activities such as depression and PTSD screening, medication histories, medication adherence, etc. This allows the health care professional to have a great deal of needed information on hand at the time of their direct service with the patient, greatly reducing costly health care professional time as this has been shifted to the CHW time.

While solutions are unlikely if exceptions are made for practices with few members of high risk special needs populations(as described in section one #2 above) They are very doable if the State were to commission the development of these tools as "add ons" available on an add needed basis for other electronic systems. The same holds true for patient portals and "spoken format" tools. These portals could be populated with "warehoused" data.

Evaluation

The group considers program evaluation essential to all programs. However there is a shared concern that because of the relatively small number of Southeast Asians in the State, these communities will be excluded from the evaluation process. However, for the first time in the state history there will be a set of measures by which the SEA community can measure the effectiveness of the care they are receiving. This will be of use in advocacy and civil right initiatives.

Closing Remarks

The group shares the vision of the State of Connecticut in terms of quality health care for all. As written the State Health Innovation Plan holds promise of improving the health everyone in Connecticut while reducing costs. We realize in reading the plan that the implementation phase will be difficult because it is changing a system that has been in place for a long time. The Southeast Asian community offers its support and its own experience with successful patient centered health plans (refugee camp model) to the state. We want to be a part of the implementation and look forward to future conversations.

In closing we would like to thank Dr. Schaefer and Mr. Michaud and their colleagues for their time and efforts to explain this complicated plan to a Limited English Speaking audience. The community expressed their appreciation and their hope for a new plan which they believe will improve their health and that of their children.