

I. Project Purpose:

Between 1975 and 1998, according to the Federal Office of Refugee Resettlement (ORR), 1,342,532 Southeast Asian refugees entered the United States. Southeast Asian Americans, who now number approximately 1.5 million (see Attachment 13), constitute the largest group of refugees ever to relocate in this country. At least 200,000 are survivors of torture who have unique and severe health problems. Cambodians make up the largest number of torture victims. Between 1969 and 1979, Cambodians lost more than one-third of their family members and nearly all of their doctors, educators, and clergy. The majority of the population experienced between four and ten years of severe malnutrition, slave labor, brainwashing, exposure to atrocities, and physical and psychological abuse. Many Cambodian Americans, who now number approximately 180,000 nationwide, have been massively traumatized and left without the resources necessary to build healthy communities.

Cambodian American communities are among the nation's most impoverished. According to the 1990 Census (the best data source until the release of 2000 Census figures), 47% of Cambodians live below the poverty line (compared with 10% of the US population and 14% of the Asian American and Pacific Islander population); only 6% of people aged 25 and older hold bachelor's degrees; and 73% of community members aged five and over "do not speak English very well."

People of Cambodian descent are among the Americans most likely to be disabled. The Federal government annually spends more than \$500,000,000 (figures based on estimates of 25,000 disabled Cambodians receiving SSI or SSD for a family of four) on basic disability payments and Medicaid for Cambodians. Less than 1% of that amount is spent on specialized health care or the prevention of disabilities. In recent years, more than half of all Cambodian American mutual assistance associations (MAAs)¹ have been forced to close, leaving limited English-speaking member of the community without access to services in the midst of an escalating health crisis.

Seven major factors motivate the current health crisis in Cambodian American communities:

1. Survivors are reaching middle age, a time associated with the onset of serious illness in concentration camp survivors and prisoners of war.
2. Many Cambodians cannot access appropriate health care services due to financial, linguistic, and cultural difficulties. US health care providers are typically not skilled in treating torture victims, and few qualified medical interpreters are available. Neither Connecticut nor Western Massachusetts has an established system for medical interpreter services.
3. Little research is available about the health status of Cambodian Americans. The President's Commission on Asian Americans and Pacific Islanders and many other organizations and agencies acknowledge that data pertaining specifically to Southeast Asian Americans are very scarce, and that this phenomenon contributes to disparities in health care.

¹ For the purposes of this proposal, mutual assistance associations (MAAs) are community-based organizations that are primarily managed by and for Southeast Asian Americans. Approximately 136 MAAs function in the United States today. For details, see the *Southeast Asian American Mutual Assistance Association Directory 2000*, which is described on SEARAC's website (www.searac.org).

4. Community-based organizations and health care institutions are not sufficiently funded to deal with the current health crisis.
5. Most torture victims lack access to appropriate health education materials and programs.
6. There is no effective method of communication between specialists treating Cambodian Americans across the country.
7. In 2003, thousands of Cambodian Americans will lose their disability benefits as a result of Federal legislation enacted in 1996. Due to psychological and cognitive illnesses, it is difficult for Cambodian survivors to pass the naturalization test. This limits their ability to access government-funded services. While waivers are available, survivors must find practitioners able to do evaluations, and only disability waivers filed prior to 1996 will qualify non-citizens for the continuation of full benefits.

Khmer Health Advocates (KHA) and the Southeast Asia Resource Action Center (SEARAC), propose the development of a telemedicine program specifically targeting Southeast Asian American torture victims, with a demonstration focus on Cambodian American survivors. KHA, the main implementing agency, is the only Cambodian health organization in the United States. SEARAC, the fiscal agent, is the national organization for Americans of Cambodian, Laotian, and Vietnamese descent.

This project will adapt broadband communications technology for use in impoverished bilingual and traumatized communities. This will be a demonstration project that will produce clear replication strategies for use with diverse refugee and immigrant groups.

Together, KHA and SEARAC will pursue the following specific solutions to the problems outlined above:

Solution One: Improve access to torture treatment services: KHA will test videoconferencing equipment and peripherals to effectively establish the use of videoconferencing as a method of patient care with at least 80 survivors in Connecticut and Western Massachusetts. These populations, which number approximately 2,500 (based on 1990 Census data) are widely dispersed across their geographical area, and are often located fifty or more miles from the nearest health care facilities offering appropriate care.

During project year one, the partners will establish videoconferencing in 5 sites, including the hub site at KHA's office in West Hartford, CT, 2 additional sites in Connecticut, and 2 sites in Western Massachusetts. These sites will use DSL-based broadband Internet or ISDN connections and have equipment and telecommunications capacity to enable doctors, nurses, and social workers to see and communicate directly with clients in areas. During project year two, the partners will establish *telehomecare* systems in the homes of 10 "high risk" patients to allow communication on a daily basis with a professional in the hub office. Currently, Cambodian Americans typically do not have access to important treatment options because their doctors fear they cannot comply with complex treatment plans. In-home care will increase the treatment options for chronically ill patients: for example, with such a system, patients can show the clinicians what pills they have taken, and clinicians will be able to monitor their patients' personal appearance. KHA will test the use of this system for patients who have complex health problems, which keep them homebound, including diabetes, hypertension, and Post-Traumatic

Stress Disorder (PTSD). This part of the project will test the use of peripheral equipment as well as the practical aspects of using DSL or POTS services.

Outcomes: (A) Patient treatment through telemedicine will be more cost-effective than treatment through ordinary means with patients who are homebound and/or located in communities that lack appropriate services. (B) This project will enable KHA to provide twice the current number of service hours to patients. (C) After 6 months, at least 50% of KHA's patients will have used teleconferencing and describe satisfaction with the system. (D) After 1 year of treatment through telemedicine, at least 60% of caregivers involved in treatment (including physicians not directly affiliated with partner organizations) describe improved compliance that allows for use of more complex treatment methods.

Solution Two: Improve the skills of health care providers to care for torture victims: During the second project year, KHA will edit and encode video materials from year one for the purpose of providing training materials via video streaming. KHA will test the use of videoconferencing with health care providers for patient consultations. The partners, led by SEARAC and with the assistance of a marketing plan created in consultation with a business school, will publicize and make available these services to other sites (including hospitals, which typically have necessary technology in place) throughout the nation.

Outcomes: (A) At least 75% of health care providers who are served will agree that the project has enabled them to offer higher quality services to their Southeast Asian torture victim patients.

Solution 3: Improve access to data collection and analysis: In 1995, Khmer Health Advocates, with funding from the Office of Minority Health, developed a bilingual assessment tool for Cambodian survivors. This tool will be modified and adapted to a website database that will allow for immediate access to health information for treating health care providers as well as analysis of data sets within the assessment format to determine the priority needs of patients. All records will be coded for confidentiality purposes, but summaries of data will be made available to specialists treating Cambodians and certain information will be made available to organizations to use in developing programs. The system for data collection will include wireless devices such as hand-held devices or laptops that will minimize provider time in assessing patients and reviewing health histories.

Outcomes: (A) At least 75% of clinicians assisted will agree that the project has enabled them to have improved access to important data about their patients. (B) At least 5 unrelated agencies will report that the data made available on the Internet will have helped them to significantly improve their existing programs, or to create new programs.

Solution 4: Improving access to health education: Cambodian Americans tend to experience severe difficulties with the English language (see p. 1). Many adults are illiterate in their native language, as formal education was rare in Cambodia. English-language learning in this population has been made more difficult by trauma-related illnesses, which often impair concentration and memory. Health education, a principle factor in the prevention of illness, is not available to many Southeast Asians either because materials are not produced in accessible forms or they are not widely distributed. Within the first 6 months of the program, KHA will

demonstrate the use of video streaming for the dissemination of bilingual health education materials via the Cambodianhealth.org website. In addition, 3 MAAs will receive assistance with the implementation of video streaming for their own materials on their own websites. SEARAC will work with the partners to publicize these sites through e-mail listservs, conferences, etc.

Outcomes: (A) During the first six months, video-streaming health education materials will be offered on KHA's website. During project year one, these materials will be favorably reviewed by at least 6 community-based organizations. By the end of the project, these materials will be used at least once per month by at least 6 MAAs. (B) By the end of year two, at least 3 MAAs will have posted their own video-streaming health education materials on websites, with project assistance. All of these MAAs will report that this activity has enhanced their service provision.

Solution 5: Spark the development of telemedicine projects with other groups: During year one, the project Advisory Committee will select 4 organizations to be sites for replicating certain aspects of this project. During project years two and three, these organizations will be mentored in their pursuit of related project goals. It is possible that these projects will focus on refugee groups from outside of Southeast Asia.

Outcomes: (A) Partners will mentor at least 4 additional refugee organizations in their pursuit of telemedicine projects. This mentoring will result in the implementation of funded projects in at least 2 organizations before the end of the three-year project.

II. Innovation:

This project develops a unique partnership for the care of survivors of torture. Each organization has more than 20 years of experience in providing services to traumatized people. This partnership brings expertise in outreach, treatment, research, education, and advocacy on local and national levels, thereby creating the potential for practical and innovative use of technology in the area of telemedicine with underserved refugee populations.

While Cambodian Americans come from a county that had little access to advanced technology, many are quite adaptable to their new culture and eager to use advanced technological tools for improving communications. When Cambodians first came to the country, many of them bought VCRs so they could access Khmer-language entertainment. Now, almost all Cambodian homes in Connecticut have computers. This population often uses the Internet to access information sources, including Khmer-language newspapers and radio broadcasts. The introduction of videoconferencing for the purpose of providing health care is new for Cambodian Americans, but we believe they will welcome it, as it offers face-to-face access to health care professionals who understand their histories and illnesses.

In 1998, Congress passed the Torture Victim Relief Act to fund the care of victims of torture. Torture treatment represents an innovative merging of psychological and medical care that is survivor-centered and committed to meeting the acute and chronic needs of the client. Telemedicine offers the possibility of adding new dimensions to this care.

Through this project, KHA and SEARAC will work together to implement an innovative and complex project focusing on the treatment of Cambodian Americans with trauma-related illnesses. The success of this project will encourage leaders of other refugee and immigrant communities to make innovative use of advanced technologies in the treatment of trauma survivors; and the lessons learned from this project will be shared with them, so they will be better able to design and implement effective programs.

III. Diffusion:

Lessons learned from Cambodians in the telemedicine project can ultimately help other Southeast Asian groups as well as other refugee populations. As stated in Section I, the partners intend for the lessons of this demonstration project to be disseminated to organizations representing many different ethnic groups throughout the country, and have committed to mentoring some groups for the realization of their own telemedicine projects.

SEARAC has a long history of providing technical support to Southeast Asian and other refugee populations. SEARAC serves a large network of organizations through e-mail listservs and an award-winning website (www.searac.org). SEARAC often gathers together refugee advocates and service providers from throughout the nation. For example, for the past eight years, SEARAC has contracted with ORR to stage annual conferences and meetings, and in 1999 it staged the largest refugee-focused conference in history (attendance: 1,600). In addition, it is now coordinating the creation of a coalition composed of national refugee-led organizations such as the Ethiopian Community Development Council, Kurdish Human Rights Watch, and the Iraq Foundation. SEARAC will use these networks to publicize the telemedicine project, and encourage organizations representing other populations to pursue similar initiatives.

KHA is a founding member of the National Consortium of Torture Treatment Programs, and will share resources within this network. In addition, KHA has a website partially funded by ORR. This site focuses on the health characteristics, strengths, and needs of Cambodian torture victims, and within the next two months it will host a full-length video called *Children of the Mahantdorai* that will be streamed in real-time by United States Video Interactive, a Connecticut-based company. This will be the first demonstration of the use of video streaming for Khmer-language substance abuse-prevention material.

IV. Project Feasibility²

The use of broadband and wireless technology is emerging with great potential for medical applications. This project will focus on the use of both Internet-based videoconferencing over DSL lines, and multiple-point conferencing using ISDN lines for patient care, health education, and consultations. A website-based database will be used to store and retrieve patient information and for the analysis of data. While these applications are successfully in use in telemedicine projects across the country, each new project must address issues of compatibility and end-user ease-of-use with particular products for service delivery. A major task of this project will be to determine which products are the easiest to use with limited English speaking

² Descriptions of partner organizations and resumes of key staff are provided in the Attachments.

people and how to overcome compatibility issues when combining T3 lines with DSL and ISDN connections.

The project will test PC-based and self-standing units for delivering patient care both in a supported site and in the patient's home. Peripheral applications for the testing of blood pressure and blood sugar will be tested also, and an objective evaluation of products shared with other organizations will be carried out. Currently there are rapid changes in the technology being offered for telemedicine projects. There are a wide variety of systems being marketed that are compatible with the various communications line necessary for videoconferencing. This project will test several different hardware and software configurations with patients as well as with providers to assure that the majority of end users are comfortable with the equipment portion of the project. For this reason, estimates of equipment cost are included in the budget that represents a median range of cost for equipment currently available. In order to make telemedicine accessible to a broad range of users from communities, the project will seek to use the most cost effective methods available.

Vital to the continuation of all programs is the collection and dissemination of information. KHA will develop an Internet-based database to document patient health and trauma histories. This system will use codes for protection of identity, but will allow for multiple-site data collection as well as analysis and dissemination.

Emerging technology is only useful if the end users can easily manage it. For this reason, KHA will invest in a Technical Director who has the capacity to adjust systems to meet the needs of the client and to ensure that the client has easy access to the system. Paul Ouk, the proposed Technical Director, is a Cambodian American multimedia professional who has broad experience in video production, programming, and website and database development. In addition to his skills with computers and other advanced technological equipment, Mr. Ouk has a background as a medic and is very familiar with medical concepts. Mr. Ouk will be hired on a full-time basis and will use his programming skills to develop a database that will be accessible via the Internet that will store medical records and analyze data. He will also install, maintain, and troubleshoot all videoconferencing equipment as well as train professional staff and patients in the use of this equipment. Mr Ouk will work with Khmer-speaking student volunteers to increase access to the video streaming portion of the project.

KHA has had extensive experience in working with the community as treatment providers as well as on the production of video and use of computers. Mary Scully, the Program Director for KHA, will act as Program Director for this project and will address the clinical issues associated with the program. She has more than 20 years of experiencing working with Cambodians and has worked extensively with Paul Ouk on video production and website management. She is committed to developing access to appropriate health care services for Southeast Asians. As chair of the Executive Committee of the National Consortium for Torture Treatment Programs, she has the ability to locate resources and share technology with other groups treating special needs patients. Theanvy Kuoch, KHA's Executive Director, is a Cambodian American torture survivor and activist for minority health issues. She has worked with Cambodian organizations for more than 20 years and is the chair of the National Cambodian American Health Taskforce.

Her role will be to demonstrate the potential use of videoconferencing to Cambodian American community leaders around the country.

The Southeast Asia Resource Action Center (SEARAC), the fiscal agent for this project, is the national organization for Cambodian, Laotian, and Vietnamese Americans. SEARAC focuses its work on technical assistance, information-sharing, research, and advocacy. In addition, SEARAC stages national meetings and conferences for ORR, and has a long history of productive engagement with Federal government agencies. Executive Director KaYing Yang (who arrived in this country as a Hmong refugee from Laos) and Director of Programs and Resource Development Max Niedzwiecki, PhD, will both participate actively in this project.

The project will seek assistance from a university business school, identified within the first six project months, to develop a marketing plan for the use of telemedicine applications in the areas of direct patient care, medical interpreter services, health education, and research.

The use of telemedicine as a tool in health care is emerging quickly, and as of October 1, 2001, Medicare will begin payments for certain telemedicine activities, thereby reducing a major barrier to growth of telemedicine as a treatment option. It is vital that high-risk populations have the foundation for the use of technology in health care. Videoconferencing for medical interpreter services, compliance with treatment programs, health education, and mental health services can reduce disabilities and the risk of early death in a population such as the one under consideration here. It is vital that this system be tested for widespread use as soon as possible.

V. Community Involvement

KHA is a community-based organization and a majority of its board members are Khmer-speaking community members. Likewise, SEARAC is a national organization managed primarily by and for Americans of Cambodian, Laotian, and Vietnamese descent. Each organization has over 20 years of experience serving these communities. Both organizations are part of the communities they serve.

In 1997, Khmer Health Advocates involved community members in the use of the Internet as part of a substance abuse prevention program. Several households had WEBTV installed in homes that are now considered havens for other members of the community. Because of language problems, community members were not able to use e-mail but did use the Internet for accessing news from Cambodia. KHA found that children in the homes were able to teach their parents how to access this service.

Several factors suggest that the community will welcome the services proposed here. The first is the impending loss of SSI for large numbers of disabled Cambodians. KHA has dramatically increased requests for service. This system will enable specialist to see Cambodians in community centers and pagodas and facilitate the writing of waivers based on medical examinations. Second, Cambodian Americans often seek health information in spoken Khmer. Two videos that KHA made are shown regularly on television stations in Lowell, MA. When KHA held a focus group on diabetes, the room was filled beyond capacity. KHA has discussed telemedicine with our current clients who expressed eagerness to use the system provided they

have support doing so. For this reason, KHA will place a system in the Association of Religious Communities in Danbury and also in the only pagoda in Connecticut, places where people now go for help. Similar systems will be placed in Massachusetts following applications for licensing in that state. Community partners for this demonstration project include the Association of Religious Communities in Danbury, the Cambodian Buddhist Temple in Newtown, and two sites in Western Massachusetts to be confirmed in the first half of year one.

VI. Evaluation:

Georgine Burke, Ph.D., and associates, who have expertise in evaluating Cambodian projects, will carry out the evaluation of the project. A medical anthropologist, Dr. Burke has expertise in reviewing cross-cultural initiatives and determining client satisfaction with services. She will develop a bilingual assessment tool for evaluating client response to the project, a process report for tracking technical problems and ease-of-use of equipment, and tools to measure progress towards the outcomes described in Section I. Evaluation methods will include focus groups, interviews, and surveys carried out with project clients and their relevant service providers and organizations. As necessary, Dr. Burke will work with co-evaluators who have experience with the advanced technological applications used in this project.

Dr. Burke or her associate will collaborate with Paul Ouk to establish a computer-based program for data collection and analysis. Written data collection forms will be reviewed by the Advisory Committee prior to the commencement of the project. Whenever possible data collection will be incorporated into the actual set-up and use of the equipment to make the process more efficient.

As a pilot project, outcome data will be available from only a limited number of participants. The evaluator will compare participants against a comparison group of Cambodian families from central Connecticut who have not yet had use of the network. These two groups will be compared on the following indicators, among others: barriers to accessing health care, health care utilization, length of time to diagnosis (if appropriate), and knowledge of preventive health practices.

Dr. Burke will submit process reports on a quarterly basis to SEARAC and the Advisory Committee for review and will participate in quarterly meetings with the Advisory Committee. The partners will use evaluation materials in order to improve project design and performance. Project design changes will be considered annually and as needed.