

## Study finds Hmong, Lu-Mien families face barriers to services

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A new community-based study by UC Davis researchers has found that children with developmental disabilities in Southeast-Asian-American families face significant obstacles to receiving intervention services. Barriers include lack of accurate information, language difficulties, lack of trust and limited outreach.

Despite these findings, study participants said that with education, outreach and culturally responsive support, families would likely accept services, which led researchers to continue to work with the community groups to develop educational opportunities to improve access and services.

Entitled "Understanding <u>Developmental Disabilities</u> in Families of Southeast Asian Origin," the study is the first to examine the perceptions of families of Hmong and Mien <u>children</u> with disabilities as well as the barriers to service. It is published online today in a special supplement to the journal *Pediatrics*, "Children and Youth with Disabilities and Special Health Care Needs from Traditionally Underserved Communities."

"These families care very deeply about their children," said Dian Baker, a postdoctoral scholar at the Betty Irene Moore School of Nursing at UC Davis and the Center for Excellence in Developmental Disabilities (CEDD) at the UC Davis MIND Institute. "It's not that they don't want to help them. It's that they don't know what to do."

Nearly one fifth, or 17 percent, of all children in the United States have



developmental disabilities, and nearly four million Americans have a developmental disorder. But information on the needs of underrepresented and underserved families of children with developmental disabilities is limited. In California, the Department of Developmental Services reports a lower overall rate of referral for Southeast-Asian people relative to the portion of the overall population they represent. California is among states with the largest Hmong and Mien populations, concentrated largely in the Central Valley.

Baker said she became interested in doing the study while working as an in-home outreach worker for a Central Valley school district. She recalled encountering a 10-year-old Southeast-Asian child with Down syndrome who was not attending school. When asked why, his parents said they didn't send him to school because they thought that nothing could be done for him.

Baker said the purpose of the study was to explore the relationship between Southeast-Asian-American families' attitudes toward receiving services for their developmentally disabled children and the reasons why they are underrepresented among recipients of special education and social services. She said the study was particularly unique because of the community-based participatory methods used that included members of the Hmong community as well as an interdisciplinary team of researchers representing nursing, medicine, education and social services. Because community-based research is conducted as a partnership between researchers and community members, partners participate in all aspects of the research process. After the data is collected and analyzed, researchers continue to work with their community partners to develop and implement strategies, such as an educational campaign, to address the barriers discovered.

For the study, Baker and her colleagues partnered with the Hmong Women's Heritage Association and the United Iu-Mien Community,



Inc., both of Sacramento, Calif., to interview representatives from the communities including Hmong and Mien individuals with developmentally disabled children and shamans who perform healing rituals. The interviews were conducted in Hmong and Mien and later translated into English.

The participants identified a variety of cultural and sociological reasons why they believe Southeast-Asian-American families receive fewer special education and social services for their children with developmental disabilities. The researchers found that a predominant theme was the perception that reliance on governmental support services is not appropriate because having a <u>family</u> member with a developmental disability is his or her responsibility.

Study participants also said that language barriers prevent families from understanding the type of health care or educational services their children may need or receive.

"We do not have Hmong words for all the diagnoses, no word for Down's syndrome ... someone has to take the time to help make the understanding," one male Hmong participant said.

"I know that my child goes to a special school because a special bus comes every morning to take her to school," said one female parent of a child with cognitive and mobility challenges, "but I have no idea what kind of school it is and what kinds of services the school is providing my child because I do not speak or understand English and I have no way of communicating with the school staff."

"In Thailand, my child was able to attend school and I knew about school ... here there are so many appointments, he can't be in <u>school</u>, can't learn, I do not know what to do, what is best? He is falling behind, how come so many appointments and meetings?" said a female parent of a



child with cognitive and mobility challenges.

Baker said that the study identified a variety of approaches to helping Southeast-Asian-American families of children with developmental disabilities. These approaches include creating social support groups for families with developmental disabilities, disseminating information through cultural events, developing partnerships with accepted community-level health-care providers, such as shamans and herbalists, and providing more culturally and linguistically appropriate information.

To that end, Baker and her UC Davis collaborators, in association with their community partners, are developing a public service campaign aimed at helping Southeast-Asian communities increase awareness and use of the services that are available for their children.

"Reducing health disparities in underserved and underrepresented populations, along with promoting early identification and intervention for children with developmental disabilities are primary goals of the CEDD," said Robin Hansen, professor and chief of the Division of Behavioral and Developmental Pediatrics at UC Davis and director of the Center for Excellence in Developmental Disabilities, who also collaborated on the study.

## Provided by University of California - Davis

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