

# **Accessibility and Barriers to Services for Children Experiencing Developmental Disabilities in the Asian Pacific Islander Community**

Dian Baker PhD(c), APRN-BC, PNP

Elizabeth Miller, MD, PhD

Michelle Dang, MSN, RN

# Public Law 106-402

- Reach and serve individuals with developmental disabilities
- University Centers for Excellence in Developmental Disabilities
- New service center:  
Center for Excellence in Developmental Disabilities the UC Davis at MIND Institute-  
serving Northern California

# Locating multiply marginalized communities

- Consumer groups
  - Rural areas
  - Urban population of underserved groups
    - Data from Regional Center and Local School District
    - Interviews with local community-based organizations

# What was the issue?

- Typically lower than expected numbers from APIA population “underrepresented”
  - (6 % Regional Center/ 11 % of general population)\*
- But within the APIA...
  - Disproportionate number of Hmong community members compared to other APIA members
  - However, after referral - low numbers of services accepted, no shows for IEPs
    - Sacramento County 7.3% APIA special education/ 13% of enrollment (2006-07)

# Hmong in the U.S.

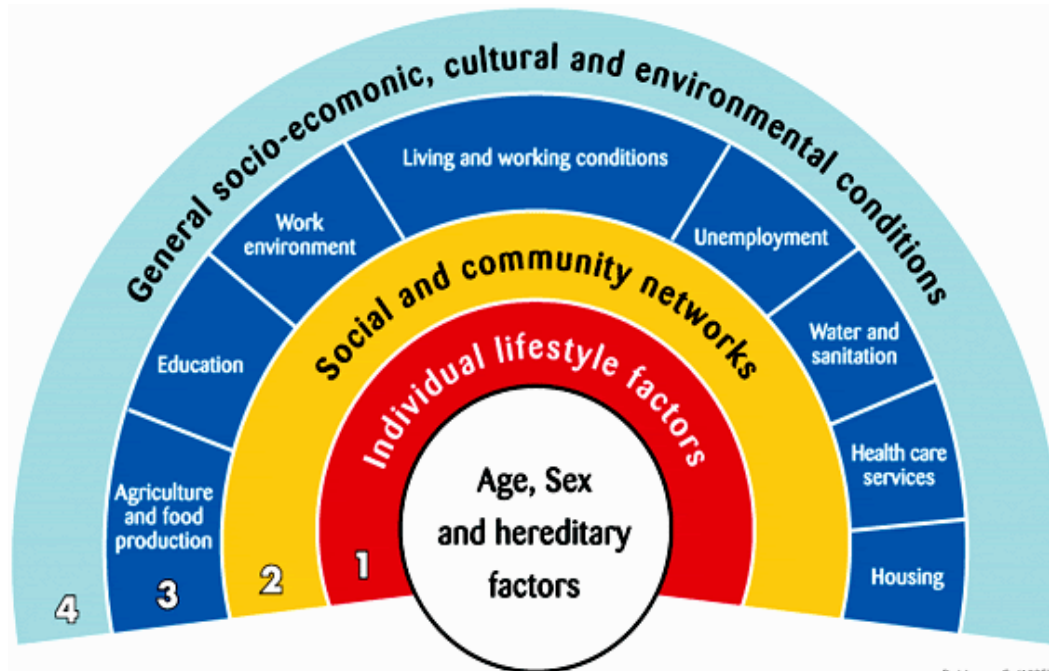


- Over 250,000 living in U.S.; but census count is probably low
- 60 to 80 thousand in California
- Majority to date (60%), still born outside U.S. and entry U.S. as refugees – recent waves in 2003-2006 WAT camps Thailand

# Researching the issue

## Social Determinants of Health

### Community-based Participatory Research



Work *with* rather  
than *in* the  
community

With the community, we decided that we needed more information about:

- the Hmong community's perception of developmental disabilities and
- their view of support services for persons with developmental disabilities



# Methods

- Exploratory, qualitative, focus groups- thematic analysis
- IRB approved UCDCMC
- Involvement and partnership with Hmong Women's Heritage Association
- Cultural Broker
- 1<sup>st</sup> - Key Informants focus group (n= 7)
- Family members (n =10)

# Results – Key Findings

- it is inappropriate to rely on governmental support services
  - related to cultural beliefs
- Significant barriers to services such as lack of accurate information that is understandable, language, transportation
- lack of trust
- lack of outreach
- All these factors interfered with the acceptance and utilization of available support services.

# Self blame or ancestor blame

I understand where this [developmental disability] came about and, uhm, the doctors can't do anything about it because it's something that I did. So, therefore I'm just gonna keep it the way it is and I think the beliefs kind of prevent the families from seeking help—

# Limited outreach and understanding

I know that my child goes to a special school because a special bus comes every morning to take her child to school, 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.

# Lack of advocacy and support

I am trying to understand what the disability is. I mean, I've gone to IEP meetings and families are like this is, you know, it's like they're here to actually, you know, create the plan already and the family's all I don't even know what the disability my child has, you know, so.

# Structural Factors – lack of access

Not understanding IEP process

Transportation

Lack of insurance

Not knowing how to get assistance

Not enough money; can't afford  
medical costs

**Even with information, not able to  
navigate system- too complex and  
confusing – feel inadequate**

# Community Assets

- Trust in local community-based agency that serve the Hmong community
- Strong desire to dispel myths about developmental disabilities and learn more
- Role of shamans
- Role of primary care provider/family doctor
- Having access to interpreters
  - *(but not consistent)*

# Sample of Recommendations

- Education – culturally responsive
- Outreach - with service coordination and support over the long term – not just referral
- Need more provider time to develop trust
- Work with cultural brokers and community leaders

# Next steps- Work together to remove the barriers

- Work with the community to develop
  - Outreach and education in small groups
  - Service coordination with active support and advocacy
  - Advocacy and education with providers
  - Monitoring of subgroups