Developing Culturally Responsive Approaches With Southeast Asian American Families Experiencing Developmental Disabilities

abstract

OBJECTIVE: Southeast Asian American families are underrepresented among recipients of special education and social services for people with developmental disabilities. Our aims were to use a community-based participatory research approach to examine Hmong and Mien families’ perceptions of developmental disabilities and understand barriers to and facilitators of service provision among families experiencing developmental disabilities. We describe here a case study of a successful attempt to engage marginalized and underserved communities to understand their needs to improve access and services for persons with developmental disabilities.

METHODS: We conducted 2 focus groups with 11 key informants and 1 focus group with 10 family members of persons with developmental disabilities, as well as in-depth interviews with 3 shamans. Using a thematic analysis approach, we coded notes and transcripts to assess community members’ understanding of developmental disabilities, experiences negotiating educational and health care systems, and barriers to high-quality care.

RESULTS: A predominant theme was the perception that reliance on governmental support services is not appropriate. Common barriers identified included lack of accurate information, language difficulties, lack of trust, and limited outreach. These perceptions and barriers, combined with limited access to services, interfere with community acceptance and use of available support services. Despite these barriers, participants indicated that with education, outreach, and culturally responsive support, families would likely accept services.

CONCLUSIONS: Community-based participatory methods are effective for eliciting root causes of health inequities in marginalized communities. Outreach to community-based organizations and an inclusive research practice identified social and cultural reasons for low service uptake and provided a pathway for the community to improve services for persons with developmental disabilities. Pediatrics 2010;126:S146–S150

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ABBREVIATIONS CEDD—Center for Excellence in Developmental Disabilities CBO—community-based organization

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In the United States, children who are diagnosed with developmental disabilities represent 17% of all children in the general population, and 3.8 million people have developmental disabilities.10 However, information on the developmental disability–related services and needs of families from certain ethnic minority groups, such as Southeast Asian immigrants, is extremely sparse.11,12 In California, government support systems for persons with developmental disabilities, such as special education and state-level regional centers, report a lower referral rate for individuals of Southeast Asian origin than that for other ethnic groups. Furthermore, even when referrals occur and services are accepted, actual expenditures for vendored services are lower for Southeast Asian clients.13 (California Department of Developmental Services, referral and services database, unpublished raw data, 2003–2007)

The Hmong and Mien, originating in Laos, are among several groups that experience health inequities related to developmental disabilities despite their arrival in the United States >30 years ago.6 These communities have a low socioeconomic status, which places them at high risk of poor health outcomes such as premature death from diabetes, cancer, and heart disease.7–9

US Pub L No. 106-402, which encompasses the Developmental Disabilities Assistance and Bill of Rights Act, requires each state to create and maintain a university center for excellence in developmental disabilities.10 In 2006, the Center for Excellence in Developmental Disabilities (CEDD) at the University of California Davis, Medical Investigations of Neurodevelopmental Disorders Institute, was established in concordance with this legislation. Reflecting the vision and objectives set by the CEDD’s primary consumer community council, the CEDD developed goals to address health inequities and outreach to individuals with developmental disabilities from marginalized communities.

In this article we describe a CEDD-sponsored case study of a successful attempt to reach marginalized and underserved communities to explore barriers to developmental disability services as reported by Hmong and Mien community members. We plan to use the results to guide the development of more culturally responsive approaches to service provision.

METHODS

We invited community-based organizations (CBOs) that serve the Hmong and Mien communities to participate in this research project to explore together the needs of persons with developmental disabilities, including their access to clinical care and services. We met 6 times with the CBOs to establish trust, discuss data that demonstrate inequities, and plan and design this exploratory study. This process of nurturing relationships and trust is essential for community-based participatory research, an approach to research that emphasizes working with, rather than in, communities. Community-based participatory research facilitates community empowerment and local advocacy to address issues of concern to the community.11,12

We used an exploratory, single-category, participatory action study to examine the perceptions and reasons for low service uptake. We conducted 2 focus groups with 11 key informants from the Hmong and Mien community and 1 focus group with 10 family members of persons with developmental disabilities. The CBOs recruited participants through word of mouth. Key informants included Hmong and Mien registered nurses, social workers, mental health professionals, Regional Center for Developmental Disabilities specialists, community advocates, and shamans. Participating Hmong and Mien families had family members with developmental disabilities (such as vision, hearing, movement, cognitive, and communication challenges) who ranged in age from 8 months to 34 years. The focus groups were guided by structured questions developed by the community-based participatory research team. We conducted all focus groups in participants’ native language, and each session lasted ~2 hours. Each focus-group participant received a $20 debit card to thank them for their time. The human subjects research committee at the University of California Davis School of Medicine approved this study.

We also interviewed 3 shamans. Among the Hmong and Mien historical cultures, shamans are health care and spiritual providers who perform healing rituals that may include preventive, diagnostic, and/or healing and therapeutic rituals.15

We audiotaped the focus-group sessions and interviews, transcribed them, and translated them into English. Two researchers used the English transcripts to independently open-code them to identify major themes and supporting comments according to Krippendorff guidelines.14 The researchers identified 2 major themes and subthemes and reviewed the themes and supporting comments with the CBOs to ensure consensus.

RESULTS

Family members and key informants described multiple barriers to services for persons with developmental disabilities. The 2 groups described similar perceptions regarding developmental disabilities and similar barriers to services. Cultural factors that influenced perceptions of developmental disabilities included perceptions of the etiologies of developmental disabilities, shame, and unwillingness to accept help. Structural barriers included lack of accurate information, language and transportation barriers,
lack of insurance and other financial burdens, lack of trust, and limited outreach by educational and service agencies.

**Cultural Factors**

Sociocultural characteristics related to developmental disabilities may interfere with acceptance of services. Participants explained that developmental disabilities may result from mistakes by themselves or their ancestors, omissions (such as improper burial location), or a “spiritual curse.” As a result of these beliefs, community members often feel that accepting services or support from others is inappropriate. Community members believe that families must take full responsibility for meeting the needs of family members with developmental disabilities. Family members reported a sense of isolation and discomfort because of the stigma of having a family member with a developmental disability, which may also limit their social functioning and attendance at community events.

“I think it has a lot to do with culture belief as well...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 families from seeking help.” [male parent of a young adult with vision and hearing challenges]

“I think there's a lot of stigma around it and the families, umh, who do have family members with a disability they, they're really protective of that individual and they try to shelter the individual because they're afraid of the stigma about you know, it's attached to the family name.” [key informant, shaman male, Hmong]

“Another way that we also look at is that if it's he's a nice person and he have a baby like that [developmentally delayed] then he would say, oh, maybe it's because his ancestor or, uh, it's been buried in a wrong place or a place that is not good, it's not blessing to his family that's why.” [key informant, female, Hmong]

**Structural Factors**

Focus-group participants and shaman's said that care systems and service-delivery mechanisms present multiple barriers to locating and using services. Participants indicated that family members lack accurate information regarding educational and health service delivery and what services their children are receiving. They were confused about medical care and the purpose of appointments or treatments.

“I know that my child goes to a special school because a special bus comes every morning to take her 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.” [female parent of an adolescent with communication and mobility challenges]

“In Thailand, my child was able to attend school and I knew about school . . . mmm . . . here there are so many appointments, he can't be in school, can't learn, I do not know what to do, what is best? He is falling behind, how come so many appointments and meetings?” [female parent of a school-aged child with cognitive and mobility challenges]

Despite legislative and policy regulations, health care and educational systems may not have appropriate mechanisms to adequately address language and cultural barriers. Structural barriers, such as lack of English fluency or transportation, may limit access to appropriate care.

“We do not have Hmong words for all the diagnosis, no word for Down's syndrome . . . . Someone has to take the time to help make the understanding.” [key informant, male, Hmong]

“Because of language barrier, I won't be able to help my child, even if mails about agency that help people with disabilities come, I wouldn't be able to read it to know that there are places that can help.” [male parent of a young adult with mobility challenges]

“I am dependent on community helper organization, such as [name deleted], but do they know about bus and schools? I need help for all the meetings, they can't always come to help, then I am alone, they [schools] just talk and send me home.” [male parent of an adolescent with communication and mobility challenges]

“I can not drive, no English, my family helps but I can not ask them anymore, I miss appointments, I need transport to the care, or it no use to me.” [female parent of a toddler with traumatic brain injury]

Participants described insurance and other financial issues as significant barriers to appropriate education and health care services for their children. They worry about the present and future impact of financial issues on their other children.

“I concern for my child future, he needs special walk help and braces, no money for this, how he walk to take of self, when I no longer here, can we get money for this?” [male parent of an adult with mobility challenges]

“They say there is special school for deaf, blind child, but it is far away, how I see my child, no money for transportation, how I know it right, I think it very expensive . . . . Who take care of this?” [female parent of a school-aged child with vision and hearing challenges]

“I am concerned about medical expenses, insurance is very good, covers most. In Thailand, we have no help like this, but still very, very, expensive, no money for my other children.” [female parent of a young adult with cognitive and mobility challenges]
ity my child has, you know, so.” [key informant, female, Mien]

“It’s their problem and not the government’s problem. So, uh, although I try to explain to them that we have these services for your, uh, son or daughter who has a disability they don’t want the, uh, the services. Although they know it’s there . . . . Sometimes because they don’t trust the government.” [key informant, male, Hmong]

“I cannot talk with doctor, I have no words to tell how I feel . . . only call my child disability, why not call her name?” [female parent of a toddler with cognitive and mobility challenges]

“We need more Hmong doctors and nurses, they would help us.” [female parent of a toddler with cognitive and mobility challenges]

“Majority of parents in our community do not know about help, we . . . no idea where resources are . . . uh, even if we do find it we don’t know how to use it right or figure out right medications and services, it is so hard when you don’t speak English.” [female parent of an adult with cognitive challenges]

DISCUSSION: IMPLICATIONS FOR PRACTICE

Recommendations from parents and key informants to address the barriers identified included creating social support groups for families with developmental disabilities, disseminating information through cultural events, working with accepted community-level health care providers such as shamans and herbalists, increasing the availability of culturally and linguistically responsive information, and providing family “navigators” in addition to traditional case management. Family navigators are not only expert cultural brokers who bridge gaps between health care providers and families, but they are also experts in available health and community support services and how to access them.

The results of our study offer information that researchers, health care providers, and members of marginalized communities can use to jointly plan interventions for improving support and services for persons experiencing developmental disabilities. A community-based participatory approach engages the community in forming questions and identifying interventions that are culturally relevant and meaningful to community members.

CBOs are well situated to provide community-based, culturally and linguistically competent linkages and support. Health care providers should confer with such organizations and make appropriate referrals. In addition, they should use a medical home point-of-care model that provides coordinated and comprehensive patient-centered care to ensure that members of marginalized and underrepresented communities receive consistent, culturally and linguistically responsive information on which to base assessments, care decisions, outreach, advocacy, and interventions.

REFERENCES


CONCLUSIONS

Community-based participatory approaches to research are effective in exploring the challenges of persons with developmental disabilities in minority populations. Additional research regarding how developmental disabilities are perceived and how services are obtained in hard-to-reach or hardly reached communities is indicated.

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