

## PROMISING PRACTICES

# Cultural Brokers Help Families and Providers Bridge the Cultural Divide

## Background

### Disparities in Access and Services

In the United States, families of children and youth with epilepsy often lack access to organized community-based health care services and family-centered systems of care. As a result, many of these children are prevented from receiving appropriate and timely medical treatment, and their families lack essential support services. The 2005-2006 National Survey of Children with Special Health Care Needs indicated that children diagnosed with epilepsy were significantly less likely than other children with special health care needs to have families who reported that they were partners in decision making and satisfied with services (National Center for Health Statistics [NCHS], 2007). Children diagnosed with epilepsy were significantly more likely than other children with special health care needs to have families who reported that they had any unmet need for health care services (NCHS, 2007). On the 2007 National Survey of Children's Health, children with special health care needs from diverse racial and ethnic groups and those residing in medically underserved areas struggled more with these issues than their non-Hispanic White counterparts (NCHS, 2008).

### A Response to Disparities

The Epilepsy Foundation of America® is the national voluntary organization dedicated solely

to the welfare of the almost 3 million people with epilepsy and their families in the United States. The organization works to ensure that people with seizure disorders are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted, and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, more than 50 Epilepsy Foundation affiliates throughout the United States serve people with epilepsy and their families.

The Epilepsy Foundation of America supports the implementation of Project Access, an initiative of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services. Project Access is a national effort to improve access to health services and to ensure early detection and treatment for children and youth with epilepsy and seizure disorders residing in rural and medically underserved areas.

The National Center for Project Access (NCPA), under the auspices of the Epilepsy Foundation of America:

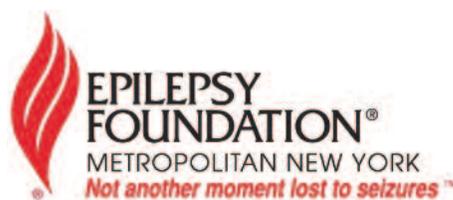
- works with states to develop public education and awareness campaigns to raise public and professional awareness about epilepsy;

*Background Continued*

- develops skill-building programs for youth and families with epilepsy and providers;
- develops and disseminates resources on trends and issues related to access to care for children and youth with epilepsy; and
- provides forums to stimulate discussion about strategies to reduce the shortage of epilepsy providers and improve access to care.

Project Access activities involve state agencies, physicians, and other health care providers; families; schools; and community resources. Project Access has been funded in three phases and has worked with 20 states to address the health care needs of children and youth with epilepsy.

In Phase Two, MCHB funded NCPA to oversee two affiliate projects in New York and Florida. In New York, The Epilepsy Foundation of Metropolitan New York (EFMNY) has been dedicated to improving the quality of life of people with epilepsy and their families. As the organization implementing Project Access in New York State, EFMNY has faced the challenge of supporting families from highly diverse racial, ethnic, and linguistic groups in New York City with children living with epilepsy.



## The Challenge

In New York City, 45.7% of the population are White; 25.1% are Black, 11.8% are Asian (the largest group is Chinese); and less than 1 percent are American Indian/Alaskan Native or Native Hawaiian or other Pacific Islander (U.S. Census Bureau, 2011a). The Hispanic population (of any race) comprises 27.4% of the city's population (U.S. Census Bureau, 2011a). There is great cultural diversity in the Hispanic population reflected in the multiple subgroups—33.3% Puerto Rican, 25.8% Dominican, 12.4% Mexican (the fastest growing group), 8.6% Ecuadorian, 4.9% Colombian, and 15% from other countries (Center for Latin American, Caribbean & Latino Studies, 2008).

New York City is also very linguistically diverse. Of the city's population, 48% speak a language other than English, and of that group almost half (49.2%) report speaking English less than very well (U.S. Census Bureau, 2011b). New York City's residents speak European, Native American, Asian and Pacific Island, Middle Eastern, and African languages as well as many

rare and nearly extinct languages (Roberts, 2010). Given the diversity of New York City, it is not surprising that EFMNY learned that there are many cultural and linguistic challenges to providing optimal care to children and youth with epilepsy and their families.

EFMNY took on the challenge of addressing the needs of New York City's very diverse populations of children and youth with epilepsy and their families by partnering with three institutions that serve diverse populations. At Montefiore Hospital in the Bronx, 85% served were Hispanic, primarily from the Dominican Republic and Puerto Rico. At the second partner site, Beth Israel Medical Center, 40% of the families served in the pediatric clinic were from Latin America and about 15% were Chinese. Finally, at their third partner, the Charles B. Wang Community Health Center, 100% of the families served were Asian (from several countries with a large percentage from China). EFMNY conducted a series of surveys, focus groups, and key informant interviews with community

*The Challenge Continued*

members, families of children and youth with epilepsy, and health care providers.

EFMNY uncovered the following challenges to ensuring appropriate and timely medical treatment and essential family support services for the populations served at the partner sites, including:

- **Community attitudes about epilepsy.** According to a community-based survey conducted by EFMNY in 2007 and 2008, about 40% of Hispanic adults stated that they believed that epilepsy was contagious and that their parents and grandparents had told them not to approach or touch someone having a “fit” because they would “catch it.” Hispanic adults also expressed the belief that someone having a “convulsion” was possessed by an “evil spirit.”
- **Very low parent satisfaction with their child’s services.** EFMNY conducted a focus group for parents at Montefiore Hospital in order to understand families’ concerns and needs for a more comprehensive system for delivering health care and related services. The results showed that about 90% of parents were not satisfied with their children’s specialty care or care provided by specialists. Parents expressed a number of concerns about their doctors including lack of

cultural sensitivity, inability to “connect” with them, and lack of communication.

- **Lack of knowledge among physicians about the cultures and language of the populations served.** According to information gained from interviews, the doctors treating children and youth with epilepsy and their families were not sure about how to deal with what they perceived as families’ resistance to epilepsy treatment and services. The doctors noted that even though they used interpreters when serving families with limited English proficiency, the families seemed to be missing important information about their children’s care. The doctors were unable to connect with the families because they were not effectively learning about and addressing the families’ values and beliefs about epilepsy and its treatment. Also, families were not always sharing their concerns and asking questions. Having the interpreters was an essential service. However, that service alone was not sufficient to support the doctors in establishing effective relationships with families, because they did not understand the cultural diversity of the Spanish-speaking populations they served. Thus, the doctors struggled to effectively interact with families.

## The Approach

EFMNY used a number of approaches to better support culturally and linguistically diverse families. One approach was to develop bilingual materials that provided information in English and another language in a side-by-side format to facilitate better communication with providers. However, EFMNY primarily relied upon a proven health intervention model used with culturally diverse populations and communities—cultural brokering. Cultural brokering has been defined as a health care intervention through which the professional increasingly uses cultural and

health science knowledge and skills to negotiate with the client and the health care system for an effective, beneficial health care plan (Wenger, 1995). A cultural broker can serve as a liaison, cultural guide, and mediator among patients, their families, and health care providers and organizations. A cultural broker can also serve as a catalyst for change to assist health care providers and organizations in adapting policies and practices to the cultural contexts of patient populations and communities served. EFMNY selected this model because of its potential to

*The Approach Continued*

directly impact the effectiveness of family and provider interactions and implemented a series of efforts to launch cultural brokering at the partner sites.

Individuals in many roles can be cultural brokers, but to be effective they must have the capacity to:

- assess and understand their own cultural identities and value systems;
- recognize the values that guide and mold attitudes and behaviors;
- understand a community's traditional health beliefs, values, and practices and changes that occur through acculturation;
- communicate in a cross-cultural context;
- interpret and/or translate information;
- advocate with and on behalf of children, youth, and families;
- negotiate health, mental health, and other service delivery systems; and
- mediate and manage conflict.

(National Center for Cultural Competence, 2004)

EFMNY identified two staff members to serve as cultural brokers between families and providers at the Montefiore Hospital Specialty Clinic and at the Beth Israel Medical Center Developmental Disabilities Center. Both are bilingual and were already serving as interpreters for some patient appointments. Jessica Morales is a native New Yorker of Puerto Rican ancestry. Helen Dao immigrated to the United States from El Salvador. Both Ms. Morales and Ms. Dao shared life experiences and possessed knowledge of the cultural traditions and norms of the families they serve. This combination of shared experience and knowledge made them excellent candidates for cultural brokering and afforded them the opportunity to explore the families' belief systems, including those related to epilepsy and

healing. Ms. Morales and Ms. Dao were able to establish rapport and talk with families about any traditional, holistic, and/or spiritual approaches to health and healing that they use. In addition to their cultural knowledge, Ms. Morales and Ms. Dao had extensive experience in health care systems, providing counseling in a women's clinic and working as specialists in intercultural communication. The cultural brokers provided language interpretation, served as mediators, and offered information to the providers about the within-group differences among the Hispanic population in their clinic. These cultural brokers also taught families about how the American health care system works and engaged them in teaching the providers about their cultures.

### How can cultural brokers help?

#### Helen Dao shared the following:

*One of the providers serving a child with severe epilepsy and her family expressed frustration that the family had not followed up on scheduled appointments and evaluations recommended by the care team. When working with the family, Ms. Dao learned that they were concerned about out-of-home care and that the appointments were all associated with residential placement. It was simply unacceptable, not at all in keeping with the family's values, to have a member cared for outside the family circle in a nursing home or other facility. The family chose not to inform the provider of their belief system because they did not want to be disrespectful. Ms. Dao was instrumental in this situation because she was able to bridge the gap between both the provider and the family through 1) clarifying the reasons why the appointments were needed and missed; 2) setting an example of how patients and providers can have a dialogue to discover their respective beliefs and practices that are immersed in culture; 3) identifying cultural beliefs and practices about respecting professionals who are in positions of authority; and 4) mediating a compromise between the family's values and practices vs. recommendations of the medical community.*

*The Approach Continued*

At the third partner site, Charles B. Wang Community Health Center (CBWCHC), the need for cultural brokers was addressed somewhat differently. The Center is staffed by individuals who are bilingual/multilingual and bicultural/multicultural. CBWCHC is well known for the provision of culturally and linguistically competent care. However, CBWCHC did not have an approach to providing support and related services for families whose children had epilepsy. Families were encountering great difficulty with specialty care delivered outside of the Center. Because of cultural barriers, these families were typically overwhelmed trying to negotiate the complex systems involved in serving their children.

EFMNY worked with CBWCHC to recruit a care coordinator for families of children with epilepsy who also served the dual role of cultural broker for the families seen at the Center in their encounters with specialty care. Like most of the families served by CBWCHC, the care coordinator was an immigrant and also spoke Mandarin. Although the care coordinator possessed the language capacity and cultural knowledge to support the patient population served by CBWCHC, she did not have knowledge and experience about epilepsy and specialty care. EFMNY provided this training and mentoring support that enabled the care coordinator to

also fulfill the role of cultural broker. EFMNY's insightful approach to professional development enabled the care coordinator to work effectively with the specialists and serve as a cultural guide. This approach in turn increased the specialists' awareness and understanding of the culturally defined values, beliefs, and practices of families of children with epilepsy. Moreover, the care coordinator facilitated support groups and provided training to families in how to use the bilingual care book and in how to be their own cultural broker.

EFMNY reported a very exciting result from the cultural brokering efforts at CBWCHC. One father was able to improve the services and support his son with epilepsy received at school. The father was able to use the bilingual (Chinese/English) care book developed by the EFMNY Project Access to communicate about his child's epilepsy care with school personnel. He reviewed the care book with the school nurse and explained the importance of understanding both his son's medical needs and the family's cultural needs and practices. The father also volunteered to share his experience with those participating in the CBWCHC support group for families with children with epilepsy. His personal experiences encouraged other families to bridge the cultural divides between school and health care systems.

## Outcomes

Although EFMNY's funding through Project Access has ended, the results have had an ongoing impact on changing the service system for children and youth with epilepsy and their families at the partner sites. The cultural brokers continue their impressive work at the two hospital partner sites. Ms. Dao notes that her presence at Montefiore Hospital was a key factor in changing providers' perceptions about families from Latin America and about the

importance of culture in the care they provide. There are now Medical Center faculty members who train residents about cultural and linguistic competence. Cultural issues are now always an important consideration to address during case conferences. Ms. Morales reports better communication between families and providers at Beth Israel. Families are better at sharing information and more willing to talk honestly about what they are doing in caring for their

*Outcomes Continued*

children. Providers have improved their openness to receive information about family approaches to caring for their children that may differ from their medical recommendations. One of the most important outcomes has been better partnerships between providers and families to create shared solutions to issues of care for children with epilepsy.

The work at CBWCHC has also been sustained. CBWCHC now funds the care coordinator, who continues to work as a cultural broker for families seeking specialty care. In the past, attempts to provide support groups for families had not been successful, but with the relationships and trust built by the cultural broker, CBWCHC has been able to offer this service for families.

### Building Trust Improves Care

**Jessica Morales shared the following:**

*As a cultural broker, Ms. Morales was successful in building a relationship of trust with the family of a child who has epilepsy. The family felt comfortable and began to share much more information about their child's care. The family shared an incident that occurred when they were traveling away from home. The child's medication supply was running low, and the family did not know how to obtain a refill where they were staying. At the suggestion of other family members, the parents cut the pills in half to make them last longer. In the past, if the parents were unsure about whether they had taken the correct action, they would never have shared this information with the doctor for fear of a negative reaction. In her role as a cultural broker, Ms. Morales served as a liaison between the family and the doctor to help build a relationship of trust. They were all able to discuss what to do in the future should the medication supply run low when the family was away from home. The doctor was pleased that she could educate the family on such an important issue. The family was relieved to have a practical solution and pleased that their child's doctor understood their dilemma.*

## Perspectives

### Perspective of the Epilepsy Foundation of America/NCPA

Cultural and linguistic competence is a core value for NCPA. Project Access seeks to improve access to comprehensive, coordinated health care and other services for culturally and linguistically diverse children and youth with epilepsy living in medically underserved and rural areas. Through the activities of the affiliates in New York and Florida, the Epilepsy Foundation of America implemented strategies to address identified disparities. The affiliates facilitated systems change at the state and local levels that 1) removed barriers to access to care; and 2) spurred quality improvement in care models that take culture and language into consideration for children and youth with

epilepsy in medically underserved urban and rural communities.

The following were additional Project Access successes:

- Outreach to families, especially families from racial and ethnic groups other than non-Hispanic White, through effective use of print media, radio, television, health fairs, festivals, churches, schools, and community-based clinics; and
- Use of culturally and linguistically competent care coordinators by some grantees to improve medical management for children and youth, reduce family stress, increase family/professional partnerships, and assist students and classroom teachers.

*Perspectives Continued*

**Perspective of the National Center for Cultural Competence**

The National Center for Cultural Competence (NCCC) highlighted the EFMNY activities because they exemplify cultural and linguistic competence in several ways:

- Cultural competence is achieved by identifying and understanding the needs and help-seeking behaviors of individuals and families. Through focus groups and surveys, EFMNY learned about the specific needs and issues that affected access to care.
- Culturally competent organizations design and implement services that are tailored or matched to the unique needs of individuals, children, families, organizations, and communities served. In each of the partner settings, using cultural brokers allowed for services to directly address the unique cultural beliefs, values, and needs of the families they served.
- Culturally and linguistically competent organizations ensure that practice is driven by client preferred choices, not by culturally blind or culturally free interventions. Through the use of cultural brokers, all three partner organizations were able to support changes in attitudes, knowledge, skills, and beliefs of specialty care physicians that changed how they provided care for the diverse Spanish-speaking and Asian children with epilepsy and their families.
- Culturally competent organizations ensure that the individuals chosen to serve as cultural brokers have the required awareness, knowledge, and skills to fulfill that role and, when needed, provide additional training and mentoring. EFMNY used a careful selection process and assessed training needs for those chosen to serve in the role of cultural broker.

**NCCC RESOURCES**

**Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programs**

[http://nccc.georgetown.edu/documents/Cultural\\_Broker\\_Guide\\_English.pdf](http://nccc.georgetown.edu/documents/Cultural_Broker_Guide_English.pdf)

**Promoting Cultural Diversity and Cultural Competency: Self-Assessment Checklist for Personnel Providing Services and Supports to Children with Disabilities and Special Health Needs and their Families**

<http://nccc.georgetown.edu/documents/ChecklistCSHN.pdf>

**Getting Started: Planning, Implementing and Evaluating Culturally and Linguistically Competent Service Delivery Systems for Children With Special Health Needs and their Families**

[http://nccc.georgetown.edu/documents/Getting\\_Started\\_CSHN\\_2003.pdf](http://nccc.georgetown.edu/documents/Getting_Started_CSHN_2003.pdf)

**Policy Brief: Cultural and Linguistic Competence in Family Supports**

<http://nccc.georgetown.edu/documents/FamilySupports.pdf>

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## About the National Center for Cultural Competence

The NCCC provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education, and advocacy.

The NCCC uses four major approaches to fulfill its mission including (1) Web-based technical assistance, (2) knowledge development and dissemination, (3) supporting a “community of learners,” and (4) collaboration and partnerships with diverse constituency groups. These approaches entail the provision of training, technical assistance, and consultation and are intended to facilitate networking, linkages, and information exchange. The NCCC has particular expertise in developing instruments and conducting organizational self-assessment processes to advance cultural and linguistic competency.

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