

PROMISING PRACTICES

Community Engagement and Partnerships Improve Access to Medical Homes

Background

Disparities in Access and Services by Race, Ethnicity, and Language

In the United States, children, youth, and families affected by epilepsy often lack access to organized community-based health care services and to family-centered systems of care. As a result, families are often prevented from receiving appropriate and timely medical treatment and essential family support services. On the 2005-2006 National Survey of Children with Special Health Care Needs, children diagnosed with epilepsy were significantly less likely than other children with special health care needs to have families who reported that they received coordinated, ongoing, and comprehensive care within a medical home (36.1% vs. 47.5%) (National Center for Health Statistics [NCHS], 2007). Children 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. These disparities in access and service were further exacerbated by race, ethnicity, and lack of English language proficiency. For example, children and youth with special health care needs, overall, who were Hispanic (32.2%) or non-Hispanic Black (36.8%) were far less likely to have families who reported that they had a medical home than White, non-Hispanic children (52.8%) (NCHS). Lack of English language proficiency had a particularly

negative impact on children and youth with special health care needs having a medical home. Of Hispanic children who lived in households where English was the primary language, 37.8% were reported to have a medical home (NCHS). In contrast, only 20.2% of children living in households where Spanish was the primary language had a medical home (NCHS).

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

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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;
- 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 Florida and New York. The Epilepsy Foundation of Florida (EFOF) serves as the lead advocate for the rights and needs of people with epilepsy and seizure disorders at the local, county, and state levels in the State of Florida. EFOF services the estimated 360,000 Floridians with the condition. Its mission is to ensure that people with seizure disorders are able to participate in all life experiences, as well as prevent, control, and cure epilepsy, through comprehensive services, education, advocacy, and research. These efforts seek to improve how people with epilepsy are perceived, accepted, and valued in society.



The Challenge

Although EFOF serves the entire state of Florida, Miami-Dade County was the focus of its initial Project Access activities. This county has extraordinary racial, ethnic, and language diversity. Currently, 65% of the population are Hispanic or Latino, 19.9% are Black, and 15.4% are non-Hispanic White (U.S. Census Bureau, 2011). Almost half of the county's residents (49.4%) were born outside the United States and are from more than 100 countries (U.S. Census Bureau). Just over 70% of the population over the age of 5 speak a language other than English at home (U.S. Census Bureau). Approximately a third (36.4%) of those who speak a language other than English live in a linguistically isolated

household in which no one over the age of 14 speaks only English or speaks English very well (U.S. Census Bureau). Thus, a large proportion of the residents of Miami-Dade County may encounter cross-cultural, language, or potential legal barriers to accessing health care for themselves and their families.

EFOF provides comprehensive case management and medical services to adults and children with epilepsy who lack private health insurance. The population served closely reflects the diversity of Miami-Dade County—65% Hispanic and 25% African-American/Black, with places of birth spanning 42 countries. Although

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the children and youth served by EFOF receive excellent neurologic care, well over half of these children lack a usual source of primary care. These mostly immigrant families, approximately a third of whom lack permanent legal resident status, use the county’s emergency department for their child’s general health needs.

The Florida State Department of Health administers the Children’s Medical Services (CMS) Network. CMS is a comprehensive system of care for eligible children and youth with special health care needs from birth through age 18 with family income up to 200% of the federal poverty level. This system of care focuses on ensuring that children and youth with special health care needs receive comprehensive, family-centered care in a medical home setting. CMS also ensures these children and youth receive a range of other intervention and prevention services through a network of local community practitioners, hospitals, and university medical centers around the state. As EFOF staff worked with families in Miami-Dade County, they discovered several disparities in families’ ability to access this comprehensive system of care within the county. First, the lack of health insurance was a barrier to having a medical home for many children and youth, and second, uninsured families were experiencing trouble enrolling in CMS.

EFOF case managers engaged key community informants and learned that parents who were recent immigrants could be fearful of seeking services from CMS. Even when the child was born in the United States and is a citizen, the parent’s lack of legal status created concerns for families. The EFOF case managers described “the system of care” as being complicated and difficult to navigate for any parent. Further, they noted that accessing the system was even more difficult when families had limited English skills. EFOF case managers reported that even when they initiated the enrollment process through referral, in many instances the child or youth was not successfully enrolled.

Data collected by EFOF revealed the following reasons:

- Staff at the local level responsible for determining eligibility were not bilingual, nor were interpreters consistently available.
- The local-level staff did not understand that epilepsy is a chronic condition and is automatically covered by CMS.
- Parents were working and not home to receive intake calls from CMS workers.
- Parents were fearful of speaking to a stranger representing the “system” or government.

The Approach

Organizational Policies and Structures to Address Cultural and Linguistic Competence

EFOF considers cultural and linguistic competence as a key component of patient safety and customer service. EFOF has incorporated a range of culturally and linguistically competent policies, structures, and procedures into the way the organization

operates and dedicates resources to implementing them, including:

- **Training and professional development.** Training on cultural and linguistic competence is incorporated into the agency’s orientation for new hires.
- **Culture and language concordant services.** EFOF works to match clients with a case

The Approach Continued

manager who is culturally and linguistically compatible.

- **Primary language data collection.** All individuals and families served are asked what their language preferences are and whether they require an interpreter. This information is documented in their electronic medical record.
- **Language access services.** EFOF ensures language access through trained staff members and certified interpreters and the use of a telephone language line. Informational brochures and materials are available in Spanish and Haitian Creole, and the agency Web site is currently being revamped to have all information posted in three languages.
- **Community engagement and needs assessment.** The agency conducts a Limited English Proficiency (LEP) survey annually to ensure that services and educational materials meet the needs of the communities served.
- **Service utilization management.** EFOF monitors its utilization data to ensure it is serving families that match the cultural, racial, ethnic, and language make-up of the community.

Changing Services to Meet Cultural and Language Needs

EFOF formed a partnership with Florida’s CMS program to address disparities in access to services, including a medical home, for children and youth from racially, ethnically, and linguistically diverse groups and their families. Initially, EFOF held a series of meetings with the CMS State Director, who was provided with information on the disparities and the critical need for services to specific populations. The CMS State Director subsequently required that meetings be held with regional supervisors to inform them about the difficulties that both families and EFOF staff encountered when attempting to enroll families in the CMS system.

Engaging the Community to Increase Access and Utilization of EFOF Services

EFOF used its LEP survey to improve engagement of families in the Haitian community in its services and programs. EFOF surveyed Haitian community leaders to learn about cultural values and beliefs related to epilepsy and its treatment and to ascertain effective communication approaches with families. EFOF discovered that a number of cultural beliefs and practices, including the belief that epilepsy is a spiritual issue and not a medical problem, impact Haitian families’ likelihood of accessing its services. Lack of trust in the government and programs viewed to be funded by or related to government is also a significant barrier. EFOF also learned that the spoken word as opposed to written materials is the best way to reach the Haitian community. Among the local media, Haitian Creole language radio is more effective than television in bringing messages to the Haitian community.

EFOF conducted an array of efforts, such as providing information about epilepsy and increasing awareness of the types of services it provides, to engage the Haitian community. Staff gave presentations to the Florida Chapter of the Association of Haitian Physicians Abroad (L’Association des Médecins Haïtiens à l’Étranger). It should be noted that none of the 80 physician members of this organization had ever heard of EFOF before intentional efforts to engage them. Staff participated in live Creole language call-in radio shows with a Haitian physician. Delivering messages in collaboration with a known and respected community member gave EFOF entrée and credibility within the Haitian community. Staff developed Creole language public service announcements that were aired on Creole language radio stations.

Staff also visited Haitian Community Centers to promote EFOF services. After these efforts, enrollment of Haitian families of children living with epilepsy increased by 20%.

The Approach Continued

A major outcome of these meetings was assigning bilingual CMS staff to the EFOF office once a week. This was an important step because the staff spoke the languages of the families in need of the program and were responsible for eligibility determination. The CMS staff, EFOF case manager, and parents/guardians met as a team. The EFOF case managers were responsible for contacting the family to schedule a meeting and for explaining what documents were required and what paperwork would be completed during the meeting. The EFOF case managers took special care to reassure the family that seeking services through CMS would not affect their immigration status in any way. All telephone calls made by CMS staff were from the EFOF offices. If families were not home at the time of the call, they recognized the telephone number on the message as being from EFOF rather than from a state agency. Therefore, they were not hesitant about returning the call to their case manager. Attendance was nearly perfect at the scheduled meetings. This response was due to the trusting relationship built between the EFOF case manager and the family, over a period of time. At the end of 1 year, all children in the program

had health care coverage, including CMS. Approximately 125 of these children and youth had been previously uninsured and without a medical home.

As a culturally and linguistically competent organization, EFOF did not consider the job “done” but continued to monitor the needs of the group of children with immigrant parents over time. A change in the regional CMS office occurred; CMS was not as open to supporting immigrant families. This change negatively impacted the previous success of the EFOF program to ensure access to services through CMS coverage. EFOF subsequently turned to other safety net programs within the community, such as community health centers and pediatric mobile health clinics, with which to partner. EFOF worked to inform and educate these community-based health care organizations about the needs of children and youth with epilepsy and their families. EFOF also worked to ensure that the community health center pharmacies stocked the specialized medications needed by this population. EFOF has plans to expand these approaches across Florida.

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 Florida and New York, 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

Perspectives Continued

- 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.

Perspective of the National Center for Cultural Competence

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

- EFOF seeks to identify and understand the needs and help-seeking behaviors of individuals and families. Through engagement with the families they serve, focus groups, and surveys, EFOF learned about the specific needs and issues that affected access to care for children and youth with epilepsy whose families were immigrants.
- EFOF implements approaches that acknowledge the importance of cultural and linguistic competence to quality care and patient safety.
- EFOF has a fully developed plan for ensuring language access services for the populations it serves. The plan, embedded in organizational policy and practice, includes:
 - asking at intake about language preferences;
 - documenting those preferences in electronic medical records;
 - providing on-site or telephone access to trained and certified interpreters;
 - creating written materials in languages of the community they serve; and
 - engaging in ongoing assessment of language access needs through an annual survey within the communities they serve.
- EFOF employs staff who reflect the racial, ethnic, and linguistic make-up of the communities they serve.

ADDITIONAL RESOURCES

Outreach Strategies for Medicaid and SCHIP: An Overview of Effective Strategies and Activities

Health Division, Children’s Defense Fund
The Kaiser Family Foundation Report No. 7495
April 2006
<http://www.kff.org/medicaid/upload/7495.pdf>

Cultural Competence California Style

Cindy Brach and Kathryn Paez and Irene Fraser
Agency for Healthcare Research and Quality
Working Paper No. 06001, February 2006
http://www.neserve.org/maconsortium/pdf/Other_Topics/Cultural_Competence_California_Style.pdf

California Insurers Work to Comply with Regulations for Interpreter, Translations Services

Article adapted by *Medical News Today*
November 2007
<http://www.medicalnewstoday.com/articles/89851.php>

Language Services Action Kit: Interpreter Services in Health Care Settings for People Limited English Proficiency

http://www.healthlaw.org/index.php?option=com_content&view=article&id=119:language-services-action-kit-interpreter-services-in-health-care-settings-for-people-with-limited-english-proficiency-revd-feb-04-&catid=40
National Health Law Program & The Access Project
Updated February 2004

Funding Sources for Language Access Services

Information and resources, including federal, state, local, and other funding sources, for language access services.
http://reachnola.org/pdfs/Funding_Sources_for_Language_Access_Services.pdf

Diversity and Cultural Competency in Health Plans

A set of resources for health plans from America’s Health Insurance Plans (AHIP), the national association representing nearly 1,300 member companies.
<http://www.ahip.org/content/default.aspx?bc=38%7C10760>

Perspectives Continued

- EFOF tailors the services it offers in ways that reflect a key principle of cultural and linguistic competence. This principle states that practice is driven in service delivery systems by client preferred choices, not by culturally blind or culturally free interventions.
- EFOF engages in ongoing monitoring of service utilization to determine whether the demographics of families served are commensurate with the demographics of the communities in Miami-Dade County.
- EFOF advocates for the specific needs of culturally and linguistically diverse groups in the communities they serve within the broader private and public health care services and financing systems.

References

National Center for Health Statistics. (2007). *National Survey of Children with Special Health Care Needs, 2005/2006*. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health Web site. Retrieved September 26, 2011, from <http://www.childhealthdata.org>

U.S. Census Bureau. (2011). *State and County QuickFacts*. Retrieved September 26, 2011, from <http://quickfacts.census.gov/qfd/states/12/12086.html>



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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