Family-centered, Culturally, and Linguistically Competent Care: Essential Components of the Medical Home

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CME EDUCATIONAL OBJECTIVES
1. Identify compelling reasons to provide care that is family-centered and culturally and linguistically competent.
2. Explain conceptual frameworks and definitions for family-centered care as well as cultural and linguistic competence.
3. Demonstrate practical approaches useful at the individual practice level that advance and sustain this type of care.

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The movements to advance family-centered care and cultural and linguistic competence in healthcare have evolved along parallel tracks. This dichotomy is evident not only in the literature but also in healthcare policy and practice. However, family-centered care and cultural and linguistic competence are actually integrally linked. Yet many within the pediatric healthcare community continue to struggle to integrate these approaches to care. It is difficult to provide a medical home, as defined by the American Academy of Pediatrics (AAP), when the healthcare provider or team does not know or understand how to address the culture and language of patients and their families (see Sidebar 1, page 506). Therefore, it is essential that healthcare professionals, who are committed to providing a medical home for a diverse population of children and families, know why and how to
Medical Home Definition

The American Academy of Pediatrics (AAP) defines a medical home as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.

REASONS TO PROVIDE CARE THAT IS FAMILY-CENTERED AND CULTURALLY AND LINGUISTICALLY COMPETENT

There are several reasons to provide care that is family-centered and culturally and linguistically competent (see Sidebar 2).

The nation’s growing diversity.

The nation’s population is increasing in racial, ethnic, and linguistic diversity, and this trend is expected to continue. Currently, one-third of the U.S. population is made up of racial and ethnic groups other than non-Hispanic whites. By 2050, it is estimated that whites (currently 69% of the population) will only make up 50% of the population, while the black population (currently 13%) will increase slightly to 15%, Hispanics/Latinos (currently 13%) to 24%, and Asians (currently 4%) to 8%.6 In 2000, 18% of the total population 5 years and older reported speaking a language other than English at home. These figures were up from 14% (31.8 million) in 1990 and 11% (23.1 million) in 1980.7,8

Persistence of healthcare disparities that continue to affect specific racial and ethnic populations disproportionately.

There is a strong body of literature that documents pediatric health care disparities as affecting specific racial and ethnic populations disproportionately (see Sidebar 3). For example, compared with white children, black and Hispanic children are more likely to be born to mothers who receive no prenatal care,9 have lower rates of immunization,10 higher rates of lead poisoning,11 and are less likely to be prescribed controller medications for asthma.12,13 Recent estimates suggest that more than 40% of blacks and one-third of Hispanic children have public insurance such as Medicaid or State Children’s Health Insurance Program (SCHIP).14 A national study of children with special health-care needs found that, when compared with non-Hispanic white families with a successful medical home (53%), 32% of Hispanics, 37% of blacks, and 47% of multiracial patients receive the components of care within a medical home significantly less frequently.15

Family-centered and culturally competent care improves quality, safety, and satisfaction with care.

Family-centered Care

Studies of family-centered pediatric care have begun to demonstrate the value of this approach for improving clinical outcomes, increasing satisfaction with care, and the effective use of resources and services16-18 (see Sidebar 4). Moreover, family-provider partnerships, a major component of family-centered care, have had a positive effect on families through improved communication to encourage patient participation in their care plans, as well as access to community-based support services.19

Cultural and Linguistic Competence

Clear and convincing evidence has documented the role and efficacy of cultural and linguistic competence in 1) increasing access to and acceptability of care, 2) improving quality and safety in the provision of care, and 3) reducing disparities in health and mental healthcare and in the health status/outcomes for racially and ethnically diverse populations.20-24

Multiple legislative, regulatory, and accreditation mandates.

Two federal requirements promote cultural and linguistic competence in healthcare: 1) Title VI of the Civil Rights Act of 1964, which prohibits discrimination based on race or origin in organizations that receive federal funds; and 2) the National Standards on Culturally and Lin-
guistically Appropriate Services (CLAS), which are a blueprint for improving cultural and linguistic competence in healthcare organizations (see Sidebar 5).

In 2008, there were significant policy and accreditation efforts enacted. The Joint Commission launched an initiative to explore additional accreditation requirements to help hospitals better address effective communication, cultural competence, and patient-centered care. The National Quality Forum released a Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency, a set of national voluntary consensus standards. Additionally, research conducted for The Robert Wood Johnson Foundation studied 14 states that have either introduced or enacted legislation that mandates the integration of cultural and/or linguistic competence into curricula, continuing education, and licensure requirements for health professionals.

Although federal legislation has proposed some requirements for medical homes, several states also have laws supporting medical homes for children with public insurance. For example, a 2008 Massachusetts law included priorities to establish 1) hospital-based, patient and family quality of care programs, and 2) hospital rapid-response methods that offer providers, patients, and family members immediate assistance for deteriorating healthcare status. A component of the Consumer Assessment of Health Plan Survey (CAHPS) specifically measures aspects of family-centered care for children and youth with special healthcare needs (CYSHCN), and its use is required in some states to assess family satisfaction with care for children served by Medicaid plans.

FAMILY-CENTERED CARE AND CULTURAL AND LINGUISTIC COMPETENCE DEFINED WITHIN THE CONTEXT OF A MEDICAL HOME

Conceptual frameworks and definitions for family-centered care and cultural and linguistic competence vary considerably. The following definitions have been selected for inclusion in this article because they are well documented in the literature, have clear relevance to the medical home, and illustrate how family-centered care and cultural and linguistic competence are integrally linked.

Family-centered Care

Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. It is the standard of care that results in high-quality services for all children.

The following describes salient aspects of this care:

- It acknowledges the family as the constant in a child’s life;
- It builds on family strengths;
- It supports the child in learning about and participating in his/her care and decision-making;
- It honors cultural diversity and family traditions;
- It recognizes the importance of community-based services;
- It promotes an individual and developmental approach;
- It encourages family-to-family and peer support;
- It supports youth as they transition to adulthood;
- It develops policies, practices, and systems that are family-friendly and family-centered in all settings;
- It fosters an environment of mutual respect and responsibility; and
- Celebrates successes.

Cultural Competence

Cultural competence requires that individuals, organizations, and systems have a congruent, defined set of values and principles as well as an ability to demonstrate behaviors, attitudes, policies, and structures that enable healthcare providers to work effectively cross-culturally (see Sidebar 6). Culturally competent healthcare organizations:

- Value diversity;
- Conduct self-assessment;
- Manage the dynamics of difference;
- Acquire and institutionalize cultural knowledge;
- Adapt to the diversity and cultural contexts of communities they serve; and
- Incorporate all of the above into all aspects of policymaking, administration, practice, and service delivery while systematically involving families/consumers, key stakeholders, and communities.

Cultural competence is a developmental process that evolves over time. Individuals, organizations, and systems are at various levels of awareness, knowledge, and skills along the cultural competence continuum. The guiding values and principles of cultural competence involving families include the following:
SIDEBAR 7.

Family-centered, Culturally, and Linguistically Competent Care: Practice/organizational Level

Value Diversity
Implement a practice model that acknowledges and is responsive to the diversity among families of children and youth with healthcare needs.

Recruit diverse staff that is representative of the populations in the service area.

Conduct Self-assessment
Implement an assessment to determine the extent to which the principles and core components of family-centered, culturally, and linguistically competent care are woven throughout the team/practice/organization.

Manage the Dynamics of Difference
Prepare and support staff, at all levels of the team/practice/organization, to communicate with and to interact effectively with each other as well as with patients and their families who are from cultures and/or who speak languages different from their own.

Institutionalize Cultural Knowledge
Establish structures that enable practice/organizational staff to:
- Share knowledge and experiences about cultural practices, traditions, and norms related to health and mental healthcare for the patient populations and communities served;
- Receive training, mentoring, and consultation to enhance knowledge and skills necessary to address culture, language, and health literacy in the provision of care for children, youth, and their families; and
- Engage cultural brokers and key informants to acquire knowledge about health beliefs and practices of emergent new populations in the service delivery area.

Adapt to Diversity and the Cultural Contexts of Communities Served
Plan and implement adaptations to patient education, prevention, treatment, and related supports based on the culturally defined preferences and needs of the children, youth, and families served.

Consider using cultural brokers, linking to community-based advocacy organizations concerned with CYSHCN, and engaging parent partners/leaders to serve as liaisons that are both vested in and reflect the communities served to enhance accessibility and acceptability of care.

- Consumers are engaged in evaluation of language access and other communication services to ensure for quality and satisfaction.31

APPLYING THESE CONCEPTS TO THE MEDICAL HOME

The conceptual frameworks and definitions of family-centered care, cultural competence, and linguistic competence are integral to each component of the medical home.

Accessibility
The AAP defines an aspect of accessibility within the medical home as being able to speak directly with the medical home provider when needed. The capacity to communicate effectively with families of any culture, including those who speak languages other than English, is essential to care that is family-centered and culturally and linguistically competent.

Continuity
The AAP defines several aspects of continuous care within the medical home. Healthcare providers need to offer assistance with the hospital discharge process and with transitions of care to school, home, other healthcare providers, and adult supervision. Eliciting and understanding the family's culturally defined preferences and needs, as well as the family's health beliefs during the planning process for any type of transitional care, enable providers to support the family in achieving healthcare goals.

Comprehensive
The AAP defines one aspect of comprehensive care within the medical home as advocating for such care for the child and family and sharing responsibility for that care. Cultural and linguistic competence within the medical home requires the capacity to advocate with and on behalf of families, children, and youth to
address healthcare disparities and promote health equity.

**Family-centered**

The AAP defines family-centered care within the medical home as 1) the existence of mutual responsibility and trust between the patient and family and the patient’s medical home; 2) the recognition of the family as the principal caregiver and center of strength and support for child; and 3) the sharing of clear, unbiased, and complete information and options on an ongoing basis with the family. The delivery of family-centered care within the medical home requires the capacity to elicit, understand, and be responsive to the cultural preferences and needs of children, youth, and families. This type of care includes, but is not limited to, understanding that families may have experienced bias, prejudice, and discrimination within healthcare systems that in turn may affect their ability to form trusting relationships with their healthcare providers and medical systems. It also requires family-professional partnership and shared decision-making.

**Coordinated**

The AAP defines coordinated care within a medical home as 1) a plan of care developed in collaboration with the family, child, and youth that is shared with other care providers and agencies; and 2) a central record or database containing all pertinent medical information that is accessible and confidential. Care that is both family-centered and culturally and linguistically competent requires the capacity to integrate the cultural, linguistic, and literacy preferences and needs of the family within the care plan.

**Compassionate**

The AAP defines compassionate care within a medical home as interactions that demonstrate concern for the well-being of the child and family. Cultural beliefs and practices influence expressions of compassion from both the perspectives of the provider and the family. Family-centered and culturally and linguistically competent care acknowledges the dynamics of difference in how compassion and empathy are both expressed and received and strives to eliminate cultural barriers in an authentic and humble manner.

**Culturally Effective**

The AAP defines culturally effective care within a medical home as making concerted efforts to ensure that the child and family understand the results of the medical encounter and the care plan, including the provision of professional translators or interpreters, as needed, and providing written materials in the family’s primary language. Delivery of culturally effective care must be supported by a defined set of values that can be delivered through the presence of policy, procedures, structures, and practices that will enable providers to work effectively cross-culturally.

**CHALLENGES**

As illustrated in two short vignettes, both families and physicians face challenges in achieving care that is truly family-centered and culturally and linguistically competent. Recognizing these challenges, and learning and practicing new approaches to overcome them, can improve the delivery of quality healthcare to families and children from diverse cultural and linguistic backgrounds.

**Vignette 1**

What follows is an excerpt from a letter from a parent of a child with special healthcare needs that was written to a family-to-family organization.

“Most of Basil’s doctors do not speak Spanish. Sometimes there is a Spanish-speaking person in the waiting area to take our insurance information, but that person does not go in to the doctor’s
office to help us interpret. Usually, we leave an appointment with a lot of unanswered questions, but we do not like to ask because we worry that the doctor will be displeased with us. We use traditional medicine as well as going to the children's hospital to see the specialists, but we are afraid to tell the doctor about our traditional practices. My mother brings medicines from Mexico for Basil and wants us to give them to him. It is hard to know what to do.”

Cultural Implications of Vignette 1

Language access services and attention to health literacy should be provided at all points of contact within the medical home. Family members may demonstrate basic English-language skills; however, they may need and prefer to receive information in their language of origin to participate fully in the care of their child.

Additionally, family norms, codes of behaviors, and communication practices that guide interactions with authority figures and/or those who are held in high esteem (i.e., physicians) should be considered by healthcare providers and staff.

The use of complementary, indigenous, and traditional healing practices should be explored by healthcare providers. Many families are reticent to share their beliefs and practices with their medical home provider because they fear being judged as less sophisticated because of their beliefs.

Some families are in the midst of the process of acculturation. They struggle to adjust to and accept new medical practices while simultaneously holding onto their traditional practices that are supported by extended family members and cultural group members.

Reflections
1. How can the issues raised by this vignette be addressed in your practice/organization?
2. What are the policies within your practice/organization on the provision of language-access services?
3. How is information from families about the use of complementary, indigenous, and traditional healing practices elicited?
4. How are trust and partnership with this family established?

For some families, the medical home provider may not necessarily be the most trusted and credible source of information.

Vignette 2

What follows is a story told by a family member seeking help from a family-to-family organization.

“I brought my daughter to the local clinic because she was constantly having ear infections. Even with her father holding her down, the physician could not complete the exam because my daughter was terrified. The physician suggested scheduling an appointment the following week, so that my daughter could be put under anesthesia in order to examine her ear. I made the appointment but did not show. I felt that the physician was too quick to recommend what I perceived to be a risky medical intervention. I read on the internet that children have increased risk of dying under anesthesia. Other members of my family strongly advised against it.”

Cultural Implications of Vignette 2

A key component of a medical home is the capacity to engage the family and to partner in decision-making. Negative consequences may result when shared decision-making is neither attempted nor honored. Also, cross-cultural communication skills are associated with the delivery of high-quality care that is effective and safe. This set of communication skills includes the capacity to convey and receive messages/information through both verbal and non-verbal expressions.

For some families, the medical home provider may not necessarily be the most trusted and credible source of information. Some families rely on the internet, family members, and friends as primary sources of advice. This reliance presents a challenge for the medical home when such medical advice is not in the best interest of the child because it may be inaccurate or applied erroneously.

Reflections
1. How could this clinical encounter have been handled differently?
2. What are underlying assumptions of the medical home provider and the family?
3. How do you negotiate decision-making with families and youth?
4. What are some approaches to query families about their primary sources of health information?

CONCLUSIONS AND FUTURE CONSIDERATIONS

Physicians and other healthcare providers can take many steps to ensure that families receive family-centered, culturally, and linguistically competent care within a medical home. Medical home providers should:

- Reflect upon their belief systems and attitudes.
Examine and refine their communication patterns and styles.

Seek knowledge about culturally defined health beliefs and practices.

Recognize and appreciate the diversity of their healthcare team and work with them to broaden opportunities for successful cross-cultural communication.

Seek to recruit a high-quality healthcare team that is representative of the populations that they serve.

Encourage families from diverse backgrounds to provide feedback about their experiences of care.

Learn about community resources that are available to the families served and periodically inquire about their effectiveness.

Invite and encourage an array of families to participate in practice/organizational advisory committees and ensure that they are supported in their roles.

Review existing policies and procedures to ensure that they are consistent with a practice model capable of responding effectively to the multiple dimensions of culture and language in the provision of care.

Striving to achieve family-centered and culturally and linguistically competent care is an ongoing process. The outcomes for the families, youth, and children served are worth the efforts to reach these significant healthcare goals. Sidebar 7 (see page 508) and Sidebar 8 (see page 509) offer an array of approaches that can be useful in this process for both individual medical home providers and their practices and organizations.

REFERENCES


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