



# AND THE Journey Continues...

Achieving Cultural and Linguistic Competence in Systems Serving  
Children and Youth with Special Health Care Needs and their Families



DEVELOPED BY THE



National Center for  
Cultural Competence

Georgetown University Center for  
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**SUGGESTED CITATION:** Goode, T. D., Jones, W., Dunne, C., & Bronheim, S. (2007). *And the journey continues...Achieving cultural and linguistic competence in systems serving children and youth with special health care needs and their families*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

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This monograph was developed with funding from the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. The NCCC operates under the auspices of Cooperative Agreement # U40MC00145. The DSCSHN Project Officer for this Cooperative Agreement is Diana Denboba.

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# Acknowledgements

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This monograph was developed by the National Center for Cultural Competence. It was written collaboratively by NCCC faculty including: Tawara D. Goode, Center Director, Wendy Jones, Director, Children and Youth with Special Health Care Needs Project, Clare Dunne, Research and Policy Associate, and Suzanne Bronheim, Senior Policy Associate.

We acknowledge the contributions of NCCC consultants Lisa Lopez-Snyder and Public Research and Evaluation Services, Inc. that collected stories from State and Territorial Children with Special Health Care Needs (CSHN) programs. We also acknowledge the contributions of Jean Anastasi, editor, Kylee Breedlove, graphic designer, and Tiffany Knight, NCCC research assistant.

We are deeply grateful for the key informants from 18 states and 1 territory for sharing their stories with us. For a complete listing of state and territorial key informants refer to the “Story Tellers” section of the monograph.

Finally we acknowledge Diana Denboba, NCCC Project Officer, for her tireless leadership, commitment, and enthusiasm to inspire others to take the journey towards achieving cultural and linguistic competence.



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# Cultural and Linguistic Competence It's a Journey... Not a Destination



As individuals and organizations strive to implement cultural and linguistic competence, they seek validation that they have “arrived”—that they as individuals and organizations have achieved cultural and linguistic competence.

The National Center for Cultural Competence (NCCC) embraces a conceptual framework and model for achieving cultural competence based on the work of Cross et al. (1989). Cultural competence requires that organizations have a defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally. Linguistic competence, as defined by Goode and Jones (2006), is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Cultural and linguistic competence are developmental processes that evolve over an extended period of time. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

Those who strive to “own” cultural and linguistic competence and to live it are on a journey. The seeking, the learning, and the changing sustained over time are the essence of the journey. The NCCC supports organizations and individuals wherever they are along the journey, and helps them to create a roadmap for the next leg of their trip.

This monograph was designed to offer insights and lessons learned by the NCCC during the past 13 years. Additionally, the NCCC is pleased to present, in this monograph, stories from the journeys of State Title V Children with Special Health Care Needs (CSHCN) programs. Through these stories, state and territorial programs share their experiences in implementing culturally and linguistically competent policies, structures, and practices.

The NCCC invites you to take an excursion, learn about the experiences of others, and consider taking some of these innovative routes on your own journey.



# Beginning the Journey



The Division of Services for Children with Special Health Care Needs (DSCSHN) within the federal Maternal and Child Health Bureau (MCHB) has provided leadership in promoting cultural and linguistic competence in organizations addressing maternal and child health at federal, state, and local levels; in family advocacy and support organizations; and among health and mental health professionals. The MCHB journey began with a small band of visionaries who recognized the need to address culture and language in fulfilling the Bureau’s mission related to children and youth with special health care needs. Efforts would eventually expand to include the entire Bureau, the Health Resources and Services Administration (HRSA), and its grantees including State Title V programs.

Early steps on the journey included addressing cultural competence in “Campaign ‘87—Commitment to Family-Centered, Community-Based, Coordinated Care for Children with Special Health Care Needs.” The kick-off meeting for the Campaign, spearheaded by then-Surgeon General C. Everett Koop, was held in Houston, Texas, in 1987.

The following year, DSCSHN’s Genetics Branch pioneered efforts focusing on disparities in access to health care, and funded a series of projects to overcome ethnocultural barriers to the use of genetic services and to increase the use of these services by populations confronted with cultural and language barriers. This initiative specified the need for cultural competence training among service providers, and for culturally and linguistically appropriate outreach and education efforts to racially and ethnically diverse communities. In 1989, two years after the Surgeon General’s Campaign, the vision of building systems to serve children and youth with special health care needs and the role of MCHB and State Title V programs were institutionalized through Omnibus Budget Reconciliation Act (OBRA) of 1989. Through this legislation, the role of State Title V CSHCN programs shifted from providing direct services to building family-centered, community-based systems of care for children and youth with special health care needs. Although the legislation did not directly specify cultural competence as an attribute of these systems, MCHB immediately included cultural competence in its guidance to states on defining systems of care.

The year 1990 was a crucial time in MCHB’s journey toward cultural competence. That year, the first cultural competence conference funded by MCHB (and the first in HRSA) was held in collaboration with Howard University’s Child Development Center. A work group comprising state programs, other grantees, and family leaders was convened to identify needs and develop plans for cultural competence in the six states attending the conference. (This work group expanded and continued for four years.) During that same year, MCHB changed its mission statement to embrace cultural competence. In 1991, to reinforce the importance of cultural competence, MCHB released the publication “Improving Services for Culturally Diverse Populations,” which described DSCSHN activities in this area.

DSCSHN took the important step of committing resources to fund a national center focusing solely on cultural competence, in order to provide knowledge, training, and support for State Title V CSHCN programs and their partners in building systems of care authorized by OBRA ‘89. The first grant for this national center, which was awarded to the Texas Department of Health, expanded the activities that were launched at the landmark conference in 1990.

Since 1995, the Georgetown University Center for Child and Human Development has been home to this center, now known as the National Center for Cultural Competence (NCCC). Other MCHB divisions, including the Division of Research, Training and Education, and the Division of Child, Adolescent and Family Health, subsequently joined DSCSHN’s leadership in cultural competence. Other federal agencies also began to focus on this issue, and provided resources to the MCHB’s Cooperative Agreement with the NCCC or contracted separately with the NCCC including the HRSA’s Bureau of Primary Health Care, Bureau of Health Professions, Office of Minority Health, Office of Performance Review and the National Institute of Child Health and Human Development, National Libraries of Medicine, Department of Education, and the Environmental Protection Agency.

Starting in 1997, the Integrated Services Branch of MCHB/DSCSHN incorporated cultural competence into all national leadership training for State Title V programs, family leaders, and other partners in building systems of care for children and youth with special health care needs and their families. In 2001, HRSA adopted a new mission statement that incorporated cultural competence.

In 2002, MCHB took another critical step forward in this journey. MCHB’s Strategic Plan and related Performance Measures (2003-2007) integrated cultural competence as a key component of the Bureau’s efforts. Goal 3 of the Strategic Plan is to “Eliminate Health Barriers and Disparities.” Key strategies are to:

- A. Develop and promote health services and systems of care designed to eliminate disparities and barriers across the MCH population; and
- B. Train a MCH workforce that is culturally competent and reflects an increasingly diverse population.

Selected performance measures include:

- The degree to which programs have incorporated cultural competence in policies, guidelines, contracts, and training;
- The degree to which grantees assist families of children with special health care needs to partner in decision-making and to be satisfied with services they receive;
- The degree to which MCHB long-term training programs have incorporated cultural competence into curricula/training; and
- The percentage of participants in long-term training programs who are from underrepresented groups.

MCHB has invited State Title V CSHCN programs, as part of its constellation of programs, to join the journey toward cultural and linguistic competence. This monograph presents the accounts of their journeys and reflects their progress on the road to fulfilling MCHB's mission to provide national leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs. MCHB promotes and supports the development of family-centered, culturally/linguistically competent, community-based systems of care to achieve its mission.



# The Journey: Postcards from the Road



## SOLICITING STORIES FROM THE ROAD

In the fall of fiscal year 2003-2004, the NCCC convened a workgroup of key stakeholders including the NCCC's federal project officer, CSHCN leadership, and family leaders to identify key content areas for the monograph, and methods of soliciting stories from states. The NCCC sent states and territories a letter inviting them to share one significant accomplishment in their efforts to achieve cultural and linguistic competence within integrated systems of services for children and youth with special health care needs and their families. Ten stories were submitted through a story collection campaign led by editor Lisa Lopez Snyder. In fiscal year 2004-2005, the NCCC contracted with Public Research and Evaluation Services to offer an online story collection process. Through this method, 13 additional stories were collected. The 23 state and territorial stories presented in this monograph represent the summation of the story collection activities.

The following “postcards from the road” provide snapshots of the accomplishments of state and territorial programs in infusing cultural and linguistic competence in policies, practices and structures. Complete stories are presented in the section entitled, “How are the States and Territories Traveling?”



DEAR NCCC,

The majority population in New Mexico is Hispanic/Latino. Your visit in 2000 energized us to address the needs of African-Americans, who have been underserved in our community. A social worker from our Children's Medical Services Family Infant Toddler program dedicated her time and energy to building relationships within African-American communities. Through connections with the NAACP and other ethnic-specific groups, she was able to educate families about early intervention. She also introduced health promotion materials on other topics of importance, including HIV/AIDS prevention, smoking cessation, and WIC. In collaboration with faith-based and ethnic-specific organizations, we have expanded CMS' reach.

Regards,  
*New Mexico*

*P.S. I almost forgot to mention this good news—with our partners at Catholic Charities, several public health employees from various disciplines have been trained as medical interpreters!*



DEAR NCCC,

The reorganization/restructuring of our program led us to place care coordinators in community-based, primary care, pediatric, and medical home practices. As you know, culturally effective care is one of the tenets of medical home practice.

In 2000, over 85% of families receiving care coordination were white, English-speaking families. In 2004, 50% of families seen within medical home practices are Hispanic, African-American, Asian, or from other racial/ethnic groups. To respond effectively to these diverse groups, care coordination staff has expanded to include more multilingual individuals who share knowledge of community resources. This helps connect clients to new resources and has resulted in improved communication and outcomes, as well as more opportunities for families to engage in recreational activities.

We'll keep you posted,  
*Massachusetts*



DEAR NCCC,

Guess what? We are partnering with the Mexican Consulate, based in Raleigh, to reach out to the Latino populations in our state. The Consulate has a program focusing on health and education, in both North and South Carolina. Through this program, families have received information about child health insurance programs. We have built a relationship between Consulate staff and state public health staff. The Consulate has offered to bring a Mexican health provider to train our public health staff on specific health topics. We also have other partners, including faith-based organizations, ethnic-specific organizations, business owners, the health department, social service agencies, and others.

As a result of this effort, over 1,000 families and 10 organizations now have materials in Spanish that are culturally appropriate! We anticipate many more benefits from these collaborations!

Sincerely,  
*North Carolina*



DEAR NCCC,

The Washington Family to Family Network is a coalition of family support programs that have joined forces to improve systems of care for children with special health care needs. One of our major goals is to recruit families who are diverse culturally, ethnically, geographically, and in other ways. We have had some encouraging success with this.

Also, as part of the Washington Integrated Services Enhancement (WISE) grant, the Family-to-Family Network established a Family Advisory group. Family members shared their suggestions for increasing family involvement in planning and policy development. The suggestions resulted in a booklet of practical tips for increasing family involvement.

We asked some of our community-based providers to test these tips and then we convened a family-professional meeting. The providers told us they were amazed to learn that some families did not find the services to be as family-centered as the providers assumed they were. The providers and families thought the tips would lead to better family-professional partnerships.

Best regards,  
*Washington*



DEAR NCCC,

Alaska, like most states, screens newborns for hearing problems before they leave a care facility or hospital. However, due to remote locations and/or lack of understanding, many native communities are not able to follow up when newborns do not pass the early hearing screening.

Our strategy has been to use the Community Health Aide Program (CHAP) as a vehicle to train Alaska Natives to serve as primary care providers in their villages, with emphasis on risk factors for hearing loss, the early screening program, and the importance of follow up. We even made our own video!

Keeping you in the loop,  
*Alaska*



DEAR NCCC,

Here in Chicago, we have experienced growth in our Hispanic/Latino populations. We responded by translating into Spanish all of our printed materials for families of children with special health care needs, and by contracting with a local phone carrier to offer access to a language line that provides interpreter services for more than 70 languages. Then we conducted training to make sure that the providers were familiar with these services. We also provided Spanish-language training to families on practical topics of interest to them.

We publish a newsletter and host a web site in both English and Spanish. We found that differences in dialects could be a problem until we located a translator who used Spanish language in a way that was accessible to our diverse Spanish-speaking consumers. We learned something new!

Regards,  
*Illinois*



DEAR NCCC,

We are such a large and diverse state, with numerous child-serving agencies. We knew there were many resources on providing culturally competent services among these agencies, but no one mechanism to collect and share knowledge of all of these resources for professionals in the state. As you remember, when you came to provide training and technical assistance for us on how to integrate cultural competence into policies, practices, and procedures, you also helped us think through a way to share resources through a statewide network.

Well, you will be happy to know that the statewide network is up and running! We have two major goals: (1) to identify existing state resources on knowledge and skills for specific cultural groups and/or services for people with diverse needs, and (2) to create an effective way to disseminate this information.

We received great responses (450!) from the state's child- and family-serving agencies. We created a database of our findings and have posted it on the web. Through the website and our listserv, we can reach almost all of New Jersey's families. We may not have exactly what they are looking for, but we now have a way to connect them with existing resources.

Best,  
*New Jersey*



DEAR NCCC,

Greetings from Missouri! We started working on implementing our cultural competence plan to address the growing cultural diversity in our state. We focused on increasing staff knowledge and skills to work cross-culturally. We developed policies and procedures on providing language access and using the language line service. Also, staff are receiving training in other languages.

We'll keep you posted on our progress!

*Missouri*



# The Journey:

## Lessons Learned by the NCCC



Since 1995, through a Cooperative Agreement, the NCCC has been privileged to support the DSCSHN's efforts to advance and sustain cultural and linguistic competence within the system of services for children and youth with special health care needs and their families.

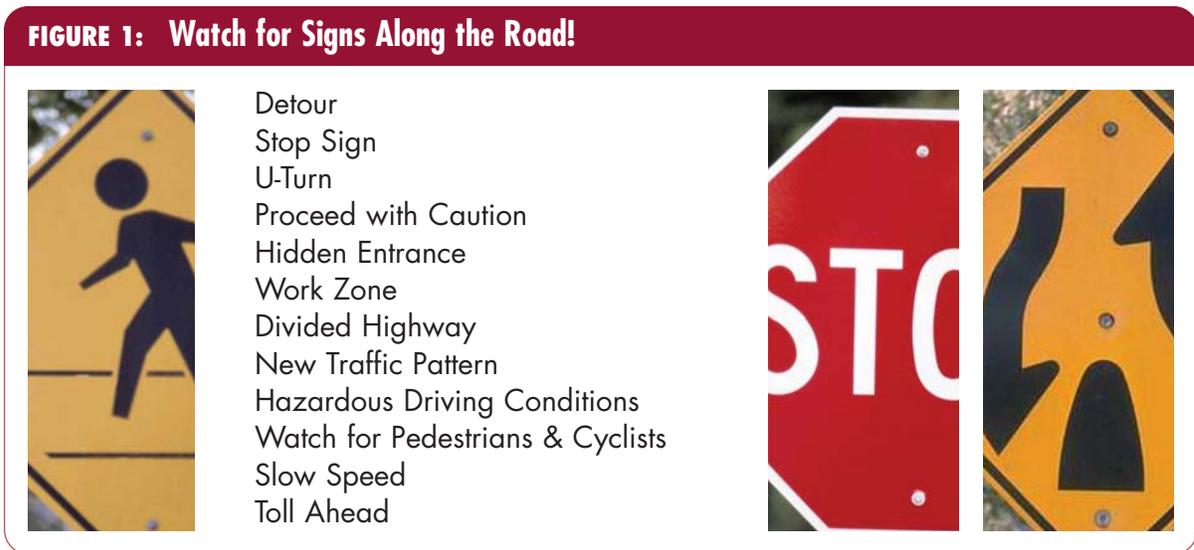
During the past 13 years, NCCC faculty, staff, and consultants have had a host of experiences and learned many lessons from families, communities, states, territories and other constituency groups concerned with achieving cultural and linguistic competence, eliminating disparities, and striving toward equity in the nation's health and mental health care systems. This section of the monograph presents key lessons learned, to provide guidance to those beginning or continuing the journey.

### **WATCH FOR SIGNS ALONG THE ROAD!**

Nationally, service systems, organizations, and programs are attempting to address the unique preferences and needs of culturally and linguistically diverse groups. As NCCC faculty and consultants, we have learned that there is no one method of beginning the journey toward cultural and linguistic competence—at either the individual or systems level. Systems and organizations that embark on this journey may differ in their point of departure and their estimated time of arrival for achieving specific goals and outcomes. Health and mental health care, human services, and family-based organizations are at various stages of developing awareness, knowledge, and skills in organizational development to fully embrace and infuse cultural and linguistic competence. We have learned and documented that few systems or organizations have evolved to a degree of proficiency in which cultural and linguistic competence is institutionalized at all levels—policy, administrative, practice/service delivery, family/patient/consumer, and community.

To illustrate this theme, we chose the analogy of a road trip and the various signs encountered along the way, as a lens for viewing and analyzing the journey (see Figure 1).

**FIGURE 1: Watch for Signs Along the Road!**



While it is virtually impossible to list all of the challenges of the journey, Table 1 depicts the collective experiences we have encountered in supporting systems, organizations, programs and their personnel on their respective journeys. Efforts to advance and sustain cultural and linguistic competence, as described in the Table 1 include such areas as:

- Policy development and administration
- Advocacy
- Compliance with federal and state mandates for language access
- Needs and assets assessment
- Organizational self-assessment
- Quality improvement
- Cost-benefit analysis
- Leadership development
- Workforce development, coaching and mentoring
- Strategic planning
- Best- and evidence-based practices
- Community partnerships and engagement
- Evaluation
- Information dissemination

TABLE 1		
ROAD SIGN ALERT		PROGRAM, ORGANIZATIONAL, OR SYSTEM CHALLENGES
<b>Detour</b>		Efforts may be new or well underway, but numerous obstacles or barriers may occur, resulting in circuitous routes and slow progress.
<b>Stop Sign</b>		Efforts come to a halt due to changes in leadership, organizational priorities, fiscal allocations, internal or external resistance, staff turnover and attrition, and sociopolitical contexts.
<b>U-Turn</b>		Efforts may be reversed due to internal or external advocacy, the threat of or actual litigation, specific events, changes in leadership, rapidly changing demographics, state and federal legal mandates and statutes, or accreditation and licensing requirements.
<b>Proceed with Caution</b>		Efforts are minimal due to fear or uncertainty about: what course to take; who can lead the efforts (i.e., only members of diverse racial or ethnic groups); loss or change in the power structure; reluctance to ask overworked staff to take on one more challenge; and perceptions that efforts are a passing trend.
<b>Hidden Entrance</b>		The benefits of efforts are often difficult to see when no structures are in place to track and measure progress over time. Many efforts build and rely upon the belief that training is the path to the hidden entrance. Investment in this strategy alone yields few results.
<b>Work Zone</b>		A core group of stakeholders may be involved in leading efforts over time and may tire during the journey; others may be asked at certain junctures to assist with initiatives that require specific knowledge or skill sets. The pace may accelerate or decelerate for various reasons.
<b>Divided Highway</b>		Efforts can be thwarted by: opposing viewpoints; overt or passive resistance; differing perceptions of urgency and need; perceived or actual differences in commitment; disputes over amount and allocation of resources (fiscal and human); rivalries between/within cultural groups; a board of directors that is not “on board”; differing opinions about who should be included under the umbrella of “culture”; and political issues that polarize communities (e.g., immigration).

Table 1 continued on next page

TABLE 1 *continued*

ROAD SIGN ALERT	PROGRAM, ORGANIZATIONAL, OR SYSTEM CHALLENGES
<p><b>New Traffic Pattern</b></p> 	<p>Efforts to increase staff diversity, if not well planned and managed, can result in tokenism, isolation, inequitable distribution of work, power struggles, and insecurities among staff who feel their skills are less valued than those of newcomers.</p> <p>Efforts to learn about and engage diverse or new/emerging communities will require: acquiring cultural knowledge (e.g., belief systems, cultural practices and norms); differing approaches to the delivery of services and supports; new skill sets for staff and volunteers; additional and/or reallocated resources; new and expanded partnerships; new technologies; participatory and inclusive research strategies and methodologies; reciprocal transfer of knowledge and skills among all collaborators and partners; and economic benefits for community collaborators.</p>
<p><b>Hazardous Driving Conditions</b></p> 	<p>Efforts may result in tension, discord, or conflict. Such issues must be attended to in an effective, timely, and sensitive manner. Knowledge and skill sets to address the hazards include cross-cultural communication, conflict resolution, negotiation, mediation, anti-bias and anti-racism policy and practice, and leadership development.</p>
<p><b>Watch for Pedestrians &amp; Cyclists</b></p> 	<p>Those responsible for leading efforts must be alert to individuals who are most vulnerable on the road. Circumstances and issues of vulnerability may change in nature and intensity over time. Addressing stress, promoting self-care, celebrating small and large victories, and providing incentives all help to sustain the journey.</p>
<p><b>Slow Speed</b></p> 	<p>Efforts must be viewed in the context of organizational and systems change, which are long-term processes. Leadership must focus on modulating speed (e.g., setting reasonable timelines for goals, having courage to push when efforts are stuck in neutral or moving in reverse, having patience to travel below the speed limit when necessary). Leadership must also attend to organizational readiness for change; the pace of change is often impacted by leadership's failure to assess readiness for change or to tailor efforts based on the well-defined stages of organizational development.</p>
<p><b>Toll Ahead</b></p> 	<p>Efforts cannot be successful without dedicating both fiscal and human resources for the journey. These are an integral aspect of budget development. Often these efforts are the first to go during times of fiscal constraint. Clear policy, careful planning, and advocacy are needed to estimate and pay for costs associated with the journey.</p>

## FIVE LESSONS OF THE JOURNEY

In 2005, the director of the NCCC was asked to identify and describe the most important lessons learned in leading efforts to advance and sustain cultural and linguistic competence. These lessons reflect efforts across multiple systems of services and supports, and among diverse audiences and constituencies, including those concerned with State Title V and CSHN programs.

After a process of careful deliberation and vetting, the NCCC identified the five lessons listed in Figure 2 as being the most essential to help ensure that cultural and linguistic competence become institutionalized.

**FIGURE 2: Lessons of the Journey**

- Leadership
- Shared Ownership
- The “ISMs”—Confronting the Undercurrents
- Keeping it Real
- Weave into the Fabric of the Organization



### LESSON 1 LEADERSHIP

Achieving cultural and linguistic competence requires strong and informed leadership to spur the necessary changes within systems, organizations, policies, and practice. Without committed leadership, these efforts typically stall. The NCCC offers the following insights based on our experiences.

There is a need for leaders with the energy, knowledge, and skills to guide the difficult work of advancing and sustaining cultural and linguistic competence in systems, organizations, and programs that develop policy, provide services and supports, conduct research, and/or advocate for children, youth, and families.

The NCCC has observed that many who are invested in these efforts are not in positions of power within their respective settings. Feeling that they lack authority to make substantive changes necessary to advance and sustain cultural and linguistic competence, they sometimes fail to see their own capacity as leaders and as agents for change.

## What is leadership?

Leadership can be defined in many ways. The NCCC selected the following definition because of its relevance and applicability to the work of cultural and linguistic competence:

*“Leadership is the ability of an individual to influence, motivate, and enable others to contribute toward the effectiveness and success of the organization of which they are members.” (p. 15) — R. J. House*

The goal, then, of leadership is to influence, motivate, and enable the contributions of others to advance and sustain cultural and linguistic competence within their respective organizations and programs, within communities, and/or among groups and constituencies of which they are members.

Leadership is not necessarily limited to an individual. The following descriptions acknowledge both singular and collective views of leadership that will be required to infuse cultural and linguistic competence into all aspects of integrated systems of services and supports.

Leadership can be:

- A person or group of persons in the vanguard of a movement.
- A person or group serving in a position, office, program, or entity, and having the knowledge, skills, and experience to effect change.
- A person or group of influence, who is respected by others.

## Who is a leader?

The academic literature on leadership differentiates between leading by virtue of one’s position or authority, and leading by influence. This view of a leader supports the value that being a leader is not limited to persons who hold a high rank or position. Rather, it is based on a set of personal attributes and skills (intuitive or acquired) that can rouse and motivate others (Northouse, 2001).

Consistent with the values espoused by the NCCC, anyone can be a leader at any time and in any context.

A leader is someone who:

- Shows or guides the way (i.e. conducts, directs, escorts, guides, pilots, shepherds, ushers, navigates and steers).
- Inspires and engenders trust in others.
- Uses and shares power to achieve a desired outcome or goal.
- Is conscious of the influence of cultural values, beliefs, and behaviors (in self and others).
- Is an influential person.

The literature on leadership also refers frequently to followers. The NCCC asserts that two essential attributes of an effective leader are: (1) the capacity and the humility to both lead and follow, and (2) the insight to discern which is more appropriate in a given situation or context.

### Is leadership influenced by culture?

Perceptions of what constitute leaders and leadership are deeply rooted in culture. Accounts of leaders' beliefs, characteristics, and styles date back to ancient history, reflecting the cultural perceptions of the time and often the cultural perspective of the historian.

*"The term culture refers to social reality. It can be defined as a complex collection of components that a group of people share to help them adapt to their social and physical world."*

YAMAMOTO, SILVA, FERRARI &  
NUKARIYA, 1997 (P. 34)

The concept of leader is influenced by factors such as gender, age, racial/ethnic affiliation, education, birth order, heredity, wealth, and political affiliation. All of these factors are mediated by culture, as they have different meanings and values for different cultural groups. For example, some tribes and clans have a tradition of matriarchal leadership, while others accept only males in formal leadership roles. Some cultural groups place value on elders and view them as leaders, while others turn to spiritual and religious figures as leaders.

In many local communities, including tribal lands and territories throughout the U.S., there are indigenous, natural, and informal leaders. These leaders are highly respected and viewed as wielding significant influence within their communities, although they may not have been formally elected or appointed. In contrast, predominant systems in the U.S. define leaders solely in a hierarchical manner based on position, authority, power, educational attainment, or wealth. The NCCC has learned that these differing cultural perspectives can present major barriers to engaging diverse communities in a meaningful manner.

### What is the role of leadership?

The role of leadership will need to be revisited periodically, given the nature of directing and supporting efforts to advance and sustain cultural and linguistic competence. At every level, leadership will need to step to the forefront of a complex set of issues with vision, courage, and integrity. Heifetz (1994) offers six practical approaches, which the NCCC has applied to the unique challenges of cultural and linguistic competence.

- **Get on the balcony.** Get to a place that provides a panoramic and objective view of the contextual realities, challenges, and opportunities of this work, both short-term and long-term.
- **Identify the adaptive challenge.** Pinpoint the changes in values, attitudes, and/or behaviors needed to advance the work. Develop a plan to address these in a forthright and effective manner.
- **Regulate distress.** This work can be particularly arduous. Provide support to staff and other key stakeholders through difficult and often tumultuous times.

*“Resistance should be expected in different stages of multicultural organizational change because the topics of prejudice, discrimination, and oppression are controversial and emotionally charged”.*

(BRANTLEY, FROST & RAZAK, 1996 IN MAYENO, LAURIN MULTICULTURAL ORGANIZATIONAL DEVELOPMENT—A RESOURCE FOR HEALTH EQUITY, 2007)

- **Maintain disciplined attention.** Multiple and competing demands, both internal and external, can distract from this work. Maintain intentional and constant focus to ensure that this work is not short-lived but rather integral to the mission and core functions of the system or organization.
- **Give the work back to the people.** Cultural and linguistic competence must have both shared leadership and shared ownership. Be sure that efforts include approaches that answer the question, “What’s in it for me?” and define roles and responsibilities for all.
- **Protect the voices from below.** Individuals and groups engaged in this work may have periods of vulnerability.

Strive to achieve an equitable environment by ensuring that all voices and points of view are heard, with no repercussions for speaking out, advocacy, and citing the real issues—”calling it what it is!”

The NCCC offers the following salient insights based on our experiences.

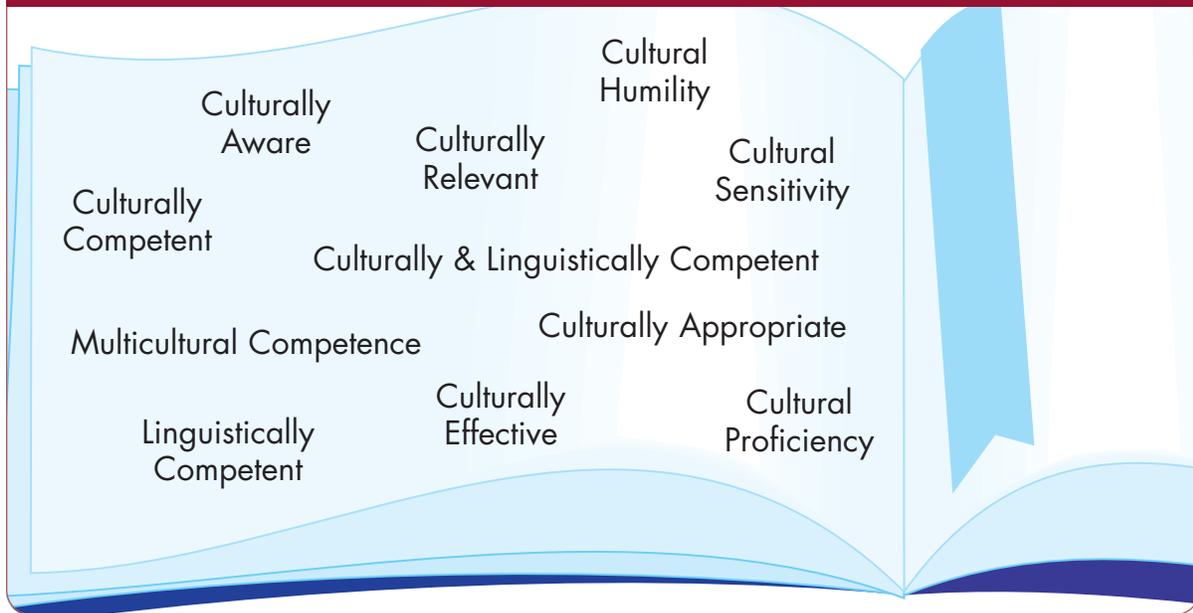
### Leadership: Lessons Learned

- Leadership to advance and sustain cultural and linguistic competence must be cultivated at all levels of an organization, system, or community.
- Some individuals lead through position, others through influence; both are valued and necessary and must be recognized.
- The traditional role of the leader must be revisited and adapted to address ongoing or emerging challenges: organizational change processes, differences across and within cultures and resulting dynamics, resistance, and differences in power.

## LESSON 2 SHARED OWNERSHIP

The NCCC strongly believes that concepts of cultural and linguistic competence cannot be owned by any particular group—they must be shared so that all have a stake in the benefits and outcomes.

Shared ownership is most effective when rooted in (1) a shared vocabulary and understanding of the concepts, (2) inclusive processes, and (3) buy-in strategies tailored to meet individual interests and needs.

**FIGURE 3: Are We on the Same Page?****Shared understanding, shared vocabulary.**

Literature reviews reveal many terms used to describe the work of achieving cultural and linguistic competence. Figure 3 depicts a number of these terms. Although each term has a different meaning, they are often used interchangeably.

Many think of cultural competence as being solely for and about people of color or members of racial groups other than white. The NCCC asserts that culture and cultural competence are relevant for all peoples—that culture is value-laden, provides identity for specific cultural groups, and dictates acceptable behaviors for members of the group. Culturally competent interventions are widely viewed as having a proven efficacy and benefit in addressing populations impacted by racial/ethnic health and mental health disparities. However, using or adapting culturally competent interventions can also benefit other (non-ethnic) cultural groups, such as those living in rural, frontier, and tribal communities; those with disabilities or other special needs; lesbian, gay, bisexual, transgender and questioning (LGBTQ) populations; and members of orthodox religious groups.

**An inclusive process.**

Without a shared understanding and inclusive processes, staff, families, key stakeholders, and community partners may not be “on the same page.” This can have a negative impact on efforts to advance and sustain cultural and linguistic competence. The NCCC has documented only a few instances in which inclusive processes were used to reach consensus on what cultural competence and/or linguistic competence mean within a given system, organization, or program. The guides and planning tools developed by the NCCC

consistently recommend that systems and organizations use structures such as work groups or committees to coordinate internal and external efforts to advance and sustain cultural and linguistic competence. Yet committees do not always represent the range of diversity within organizations. Often, committees comprise only members of racial and ethnic groups other than white. This may give the impression that specific racial groups are neither valued nor welcomed, or that such groups are not interested; generally, this is not true.

Additionally, committees rarely invite those who are considered “naysayers,” referred to as the indispensable opposition. Dissenting opinions should be represented and heard around the table; they can help shape strategies and approaches to better address and counter opposition. It is particularly beneficial when a dissenting member is “converted” and becomes a credible voice within the opposition.

### **Buy-in strategies tailored to meet individual interests and needs.**

To elicit buy-in, the NCCC recommends conducting inclusive processes to examine the relevance of cultural and linguistic competence to a particular system’s or organization’s mission, goals, and values. Marketing cultural and linguistic competence within systems, organizations, and communities should be well planned, deliberate, and strategic. It may be helpful to develop a logic model—a visual schematic that summarizes the relationship between the resources, activities, and outcomes of a culturally and linguistically competent system of services and supports.

Additionally, it is important to clearly define the rationale and benefits of cultural and linguistic competence for the health and well-being of those in a particular community or geographic locale. The NCCC has found that tailoring buy-in strategies to the unique perspectives of a specific audience has proved successful. Such efforts must be based on understanding differing needs and perspectives within the community. What resonates with one segment of the community may not resonate with others. For example, providers may be concerned primarily with the relationship between cultural and linguistic competence, quality of care, and reducing disparities, whereas policy makers may be more concerned with cost parameters. Patients and members of the diverse community may be concerned with the role of cultural and linguistic competence in promoting health and mental health care equity.

### **Shared Ownership: Lessons Learned**

- Staff, families, community partners, and key stakeholder need to be on the same page with a shared understanding of the conceptual frameworks and benefits of cultural and linguistic competence.
- Culturally and linguistically competent health and mental health systems and organizations should involve and benefit all.
- Structures to advance and sustain cultural and linguistic competence must be inclusive to be effective.

### LESSON 3 THE ISMs—CONFRONTING THE UNDERCURRENTS

Concerted efforts to advance and sustain cultural and linguistic competence have been derailed by one or more of the “ISMs.” The “ISMs” is a catch-all term used to refer to a range of attitudes and behaviors that involve perceived superiority, oppression, and discrimination based on such factors as race, national origin, ethnicity, language, class, disability, and sexual orientation and identity. Figure 4 lists strategies that the NCCC has found effective in confronting the “ISMs” within systems and organizations.

#### FIGURE 4: The “ISMs” Confronting the Undercurrents

- Call it what it is!
- Create a climate of intolerance
- Offer a safe refuge for authentic discussions
- Use conflict management & resolution
- Invoke legal interventions when necessary

It would be naïve of us to think that deeply rooted patterns of race, ethnicity, culture, class, and the “ISMs” that permeate U.S. society would be absent from our health and mental health care systems. More than 25 years ago, Kenneth Clark, a renowned researcher, educator and psychologist, commented that “students, research workers and professionals in the behavioral sciences—like members of the clergy and educators—are no more immune by virtue of their values and trainings to the disease and superstitions of American racism than the average man” (1972, cited in Mazel, 1998, p. 19).

Clark’s observations were reinforced more recently in the Institute of Medicine’s landmark study *Unequal Treatment* (2002), which states: “Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life” (p. 6-7).

Given these realities, all efforts to advance and sustain cultural and linguistic competence must address the “ISMs” in their many manifestations, both overt and subtle. Five key strategies follow.

**Call it what it is!** There is often a reticence about using the term “racism” or other terms to describe these insidious behaviors on an individual or institutional basis. In many instances, references to such behaviors are couched in softer language (e.g., lack of sensitivity, unintentional mistake or error, no intention to offend). Those who believe they are victims of bias or racist behaviors or policies see this as deliberate avoidance of calling it what it really

is. It is essential to name behaviors such as bias, stereotyping, discrimination, elitism, prejudice, homophobia and the other “ISMs” in order to address the undercurrents effectively. This allows difficult and challenging issues to be put on the table and discussed without masking harsh realities with softer terms.

**Create a “climate of intolerance.”** Many national initiatives promote tolerance of diversity and difference. However, in the case of the “ISMs”, there should be a clear policy and practice of intolerance: certain behaviors are neither valued nor accepted in the system or organization. Large corporations such as Nike, Adidas, and Timberland were early adopters of campaigns to draw attention to institutional racism as unacceptable. Many municipalities, universities, and organizations have launched anti-racism and anti-bias initiatives. In 2003, Blue Cross/Blue Shield of Massachusetts implemented the “No Place for Hate” campaign for staff, contractors, and programs (Blue Cross/Blue Shield, 2005). Initiatives such as these explicitly state and reinforce core values and policies, within the organization and to the public at large. Given the persistence of racial/ethnic health and mental health disparities, public health and mental health systems and organizations could benefit from the messages and intent of these campaigns.

**Offer a safe refuge for authentic discussions.** People are often reluctant to discuss issues of stereotyping, bias, prejudice, and other “ISMs.” Race, ethnicity, culture, class, sexual orientation and identity, and religious affiliations/beliefs often evoke such deep emotions that people cannot engage in civil discussion (Dunne & Goode, 2004).

*“Our truncated public discussion of race suppresses the best of who and what we are as a people because they fail to confront the complexity of the issue in a candid and critical manner.”*

CORNEL WEST, 1993 (P. 135)

There are few opportunities and forums to share perspectives in a safe and authentic manner. Identifying approaches to confront attitudinal barriers in open, honest, and supportive ways, and charting a course for change remain among the most difficult, yet necessary paths on the journey to advance and sustain cultural and linguistic competence.

The NCCC conducts many of these forums and recommends that systems and organizations adopt practices to begin the hard work of confronting the undercurrents and engendering an environment of trust, respect, and shared power.

**Use conflict management & resolution approaches.** Systems and organizations need to invest resources, including training and coaching, to help staff acquire skills to address difficult situations that are often rooted in the dynamics of difference. Approaches include conflict management, values-based negotiation, consensus building, mediation, cross-cultural communication, and strategies to equalize power. The outcome of these efforts is a workforce equipped with insight and skill sets to address adversity confidently and effectively.

**Invoke legal interventions when necessary.** When the “ISMs” are not addressed in a system or organization, the results may include: (1) a hostile and unhealthy work environment; (2) widespread dissatisfaction among staff and volunteers, (3) dissatisfaction among patients, consumers, and population groups, and (4) compromised capacity to deliver quality services and supports. Systems and organizations that fail to address the “ISMs” and their undercurrents are vulnerable to grievances and litigation. Legal interventions are typically sought when employees, patients, and consumers feel they have no other recourse to seek relief from perceived bias and discrimination. Many within disaffected groups and communities use litigation as a tool to ensure their legal rights or to seek redress for alleged harm or injury. Concerted efforts must be devoted upstream to stop the flow of the “ISMs” from polluting the work environment in order to lessen the burden on the victims as well as the legal system.

### The “ISMs”: Lessons Learned

- Addressing racial and ethnic disparities in health and mental health care demands an intentional focus on conscious or unconscious bias, prejudice, stereotyping, and discrimination.
- Efforts to advance and sustain cultural and linguistic competence will have little or no success unless the “ISMs” are confronted with integrity, in a humane and effective manner.

## LESSON 4 KEEPING IT REAL

The NCCC has found that unless people see cultural and linguistic competence as relevant to their day-to-day work, they may resist, undermine, or ignore it, or put forth only half-hearted efforts. To advance and sustain cultural and linguistic competence, the concepts must be tangible—touching the real lives of staff, contractors, and volunteers. Creating a work environment that values, encourages, and prioritizes continuous learning is a fundamental practice that must be embedded in organizational policy, structures, and allocation of adequate fiscal and human resources.

“Keeping it Real” requires that areas of awareness, knowledge, and skills related to cultural and linguistic competence must be:

- Clearly delineated
- Linked to job functions
- Included in performance evaluations, and
- Acknowledged in processes for compensation, promotions, and incentives.

### Keeping it Real: Lessons Learned

- Create and nurture a community of learners as part of the organization's commitment to promote continuous professional growth and development for staff, volunteers, and board members to acquire the knowledge and skills necessary to advance and sustain cultural and linguistic competence.
- Provide highly relevant training and technical assistance based on individual interests, needs, and preferred learning methods of staff. Consider formal and informal learning opportunities, such as continuing education/academic courses, coaching, mentoring, shadowing, language instruction, book clubs, visiting scholar/practitioner programs, and other experiential activities.
- Revisit position descriptions and job functions to ensure they define the qualities, experience, knowledge, and skills sets needed to promote culturally and linguistically competent services and supports.
- Establish a system of incentives that acknowledges and celebrates staff efforts and achievements in advancing and sustaining cultural and linguistic competence.

## LESSON 5 WEAVE INTO THE FABRIC OF THE ORGANIZATION

The NCCC has found that cultural and linguistic competence are typically perceived as “add-ons” that are not integral to the system or organization as a whole. Although efforts may be championed by certain staff, community members, or advocates, in many instances, their efforts are marginalized. The conceptual frameworks and definitions espoused by the NCCC state that elements of cultural and linguistic competence must be present in all aspects of a system or organization, from policy making and administration to practice/service delivery, and systematically involve families, consumers, and communities.

Figure 5 poses some key questions to consider in infusing cultural and linguistic competence within systems and organizations. Weaving these concepts into the fabric of the system or organization will require changes that include but are not limited to:

- Values, mission, policies, and structures
- Composition of governance and advisory boards
- Budgets and allocation of fiscal resources
- Staffing patterns, position descriptions, performance measures
- Approaches to practice, treatment, interventions
- Provision of supportive services
- Quality improvement and program evaluation
- Professional development, pre-service and in-service training, continuing education
- Community engagement and partnerships
- Methods of disseminating information internally and externally
- Telecommunications, information technology/management systems; and
- Facility design and décor

**FIGURE 5: What are the Implications for Cultural & Linguistic Competence Related to...**

- **CORE FUNCTIONS**  
*What we do...*
- **HUMAN RESOURCES & STAFF DEVELOPMENT**  
*Who we are...*
- **FISCAL RESOURCES & ALLOCATION**  
*Where the money goes...*
- **COLLABORATION & COMMUNITY ENGAGEMENT**  
*Who our Partners are...*
- **CONTRACTS**  
*Whom do we entrust to deliver services and supports...*

**Weave into the Fabric of the Organization and Lessons Learned**

- Eliminate the perception of cultural and linguistic competence as “add-ons” by ensuring principles and practices are woven into the culture of the system or organization.
- Establish a clear business case for cultural and linguistic competence within the specific contexts of the system, organization or program.
- Promote the understanding that cultural and linguistic competence are integrally linked to quality of care—you can’t have one without the other.
- Institutionalize cultural and linguistic competence in policies, structures, practices, procedures and dedicated resources within systems and organizations.
- Establish bench marks and measure progress at regular intervals.

The NCCC hopes that these lessons learned will help others along the way. There will be new lessons learned as the journey towards cultural and linguistic competence continues with families, communities, and those invested in the integrated system of services and supports for children and youth with special health care needs. Remember to watch for road signs and that...



Cultural and linguistic competence  
It's a life's journey...  
Not a destination  
Safe travels!



# How are the States and Territories Traveling?



To answer this question, the NCCC used the conceptual frameworks and definitions of cultural competence and linguistic competence as roadmaps to analyze the 23 stories that were submitted. A summary of this analysis follows.

## Linguistic Competence

Linguistic competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. Linguistic competency requires organizational and provider capacity to respond effectively to the health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity. (Goode & Jones, 2006).

The majority of the stories focused on various aspects of linguistic competence, as defined above, specifically increasing access to care and the capacity to respond to the emerging populations that speak languages other than English. Almost all addressed language access services for Spanish speaking families that were in direct response to significant demographic shifts among Latino/Hispanic populations in their states. Such efforts involved compliance with federal Title VI mandates for language access and the Culturally and Linguistically Competent Standards in Healthcare (CLAS), promulgated by the U.S. Department of Health and Human Services, Office of Minority Health.

- **Policy.** Most of the stories did not describe specific changes in internal policy related to language access. Rather, the focus was compliance with federal and/or state policies.
- **Structures.** Few stories described creating new structures to address linguistic competence. A noticeable trend was reinvigorating or using existing structures to plan for and implement enhanced language access

services. This entailed collaboration with community partners and/or divisions within the health care system or entity (e.g. collaborate with existing cultural brokers, Promotores/as, Mexican Consulate's mobile clinics).

- **Practices.** A number of stories identified an array of practices to improve language access which involved the use of technology (e.g. pagers, cell phones, telephonic interpretation systems, web sites) and training to build new skill sets for personnel (i.e. dedicated interpreters, dual-role bilingual staff, monolingual English speaking staff).
- **Procedures.** Several stories reported establishing new procedures for linguistic competence that included reimbursement for interpretation services, expanded service delivery sites, and required staff orientation on accessing language services.
- **Dedicated resources.** None of the stories directly addressed budget and funding issues associated with language access.

The analysis revealed that state and territorial attention is focused on implementing myriad practices to respond to linguistically diverse populations. Additional inquiry would be beneficial to elicit data on the underpinning policy and fiscal resources necessary to provide language access and sustain linguistic competence.

### Cultural Competence

Cultural competence requires that systems and organizations:

- Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally.
- Have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of communities they serve.
- Incorporate the above in all aspects of policymaking, administration, and practice and service delivery; systematically involve consumers, families, and communities.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness knowledge and skills along the cultural competence continuum. (Adapted from Cross et al., 1989).

All of the stories show a progression along the cultural competence continuum. Efforts are documented for each of the five elements of cultural competence delineated below.

- **Value diversity.** All of the stories demonstrated an understanding of and value for diversity both among the children, youth and families receiving services and supports and the personnel providing such services and supports.
- **Conduct self-assessment.** A number of stories reported engaging in organizational self-assessment processes that resulted in changes in practice and procedures. However none reported changes in organizational policy as a prerequisite for sustaining cultural competence.
- **Manage the dynamics of difference.** Training and staff development and community partnerships were the primary vehicles described in the stories used to address the dynamics of difference. This largely entailed training on cultural awareness, skill building activities for cross-cultural communication, and using key informants to increase awareness of community beliefs and resources. None of the stories referenced the most challenging aspects of managing the dynamics of difference such as encountering conflict, bias, stereotyping, discrimination, racism, and other “ISMs”.
- **Acquire and institutionalize cultural knowledge.** Several of the stories reported approaches to acquire knowledge about specific racial, ethnic and cultural groups (i.e. family partners, cultural brokers, key informants, and community-based and ethnic-specific organizations). These efforts were often relegated to or initiated by an individual staff. However, none of the stories described policies, structures, and practices to institutionalize the function of acquiring cultural knowledge throughout the entire organization.
- **Adapt to diversity and the cultural contexts of communities they serve.** All of the stories acknowledged a clear and compelling need to adapt services for families and communities. Various means were employed to seek information, plan and implement service adaptations including convening focus groups, advisory/network retreats, key family and community informants, data and utilization review processes, and cultural competence committees. None of the stories reported approaches to evaluate the effectiveness of service adaptations or the policy changes necessary to sustain such efforts.

The analysis revealed that state and territorial efforts are primarily concentrated on advancing cultural competence without the necessary policy and structures to sustain them. Consistent with the cultural competence continuum, additional inquiry is merited to assess the extent to which enactment of policy and establishment of structures have evolved since these stories were collected by the NCCC.

In conclusion, this analysis indicates that state and territorial journeys are at different points and are using different pathways toward achieving cultural and linguistic competence. Table 2 lists the pathways that states and territories have chosen.

<b>PATHWAYS</b>	<b>STATES &amp; TERRITORIES</b>
<b>Training &amp; Personnel Development</b>	CT, FL, IL, KY, MA, MO, NC, ND, NM
<b>Increased Access to Care &amp; Adaptations to Services and Supports</b>	AK, FL, IL, KS, KY, MA, MO, MS, NC, ND, NM, TN, UT, WI
<b>Organizational Policy &amp; Structures</b>	CT, Guam, MO, NJ, NM, TN, WI
<b>Language Access</b>	Guam, IL, KS, KY, MO, MS, NC, NM, OK, UT, WI
<b>Partnerships and Collaboration</b>	AK, FL, Guam, IL, KY, MA, MS, NC, NJ, NM, OK, TN, UT, WA, WI

## ALASKA

### Alaska Department of Health and Social Services, Early Hearing Screening Program

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Partnerships & Collaboration

**Description** Staff in the Alaska Department of Health and Social Services (DHSS) saw the need to increase the participation of rural Alaska Native children ages newborn to 3 years in early hearing detection and intervention (EHDI) so that those who did not pass the screening could be enrolled as quickly as possible for diagnostic audiologic evaluations and treatment.

**Challenges** Detecting and treating hearing loss early in a child’s life is critical, as speech and language development begins in infancy and continues throughout early childhood. If a child is diagnosed with hearing loss and enrolled in rehabilitation services by 6 months of age, the child’s language development can improve to approximate that of a child with normal hearing. However, most rural communities are remote and have populations of 100 or less, with no physician. This makes it difficult for families to learn about the importance of newborn hearing screening to detect otitis media and other conditions. Without pediatricians or family practice doctors to serve these communities, there has been a critical need for public information on risks of hearing problems in newborns and children, as well as information on who to contact and where to seek help.

**Response to Challenges** In order to reach the remote native communities, the DHSS identified its rural-based providers in the community health aide program (CHAP) as a key resource to help educate these communities about EHDI, including high-risk factors and protocols for children diagnosed with hearing loss. The community health aides are Alaska Natives who have participated in training to serve as primary care providers in their villages. They have received training at the Alaska Native Medical Center in Anchorage; this hospital, which is

owned and managed by Alaska Natives, serves 229 tribes. The community health aides coordinate and facilitate communication with health providers in larger communities to address the health needs of the smaller villages. In most of these smaller communities, the community health aide is the only primary care provider.

DHHS took two steps to create an educational program for the community health aide practitioners by (1) developing a 13-minute culturally and linguistically appropriate educational video for community health aides to use in their villages, and (2) incorporating the EHDI program into the training curriculum for new community health aides.

- Outcomes**
- The video is being used to train new health aides and to provide continuing education units for current aides.
  - The video has been distributed to 400 community health aides in 200 communities around the state.
  - The EHDI program has been integrated into the new health aide curriculum during the Alaska Native Medical Center's review of its curriculum.
  - The EHDI information is now a permanent part of the new CHAP curriculum.
  - DHSS developed a media campaign, including television and radio public service announcements, to inform the public about EHDI.

## CONNECTICUT

### State of Connecticut Department of Public Health, Maternal and Child Health Unit, Children with Special Health Care Needs Program

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Organizational Policy and Structures, Training & Personnel Development

- Description** Standard policy on cultural competence was included in all contract language. State Title V also standardized, through policy, (1) the inclusion of cultural sensitivity and family strengths in provider trainings, and (2) the use of consumers as experts in research and evaluation of programs.
- Challenges** There was a lack of consensus and framework on the meaning of cultural competency and measurement standards.
- Response to Challenges** Educating staff and building awareness of how to start addressing cultural competence in a meaningful way helped bridge the challenges.
- Outcomes**
- Standardizing policy requiring aspects of cultural competence in provider training helps to institutionalize cultural competence in the system of services for children with special health care needs.
  - A focus on cultural competence was included in the audit tool for site visits, after standardizing cultural competence policy in contracts.
  - With information gained through focus groups of experienced consumers, a tool kit was developed to support family members who provide quality respite care to children with special health care needs.

## FLORIDA

### Florida Department of Health, Children’s Medical Services (CMS)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Training & Personnel Development, Increased Access to Care & Adaptations to Services and Supports

<b>Description</b>	Using the results of a consumer survey, CMS developed a training initiative to address gaps in provider, staff, and family knowledge around cultural competence. Part of the initiative involved collaborating with the Florida Institute for Family Involvement (FIFI) and the National Center for Cultural Competence (NCCC) to plan and conduct training for a range of key stakeholders.
<b>Challenges</b>	CMS conducted a survey of consumers regarding their perceptions of providers’ and staff members’ listening skills, in order to identify training needs for promoting more family-centered, culturally competent care. Survey results showed the need to (1) increase awareness of cultural competence among providers and staff, and (2) integrate cultural competence into policies, practices, and procedures.
<b>Response to Challenges</b>	CMS arranged for training to address needs identified through the consumer survey. Specifically, Florida providers participated in the medical home learning collaborative and attended training conducted by the NCCC. In its role as a family support, education, and training organization, FIFI convened annual conferences attended by family professionals, CMS staff, consumers, and youth. Each year, the conference included different aspects of cultural and linguistic competence.
<b>Outcomes</b>	None reported.

## GUAM

### Guam Department of Public Health & Social Services, Maternal and Child Health Program

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Organizational Policy & Structures, Language Access, Partnerships & Collaboration

<b>Description</b>	The Maternal and Child Health Program developed policies in response to the MCH Block Grant
<b>Challenges</b>	Resources, specifically time and money, were the identified challenges.
<b>Response to Challenges</b>	The Maternal and Child Health Program collaborated with health department staff, the governor’s office, the nursing department, community-based organizations, and parents to develop policy and strategies to inform Guam’s linguistically diverse populations about the dangers of smoking during pregnancy.
<b>Outcomes</b>	<ul style="list-style-type: none"><li>• Policies on language access were established.</li><li>• Campaigns were carried out in three different languages to disseminate information broadly on the dangers of smoking during pregnancy.</li></ul>

## ILLINOIS

## University of Illinois at Chicago, Division of Specialized Care for Children (DSCC)

## Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Language Access, Training & Personnel Development, Partnerships & Collaboration

**Description** DSCC used its partnerships with a number of local community-based Hispanic organizations to assess its interpretation and translation services, printed materials, and access to translation resources, including information needed to establish a toll-free Spanish-language hotline. The Division also sought the help of its family advisory group to develop a family needs assessment questionnaire to better meet the preferences and needs of families. The medical advisory group and the family advisory group comprise individuals from various backgrounds and communities representing African-American, Hispanic, and Asian populations.

**Challenges** The Chicago area continues to experience a rapid growth in diverse populations. Of the four regions served by DSCC, the Hispanic population is the largest. As a result, the Division saw the need to ensure that all of its printed materials for families of children with special health care needs were translated into Spanish. There was also a need to ensure that phone lines were available to the Spanish-speaking communities, and to train staff regarding these efforts and the use of communication technologies.

**Response to Challenges** All DSCC forms and information on eligibility and patient rights were translated, including documents describing families' rights to medical eligibility, interpretation services, financial eligibility, and a meeting in the regional office in their community. Spanish-speaking families received training on (1) using specialized equipment, (2) recording and maintaining logs to aid in reimbursement for travel and prescription expenses. DSCC publishes a bilingual newsletter for families twice a year, and maintains a family-oriented English/Spanish web site called Special Addition. The Division also provides a language line that connects callers to interpreters with the capacity to communicate in more than 70 languages. Interpreters are also provided in physicians' offices.

DSCC engages in activities to promote cultural competence and to help families who speak languages other than Spanish. For instance, the Division provides a facilitator for pediatric practices in Illinois to improve families' access to quality health care. During the initial practice assessment, this facilitator uses the questionnaire developed by the National Center for Cultural Competence. Medical staff were oriented to the enhanced services through a series of cultural competence training sessions convened at the central office. Providers and staff learned about the Division's various services and outreach initiatives targeting diverse families, including information on finding and accessing services. They also received printed job aids and operational manuals to guide them in assisting families.

**Outcomes** The ready availability of forms, brochures, and other information in different languages:

- Increased access to such materials by diverse families,
- Increased family receptivity to the Division's services, and
- Created trust in the organization's commitment to serve diverse populations.

## KANSAS

### Kansas Department of Health and Environment, Children with Special Health Care Needs Program

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Language Access

**Description** In response to a growing number of families who speak Plattdeutsch and Spanish, the Kansas CSHCN program reviewed Office of Civil Rights policy guidance on providing language access to individuals with limited English proficiency. The CSHCN program decided to expand interpretation services to have interpreters accompany families to outpatient appointments. Interpretation services were also used to respond to the linguistic needs of families who call the CSHCN office.

In addition, the Kansas CSHCN program:

- Allocated funds to provide specialized interpreter training, “Bridging the Gap,”
- Arranged for reimbursement of interpreter services provided in outpatient settings, and
- Translated documents (letters, communiqués, selected forms) into the two targeted languages.

**Challenges** Some of the Plattdeutsch or Spanish speaking families were not able to read translated documents.

**Response to Challenges** To meet this challenge, the CSHCN Program collaborated with health staff from the Kansas farm worker program and individuals from the migrant health program to identify interpreters who could not only provide interpretation services but also assist families with completing forms and the application process.

**Outcomes** This initiative:

- Reduced language barriers for families using CSHCN program services
- Increased communication with families who call in for services and/or use outpatient services
- Increased the number of documents and forms translated into Spanish
- Increased the capacity of the interpreter pool through training
- Supported sustainability of interpreter services through expanded reimbursements and collaboration.

## KENTUCKY

### Kentucky Commission for Children with Special Health Care Needs (CCSHCN)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Training & Personnel Development, Partnerships & Collaboration

**Description** The Executive Director of the CCSHCN extended the vision of building community partnerships with school systems and educators at local, regional, and state levels to all staff. Title V personnel received a request to provide services for a Chinese immigrant family. The boy spoke English as a second language, had multiple medical health issues, and was experiencing behavioral difficulties in school. Title V care coordinators worked to engage the child's mother, who did not speak English.

**Challenges** There were both family and systems challenges. The mother and son had lived in multiple states, were separated from the father, and were experiencing financial difficulties including lack of child care and transportation. The mother worked long hours at a restaurant and had few connections to other Chinese-speaking individuals with the exception of her employer, landlady, and neighbor.

At the systems level, Western Kentucky was beginning to experience demographic changes similar to those happening across the country. The system did not have knowledge of the cultural nuances that might impact service delivery to Chinese immigrant families, and did not have interpretation services available.

**Response to Challenges** The care coordinator collaborated with the school, informal community, and family supports to meet the family's immediate needs. For example, the care coordinator contacted the school to schedule an emergency meeting, during which the educational team, comprised of school officials, care coordinator, family and interpreter, scheduled after-school services for the child, arranged for appropriate psychological and academic testing, and shared important information about the child's medical condition with the school. The care coordinator also worked with the informal community and family supports for interpretation and a host of other services, including advocacy, child care, and behavioral intervention.

**Outcomes**

- Multiple systems (school, refugee center, CCSHCN) worked together to positively impact the health and well-being of this family.
- The CCSHCN and the school increased their cultural awareness of issues that affected this family and may affect others.
- CCSHCN care coordinators initiated new outreach with other culturally diverse families.
- Care coordinators are available to attend IEP meetings and provide outreach to let families know about this capacity.
- Care coordinators continue to build relationships with schools, providing supports to youth to promote successful transition from school to work.

## MASSACHUSETTS

### Massachusetts Department of Health, Bureau of Family and Community Health, Division for Special Health Needs

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Partnerships & Collaborations

**Description** Between 2000 and 2004, the Care Coordination program in Massachusetts was reorganized to place staff in community-based, primary care pediatric practices that served as a medical home. Working with physicians, nurses, and office staff, care coordinators function as part of the practice team, and are now able to provide services to many more children with special health care needs and their families. Their presence supports primary care physicians' commitment to help families access resources and opportunities beyond their medical care.

**Challenges** Both families and staff perceived this new service model as challenging. Families were concerned that their children would not receive the same level of service from their care coordinators. Care coordinators were intimidated by the idea of a new workplace and were concerned that they would not be able to serve their clients as effectively if their caseloads were expanded. At the same time, economic conditions in our state resulted in early retirements and layoffs that reduced the size of the care coordination staff.

**Response to Challenges** The impetus for this accomplishment was a growing national recognition of the importance of providing services to children and youth with special health care needs in a coordinated, comprehensive, culturally competent, community-based, family-centered fashion within a medical home, as envisioned by the American Academy of Pediatrics (AAP). A number of collaborators assisted in developing the medical home initiative. A grant from MCHB funded the initial process. In partnership with the state AAP chapter, two training sessions, "Every Child Deserves a Medical Home," were hosted at Shriner's Hospital, resulting in ongoing dialogue with physicians and families.

A team of Title V staff, parents, and physicians attended the first national AAP medical home conference and formed a Medical Home Steering Committee that guided state activities. New England Serve, a 20-year-old health policy organization, assisted in planning and implementing initiatives. New England Serve convenes the Consortium for Children with Special Needs, a group of representatives from state agencies and health plans, physicians, families, and academics, committed to implementing Healthy People 2010 goals. The Consortium brought together many collaborators invested in the medical home and an expanded model of care coordination. Additionally, the new Care Coordination Program Director worked with staff to process the many changes and instituted a number of team-building activities and other supports. He advocated strongly to increase staffing positions.

**Outcomes**

- The Massachusetts Department of Health contracted to place care coordinators in 6 community-based practices in 2002, 7 in 2003, and 13 in 2004.
- Over a three-year period, the care coordination caseload increased almost 100%.
- In 2000, 85% of those receiving care coordination were white, English-speaking families. Today, 50% of families seen within medical home practices are Hispanic, African-American, or Asian.
- Care Coordination program staff expanded to include more multilingual individuals who share their knowledge of community resources and opportunities across the state.
- Expanded information-sharing with practice staff and clients helps to connect them with a variety of new resources, resulting in improved communication between primary and specialty care, and improved outcomes for children and families.

## MISSISSIPPI

### Mississippi State Department of Health, Children with Special Health Care Needs, Children's Medical Program (CMP)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Language Access, Partnerships & Collaboration

- Description** A family was referred to Mississippi State Title V CMP for comprehensive orthopedic evaluation and treatment at a local clinic. CMP collaborated with multiple partners and leveraged resources to provide transportation, interpreter services, and other family supports to access needed care for the young child.
- Challenges** Changing demographics in Mississippi underscored the importance of increasing capacity to address language needs and provide other family support to ensure access to care. Specific challenges included the seasonal nature of the parents' employment (which presented complexities in their eligibility for Medicaid or SCHIP and Medicaid-funded transportation services) and the rural location of the parent's household.
- Response to Challenges** CMP leveraged resources from a broad range of partners to address transportation, language, health services, and financing for needed supports. Partners included the Migrant Education Program, Catholic Charities of Jackson, Immigration and Refugee Minor Program, Catholic Diocese of Jackson, and University of Mississippi Medical Center Pediatric Orthopedic Clinic.
- Outcomes** As a result of interpretation services:
- The family was able to understand the child's health condition and the reasons for recommended surgical intervention.
  - Health care providers were able to communicate effectively with the family and understand the family's strengths, needs, and preferences.
  - The child received the surgical invention to correct an orthopedic birth defect and is now flourishing (to the delight of her parents).
- After the experience gained in addressing these needs, the Mississippi CMP is better prepared to address similar challenges in the future.

## MISSOURI

### Missouri Department of Health and Senior Services, Special Health Care Needs Unit

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Language Access, Training & Personnel Development

**Description** Bureau of the Census data (2002) demonstrated the true nature of the increase in diversity in Missouri. Of the state's 5.5 million residents, more than 151,000 were born in another country: 25,000 in Mexico; 9,700 in Germany; nearly 8,800 in Vietnam, and 7,500 in India. Administrators in the Department's Special Health Care Needs Unit (SHCN) knew that the Census data sent a clear message: cultural competency must be incorporated in SHCN policies, practices, and procedures. This would be essential to reach the goal of engaging families of children with special health care needs as partners in decision-making at all levels, and ensuring that families are satisfied with the services they receive.

**Challenges** The primary challenge was to increase the percentage of diverse families that (1) use SHCN services, (2) partner in decision-making, and (3) are satisfied with the services they receive.

**Response to Challenges** To address the goal of improving services to this diverse population, in 2002, a SHCN work team comprising the quality assurance consultant, community health nurse, and all five area office coordinators, developed a plan to assess and increase cultural competence. The plan delineated several key areas: (1) creating a definition of cultural competence; (2) communicating information on federal laws regarding language access for persons with limited English proficiency; (3) providing guidance for coordinating cultural competence efforts across the Department's programs; (4) conducting an inventory of the SHCN Unit's cultural competence efforts; and (5) creating a list of the Unit's strategies and action plans for implementing culturally competent policies and practices.

The SHCN Unit:

- Disseminated supportive materials and resources to increase the awareness, knowledge, and skills of area coordinators and their staff;
- Revised the SHCN operational plan to include the goal of increasing the percentage of culturally diverse participants/families of children to help in decision-making at all levels;
- Incorporated cultural competence activities into the area office business plans and monthly activity reports;
- Completed a cultural competence self-assessment by area coordinators, life-stage program team leaders, and the family partnership coordinators; and
- Provided staff training on (1) Missouri Department of Health and Senior Services language services policy and procedures; (2) use of the language line for over-the-phone interpretation services; (3) cross-cultural communication, and (4) training in other languages (primarily Spanish).

**Outcomes** The initiative achieved the following outcomes:

- The percentage of Hispanic families seeking and participating in SHCN Unit programs increased from 1 percent in 2001 to 7 percent in 2003;
- Individuals from other communities (East Europeans, and West Africans) increasingly seek assistance;
- The comprehensive design of the cultural competence plan helps to engage families as decision-making partners in the services they receive.

## NEW JERSEY

## New Jersey Department of Health and Senior Services, Family Health Services

## Pathways on the Journey to Achieve Cultural and Linguistic Competence

Partnerships &amp; Collaboration, Organizational Policy &amp; Structures

- Description** With a number of agencies and organizations serving children and families throughout New Jersey, many provider resources were available, yet there was a need to develop and share resources on culturally competent policies, procedures, and practices. The state had many resources, yet lacked a central repository with easy access for all.
- Challenges** The major challenge was in gathering together 60 agencies and organizations to plan and develop a mechanism for sharing information and resources to benefit children, youth, and families across the state.
- Response to Challenges** The Department was one of a number of organizations serving families of children with special health care needs that participated in training and technical assistance provided by the National Center for Cultural Competence in June 2002. The purpose of the training was to address how to develop and carry out culturally competent policies, procedures, and practices. Approximately 60 individuals participated in this activity, including Department staff, community partners, and family members. Participating organizations included the Regional Early Intervention Collaboratives (REIC), a network of providers focused on community-based, culturally competent, and consumer-driven early intervention systems; Maternal and Child Health Consortia, a group of private nonprofit organizations; Elizabeth M. Boggs Center on Developmental Disabilities at the University of Medicine and Dentistry of New Jersey; Statewide Parent Advocacy Networks (SPAN), whose services empower families and inform and involve professionals; New Jersey Protection and Advocacy, Inc., a consumer-directed, nonprofit organization serving persons with disabilities; and New Jersey Council on Developmental Disabilities. A major action step led to the formation of the New Jersey Statewide Network for Cultural Competence, which collects and shares information and resources statewide. The Network launched a strategic planning process that included developing a mission statement, defining the population of people with diverse needs, and putting together a strategic plan.
- The executive committee set two goals: (1) To identify existing state resources such as agencies and individuals with knowledge and skills in specific cultures and/or services for people with diverse needs, and (2) to create a way to disseminate this information. The committee developed a survey questionnaire eliciting four types of information: individual and organizational contact information, types of services provided, counties served, and languages and communities served. Through a personalized campaign, committee members forwarded a letter and survey to other individuals and organizations, and followed up with personal contacts. The campaign was a major success, garnering 450 responses. In 2004 the Network organized the collected information in a database and developed a web site.
- Outcomes**
- Since its creation, the New Jersey Network for Cultural Competence has grown to represent approximately 30 agencies throughout the state.
  - The Network represents a successful collaboration, involving a number of agencies and individuals who provide perspective to ensure that all communities are represented.
  - The initiative facilitates easy dissemination of information and sharing of best practices, policies, and procedures.
  - The listserv and web site have proven to be quick and easy ways for individuals to share information.

## NEW MEXICO

### New Mexico Department of Health (DOH), Public Health Division, Family Health Bureau, Children’s Medical Services (CMS)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Organizational Policy & Structures, Partnerships & Collaboration

<b>Description</b>	New Mexico DOH/CMS sought to expand membership in the Cultural Competence Committee to include community stakeholders and all interested DOH employees. The goal was to bring everyone together to discuss cultural competence and plan for its integration in CMS activities across the state’s health districts.. A review of committee membership found that only social workers from CMS were members. To address this lack of diversity, CMS staff decided to expand recruitment efforts for the committee as part of their strategic plan.
<b>Challenges</b>	There were difficulties in reaching DOH employees across the state’s five health districts.
<b>Response to Challenges</b>	Committee members initiated recruitment activities, including presentations to program managers for each of New Mexico’s five health districts and across all programs, expanding beyond CMS. These new stakeholders included personnel from the Community Access Programs (CAPS), WIC, Families First, and Health Promotion.
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• The Cultural Competence Committee reports having received more ideas and innovative ways to reach and involve community stakeholders.</li> <li>• The committee convenes quarterly meetings, during which new members are welcomed.</li> <li>• Members contribute articles on cultural diversity and related areas to their online newsletter.</li> <li>• The Connexiones newsletter increased the committee’s ability to reach DOH employees statewide.</li> </ul>

### New Mexico Department of Health (DOH), Public Health Division, Family Health Bureau, Children’s Medical Services (CMS)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services and Supports, Training & Personnel Development, Language Access, Partnerships & Collaboration

<b>Description</b>	CMS’ Cultural Competence Committee (with representation from New Mexico’s five health districts and from the community) provides monthly in-service/staff development training to address issues of cultural and linguistic competence. Through the committee’s efforts, it was determined that CMS staff had varying capacities related to cultural and linguistic competence. An intervention was required to equalize knowledge and skills. The committee further identified the need to increase the medical and developmental Spanish-language capacity of staff so they could better meet the needs of children and youth with special health care needs and their families.
<b>Challenges</b>	Promoting cultural competence as an important endeavor was a major challenge. Time, lack of funding, and competing work responsibilities created conflict for staff in terms of participating in staff development and in-service training. Lack of financial incentives to reimburse staff for specific skills, such as providing medical interpretation, was also a significant challenge.
<b>Response to Challenges</b>	In response to identified needs, CMS, in collaboration with the District Director and Public Information Officer, developed an online newsletter called CONNEXIONES. The newsletter addresses issues of culture and diversity, and is available to employees statewide. The CMS

office in Las Cruces (District 3) established a Cultural Competency Library that contains books, videos, and other materials on culture, language, diversity, and related topics. The library is available to all CMS staff, and offers opportunities for individualized education in cultural competence. A staff clerk assumed responsibility for cataloging the materials and now serves as the librarian. CMS became a member of the Southern Area Health Education Center sponsored by New Mexico State University, and developed a three-tiered (beginning, intermediate, and advanced) cultural competence training module series to increase awareness, knowledge, and skills of staff in all departments.

Spanish-language instruction (optional for some and mandatory for others) was offered to CMS staff in District 2 to increase linguistic capacity. This helped to improve both the knowledge and fluency of bilingual/bicultural staff. The instructor not only provided Spanish-language instruction, but also taught language within the cultural and regional context of New Mexico, sharing information and discussing issues of critical concern to the Hispanic community. In addition, staff interpreters received instruction in medical interpretation.

- Outcomes**
- Staff gained increased knowledge of Spanish language and cultural issues;
  - Staff increased their ability to provide medical interpretation; and
  - A culturally and linguistically competent transition assessment tool for youth with special health care needs was developed and tested, and is currently in use.

### **New Mexico Department of Health (DOH), Public Health Division, Family Health Bureau, Children’s Medical Services (CMS)**

#### **Pathways on the Journey to Achieve Cultural and Linguistic Competence**

Increased Access to Care & Adaptations to Services & Supports, Partnerships & Collaboration

**Description** The NCCC conducted a cultural competence organizational self-assessment for CMS in 2000. As a result, CMS recognized the need to increase its knowledge of the needs, preferences, and help-seeking practices of the African-American community. Vivian Tucker, a CMS social worker who serves families with infants and toddlers, took a leadership role in increasing outreach to the African-American community.

**Challenges** Historically, CMS did not have a presence in New Mexico’s African-American communities. Alicia Williams, CMS program manger in Albuquerque, spoke with Ms. Tucker and asked for her assistance in increasing outreach to the African-American community. An additional challenge involved tracking and monitoring the effectiveness of outreach efforts.

**Response to Challenges** Ms. Tucker, a member of DOH’s Increasing Minority Participation Task Group (IMPART), spearheaded outreach and community engagement activities in African-American communities for CMS. She established links with formal community networks of support, including attending an NAACP conference where she exhibited CMS brochures and educational materials and was available to answer questions from conference attendees. Interest in health issues and concerns in the African-American community led her to participate with the Office of African American Affairs in the Second Bi-Annual People of African Descent Tobacco Forum. In the spirit of leadership, Ms. Tucker forged relationships with African-American faith-based organizations and worked to share health information and educational materials on topics such as HIV/AIDS and its impact on the African-American community, specifically the increased incidence in women, and related issues such as causes and social stigma.

The District I Cultural and Linguistic Access Services (CLAS) Committee was created in 1998 to address issues of cultural competence, linguistic access, and health disparities. The

*Continued*

*New Mexico Department of Health (DOH), Public Health Division, Family Health Bureau, Children’s Medical Services (CMS) Continued*

CLAS committee is a multidisciplinary team of public health professionals, including a CMS social worker, health promotion specialist, program manager, WIC nutritionist supervisor, District Health Officer (a physician), Director of Nursing Services, other nurses, and clerks. Committee members joined together to address the issue of monitoring and measuring outreach activities in the African-American community. Partners in this accomplishment included CMS social workers at the North Valley Public Health Office, DOH coordinator of the Office of Health Equity, CMS State Office administrative staff, WIC, nursing services and health promotion, the NAACP, Office of African American Affairs, and African-American churches throughout Albuquerque.

- Outcomes** This initiative resulted in:
- An increased presence of DOH/CMS in New Mexico’s African-American communities.
  - An increased awareness of culture and how it impacts service delivery in District I.

**NORTH CAROLINA**

**North Carolina Department of Health and Human Services, Division of Public Health (DPH) and the Division of Medical Assistance, North Carolina Health Check, North Carolina Health Choice for Children.**

**Pathways on the Journey to Achieve Cultural and Linguistic Competence**

Increased Access to Care & Adaptations to Services & Supports, Partnerships & Collaboration

- Description** Continued growth of the Hispanic/Latino population, largely Mexican, prompted the North Carolina DPH’s Medicaid program (Health Check) and it’s State Children’s Health Insurance Program (NC Health Choice) to increase outreach efforts to Hispanic families.
- Challenges** The greatest challenges in working with the Hispanic/Latino community involved trying to explain how health insurance works, how immigration issues impact eligibility for public insurance, and how to navigate the state’s rather complex health care system.
- Response to Challenges** In an effort to reach Latino families in North Carolina, Kimberly Duarte Sauls, the Health Check/NC Health Choice Minority Outreach Consultant, collaborated with a number of partners serving the Hispanic/Latino-community. Partners included North Carolina Healthy Start, the Mexican Consulate, churches, health departments, business owners, social service departments, and a range of state, regional, and local Hispanic/Latino organizations. As a result of its interest in DPH programs, especially child health insurance, the Mexican Consulate championed outreach efforts to the Latino population. For example, the Consulate’s education and health program and mobile Consulate sites across the state collaborated with Ms. Sauls and facilitated information exchange with Latino families and Latino-serving organizations.

Collaboration with the Mexican Consulate began with an initial visit to the Raleigh office to meet with two staff serving six sites in North Carolina, and to orient them to Health Check and NC Health Choice. This led to a meeting with the Consul, followed by an additional meeting with 20 Consulate staff who has access to Latino communities across the state. This relationship-building enhanced collaboration and augmented outreach activities through the work of Consulate staff who promoted DPH child health insurance programs to a receptive Latino community on North Carolina’s east coast and in the Unifour (Hickory) area. Health outreach efforts by the Consulate’s mobile sites in Charlotte, Supply, and Booneville provided extended opportunities to share information about health insurance, and specifically

about Health Check and NC Health Choice, and how immigration issues impact this community's eligibility for public insurance.

- Outcomes**
- A strong collaborative relationship was built between the Mexican Consulate and the DPH; other DPH branches have also collaborated with the Mexican Consulate on issues such as immunizations.
  - More than 1,000 Latino families have received culturally and linguistically appropriate information and materials about Health Check and NC Health Choice.
  - Ten Latino-serving organizations gained knowledge of Health Check and NC Health Choice.

### **North Carolina Department of Health and Human Services, Division of Public Health (DPH) and the Division of Medical Assistance, North Carolina Health Check, North Carolina Health Choice for Children**

#### **Pathways on the Journey to Achieve Cultural and Linguistic Competence** Partnerships & Collaboration, Training & Personnel Development

**Description** North Carolina's Department of Health and Human Services and its Division of Public Health recognized the health needs of the state's tribal populations and took action to address these needs by promoting awareness of two state health insurance programs: Health Check (the state's Medicaid program), and North Carolina Health Choice for Children (the State Children's Health Insurance Program). The Health Check/NC Health Choice Minority Outreach Coordinator, Kimberly Duarte Sauls, initiated an outreach campaign to build connections and share information with state tribal entities to improve the health of children in these communities.

**Challenges** Entering a tribal community as an outsider can be a significant challenge. First attempts at engaging tribal communities were hampered by a lack of knowledge of traditional ways of gaining access to this population. Distributing flyers or brochures and making telephone contacts were nearly futile because a sense of trust had not been established; the DPH was not well known in the community and had little or no relationship with tribal leaders. The time and personal effort needed to build relationships and engender trust were challenging. Lack of understanding the community's issues and concerns was also a barrier.

**Response to Challenges** Collaboration with North Carolina's Commission of Indian Affairs provided information and historical perspective on the state's tribal communities, especially their political structures and community characteristics. The Minority Outreach Coordinator collaborated with a North Carolina tribal member who was also a DPH consultant; this trusted tribal member introduced the Minority Outreach Coordinator to key leaders of tribal communities, resulting in an invitation to visit one of the six tribal communities. This led to opportunities to meet and speak with tribal administrators, elders, and chiefs.

Other organizations and entities supported this collaborative effort, including the Office of Minority Health, Covering Kids & Families Project, DPH's Immunization Branch, and, significantly, the other five tribal governments. Broadening this collaboration enabled DPH to enhance its visibility and relationships within the tribal governments in order to address the health and well-being of these communities. Over time, relationships were forged with tribal health deputies who learned about Health Check/NC Health Choice and assigned one person in each of the six tribal health offices to promote these state health insurance programs as a priority.

- Outcomes** This collaborative project achieved:
- Institutionalization of outreach efforts to the state's tribal communities;
  - Greater understanding of tribal communities and their organization; and
  - Increased awareness of the importance of learning about a community's preferred ways of gaining entrée, establishing trust, credible voices, community strengths, and resilience.

## NORTH DAKOTA

### North Dakota Department of Human Services, Children's Special Health Services (CSHS)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services & Supports, Training & Personnel Development

**Description** In 2003, state CSHS staff attended cultural competence training that provided an assignment for action. Staff selected training and skills-building in cultural competence as their focus for staff development.

In collaboration with local county social services and public health care coordination staff, CSHS program staff developed a plan for in-service training to:

- Build awareness of culture and diversity within North Dakota, and
- Increase knowledge of cultural competence in transition issues for youth with special health care needs, in order to promote comprehensive service planning

This training session also generated participant suggestions for strategies to engage families in learning about cultural perspectives and values in key areas: disability and illness, communication, family roles, problem-solving, child rearing, and health- and help-seeking behaviors.

The CSHS program also conducted a mini cultural self-assessment, using an NCCC Self-Assessment Checklist.

**Challenges** There was a lack of staff time to implement and coordinate this planned staff development initiative.

**Response to Challenges** The staff and their collaborative partners developed an action plan to achieve project goals. In joint planning sessions, the partners identified specific tasks and resource materials needed, then divided tasks among the group members.

**Outcomes** This project:

- Developed a service plan to address cultural issues identified in training, and
- Improved awareness and knowledge of cultural issues and how to better provide services to families of diverse cultural backgrounds.

## OKLAHOMA

### Oklahoma Department of Human Services, Family Support Division, Children with Special Health Care Needs Program grantee, “Sooner SUCCESS”

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Language Access, Partnerships & Collaboration

- Description** The CSHCN grantee program, Sooner SUCCESS, convenes periodic coalition meetings. During one of the meetings, a representative of a Hispanic community requested assistance in intervening with the school system for a family with limited English proficiency. This family sought information on community-based resources and/or after-school music programs to address the extracurricular needs of their child. Sooner SUCCESS contacted the school principal and set up a meeting.
- Challenges** Misunderstandings due to cross-cultural differences persisted, even with the assistance of a school interpreter. Problems were based primarily on differing expectations and cultural perspectives of the family and the school administration. The school assumed that every request from a family member would require more services at greater expense; the family, based on cultural experiences, assumed that the school would take a more comprehensive role in the development of all aspects of the child’s life. The school system’s interpreter provided a literal translation of spoken words and did not explain cultural nuances/meanings.
- Response to Challenges** A representative of the Hispanic community acted as a cultural broker and helped foster an understanding of the underlying messages in communications between school and family. The school, the family, Sooner Success, and the cultural broker all gave time to discuss issues and clarify meaning to resolve misunderstandings.
- Outcomes**
- The cultural broker interpreted the meaning and perspectives of both the school and family, and placed them in appropriate cultural contexts.
  - Cross-cultural misunderstandings that had been a source of conflict and a barrier to services were eliminated.

## TENNESSEE

### Tennessee Department of Health, State Title V Program, Children's Special Services (CSS)

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services & Supports, Partnerships & Collaboration

<b>Description</b>	Tennessee's expanded Medicaid program (TennCare) formerly provided health care insurance for all eligible children in the state of Tennessee, including children without documentation. Because of changes in TennCare eligibility, the only avenue for medical care for undocumented children was the emergency room. CSS developed the program Hispanic Friends to provide medical coverage for undocumented Hispanic children.
<b>Challenges</b>	A key facet in implementing Hispanic Friends involved care coordinators who conducted home visits. However, CSS care coordinators found that families were unwilling to talk to them because of a lack of trust. When the care coordinators were able to make contact with a family, the contact was usually with the mother. In some cases, the care coordinators were not able to enroll eligible children in the program because they had not been able to establish a connection with the fathers, who were the family decision-makers.
<b>Response to Challenges</b>	As part of their implementation strategy, CSS care coordinators joined with other CSS employees of Hispanic origin to collaborate with local Hispanic community organizations. This collaboration helped to provide access to the families and also to leverage resources, especially in rural areas. The care coordinators were able to establish connections with the fathers and to inform them of services and supports available through the program to address their children's special needs.
<b>Outcomes</b>	<ul style="list-style-type: none"><li>• Through the Hispanic Friends program, CSS has been able to provide medical coverage to children with kidney disease, cancer, and heart problems.</li><li>• At a systems level, CSS increased efforts to recruit and hire bilingual staff, including salary incentives for language ability.</li><li>• CSS developed a growing awareness of the need for a diverse staff who are representative of the community.</li><li>• Because of limited fiscal resources specifically for the Hispanic Friends program, there was a greater awareness of the need to extend collaborations with Hispanic community-based organizations to:<ul style="list-style-type: none"><li>– Leverage resources,</li><li>– Serve as cultural brokers or liaisons to increase awareness and knowledge of services offered by the Hispanic Friends program, and</li><li>– Assist in identifying families with children who have special health care needs.</li></ul></li></ul>

## UTAH

## Utah Department of Health, Division of Community and Family Health, Bureau of Children with Special Health Care Needs

### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services & Supports, Language Access

**Description** Of the seven clinics in the Utah Collaborative Medical Home Project, one site primarily serves Spanish-speaking families of children with special health care needs. Many of these families are undocumented. Although several members of the medical home team, including the physician, are Spanish-speaking and sensitive to the cultural issues of these families, many barriers to accessing health care remained.

**Challenges** Overcoming barriers that prevented families from accessing care was a considerable challenge. Conducting a process to identify and address access issues was also challenging.

**Response to Challenges** The Utah Medical Home Project is a collaboration between the Utah Department of Health, Bureau of CSHCN, Medicaid, Utah State University, Utah Family Voices, and the University of Utah's Department of Pediatrics. The project's seven pediatric offices and one family practice office enhanced their ability to provide medical homes for children with special health care needs and their families. The South Main clinic is the focus of this story.

The Parent Advocate on the medical home team, a Latina mother of a child with disabilities, was instrumental in establishing trusting relationships with families and sharing information with the team about barriers and issues identified by families. Additionally, Utah State University conducted a series of family focus groups on behalf of the project to gather information. As a result of these focus groups, the South Main Clinic identified the following issues:

1. Access to health care. Families did not have easy access to their providers or members of the Medical Home team; families could not get appointments quickly or arrange appointments of sufficient length to discuss complex health issues.
2. Access to community resources. Families were unable to get information and resources for undocumented individuals.
3. Language barriers. Families who had questions after office hours had difficulty finding available Spanish-speaking staff on-call.
4. Challenges for newly arrived families. These families lacked knowledge of the health care system and had difficulty asking for assistance.
5. Isolation. Families, especially mothers of children with special health care needs, felt isolated because of language, socioeconomic, and transportation factors.

**Outcomes**

- The concept of medical home is now well established in the South Main Clinic, which serves children with special health care needs and their families.
- A method of flagging patient charts has been established to ensure that children with complex medical conditions received enhanced attention in the medical home; special extended appointment times were made available.
- Volunteers, Promotores/as, and the parent advocate helped link families to resources.
- The Spanish-speaking clinic coordinator and the parent advocate triaged calls to determine when to contact the doctor for after-hours care; the medical home team purchased a pager and provided families with the number.
- The parent advocate and the Family Voices coordinator helped families to access support from the clinic and the community in which they felt comfortable.
- The parent advocate was recognized as a valuable asset and was hired as a permanent employee.
- The clinic earned a reputation within the community for being a wonderful health care resource for Spanish-speaking families.

## WASHINGTON

### Washington State Department of Health, Children with Special Health Care Needs Program (CSHCN), Family to Family Network

Pathways on the Journey to Achieve Cultural and Linguistic Competence  
Partnerships & Collaboration

**Description** The Washington Integrated Services Enhancement (WISE) project was funded to recruit, mentor, and involve family members at all levels to improve family participation in systems of services for children with special health care needs. Although the project did increase family involvement, the participating families did not fully reflect the diversity within the state. To address this concern, the Department of Health’s CSHCN program initiated activities to increase the involvement of families from diverse racial, ethnic, cultural, and geographic backgrounds in the program’s planning and policy development.

**Challenges** Working together with a large number of stakeholders was challenging. So, too, were efforts to increase representation and engagement of diverse families in achieving the six components of a system of services for children and youth with special health care needs.

**Response to Challenges** The CSHCN program, through WISE project activities, capitalized on collaborative relationships with agency and community partners to establish the Washington Family to Family Network (WFFN), representing 11 agencies and organizations. The main goal of this group has been to solicit input from members on how to recruit additional families from diverse populations. The WFFN supported the CSHCN family consultant by establishing recruitment criteria and assisting in a promotional campaign to recruit a more diverse group of parents. Additionally, the WFFN assisted in the review and selection process for Family Advisory Network (FAN) and developed a mentoring strategy for new family advisors. The Family Advisory Network members received an orientation packet developed by the WFFN, which outlined members’ roles and responsibilities as well as planned activities for the WISE project.

The Family Advisory Network convened a retreat and identified the need for a guide to help CSHCN coordinators and family-serving organizations include more diverse families in planning and policy development. Family participation in planning and policy development would help to ensure that services are family-centered and culturally appropriate. Following the retreat, the Network conducted an informal family focus group to elicit suggestions on strategies to recruit and engage more diverse families. Feedback from the focus group is presented in the booklet “Practical Tips for Involving Family Consultants in Program and Policy Development.” Community-based providers were invited to test the tips. Providers attending a family-professional meeting stated that they found the practical tips to be useful, and were surprised to find that families reported services to be less family-centered than providers assumed.

**Outcomes**

- Additional families have been recruited from diverse cultural, ethnic and geographic backgrounds;
- WFFN network members work more collaboratively in efforts to achieve the six components of a system of services and supports for children and youth with special health care needs and their families.
- Family Advisory Network members have taken on mentorship roles with newer, less experienced individuals and families.
- The project applied for and received a Champions for Progress incentive award to develop a Family Leadership Institute, convened in November 2004.

## WISCONSIN

### Wisconsin Department of Health and Family Services, Children with Special Health Care Needs (CSHCN) Program

#### Pathways on the Journey to Achieve Cultural and Linguistic Competence

Increased Access to Care & Adaptations to Services & Supports, Language Access, Partnerships & Collaboration, Organizational Policy & Structures

- Description** The Wisconsin Title V CSHCN Program identified cultural competency as one of its five guiding principles. All programs funded by the Wisconsin Title V Program work to address these principles. Eliminating health disparities is also a key goal of Healthiest Wisconsin 2010. The Title V CSHCN Program funds five regional CSHCN centers, which provide information, referral, and assistance to families and providers; conduct parent support activities; and facilitate service coordination through contracts with local health departments and other community agencies.
- Challenges** A survey conducted by the Regional Centers documented that Hispanic families underutilize the Centers' services. In one area of the southeast region, limited access to interpreter services impacted service utilization. Another challenge was to ensure family participation and partnership in all aspects of developing and implementing program activities.
- Response to Challenges** The Southeastern Center launched an initiative to build partnerships with Latino families and their providers. Center staff hired a Hispanic father to lead community outreach and serve as a cultural broker through one-on-one services to help families navigate the health care system. Center staff increased the number of materials available for Hispanic families and convened community meetings to identify strategies to improve family access to health information and services. Responding to the lack of interpreter services, Center staff partnered with a local college and a county early intervention program to arrange for college students to provide interpreter services, and developed a training curriculum to help standardize the quality of these services.
- Center staff also partnered with families and the community to conduct a conference to increase providers' knowledge and cultural awareness of Hispanic/Latino population groups. Additional partnerships were formed with the public schools and other Milwaukee community agencies to host a Latino forum addressing special education issues, access to health care services including transition, and related community resources.
- To ensure family participation and partnerships in all aspects of developing and implementing program activities, the Center collaborated with leaders in the Hispanic/Latino community and partnered with community agencies, including churches, to enhance recruitment efforts. To address limitations in interpreter services, the Center collaborated with local public health (early intervention), public schools, county health and human services, community agencies, churches, health clinics, and hospitals to provide such services.
- Outcomes** This collaborative project:
- Increased awareness of strengths and needs of the Hispanic/Latino community,
  - Increased collaboration between community agencies, and
  - Increased access to interpreter services.



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