

Special Addition



children with special health care needs

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FEDERAL VIEWPOINT

Cultural Competence What it is What it's not

by Diana Denboba, Health Resources and
Services Administration



Diversity. Cultural awareness. Cultural sensitivity. Cultural effectiveness. Cultural competence. You may think these terms are interchangeable, but they're not. The Maternal and Child Health Bureau (MCHB) has chosen to use the term cultural competence as a value across all of its activities and partnerships.

Culture means the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group. It is learned behaviors common to a human society that acts like a template, shaping behavior and consciousness from generation to generation.

(Federal Viewpoint) please see page 2

In this Issue

- 4 Family Voices
- 4 Illinois Families for Hands & Voices
- 5 Pooh Moments
- 6 The Power of Partnership

LOCAL VIEWPOINT

Cultural and Linguistic Competence – My Passion!

by Claudia Fabian, Chair - DSCC Family Advisory Council

When Bob Cook mentioned that the next issue of Special Addition was going to be dedicated to Cultural Competence, I jumped at the opportunity to write something and to

share with you some of my ideas. You may not know that I was born in Buenos Aires, Argentina, a very long time ago (you do not need to know how long ago, right?)

(Local Viewpoint) please see page 3



Culture is not synonymous with race. From Russian immigrants to rural Appalachians, to the Amish, to you and me, everyone has a culture.

(Federal Viewpoint) continued from page 1

Competence is the ability to function effectively.

Many definitions of cultural competence have evolved from diverse perspectives, interests, and needs. Definitions are incorporated in state legislation, federal statutes and programs, private sector organizations, and academic settings and accredi-

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tation criteria. Any comprehensive definition must address not only attitudes but actions and practices.

Cultural competence defined

Cultural competence, as defined in The Developmental Disabilities Assistance and Bill of Rights Act of 2000, means services, supports, or other assistance conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program.

The reality of striving to achieve cultural competence is a dynamic, ongoing, developmental process that requires a long-term commitment. At a systems, organizational, or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions at the levels of:

- policy making;
- program administration and evaluation;
- the delivery of services and enabling supports; and
- the individual.

Five essential elements that contribute to a system's, institution's, or agency's ability to become more culturally competent include:

- valuing diversity;
- having the capacity for cultural self-assessment;
- being conscious of the dynamics inherent when cultures interact;
- having institutionalized culture knowledge; and
- having developed adaptations to service delivery, outreach, and advocacy reflecting an understanding of cultural diversity.

Did you know that...

- The perception of illness and disease and their causes varies by culture.
- Diverse belief systems exist related to health, mental health, healing, and well-being.
- Culture influences help-seeking behaviors and attitudes toward care providers.
- Individual preferences affect traditional and other approaches to care.
- Patients must overcome historical and personal experiences of biases within the health care system.
- In some communities, care providers from culturally and linguistically diverse groups are under-represented.

At the individual level, cultural competence is an examination of our own attitudes and values, and the acquisition of the values, knowledge, skills, and attributes that will allow us to work appropriately in situations with other cultural groups. Such self-reflection is an ongoing journey.

Consider this example:

■ “Scheduling appointments (with my child’s doctor) is difficult. You have to prepare for a ceremony...so you can’t make the appointment... then there’s a big NO SHOW in your chart. They (providers) need to be flexible.” This Native American parent is saying that, at times, they cannot make scheduled appointments if they have to attend healing or other ceremonies. Has this Native-American family been unfairly labeled noncompliant?

(Federal Viewpoint) please see page 7

(Local Viewpoint) continued from page 1

and that I came to this country when I was 27. I married, and a few years later my son Auggie was born. What a moment!!!! As many of you, I was a first time mother, and as many of you, I had to confront the same shock every parent experiences when the doctors tell them that their child was born with disabilities... For me, to complicate matters further, I also had to deal with my inability to understand half of what was being said. I just couldn't put everything together: the language, the lack of compassion (at least, that's how I lived it then), the lack of warmth I so desperately needed, something that I was missing from my culture, my family, my home... So, there I was, trying to make sense of something that nobody usually can make sense of, in a language so difficult for me, that I felt desperate... almost frozen by fear and sorrow...

So, what are the experts saying about cultural and linguistic competence?

Cultural competence is a set of congruent practice skills, attitudes, policies and structures that come together in a system, agency or among professionals and enable that system or those professionals to work effectively in cross-cultural situations. Cultural competency is the acceptance and respect for difference, continuing self-assessment regarding one's own or another culture, attention to the dynamics of difference, ongoing development of cultural knowledge and resources and flexibility within service models to work towards better meeting the needs of diverse populations.

The concept of diversity encom-

passes acceptance and respect. It means understanding that each individual is unique, and recognizing our individual differences. These can be along the dimensions of race, ethnicity, gender, sexual orientation, socio-economic status, age, physical abilities, religious beliefs, political beliefs, or other ideologies. It is the exploration of these differences in a safe, positive, and nurturing environment. It is about understanding each other and

The concept of diversity encompasses acceptance and respect.

moving beyond simple tolerance to embracing and celebrating the rich dimensions of diversity contained within each individual. (University of Oregon, www.gladstone.uoregon.edu).

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. The organization must have policy, structures, practices, procedures and dedicated resources to support this capacity. (Goode & Jones, 2004, National Center for Cultural Competence, Georgetown University Center for Child & Human Development, <http://gucchd.georgetown.edu/nccc/framework.html>).

For me, being Auggie's mother in a St. Louis Children's Hospital back in 1990, cultural and linguistic competence would have meant to have somebody from the medical profession by my side, using my own language to explain why my son was so ill and dying, and that the same person stayed with me throughout our stay at the hospital

(instead of having different translators every shift.) I would have loved to have had somebody asking if I needed to connect with another Latino parent, if I needed a clergy who spoke my language... I think it would have made a huge difference! Today, as I try to help other families, telling them to make their needs known to hospitals, doctors, nurses, and to be persistent, I also share my experiences with medical professionals hoping to make a difference. You can also help, telling your story in your own communities, mentoring and supporting other parents, or joining our DSCC Family Advisory Council.

The sooner we can move "beyond simple tolerance to embracing and celebrating... diversity...", the sooner we'll become a better society, where no parent has to feel alone and isolated in a hospital PICU or NICU in this great country of ours. □

THANK YOU!!
THANK YOU!!

We want to thank all the families who completed the "Illinois Children with Special Health Care Needs Survey". The Survey results are being compiled and the results will be highlighted in the next "Special Addition".

THANK YOU!!
THANK YOU !!

FAMILY VOICES

Family Voices (FV) is a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs. FV stays on top of public and private sector health care changes that affect our children and families through the collective efforts of our families: a volunteer coordinator in every state; 10 regional coordinators; and a small staff working in several locations around the country. Together, FV shares the expertise and experiences of families from around the country with state and national policymakers, the media, health professionals, and other families. There are almost 40,000

Family Voices members - families of children with special health needs and friends and professionals who know and love our children.

For additional information contact Family Voices:

National Office
3411 Candelaria NE, Suite M
Albuquerque, NM 87107
1-888-835-5669

E-mail
kidshealth@familyvoices.org

Web
<http://www.familyvoices.org>

**VISIT THE DSCC
WEBSITE**

www.uic.edu/hsc/dsc/



This newsletter is available online and in alternate formats in English and Spanish upon request by calling 1-800-322-3722.

Illinois Families for Hands & Voices

Illinois Families for Hands & Voices is a new, parent-driven organization dedicated to providing non-biased support to parents of deaf and hard of hearing children. We are a state chapter of Hands & Voices National (www.handsandvoices.org).

What makes us unique? We have families who use many different methods of communication. We have families who use an Auditory Verbal approach, families who are Oral, families who use Cued Speech, families who use American Sign Language or other sign systems and families who employ a variety of approaches. We are parents of children with a variety of hearing losses.

We have a parent listserv located at <http://groups.yahoo.com/group/ILHandsandVoices/>. We host Parent Connection meetings which are gatherings that allow parents to connect with other parents and share any thoughts or concerns they may have. Parent Connection meetings are posted on our website: www.ilhandsandvoices.org and listed under "Events."

We have several stories from deaf and hard of hearing adults and teens as well as stories from parents raising deaf and hard of hearing children. These stories can also be found on our website under "Stories from Illinois."

Membership is open to anyone and includes a local newsletter as

well as membership in Hands & Voices National. The membership includes "The Communicator," a national newsletter that is distributed four times a year. A membership application and brochure can be found on our website: www.ilhandsandvoices.org or requested via: 888-482-4281 V/TTY. For more information contact Karen Putz: support@ilhandsandvoices.org. □

Karen Putz - Illinois Families for Hands & Voices
www.handsandvoices.org
www.ilhandsandvoices.org

"The moment at hand is the only thing we really own"

John Denver

Pooh Moments

It was in the Hall of Fame room at Mickey's Toon Town Fair in DisneyWorld where I had my first 'Pooh Moment'. My then 4 year-old son eased out of his wheelchair and steadied himself in his walker. He hobbled up to the line-up of characters: The Wicked Queen, Eyeore, Pooh, Sleeping Beauty, Tiger, Goofy, Snow White and Minnie Mouse. Matt presented himself to Winnie the Pooh and said: "How ya' doin' Pooh?"

I stifled my sobs of joy from behind the video camera as I was overcome with the joy of seeing my child walk and talk again and say hello to Pooh!

Matt was just a little over 2 years out of surgery from his brain tumor. We were experiencing the magic of Disney and emotional healing that only comes from great organizations like the Make-A-Wish Foundation.

Another 'Pooh Moment' came for me just last week, but not at Disney-World this time. It came while Matt stood strong and steady in the front row of his 4th grade music performance. No wheelchair, no walker, no loftstrand crutch, no paraprofessional; just Matt standing alone with all the balance in the world he needed for those 35 precious minutes. The tears trickled down my cheeks from behind the video camera.

Matt's recovery has been slow but steady. His brain tumor zapped his balance and coordination functions. The complications from surgery and treatment zapped neurological and cognitive functions. Time, therapy, and special education support with inclusion, and lots of patience have made significant

impacts on his development.

At one point he was on the DSCC home waiver program...those were the hard, "medical" days! Then we moved into the care coordination model with DSCC. Today, I ask his care coordinator to attend his annual IEP meeting and keep her abreast of his follow-up appointments with the oncologist, neurologist, endocrinologist, and the psychiatrist. It has been a happy marriage with DSCC and a "lived happily ever after" ending for us! We celebrate many Pooh moments, although now they look more like Jimmy Neutron and Sponge Bob moments! ☐

Sheri White
Mom to Matt, age 11
3/05

Illinois Centers for Independent Living

DHS' Division of Rehabilitation Services is the state's lead agency serving individuals with disabilities. DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities. One of the programs DRS monitors and provides technical assistance to the 24 Centers for Independent Living located across the State.

Centers for Independent Living (CILs) are private, not-for-profit, community-based organizations that provide accessible programs and services to all people with disabilities. These services are

designed to help people with disabilities help themselves live more independently and realize their dreams. CIL services and programs are provided mostly by people with disabilities.

In fiscal year 2001, 83,885 Illinois residents with disabilities received services from Illinois' 24 CILs.

Centers for Independent Living must provide these four core services:

Peer counseling

Advocacy

Information and referral

Independent living skills training

CILs may also provide other services to meet the needs of people in their communities, including, but not limited to:

Housing services and training

Accessibility services

Job readiness training

Youth programs

Community Reintegration programs

Personal Assistance programs

For more information on the nearest CIL contact:

**Voice/Toll-Free
1-800-843-6154,
Option #4**

or

1-800-447-6404 (TTY)

The Power of Partnership

by Nancy Hall, DSCC

In Metropolis, Illinois, a rural town of 6,482 citizens in the southernmost area of the state, a statue commemorates Superman, the comic book superhero who, thanks to the Earth's yellow sun, is able to fly to rescue the citizens of the mythical city of Metropolis.

For John Fisk, M.D., professor at the Southern Illinois University (SIU) Surgical Division of Orthopedics and Rehabilitation, and Jeri Beth Karkos, M.D., SIU Associate Professor of Developmental Rehabilitation, flight has nothing to do with superpowers. Their flights for the University of Illinois at Chicago Division of Specialized Care for Children (DSCC) clinics are the result of a partnership between the SIU School of Medicine and DSCC. The true winners of this partnership are underserved families of Southern Illinois with children who need pediatric specialty services. Without DSCC clinics, specialized diagnostic and follow-up care wouldn't be available in their area.

Through a grant for underserved populations, SIU supports the physicians' flights to Metropolis and Herrin, which cost about \$1,000 for each flight. According to Phil V. Davis, Ph.D., SIU Associate Dean for External Development and Health Affairs, the Rural Downstate Health Act was enacted to make specialty care more available to underserved families living in rural areas of the state. Because of this grant, the SIU physicians are able to fly to DSCC clinics when more than two hours travel time is required.

Typically, 25-35 children attend the DSCC clinics held in Metropolis and Herrin. "Without these clinics, families in need of pediatric orthopedic care usually have to travel three or four hours one way to access care," Jan Wieland, DSCC Program Services Manager, says. She adds that besides easier access, the clinics provide a more family-friendly setting for those children served by DSCC and more one-on-one time with Dr. Fisk and Dr. Karkos. Because orthotists and equipment providers also attend the clinic, the clinics offer families one-stop access to these other services if needed.

Other local partners for DSCC clinics include community organizations, such as hospitals or clinics that donate sites. The clinics need access to x-ray and laboratory services as well as examination rooms. Massac Memorial Hospital donates clinic space for the Metropolis clinic. For the Herrin clinic, the Southern Illinois Orthopedics Associates donates space, and in turn, Dr. Fisk provides consultation with the physicians in that group on pediatric cases.

DSCC clinics provide a unique educational experience for SIU pediatric medical students and orthopedic residents who sometimes accompany Dr. Fisk and Dr. Karkos. Dr. Fisk finds the clinics increase their knowledge of delivering health care services to underserved people who face unique challenges

that vary from transportation issues to the scarcity of needed services. He says experience with a child who can't eat and who requires special therapy for feeding broadens students' and residents' perspective of what it takes for those families living in underserved areas to get to the needed therapy. The clinics also offer students and residents understanding of diagnoses

and pathologies that may be unique to families in underserved areas.

In addition to the clinics in Metropolis and Herrin, DSCC supports specialty clinics in eight additional



Clinic flights made through partnership

sites throughout the state. About sixty clinics are held each year, providing access to pediatric specialty care for approximately 1,600 children annually. To coordinate the clinics, DSCC provides care coordination and support staff from their local regional offices. DSCC also pays a clinician fee and related travel costs.

Dr. Fisk admits the flights to Southern Illinois aren't without challenges. Unlike Superman, Kryptonite rarely slows Dr. Fisk and Dr. Karkos; however, thunderstorms, foggy mornings and snowfall have been known to temporarily impede their travel, causing occasional diversions, delays or cancellations. Luckily, the families of Southern Illinois don't have to rely on mythical superpowers. The power of partnership provides wings for Dr. Fisk and Dr. Karkos. □

(Federal Viewpoint) continued from page 2

Linguistic competence

A component of cultural competence is *linguistic competence*, 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 are not literate or have low literacy skills, and individuals with disabilities. Let's look at a few scenarios:

■ “You go to a meeting concerning your child, and they talk 90 miles an hour, and you're hearing it at 5 miles an hour, and understanding at maybe 2 miles an hour.” Has this family with English as a second language really understood the diagnosis and treatment prescribed?

■ “I do this dance all of the time (trying to elicit information with families). Sometimes its forthcoming and sometimes it just simply is not.” Is this provider understanding the cultural implications for some families of sharing information?

The 2000 Census data show that over 47 million people speak a language other than English at home, up nearly 48% since 1990; and, although the majority are able to speak English, over 21 million speak English less than “very well,” up 52% from 14 million in 1990. Are we prepared to serve and outreach to this population?

Cultural competence and family-centered care

Cultural competence is intricately linked to the concept and practice of family-centered care. Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors



Cultural brokering is the act of bridging, linking, or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change. A cultural broker acts as a go-between, one who advocates on behalf of another individual or group.

the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high-quality services.

The foundation of family-centered care is the partnership between families and professionals, so that families feel they can be decision-makers with providers at different levels—in the care of their own children and as advocates for systems and policies supportive of children and youth with special health care needs. It requires culturally competent attitudes and practices. It often requires building relationships with community cultural brokers (see box above), who can assist in understanding community norms and can provide links with other families and organizations, such as churches, beauty shops, and social clubs.

National Centers for Cultural Competence

The Division of Services for Children with Special Healthcare Needs (DSCSHN) within MCHB is currently funding its 4th National Center for Cultural Competence (NCCC), through competitive funding opportunities; the first was with the Texas Department of Public Health, and the last three, with the Georgetown Child Development Center. DSCSHN, in collaboration with these national centers, families, State Title V programs, and grantees have promoted and helped put cultural competence into action at the policy, guidelines, and practice levels in many Title V and Sudden Infant Death Syndrome (SIDS) programs, Substance Abuse and Mental Health Administration (SAMHSA) activities, and in research and training programs.

The mission of NCCC is to increase the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. The NCCC has been able to provide on-site organizational assessments with Title V/Public Health programs that have included community partners and focus groups with families. A “Cultural and Linguistic Competence Self-Assessment Questionnaire” developed by James Mason (OR) has versions relevant for administrators/policy makers, consumers, and providers.

Organizational self-assessment can lead to a collaboratively developed plan of action with clearly defined short and long-term goals, measurable objectives, and identified resources. It provides a vehicle to measure outcomes for person

(Federal Viewpoint) please see page 8



The Washington Father's Network produced an award winning video that shares the perspectives of African-American fathers.

(Federal Viewpoint) continued from page 7

nel, organizations, and the community at large. NCCC is also developing self-assessments that can be used by family organizations and hospitals.

In addition, the NCCC provides a number of services, including the provision/coordination of on-site consultation by its staff or state and local leaders in the area of cultural competence; assistance with planning and needs assessment processes; a variety of materials, family stories and a Spanish language portal that can be accessed on the website www.gucchd.georgetown.edu/nccc/.

The vision of MCHB

Cultural competence has been incorporated into MCHB goals, key strategies, and performance measures across MCHB programs. Other Division grantees have been integrating cultural competence into their activities and philosophy as well. Through funding from MCHB and Centers for Medicare and Medicaid (CMS), Family-to-Family (F2F) Health Information Center and Family Voices network, members have been able to increase their

Look what other centers are doing around the country:

—The Florida Institute for Family Involvement (FIFI) has a cultural competence advisory committee that assists with activities and reviews materials.

—The California Family to Family (F2F) Center, Support for Families of Children with Disabilities, has linked with translators and has family information, education, and support in a number of languages, including English, Spanish, Cantonese, Mandarin, Hmong, Vietnamese, Hindu, Urdu, Farsi, Hebrew, Japanese, and Tagalog.

—The PACER F2F Center in Minnesota (Parent Advocacy Coalition for Educational Rights) uses American Sign Language interpreters and makes use of PACER's Simon Technology Center with information about Braille and assistive technology.

—In the F2F centers in Maine (Project REACH) and Vermont (Parent to Parent), family health partners are located across the states in community-based organizations to reach isolated, rural families.

—In Tennessee, the F2F center with the TN Disabilities Coalition is outreaching to the Hispanic and Appalachian population using cultural brokers.

—New Jersey's Statewide Parent Advocacy Network (SPAN) program provides training to organizations/providers on how to recruit, train, and maintain relationships with diverse family members for committees and ongoing feedback.

—Maryland's F2F center, and their organization Parents' Place of Maryland, along with NCCC, has made a commitment to cultural competence with infrastructure and other changes, increasing the participation of culturally diverse families by 11%.

outreach and services to culturally diverse and geographically isolated communities.

Family Voices, Inc., with funds from MCHB has a cultural competence/outreach initiative and has their commitment to diversity and cultural competence on their website. They work collaboratively with NCCC and will be piloting the family organization self-assessment.

State Title V Programs have also been busy integrating cultural competence into policies, guidelines, and activities. The Washington state CSHCN program hosted a "Family Gathering on Cultural Competency." This meeting brought together four Department of Health/CSHCN program contracts that focus on parent issues: Washington State Parent to Parent, Washington Fathers Network (WFN), The Medical Home Leadership Network, and Children's Hospital and Regional Medical Center. The family gathering was an opportunity for contractors and MCHB staff, as well as parents, to listen to Parent to Parent Ethnic Outreach

Coordinators describe strategies that increase cultural competency and reach diverse populations. Contract managers and staff were exposed to creative ideas and strategies as they developed their contracts for the next year.

MCHB envisions a nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting. □

Special thanks to Trish Thomas, Wendy Jones, NCCC, FIFI, and those families and providers who shared their stories.

For additional information visit:
www.hotculture.com
www.gucchd.georgetown.edu/nccc