Special Addition

children with special health care needs

summer/fall 2005

A Newsletter for Michigan Families

In this Issue

This publication replaces the September 2005 *Heart-to-Heart Information Updates* from Mary Marin, Parent Participation Program (PPP) executive director. PPP is a section of the Children's Special Health Care Services program of the Michigan Department of Community Health. The update resumes in October. Request it by mail at 1-800-359-3722. Or, read it online at www.michigan.gov/cshcs.

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. ***Competence*** is the ability to function effectively.

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Local Viewpoint

CSHCS turns words into action

Mary Meadows matter-of-factly describes her evening meeting with parents at their farm. "It was easier for *me* to drive to *them*," said the registered nurse who coordinates the Children's Special Health Care Services (CSHCS) program in southwest Michigan. "They would have had to hire a driver to get to me."

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

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

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State News Editors
Mary Marin and Linda Lyles Daniels
The Parent Participation Program
3056 W Grand Blvd STE 3-350
Detroit, MI 48202-6003
1-800-359-3722 email: ppp@michigan.gov

State Director
Kathleen A. Stiffler
Children's Special Health Care Services
Michigan Department of Community Health
400 S. Pine St., Lansing, MI 48933-2250
(517) 335-5008

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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;
- infrastructure building;
- 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 health care systems.
—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 can not make scheduled appointments if they have to attend healing or other ceremonies. Has this Native-American family been unfairly labeled noncompliant?

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 and hour, and understanding at maybe 2 miles an hour."* Has this family with English as a second

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The family is Amish. That means, Meadows knows, they value self-sufficiency. Strict sects shun modern ways, such as cars. Meadows honored the dad's wish to be part of a meeting about CSHCS services. She drove to the farm. To meet after farming work was done, Meadows flexed her hours.

A similar family followed their faith's practice of involving a bishop in a health decision. They included Meadows in the meeting. "A little guy needed to have a 'trach' and vent," she remembers. "We had to get special dispensation for electricity."

Summing up her experiences, Meadows said, "I think a lot of the trust I have built is because they know I respect their culture."

In CSHCS offices statewide, respecting families' values and cultural practices is the norm. Like Title V programs nationwide, Michigan's program is committed to cultural competency. Efforts at the practice level are built on a firm base of family-centered state and federal policies.

Routinely, CSHCS coordinators accommodate families' needs. Several offices are open evening hours. All applications can be faxed or mailed. CSHCS coordinators can make home visits. Many partner with community agencies to have foreign language or American Sign Language interpreters take part in meetings.

All Michigan families can make a phone call free to any CSHCS office by dialing the CSHCS Family Phone Line (1-800-359-3722).

Local Viewpoint

Language Line

Families who call **any CSHCS office** can speak the language they prefer. CSHCS subscribes to Language Line, an over-the-phone foreign language translation service. A translator can be put on the line in minutes by a local CSHCS representative or by an operator on the CSHCS Family Phone Line (1-800-359-3722). CSHCS staff also can tap into Language Line for their calls to families.

In July, Language Line translated 149 CSHCS calls. The top request was for Spanish from 127 or 85% of the families. Others spoke Arabic (8), French (4) and Bengali (3). Two each spoke Albanian and Punjabi. One caller each spoke Bosnian, Dutch and Polish. The longest call was 17 minutes. Ten minutes was average.

Families who speak Spanish can get immediate translation on the CSHCS Family Phone Line. One of the full-time operators speaks Spanish.

Information about CSHCS also is printed in foreign languages. Brochures on CSHCS and its Family Support Network of Michigan are available in Spanish and in Arabic. An introduction to the online CSHCS course (see page 6) is in those languages. It tells visitors that translators are available on the CSHCS Family Phone Line.

CSHCS staff can communicate with persons who have speech or hearing disabilities through the Michigan Relay System. It uses TTY machines and operators to help callers.

Language Data

Removing language barriers opens the doors to service for many Michigan families. Census data on language in Michigan mirror statistics in this issue's *Federal Viewpoint*.

In 2000, more than 780,000 Michigan residents spoke a language other than English at home, up 37% since 1990. As across the U.S., the majority of Michigan residents are able to speak English.

However, a growing number speak English "less than very well." The Census counted 294,606 Michigan residents in that category in 2000, up 56% from 188,662 in 1990.

CHILDREN'S SPECIAL HEALTH CARE SERVICES PROGRAM *MISSION*

CSHCS strives to enable individuals with special health care needs to have improved health outcomes and an enhanced quality of life through the appropriate use of the CSHCS system of care.

Our goals are to:

- Assist individuals with special health care needs in accessing the broadest possible range of appropriate medical care, health education and supports.
- Strive for the delivery of these services and supports in an accessible, family-centered, culturally competent, community-based and coordinated manner.
- Promote and incorporate parent/professional collaboration in all aspects of the program.
- Strive to remove barriers that prevent individuals with special health care needs from achieving these goals.

Local Viewpoint

Culture shapes parent support

A casino may seem an unlikely place for parent support training. But its meeting rooms are just right for a gathering of Native American mothers of children with special needs.

That's the kind of insight Randy Krause gained by working with cultural brokers. Randy is statewide coordinator of the Family Support Network of Michigan, the parent-to-parent support arm of CSHCS. She worked with the Intertribal Council of Michigan to design parent support appropriate for Native American families. Tribes choose the locations. Most Michigan casinos are on an Indian reservation.

”We have to allow more time to share stories,” noted Krause. “Native Americans teach in stories – that's how they pass on their history and lessons. And, the stories must integrate cultural icons, such as 'grandfathers of regions.'”

Krause's relationships with tribal cultural brokers developed naturally in her community. One was a high school peer. Another is a fellow mom whose son attended school with one of Randy's sons.

The women introduced Krause to tribal leaders. This was a vital first step. Krause had to get permission for parent-to-parent training from the tribal elders, a cultural norm in their society. In turn, tribal leaders guided Krause's development of the training in three sessions before it was deemed culturally appropriate. The emphasis turned more to sharing information, she said. In a community with “built-in” acceptance, there is a lesser need for emotional support.

“People with differences are absorbed into their community more than our culture as a whole,” explained Krause. “In general, they are more accepting of children with special needs, especially on the reservations. They do look out for each others' children. They seem more accepting, less critical of children with A.D.D. who make mistakes, for example.”

As the result of offering training sessions in three locations, today Krause has a database of Native American support parents. She pinpoints her community contacts as the first step in her success. “We had brokers to help develop trust in us as part of CSHCS. They validated who we were and built trust in what we offered to do.”

The Family Support Network of Michigan

All Michigan families of children with special needs are welcome to join the Family Support Network of Michigan (FSN). It offers information and emotional support. Trained volunteer support parents offer practical suggestions for day-to-day living and other information to help families.

Services include:

- Parent support groups
- One-to-one support
- Training programs for parents
- Information about programs for brothers, sisters, fathers and grandparents of children with special needs
- Family social events
- Information about local, state and national resources

Local FSN programs are directed by families, for families. All services are free and for families with children of all ages. FSN is a program of the Parent Participation Program, a section of CSHCS. For a brochure or more information, phone the CSHCS Family Phone Line at 1-800-359-3722.

Kent County offers cultural competency training

A 15-hour training program aims to boost the cultural competency of health care professionals. Five three-hour modules cover:

- the importance of cultural competence in healthcare,
- healthcare disparities,
- individual and group health-care beliefs and behaviors,
- an individual's cultural perspectives, and
- communication skills that help provide competent and inclusive care to diverse patients.

The Woodrick Institute designed the series for the Study of Racism and Diversity at Aquinas College. It is a training project of Kent County's *Task Force on Health Care for People of Color*.

Training begins Sept. 21, Nov. 1 and Nov. 3 at three facilities in Grand Rapids. There is no charge for Kent County health care professionals and college students. Others may take part when space permits. Nurses can earn continuing education hours.

Registration deadline is one week before training begins. Participants may attend individual modules or the series of five. Participants who complete the series may earn one hour of credit from Aquinas College.

Register online at www.aquinas.edu/woodrick or phone the institute at (616) 632-2177. For Task Force details, phone Teresa Branson, project coordinator, at (616) 632-7241 or send email to teresa.branson@kentcounty.org.

Resources

Sept. 18 is the deadline for young persons age 16 through 25 to apply to join the National Council on Disability. The federal advisory group is seeking members from a cross section of disabilities, cultures and geographic regions. Read an online announcement in *What's New* (August 2005) from the National Collaborative on Workforce and Disability/Youth at www.ncwd-youth.info/new.

New accessible playgrounds are opening in 12 Michigan cities. A *Detroit Free Press* Aug. 16 article highlights one at the Washtenaw County Intermediate School District's campus, west of Ann Arbor. The article reports that W.K. Kellogg Foundation pledged $7.5 million to fund 19 statewide, in support of the National Center for Boundless Playgrounds. To locate all open or under construction in Michigan, click to http://boundlessplaygrounds.org/findplaygrounds or phone (860) 243-8315.

Family Rules and Special Needs is among topics covered in the Summer 2005 issue of *Bright Futures: Family Matters*. Read it at www.familyvoices.org/BrightFutures/Newsletters.htm. *Family Voices* is a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs.

Events

The annual **Buddy Walk** of the *Down Syndrome Association of West Michigan* (DSAWM) takes place at 10 a.m., Saturday, **Sept. 24**, at Millennium Park in **Grand Rapids**. DSAWM is a group of parents who have children with Down syndrome. The goal of the Buddy Walk is to promote understanding and acceptance of people with Down syndrome. For details, phone DSAWM toll-free at (866) 665-745. Or, go online to www.dsawm.org.

Making the World Work for ALL is the theme of the **Oct. 14** conference of the *West Michigan Inclusion Network* (WIN) in **Grand Rapids**. Breakout session topics include: positive behavior supports, early childhood inclusion, inclusive recreation, college experiences of students with moderate disabilities, and legal issues.

The topic of motivational speaker Dr. Don Bartlette is "Macaroni at Midnight." WIN states that he "communicates a message of hope and courage… His presentation is an autobiographical profile of his social, psychological, and educational experiences as a Native American Chippewa child growing up with emotional, speech, and physical disabilities in an environment of poverty, family and school violence, racism, and alcoholism."

For registration details, phone WIN at (616) 889-3808 or e-mail to wmichinclusion@aol.com. Read about the group on its pages at www.wmin.org.

PPP hosts a one-day **Sibshop Training** for parents and professionals on Friday, **Nov. 4**, in **Grand Rapids**. Training leader is sibling issues expert Don Meyer. He created the Sibshop concept. Teams of social workers, teachers, psychologists, and more are welcome to learn how to run a Sibshop for brothers and sisters of children with special needs. There is no fee. Advance registration is required. To sign up, phone Jeannie at (313) 456-4382 or the CSHCS Family Phone Line at 1-800-359-3722.

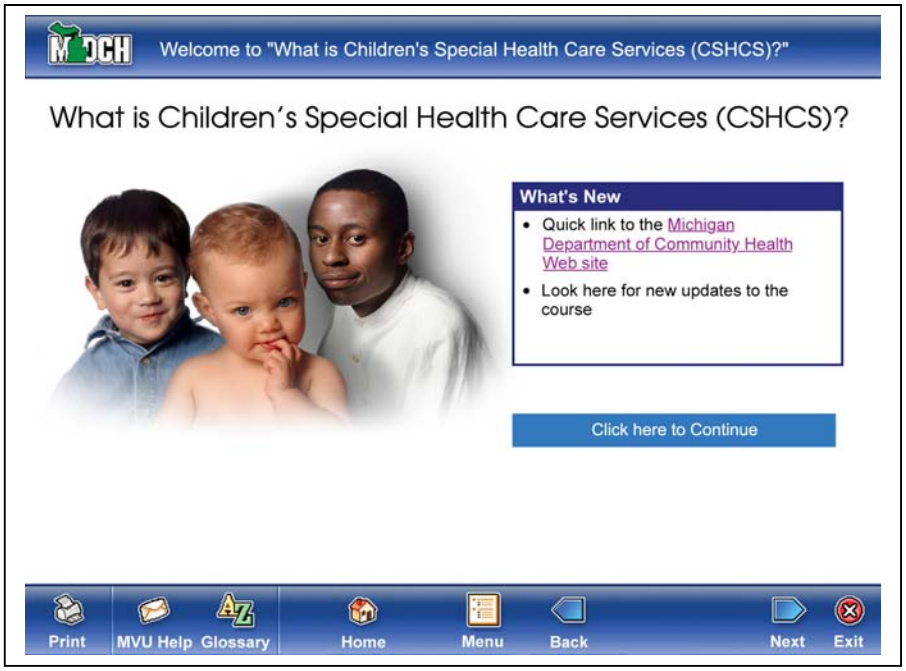
Don Meyer also headlines ***Relatively Speaking***, PPP's **Nov. 4 - 6** conference in Grand Rapids that gives information and support to young siblings of children with special needs. Siblings share their unique concerns in creative, fun ways. Their siblings with special needs attend activity workshops. A third set of sessions is just for parents. Registration deadline is Sept. 30. For details, download a brochure at www.michigan.gov/cshcs or phone 1-800-359-3722.

The Parent Participation Program (PPP) welcomes information about statewide events of interest to families of children with special health needs. Only by chance does this events list spotlight one region.

Call in items to the CSHCS Family Phone Line at 1-800-359-3722, fax to (313) 456-4379 or send e-mail to ppp@michigan.gov.

“WHAT IS CHILDREN’S SPECIAL HEALTH CARE SERVICES?”

a free, online course about Michigan’s program for children with special needs



What is Children’s Special Health Care Services (CSHCS)?

What's New

- Quick link to the Michigan Department of Community Health Web site
- Look here for new updates to the course

The course covers the basics of Michigan’s Children’s Special Health Care Services (CSHCS) program.

Professionals and families who are in touch with persons with special needs will gain straight-forward, useful information.

The aim of offering this course is to boost understanding so that all who may be eligible will be referred to CSHCS.

Features of the course

- Ten sections cover a wide range of topics
- Links to resources for families of children with special needs
- Readily accessible and easy to use
- Take the whole course or one part at a time
- Average completion time: 45 minutes or less

To access the course:

Go to www.training.mihealth.org
Under "New Featured Courses," click on "What is Children’s Special Health Care Services (CSHCS)?"
Above the course description, click on the title "What is CSHCS?"
On the Login page, register or enter your ID and password, then click on "Go"
On the Welcome page's upper right corner, click on "My Learning Path"
On the My Learning Path page, at the lower left corner, click on the number "3" (a page number)
On page 3, click on the class name: "What is CSHCS?"

The course is offered by the Michigan Department of Community Health. General CSHCS information and a monthly Heart-to-Heart Information Update also are online at www.michigan.gov/cshcs. Families may call the CSHCS Family Phone Line at 1-800-359-3722.

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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 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 at right), who can assist in understanding community norms and can provide links with other families and organizations, such as churches, beauty shops, and social clubs.

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.

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, 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 personnel, 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 outreach and services to culturally diverse and geographically isolated communities.

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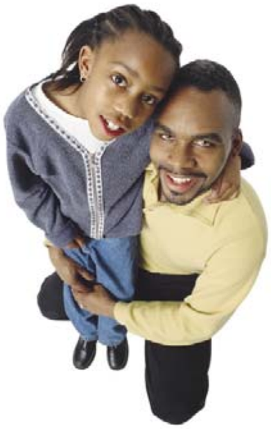

The Washington Father's Network produced an award winning video that shares the perspectives of African-American fathers.

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** 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%.

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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

The Parent Participation Program
Children's Special Health Care Services
Michigan Department of Community Health
3056 W Grand Blvd STE 3-350
Detroit, MI 48202-6003