Special Addition

children with special health care needs

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A Newsletter for Missouri Families

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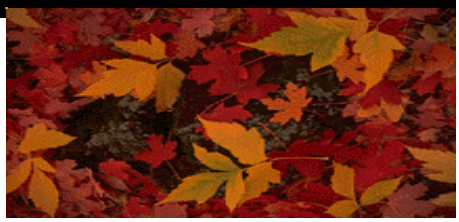

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Cultural Competence

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.

Many definitions of cultural com-

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Local Viewpoint

Emotional damage from natural disasters can add to stress levels long after the crisis is over

by Linda Yager, Communications Officer, Extension and Ag Information, University of Missouri Extension

The emotional damage of droughts, floods and other natural disasters can be felt long after the immediate crisis is over, according to a licensed clinical social worker at the University of Missouri.

Families should watch the signs of stress and depression, and get help if needed, said Sherry Nelson, an MU Extension human environmental sciences specialist in Palmyra, MO.

"People have different sensitivities

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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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petence 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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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.

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?

Did you know that...

—**T**he perception of illness and disease and their causes varies by culture.
—**D**iverse belief systems exist related to health, mental health, healing, and well-being.
—**C**ulture influences help-seeking behaviors and attitudes toward care providers.
—**I**ndividual preferences affect traditional and other approaches to care.
—**P**atients must overcome historical and personal experiences of biases within health care systems.

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 language really understood the diagnosis and treatment prescribed?

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to stress," she said. "Some people are more likely to experience the symptoms of stress, depending on their physical or psychological makeup.

"The thing about stress is that it tends to pile up. Often the straw that broke the camel's back may be pretty little," Nelson said. "With drought, it's a slow process. Little things can pile up.

"It may not come up as an obvious money issue," she said. "It may come up in other ways."

Sleepless nights, changes in appetite, excessive use of alcohol or drugs, headaches, forgetfulness, irritability, fatigue, anxiety and depression are common among people suffering from prolonged stress.

Avoidance and denial also are common, Nelson said. "Sometimes people think 'If I just work harder, this will all come out OK.'"

That approach may work against you, she said, adding that stress can affect the ability to concentrate making a person more prone to injuries, she said.

"Depending on how severe the stress is and if we catch it early, we can do things to alleviate it," Nelson said. "Often being able to talk about it does us so much more good than keeping a stiff upper lip."

Nelson recommends that family members discuss their current situation and what it may mean for the future.

"Finances are not easy to talk about," she said, but good communication among couples is an important part of problem solving. "Sometimes we figure out our own solutions by talking to someone."

Spouses should not only discuss the family's financial situation among themselves, they should be open with children living at home.

"Kids are pretty smart and can pick up on the fact that something's wrong," she said, "so it's important to talk about what's going on, instead of letting them guess or make up what's going on."

How much detail parents share will depend on the child's age, maturity and involvement in the farming operation, Nelson said.

"You don't have to go into a lot of specifics about the family finances," she said. "It might just be talking about the things you can't afford right now, for example, stopping and getting fast food."

Talking with someone outside the family, a close friend or member of the clergy, who can be non-judgmental about the situation, also can be helpful, she said.

"Farming is often a somewhat isolated profession," she said. "Forming those support groups can help you get through a difficult situation."

If the symptoms of stress are severe or if a person begins thinking about suicide, Nelson said, it is time for professional help.

"We're talking about a situation where people are under a tremendous amount of stress," she said. "With professional help, they can get what they need to pull themselves back from that edge.

"Mental health professional are simply another resource in coping with a health problem."

People who need help can contact their physician, local mental health centers of the Missouri Department of Health at (800) 364-9687 or visit www.dmh.missouri.gov.

"Many providers offer services on a sliding scale, and services are often covered by health insurance," Nelson said.

Making back to school-COOL!

by Angie Fletcher, Human Development Specialist in Douglas County, University of Missouri Extension

The short summer months will soon begin to wind down and school bus trips will take the place of car trips to the lake. Back to school time is often a time of change for many families. First day of school, new schools, and new teachers, are only a few of the many changes children and families encounter at the beginning of a new school year. Making a smooth transition between the summer break and the beginning of school can help children feel good about themselves and help everyone in the family create and maintain a positive outlook about the coming school year. Parents play an important role in helping make this transition a smooth one. Here are some tips to help make this transition more relaxed and enjoyable for everyone.

- **Establish a Routine**
  Bed times, rise times, where do I put my backpack and important notes when I get home — whatever your routine/schedule will be, begin following it at least a week or so before school actually begins. This will help adjust you and your child to the routine early.
- **Take a School Tour**
  This is especially important if your child is new to the school system or building. Knowing where to go on the first day can relieve a lot of stress.
- **Meet With Your Child's Teacher(s)**
  Introduce yourselves. Discuss what will be happening in the classroom, or any special needs or situations your child may have. Is there any way you can help out in the classroom?
- **Make Sure All School Records are Up-to-Date**
  Make sure the school has any new phone numbers, changes of address, immunization updates, etc. Having

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these in an emergency can save precious minutes.

- **Get All Required Examinations**
  Try to schedule appointments for sports physicals, immunizations, dental exams, etc. before school starts. This will help avoid absences from school.
- **Be Sure Your Child Knows Their Address and Phone Number!**
  This is especailly necessary if you have just moved!
- **After School Care**
  Make necessary arrangements and be sure your child knows where they are to go and what they are to do after school. It is also a good idea (especially for elementary school students) to inform the teacher of these plans also.
- **Purchase School Supplies**
  Check with your child's teacher or school for a list of needed supplies, for sports physicals, immunizations, dental exams, etc. before school starts. This will help avoid absences from school.
- **Create a Homework Center**
  Stock it with extra crayons and supplies to complete homework. Make sure no television is near and distractions are few.
- **Stress the Importance of Good Nutrition**
  Healthy, well-balanced breakfasts, lunches, snacks, and dinners can unleash the Brainiac in your child! Studies have shown that good nutrition helps keep children focused, their energies high, and their moods balanced — all of which are factors that promote learning.

Your cell phone could be a lifesaver

by Joel Currier, St. Louis Post-Dispatch

Some people want you to put your cell phone on ICE. And that, they say, would be a good thing.

Emergency officials are urging cellular telephone users to enter into their phone the acronym ICE, which stands for "in case of emergency." The effort is aimed at giving emergency workers a faster way to contact family members or associates of accident victims. The notion has picked up considerable momentum following last month's terrorist attacks in London.

"This makes it a lot easier to find next-of-kin in the event of an emergency and also finding any medical history or allergies," said Dr. Mark Levine, 34, an emergency department physician at Barnes-Jewish Hospital.

"It cuts down on medical errors and the amount of time it takes for (family members) to come to the hospital in the event that something happens."

Punching into your cell phone "ICE Dad" or "ICE Doctor," for example, allows emergency workers quick access to emergency contacts in a medical emergency.

As the idea gains momentum, though, some emergency responders have warned that the potential is limited.

The Los Angeles Fire Department this month said that while ICE can be a helpful tool in an emergency, it's "not something that paramedics will rush to look for the instant they arrive at an emergency," a news release said.

Los Angeles firefighters suggest that people add ICE to their cell phones as well as attach similar information to the photo identification they routinely carry with them.

St. Louis County police Capt. Robert Young, a commander of emergency management, says paramedics are probably too busy to check a victim's cell phone for emergency contacts.

In an accident scene, paramedics are preoccupied treating victims and transporting them to the nearest hospital, Young said. ICE might be more useful to police officers who collect data for accident reports.

The ICE idea is the brainchild of a British paramedic who recognized the problem of contacting family members of accident victims who usually don't carry contact information with them.

Missouri Gov. Matt Blunt and the Missouri Department of Public Safety endorse the idea.

The practice is free, but a wave of online warnings claim that ICE is part of a computer virus or scam that could lead to costly or annoying problems. Some e-mails have said that a virus could wipe out the cell phone's directory.

But the Web site Snopes.com, which researches and debunks Internet legends and myths, says the warnings are hoaxes. At the very least, ICE provides a valuable reminder that people should carry emergency data on cards in their wallets or purses, Young said. The card he carries includes contact and medical information about himself, his wife, children, family doctors, blood types, allergies and Social Security numbers.

Robert Hardy, 49, EMS chief for the St. Louis Fire Department, says paramedics face difficulties when people forget to carry identification.

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Storing ICE into cell phones would save hospital workers time and stress, Hardy said. He plans to spread the word about ICE throughout the fire department and urges St. Louisans to learn more about the new initiative.

"There are a whole lot of people walking around the streets of St. Louis with no identification whatsoever," said Hardy, a 30-year veteran of the Fire Department. "The patient would benefit from (ICE), and that's the bottom line."

For more information, go to: www.icecontact.com/. http://www.snopes.com/crime/prevent/icephone.asp

Before you ICE:

- Be certain that the person (or persons) whose name and number you provide agrees to be your ICE partner (or partners).
- Check to find out that your ICE partner knows whom to contact on your behalf, including your employer.
- Make sure phone numbers for our ICE partner are easy to reach. Home telephone numbers, for example, may be useless during the day if your ICE partner has a full-time day job.
- Make sure your ICE partner knows of any medical conditions that could affect your emergency treatment, such as allergies or medications.
- If you are younger than 18, make sure your ICE partner is a parent or guardian who can make medical decisions on your behalf.

2005 dietary guidelines for Americans: what it means for children with special health care needs (CSHCN)

by Jean Trae, PhD, RD, LD, Child Nutrition Coordinator, WIC and Nutrition Services

The Rebuilding of the Food Guide Pyramid!

In January, the Secretaries of Agriculture and Health and Human Services released the 2005 Dietary Guidelines for Americans. The Dietary Guidelines provide valuable and realistic recommendations based on the latest scientific research to help people eat well and stay healthy.

The new Dietary Guidelines will set the nation's policy direction for the next five years for all government nutrition programs, including nutrition research, education, food assistance, labeling, and promotion.

In April 2005, the U.S. Department of Agriculture (USDA) unveiled MyPyramid, a new symbol and interactive food guidance system, to replace the Food Guide Pyramid introduced in 1992.

MyPyramid was developed to carry the messages of the Dietary Guidelines and to make Americans aware of the vital health benefits of simple and modest improvements in nutrition, physical activity, and lifestyle behavior.

MyPyramid's central message is "Steps to a Healthier You."

What key recommendations from the Dietary Guidelines are pertinent to CSHCN?

- Activity - Be physically active every day.
- Variety – Consume a variety of nutrient-dense foods and beverages.
- Proportionality - Make smart choices from each food group with an emphasis on fruits, vegetables, whole grains, lean meats, poultry, fish, beans, eggs, nuts, low-fat milk and milk products, and calcium-rich foods.
- Moderation - Keep saturated fats, trans fats, cholesterol, added sugars, and salt low in your diet.
- Gradual Improvement - Individuals can benefit from taking small steps to improve their diet and lifestyle each day.
- Safety - Know how to prepare, handle, and store food safely to keep you and your family safe.

What common message does MyPyramid share with CSHCN?

One size doesn't fit all! The rebuilt pyramid, MyPyramid, symbolizes a personalized approach to healthy eating and physical activity. It is appropriate for children aged 2 and up. Many CSHCN can be considered healthy. MyPyramid can be used as a starting point for evaluation of CSHCN.

However, an individualized approach to evaluate the unique needs of each child is required based on the diagnosis, medical status, specific growth and weight gain patterns, medication use, activity level, and specific needs for individual nutrients. Continued monitoring is recommended to ensure adequate nutrient and energy intake for growth, development and health, and also to make adjustments during periods of stress and illness.

What challenge does USDA have for adults in helping kids make healthy choices?

- You can make a difference.
- Eat smart.

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- Play hard.
- When you do, your kids will too!

2005 Dietary Guidelines for Americans Web Site:
www.healthierus.gov/dietaryguidelines/
MyPyramid Web Site:
www.mypyramid.gov/

Snacking "Cents"

"Keep your wallet and your tummy happy"

by Amanda Stevens, Dietetic Intern
University of Missouri-Columbia and
Candance Gabel, MS, RD, LD,
Associate State Nutrition Specialist
University of Missouri-Columbia

Today many people are eating more snacks and fewer meals. Snacks have replaced one or more meals for the growing number of "short-on-time" consumers who graze throughout the day. Snacking, however, is not the problem; it's the type of snacks. The snacks that we choose most often are those of "empty" calories and are higher priced. Snacking can be a habit that nourishes and sustains you or a source of excess calories and fat. Trying to "eat healthy" when on a budget can seem to be a challenge for most people. Here are some ideas to help cut food costs:

Shopping tips:

- Make out a grocery list. You can plan your snacks and make sure you keep buying those cheaper and healthier items on hand. Sticking to your list will prevent impulse buying.
- Avoid shopping on an empty stomach. Hungry shoppers buy more than they need.
- Prevent spoilage and food waste by buying quantities that you can readily use or easily store.
- To save money, purchase store brand or generic products. They are typically less expensive than the brand name products.
- Beware of sale gimmicks. End-of-aisle displays are not always specials.
- See the whole shelf. The best values are usually above or below eye level. High-ticket items are often at eye level. These items are usually less healthy items and are packaged in larger quantities.
- Compare prices by the unit to get the best bargain and look at nutrition labels for serving sizes and ingredients. You want a healthy deal.
- Avoid buying at convenience stores. You'll pay for the extra convenience. An apple at the grocery store may cost around 30 cents compared to 75 cents at the convenience store!
- Use coupons only for products that you purchase regularly to prevent buying extras that you don't really need.
- Plan your snacks. Having a healthy snack with you when you go places will save you money instead of buying snacks from vending machines and convenience stores.
- If you forget to plan a snack, look for higher nutritional items in the vending machine or at the conveneince store. There are some cheaper and healthy items available.
- Eat breakfast at home or bring food with you on the run. The cost of purchasing a muffin and a coffee every day can add up to $50 per month!
- Fill plastic drink containers with juice from home instead of buying individual juice boxes.
- Pack raw veggies or fruit, dried fruit, yogurt, a muffin, dry cereal, bagels, cheese, crackers, hard cooked eggs, rice cakes, leftovers or a sandwich.
- Milk costs less and offers more nutritional value than soft drinks. Try flavoring your milk with fruits or juices for a "new" drink.
- Fruits are an inexpensive nutritional choice all year. Try a new exotic fruit every week or "spice" up traditional fruits by adding cinnamon, allspice, or honey.
- Buy fresh produce in amounts that you can use before they go bad. If you don't need 10 but it's cheaper to buy 10, think of the savings after waste. You're not really saving.
- Vegetables are a cheap and easy item to carry with you for a quick bite. Many vegetables now come in convenient packaging for eating on the go.
- Pre-cut your own veggies. Keep them sealed in a container or zipper bag to prevent them from drying out.
- Not all juices are created equally. When choosing a juice, make sure that it is a juice, not a drink. Drinks contain a lot of sugar and little nutrition.

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"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.

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.

Family Voices, Inc., with funds from MCHB has a cultural competence/

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

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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. O

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

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%.

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

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