Cultural and Linguistic Competence in Family Supports

The Compelling Need for Family Supports

The federal Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) defines children and youth with special health care needs as those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally. The families of children and youth with special health care needs know, however, that these children also require more intensive and specialized day-to-day care than other children. Although all families encounter a series of triumphs and challenges in raising their children, families raising children and youth with special health care needs experience an additional set of challenges that may involve:

- providing medical treatments, operating medical equipment, or managing complex medical regimens that require a high degree of skill with minimal training and support;

- providing specialized or additional assistance in daily living tasks such as eating, dressing, bathing, and toileting;

- physically moving and lifting children who are beyond the toddler years;

- managing complex and atypical behavioral and emotional problems;

- attending frequent treatment appointments and meetings related to service and care plans for their children;

- experiencing financial difficulties due to no insurance or underinsurance for the child's health and other service needs;

- experiencing increased emotional stress due to personal reactions to a child's illness or disability and to possible stigmatization, personal reactions, and social exclusion from family, friends, and community;

- experiencing stresses on family and marital relationships; and

- providing care and support beyond the traditional childhood years (including elderly family members caring for adults), because the system does not adequately provide for transition to a productive and independent adulthood for youth with special health care needs

(Abelson, 1999; Sherman, 1995; Donelan et al., 2002; Agosta & Melda, 1999).

Families face many of these challenges while dealing with a fragmented, complex system of services and supports.

■ Impact on Family Financial Resources

Traditionally, the services for children and youth with special health care needs and the processes for financing them focused on child-related needs. Yet, the impact of the intensive care-giving needs on families is considerable. Within our current health care system, 80% of such long-term care across the life-span is provided

by families (Agency for Healthcare Research and Quality, 2000). There are financial consequences to families for providing this care. The National Survey of Children with Special Health Care Needs found that approximately one fifth of all children with special health care needs have families who report experiencing financial problems due to their child's health. In addition to the direct costs of care for the child or youth, families are affected by lost or limited opportunities for employment (Data Resource Center for Child and Adolescent Health, 2005). Caregivers for sick or disabled family members are less likely than non-caregivers to be employed and when employed, miss more days of work (Ho, Collins, Davis, & Doty, 2005). Children with special health care needs, whose families are least able to afford it, are most likely to have families who report being economically impacted by their child's special health care needs. Children with special health care needs living in households with incomes below 200% of the federal poverty level are more likely to have one or more family members who cut down on hours of work to care for their child or stopped work altogether to care for their child (Data Resource Center for Child and Adolescent Health, 2005).

■ Impact on Health and Well-Being of Caregivers
In addition to financial stresses, caring for a child or youth with special health care needs can impact the health and well-being of the family members providing that care. The most recent Commonwealth Fund Biennial Health Insurance Survey (Ho et al., 2005) indicates that those who care for a sick or disabled family member are more likely to report health problems of their own. For example, caregivers reported chronic conditions at nearly twice the rate as non-caregivers. There are also emotional impacts on siblings who are affected by the time required to care for the child with special health care needs and by the stress experienced by the caregivers in their family.

■ Impact on Public Policy
In response to these challenges, families and disability advocacy groups took the lead to advocate for the creation of family supports as part of the systems serving children and youth with special health care needs, adults with disabilities, and their families. The need for family supports is now acknowledged in federal legislation for special education services, individuals with developmental disabilities, child welfare, and family preservation. (108 P.L. 446; 118 Stat. 2647; 2004 Enacted H.R. 1350; 108 Enacted H.R. 1350, PUBLIC LAW 108-446 [H.R. 1350], DEC. 03, 2004, Individuals with Disabilities Education Improvement Act of 2004; 107 P.L. 133; 115 Stat. 2413; 2002 Enacted H.R. 2873; 107 Enacted H.R. 2873, PUBLIC LAW 107-133 [H.R. 2873], JAN. 17, 2002, Promoting Safe and Stable Families Amendments of 2001 Legislation in many states has also set forth the concept of family supports and the systems to deliver them. In addition, family supports are now key components of federal, state, and private initiatives in children's mental health and for children and youth with special health care needs. (Pires, 2002)

What are Family Supports?

On the broadest level, family supports are "a set of beliefs and approaches to strengthening and empowering families and communities so that they can foster the optimal development of children, youth and adult family members" (Family Support America, 2004). More specific to children with special health care needs is the definition in Title II of the federal Family Support for Children with Disabilities Act of 2000 that is the model for much state legislation and other initiatives:

> "Family Support for Families of Children with Disabilities means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to:
>
> A. support families in the efforts of such families to raise their children with disabilities in the home;
>
> B. strengthen the role of the family as primary caregiver for such children;
>
> C. prevent involuntary out-of-the-home placement of such children and maintain family unity; and
>
> D. reunite families with children with disabilities who have been placed out of the home, whenever possible."

Effective family support programs make use of structured services as well as informal or natural supports such as extended family, friends, neighbors, and faith communities. They build on the strengths of and help address the unique challenges of each family. Effective supports are family centered, based on the culture, values, preferences, and needs of the family, and provided in the family's preferred language.

Examples of family supports include in-home care and services; temporary relief and respite care; child care; financial assistance; assistance in accessing and coordinating needed resources; family-to-family support; education and skill building to provide effective parenting and care; modifications to the family's dwelling; future financial planning; and social, spiritual, and emotional support for all family members (Agosta & Melda, 1999). *No predetermined list, however, can capture the range of possibilities to meet each family's needs at any given point in time. At the broadest level, family supports are anything the family says it needs for the development of its children and the functioning of the family unit as a whole.*

Family-Driven Support System

The state of Wisconsin has long had a flexible, family-driven approach to providing family supports. The C. family had three sons. They wanted their youngest son T., who used a wheelchair for mobility, to be included in the social life of the children in their neighborhood. When the Family Support Board asked what would help, the family had a very specific request. They had a basketball hoop in their driveway, and after school, all the neighborhood children gathered there to shoot baskets and play pick-up games. T. had a great shot, but the gravel driveway made it impossible for him to maneuver his wheelchair to be part of the action. The C. family asked for, and received, funds to pave their driveway so that T. could be included with his brothers and friends. This simple solution certainly strengthened and empowered the C. family so that they could foster the optimal development of all family members. (Bronheim, Keefe, Morgan & Magrab, 1993)

Policy Implications: The National Center for Cultural Competence (NCCC) recommends that policies to support cultural and linguistic competence in family supports allow for maximum flexibility in the use of these resources that enable families to choose the solutions that fit their unique need.

Rationale for Cultural and Linguistic Competence in Family Supports

■ Racial, Ethnic, Cultural, and Linguistic Diversity

Given the great diversity in the country, providing family supports that respect the culture, values, preferences, and needs of each family presents many challenges. Organizations providing and coordinating family supports are faced with changing demographics and a need to understand and address a multiplicity of cultures, languages, and values in the families with whom they partner. African Americans compose 13% of the population. The Hispanic population has grown from 4.5% of the population in 1970 to 14.2% in the last census (U.S. Census Bureau, (2004b). The population of Asian and Pacific Islanders from many different countries and cultures grew 72% from 1990 to 2000. The Native

NCCC Definition of Culture

Culture is an integrated pattern of human behavior which includes but is not limited to thought, communication, languages, beliefs, values, practices, customs, courtesies, rituals, manners of interacting, roles relationships, and expected behaviors of a racial, ethnic, religious, spiritual, social, or political group; the ability to transmit the above to succeeding generations; and dynamic in nature (2002).

American and Alaska Native population is also growing faster than the general population—26% since 1990. Immigration contributes to the increasing diversity in the United States—between 1990 and 2000 the number of immigrants in this country increased by approximately 50%. (U.S. Immigration and Naturalization Service. 2002). **Click here for more information about growing diversity.**

Supporting Cross-Cultural Encounters

Mr. and Mrs. W. tell the story about their first encounter with in-home family support services. They have children with developmental disabilities. Mr. and Mrs. W. needed support in daily care and in dealing with challenging behaviors. The family's cultural tradition is to eat meals with their hands. The first aide who was assigned to them was very upset that the children were not using utensils. She lectured the parents about the importance of using utensils and about the importance of reinforcing proper eating skills for the children. Mr. and Mrs. W. got the impression that the aide looked down on eating with one's hands. It took a great deal of negotiation to help the aide to understand and accept that the family traditions and values involved eating with their hands at home. At school, however, the children used utensils well.

Policy Implications: Policies that require new employee and ongoing professional development and in-service training enhance the cultural competence of staff providing family support services. In addition, organizations build cultural and linguistic competence by including areas of knowledge and skill sets in job recruiting announcements, position descriptions, and performance review criteria.

■ Linguistic diversity

Census data indicate that the United States has over 48 million persons who speak a language other than English at home. Of these, nearly half speak English less than "very well." Based on the 2000 Census, 11.9 million people live in linguistically isolated households where no one over the age of 14 speaks English "very well" (U.S. Census Bureau, 2004c). **To learn more about linguistic diversity, click here.**

■ Linguistic competence

Families of children and youth with special health care needs encounter fragmented and complex health care, mental health care, and other service systems; often implement medical and behavioral treatment plans at home; have to learn about and access community resources; and keep records about their child's or youth's treatments and services sought. Many factors, including the linguistic competency of the organizations providing services and supports, may impact a family's ability to meet these demands successfully.

The following definition, developed by the NCCC, provides a foundation for determining linguistic competence in health care, mental health, and other human service delivery systems. It encompasses a broad spectrum of constituency groups that could require language assistance or other supports from an organization, agency, or provider.

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. **For a fuller definition of linguistic competence click here. To learn more about language access click here.**

Language Access, a Key to Service Access

The M. family recently immigrated to the United States and spoke very little English and did not read English. Their young son was born with significant health problems that required constant medical care at home. The young couple took turns staying home with him, working alternate shifts, and never had the chance to go out together, because no one else felt comfortable with his complex care. Family members wanted to help, but didn't feel qualified to care for him and Mr. and Mrs. M. felt that a typical baby-sitter was out of the question. When Mrs. M. learned that her younger sister was getting married out-of-town, she was crestfallen. There was no way she and her husband could attend, because no one could care for her son. Another mother who worked with the local family advocacy agency and who spoke Mrs. M's language

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told her about an agency that provided respite services for no or low cost. Excitedly, Mrs. M. called the agency that provided these services—she asked her teenage nephew to make the call with her, because she feared no one in the agency would speak her language. When they called, she learned that the services were available on a first-come, first-served basis and that this late in the year no more families could be served. She wondered why no one in her community had known about the resources. It turned out that the agency had pamphlets and information only in English.

Policy Implications: Organizational policies are needed that ensure information about the program, access to the program, and services are available in the languages spoken by families in the area served. In addition, there is a need for organizational policies and structures that (1) support community engagement, including periodic review of local demographics to determine current and emergent population trends and (2) delineate community and consumer participation in planning, implementing, and evaluating the delivery of services and supports. When resources are limited, it is essential to engage communities to set policies to determine how such resources are administered.

■ Literacy

Issues related to literacy can undermine a family's ability to care for and support their child or youth with special health care needs. Forms, discharge plans, care plans, information about health plans, and informational and other materials are key to using the systems that serve children and youth with special health care needs and their families. Yet, some families may lack the literacy skills to benefit from written information. The 2003 National Assessment of Adult Literacy (NAAL) defines literacy as "using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential." Results of the NAAL indicated that 14% of adults in the United States demonstrated skills at the lowest levels of reading prose literature. An additional 29% were at only the Basic level. A disproportionate percentage of Black and Hispanic adults in the sample were at the Below Basic level in prose literacy, and since the 1993 survey, the average literacy scores for Hispanics fell. Adults over age 65, those with less than a high school education, and those with multiple disabilities were also overrepresented in those adults with Below Basic skills. Approximately 5% of the sample had no literacy skills in English. In addition, there has been a drop in the percentage of adults with proficient literacy skills (Kutner, Greenberg, & Baer, 2005).

■ Health literacy

In 2004, the Institute of Medicine (IOM) described health literacy as a critical issue impacting the U.S. population. Health literacy has been defined as the "ability to use English to solve health-related problems at a proficiency level that enables one to achieve one's health goals and develop health knowledge and potential" (Rudd, 2001). Health literacy has also been defined as the "degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions" (Healthy People 2010, 2000).

The IOM estimated that nearly half of all American adults—90 million people—have difficulty understanding health information. The IOM notes that health literacy is not only related to education, but is also the convergence of cultural and social factors as well as health services with educational status (IOM, 2004). Analysis of the National Adult Literacy Survey indicates that 12% of the U.S. adult population had skills at the lowest level on a newly devised scale, the Health Activities Literacy Scale (HALS). An additional 7% would have great difficulty performing even these basic tasks with a high degree of proficiency (Rudd, Kirsch, & Yamamoto, 2004). **For more on health literacy, click here.**

Families of children and youth with special health care needs should be able to read, listen to, and understand and act on complex medical and health information. Yet, many in this country lack the basic health literacy skills needed to deal with such specialized care. Family supports must address the health literacy needs of the populations served. Organizations that provide family supports to families need to provide help in increasing health literacy skills and in adapting communications to ensure that families have the information they need to care for their children.

■ Communication accommodations

Linguistic competence also extends to ensuring that individuals with disabilities can effectively communicate within service delivery or family support systems. Accommodations for individuals with sensory impairments (e.g., sign interpreters, large print, or Braille materials), motor and expressive communication impairments (e.g., extra time to express thoughts and assistive technology), and cognitive impairments (e.g., information expressed at appropriate levels, and use of pictures and demonstrations) are vital and require aspects of linguistic competence. **For more information on accommodations for people with disabilities, click here.**

Ensuring Language Access for Individuals With Disabilities

Ms. M. is twenty-two years old and has cerebral palsy. She has just completed college and is now working at her first job. Ms. M. and her parents have also been working for several years with her pediatrician to make the transition to independence in adulthood. Part of that plan includes having Ms. M. work with the local advocacy group where her mother had volunteered for years. Ms. M. feels that she now wants to ensure that the concerns of young adults are part of the advocacy agenda. At a meeting of the advisory committee led by an outside facilitator, Ms. M. frequently had contributions to make. Because her cerebral palsy impacts her speech, others often have some initial difficulty in understanding her and she takes a longer time to express her ideas. After she had made several comments, the facilitator told her that because the group had limited time, Ms. M. should e-mail any further comments to the facilitator. The facilitator also suggested that in the future Ms. M. attend the meetings accompanied by another member of her family who could more effectively explain what she wanted to say.

Policy Implications: Organizational policies that support linguistic competence should focus on (1) providing intake forms and procedures that capture the communication needs and special accommodations of individuals served; (2) building in extra time for appointments or meetings for individuals with disabilities who require and ask for this type of accommodation; (3) providing training for all staff, consultants, and volunteers in how to work effectively with individuals who have a range of communication needs; and (4) ensuring that all consultants and contractors adhere to stated policy and procedures.

■ Racial and Ethnic Disparities in the System of Care

The system of services and supports needed by children and youth with special health care needs is complex, fragmented, and often difficult to navigate. The federal MCHB, HRSA, of the U.S. Department of Health and Human Services, identified six key components of an effective system of care for children and youth with special health care needs that have been incorporated into the **President's New Freedom Initiative**.

SIX CORE OUTCOMES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

- Families of children and youth with special health care needs will partner in decision making and will be satisfied with the services they receive.
- All children and youth with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
- All children and youth with special health care needs will have adequate public and/or private insurance to pay for the services they need.
- Children will be screened early and continuously for special health care needs.
- Community-based services for children and youth with special health care needs will be organized so families can use them easily.
- Youth with special needs will receive services necessary to support the transition to adulthood.

The National Survey of Children with Special Health Care Needs in 2001 sought to determine the extent to which these outcomes were being realized. Although many families did not experience these core components within systems of care, there is a disparity in findings reported by families from culturally and linguistically diverse groups:

- On the basis of multiple questions within the survey, it is reported that Hispanic and Black children with special health care needs are significantly less likely than non-Hispanic White children with special health needs to have parents who report that they are partners in decision making about the services they and their children receive.

- Hispanic, Black, and multiracial children with special health care needs are less likely, when compared with non-Hispanic White children with special health care needs, to have parents who report that they and their children receive coordinated, ongoing, comprehensive care in a medical home.

- Black and Hispanic children with special health care needs are less likely than non-Hispanic White children with special health care needs to have parents who report that the family's insurance coverage is adequate for the health needs of their children.

- And, significantly fewer Black and Hispanic children with special health care needs than White non-Hispanic children with special health care needs have parents who report that community-based service systems are organized for easy use.

The impact of caring for and raising a child or youth with special health care needs is also greater for racially and ethnically diverse families, as reported on the National Survey of Children with Special Health Care Needs. Significantly more Hispanic and Black children with special health care needs than White, non-Hispanic children with special health care needs have families who report spending more than 5 to 10 hours a week providing or coordinating care. Although about one fifth of all children with special health care needs have families who report experiencing financial problems due to their child's health, Hispanic children were more likely than other children with special health care needs to have families who reported this concern (Data Resource Center for Child and Adolescent Health, 2005). Given the greater likelihood that the system is not meeting the needs of children with special health care needs from diverse families, it is critical that family supports be provided in culturally and linguistically competent ways.

A full picture of how the system is working for families who speak a language other than English and need to respond to the survey in another language is still missing. The survey methodology relied solely on telephone access and response rates for families who spoke languages other than English and Spanish were low.

Addressing Bias and Discrimination in Family Supports

Ms. T. is a nurse who works as a family advisor and advocate and who runs support groups for families who have children and youth with special health care needs. She developed support groups to meet the unique needs of African American families in her area. On the basis of her own experience and that of the other families in these groups, she is amazed and saddened that so few families in the African American community she serves know about the array of programs and family supports that could be available to them. Ms. T. notes that two factors seem to contribute to this problem. First, service and family support programs seem to rely on the same parent networks over and over to publicize what is available. These parent networks have involved very few African American families. The organizations providing family supports have not engaged and created partnerships with the natural support networks that the African American families in her community use to inform parents about available services. Second, many of the families she sees are afraid to express how overwhelmed they are by the care of their children. They, or others they know, have experienced such pleas for support being misinterpreted and leading to referrals to child protective service agencies. These experiences reflect the bias and discrimination that exist in our systems and services for families and that prevent families from accessing the supports they need.

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Policy Implications: Policies that support effective community engagement and the use of trusted cultural brokers in providing family supports would help a broader sector of families access needed services.

Policies that require periodic assessment of attitude, values, and practices of an organization are important to (1) gauge the extent to which the needs and interests of diverse populations are being met, (2) improve access and use of services and supports, and (3) increase family satisfaction with services received.

Despite the increased potential need for support of racially and ethnically diverse families, family support programs continue to report difficulty in meeting those needs. In a survey of state and territorial programs funded through the Administration on Developmental Disabilities, 23% reported that one of their three greatest challenges was providing family supports in a culturally competent manner. They reported difficulty identifying, involving, and serving culturally diverse, underserved, and unserved families and difficulty recruiting bilingual and culturally diverse staff. Some noted that there were virtually no family support groups for immigrant families and that even finding culturally diverse families to connect with family supports was a challenge. Respondents noted that limited cultural competence throughout the system makes it difficult to offer culturally responsive services, do outreach, and build connections to the community (Agosta, no date).

■ Cultural Factors That Impact Family Supports

Given the diversity of families in this country, it is key to understand how cultural factors impact family support. Culture structures perceptions, shapes behaviors, and is the total way of life because it tells group members how to behave and provides their identity. Cultural factors that reflect diversity among individuals and groups involve much more than race and ethnicity. Such factors include, but are not limited to, language, national origin, tribal or clan affiliation, gender, age, education, literacy, socioeconomic status or class, sexual orientation and sexual identity, religious or spiritual beliefs, geographic or regional patterns, legal status, acculturation, and assimilation. **To learn more about culture, click here.**

Providing supports to fathers is different from providing supports to mothers. Successfully supporting young parents may require different approaches from supporting grandparents raising their grandchildren or other relatives providing kinship care. Newly immigrated families may have different needs from families of the same background who have lived in this country for generations. Designing and delivering supports will also differ based on geographic locale such as urban, suburban, rural, and frontier areas of the country. This complex array of factors impacts the way in which family supports are conceptualized, designed, and delivered.

PORTRAIT OF FAMILIES LIVING IN AMERICA

The 2000 Census in the United States reflects the diversity in the constellation of families raising children:

- 27 percent of all children in the United States live in single-parent families.
- Children from diverse racial or ethnic backgrounds are less likely to live with both parents.
- Although 15% of children are Black, they account for 34% of children living in mother-only family groups.
- Although 17% of all children are Hispanic, they compose 25% of children without either parent in their household.
- 72.1 million children younger than 18 live with relatives other than their parents.
- 5.8 million children live with grandparents, and 39% of grandparent caregivers had cared for their grandchildren for more than 5 years.
- Children ages 5 to 17 with disabilities are more likely than children in general to be living with grandparents, with other relatives, or in foster care.

(U.S. Census Bureau 2001, 2003, 2004a)

The diversity and constellation of U.S. families mandate that family supports be culturally and linguistically competent. Cultural and linguistic issues must be considered to provide families with an array of supports they need and prefer for their children.

Policies to Promote and Sustain Cultural and Linguistic Competence in Family Supports

Organizations need to align policies, structures, and practices to resource and institutionalize cultural and linguistic competence in the provision of family supports. At a minimum, organizations should commit to the following:

- A mission statement that articulates values and principles for culturally and linguistically competent family supports

- Establishment of policy, structures, and resources to conduct organizational self-assessment of cultural and linguistic competence at regular intervals.

- Strategic planning processes that incorporate principles and practices of cultural and linguistic competence into all aspects of program design, implementation and evaluation.

The following sections are provided to assist organizations that provide family supports to assess their policies and determine directions for future policy development and implementation that advance and sustain cultural and linguistic competency. They address cultural and linguistic competence in *how* family supports are provided, *what* supports are provided, *where* supports are provided, and *who* should provide supports. Each section offers a description of these areas and a checklist of suggested policies for organizational cultural and linguistic competence.

■ Cultural factors affect *how* family supports are offered.
Beliefs and values that make it difficult for some families to access supports include cultural and family sense of stigma associated with physical and mental illness or disability, traditions that discourage going outside the family for support, or reluctance to take what may be perceived as government "hand-outs." Family patterns related to decision-making and help-seeking behaviors affect the way in which supports are sought and chosen.

Supporting Family Values of Self-Reliance

Mrs. G. describes the first time she applied for family supports through her state's Developmental Disabilities program. She has twin girls with severe autism and behavioral problems. She and her husband had always paid for their services privately or through the limited coverage of their health insurance. She had been comfortable in advocating for her daughters' rights under the Individuals with Disabilities Education Act—after all, the family paid taxes and these services were a right for her daughters. She and her husband had always avoided seeking services from the state, because in the country where they grew up only the poorest of the poor took hand-outs. Her husband often noted that he had come to the United States with $10 in his pocket. Through hard work, he had completed his education and now supported his family very well. Mrs. G. also felt shame at the thought of asking for help. It took a crisis—both daughters trying to run away—to finally bring her to ask for emergency help. She cried the whole way to the office to apply for the help they needed in creating a structured behavior plan at home. The staff emphasized her needs and what she and her family couldn't do for their children, and this only intensified her sense of shame. In retrospect, Mrs. G. says that she would have felt much more comfortable asking for help had the family support organization focused on how much the family's care and expenditures contributed not just to her own family, but to saving the public system's resources.

Policy Implications: The NCCC recommends that organizational policies (1) emphasize strengths-based assessments that identify and value the family's contributions to the care of their children, (2) consider models such as sliding-fee scales that allow families to make a contribution, and (3) create job descriptions and expectations for employees that require and value interacting with families in ways that reflect reciprocity and partnership.

To address cultural and linguistic competence in *how* family supports are provided, organizations should consider the following:

☐ Structures for diverse family and community representation on planning, advisory, and/or governance boards.

☐ Policies related to procurement and reimbursement for family participation that:

    ___ respect the time spent and expenses incurred by families who participate in planning, advisory, governance or training activities and

    ___ take into account the impact on issues such as eligibility for income-based benefits, immigration status, and others.

☐ Position descriptions and performance review criteria for staff and volunteers that include the knowledge, attitudes, and skill sets needed to work effectively in cross-cultural situations.

☐ Policies and resources to support ongoing staff/volunteer development and in-service training on culturally and linguistically competent values, principles, and practices.

☐ Policies, procedures, and fiscal planning for the provision of language access, in keeping with Title VI of the Civil Rights Act, including:

    ___ interpretation and translation services;

    ___ accessible telecommunications systems; and

    ___ materials in alternative formats for individuals with limited English proficiency, low literacy or no literacy or with disabilities that impact communication and use of written materials.

☐ Policies and procedures incorporate the Office of Minority Health standards for Culturally and Linguistically Appropriate Services (CLAS standards).

☐ Policies and resources to support ongoing staff/volunteer development and in-service.

☐ Policies and procedures to periodically review the current and emergent demographic trends for the geographic area served to determine needs for staff or volunteer training and different language access services.

☐ Policies, guidelines, fiscal arrangements, and quality assurance mechanisms that allow for maximum flexibility and family choice in how services are delivered, including:

    ___ concern for confidentiality;

    ___ options for social and emotional support besides support groups; and

    ___ choice of providers, including extended family and natural support networks

☐ Policies that minimize competition among families for resources and that develop a rationale related to demographics of the area served for allocation of limited resources.

☐ Policies and practices that create reciprocity with families and recognize the contribution of families to caring for their own children and to the system as a whole.

■ Cultural factors affect *what* family supports are offered.

Cultural and family beliefs about issues such as the cause of illness or disability, child rearing, gender and generational roles, and community inclusion and integration of individuals with disabilities, affect supports families will choose.

Getting Fathers on the Team

A family support organization was struggling to involve families from the burgeoning Hispanic/Latino population in their community. They had finally succeeded in attracting several mothers of children with special health care needs to their support groups and activities, but could not attract any of the fathers to their groups. To better understand the fathers' needs and attitudes, the agency organized a focus group, in Spanish, with fathers of children with special health care needs. The fathers expressed concerns about the fact that their children were not accepted within their community. They worried about acceptance at school and in church. The fathers were also clear that they were not interested in sitting around talking with women about their children's issues. One father approached the agency, however, and asked whether it could sponsor the local baseball team that several of the fathers had joined. Organization staff were not sure that they could use funds for such an endeavor, but decided, based on their value that family support is defined by families, to sponsor the team. The fathers began bringing their children with special health care needs to the games with them. They found support among their teammates and began to find acceptance for their children in the broader community.

Policy Implications: The NCCC recommends organizational fiscal policies that are flexible and able to meet the unique needs of the families served, and the differing needs of family members, based on gender, age, and status in the family.

To address cultural and linguistic competence in *what* family supports are provided, organizations should consider the following:

☐ Policies and practices that allow families to design supports rather than choose from a predetermined list of services.

☐ Policies and fiscal practices that allow for flexible use of resources to ensure that supports are based on the unique culture, values, preferences, and needs of each individual and family.

■ Cultural factors affect *who* provides family supports and *where* they are provided.

A family's willingness to interact with organizations providing supports may be affected by experiences of bias, discrimination, and racism, immigration status, and English proficiency. Organizations or individuals that are not trusted by families cannot effectively deliver family supports.

Adapting Service Delivery

Over 15 years ago, the Westchester Community Network in Westchester County, New York, began working, community by community, to form Children and Family Networks. Although there was a burgeoning Latino population in the county, only a few Latino families came to network meetings, which were held in a centrally located government building. "We didn't get it right away, but finally, we understood the reason," Westchester Community Network director Myra Alfreds notes. "Latino families, many of whom were undocumented, had to go past the courtroom and the police station on their way to the meetings. We learned from that experience that where you meet is important." The network then moved into a Youth and Family Resource Center in a local school and saw a rapid increase in attendance. "It's now a very successful network," she adds, noting that the leadership reflects the Latino community and that meetings are often held entirely in Spanish, with English interpretation, only if needed.

Continued

Policy Implications: The Westchester Community Network was selected to highlight in this brief because it exemplifies cultural and linguistic competency in the provision of family supports. The supports include policies to (1) keep current on new and emerging demographic trends, (2) acquire knowledge of critical issues impacting specific cultural groups in their area and use it to modify the provision of services and supports, and (3) engage in partnerships with local community organizations and groups that have gained the trust of families (NCCC 2005).

To address cultural and linguistic competence in *where* family supports are provided and *who should provide them*, organizations should consider the following:

☐ Policies and procedures to periodically review the current and emergent demographic trends for the geographic area served to determine needs resulting from new community partnerships; the effectiveness of current locations for providing services, resources, and supports; and staff/volunteer make-up in providing family supports.

☐ Policies and procedures for recruiting staff and volunteers to ensure that those providing family support reflect the diversity of the community served.

☐ Policies and practices that support partnering with community-based, family advocacy, and faith-based-organizations that are part of a trusted natural support network for families in the area served including:

___ processes for identifying natural support networks;

___ resources and structures to identify and work with cultural brokers;

___ training and fiscal support of staff/volunteers to develop relationships for meaningful community engagement and partnership; and

___ fiscal policies that allow for financial connections with family advocacy, community-based, and faith-based organizations.

References Used to Prepare This Policy Brief

Abelson, A. (1999). Economic consequences and lack of respite care. *Psychological Reports, 85*, 880-882.

Agency for Healthcare Research and Quality. (2000). *The characteristics of long-term care users*. Silver Spring, MD: Author.

Agosta, J., & Melda, K. (1999, Fall). *Children with disabilities, their families and present policy concerns* (Family Support Policy Brief No. 1). Portland, OR: National Center for Family Support. Retrieved October 23, 2002, from http://www.familysupport-hsri.org/resources/policy_1.html

Agosta, J. (n.d.). *Family Needs: Summary results from ten years of research* (Family Support Policy Brief No. 2). Portland, OR: National Center for Family Support. Retrieved October 23, 2002, from http://www.familysupport-hsri.org/resources/policy_2.html

American Academy of Family Medicine. (1984, 2003). "Definition of Family." Retrieved May 5, 2005, from http://www.aafp.org/x6799.xml

Bronheim, S., Keefe, M., Morgan, C., & Magrab, P. (1993). *Communities Can Building blocks of a community-based system of care: The Communities Can! experience*. Washington, DC: Center for Child Health and Mental Health Policy, Georgetown University Child Development Center.

Data Resource Center for Child and Adolescent Health. (2005). Retrieved January 24, 2005, from http://www.cshcndata.org

Donelan, K., et al. (2002, July/August). Challenged to care: Informal caregivers in a changing health system. *Health Affairs*, 222-231.

Family Support America. (2004). "Family Support Is…". Retrieved April 14, 2004, from http://www.familysupportamerica.org/content/aboutus.htm

Healthy People 2010. (2000). Retrieved October 3, 2005, from http://www.healthypeople.gov. Washington, DC: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion.

Ho, A., Collins, S., Davis, K., & Doty, M. (2005, August). *A look at working-age caregivers' roles, health concerns, and need for support*. New York, NY: The Commonwealth Fund.

Kirsch, I., Yamamoto, K., Norris, N., Rock, D., Jungeblut, A., & O'Reily, P. (1993). *Adult literacy in America: A first look at the results of the National Adult Literacy Survey*. Washington, DC: U.S. Department of Education, National Center for Education Statistics.

Kutner, M., Greenberg, E. and Baer, J. (2005). *A first look at the literacy of America's adults in the 21st century*. Washington, DC: U.S. Department of Education, National Center for Education Statistics.

Institute of Medicine. (2004). *Health literacy: A prescription to end confusion*. Washington, DC: National Academies Press.

National Center for Cultural Competence. (2005). Latino network: A natural fit in a community-driven model—Westchester County Community Network. Washington, DC: National Center for Cultural Competence. Retrieved September 2, 2005, from http://gucchd.georgetown.edu/nccc/promisingpractices/Westchester.pdf

Pires, S. (2002) *Building systems of care: A primer*. Washington, DC: Georgetown University Center for Child and Human Development.

Potter, L., & Martin, C. (2003, September). Who has health literacy problems? Retrieved June 5, 2005, from http://www.chcs.org/publications

Rudd, R. E. (2001). Health literacy overview. Electronic slide presentation. Retrieved March 9, 2005, from http://www.hsph.harvard.edu/healthliteracy/overview.html#one

Rudd, R. E., Kirsch, I., & Yamamoto, K. (2004). *Literacy and health in America*. Princeton, NJ: Educational Testing Service.

Sherman, B. (1995). Impact of home-based respite care on families of children with chronic illnesses. *Children's Health Care, 24*(1), 33-45.

U.S. Census Bureau. (2001, September). *Census 2000 Special Reports: Households and families: 2000*. Washington, DC: Author.

U.S. Census Bureau. (2003a, February). *Census 2000 Special Reports: Grandparents living with grandchildren: 2000*. Washington, DC: Author.

U.S. Census Bureau. (2004a, February). *Census 2000 Special Reports: Children and the households they live in: 2000*. Washington, DC: Author

U.S. Census Bureau. (2004b). American Fact Finder: People: Race and ethnicity. Retrieved April 18, 2004, from http://factfinder.census.gov

U.S. Census Bureau. (2004c). American Fact Finder: Ability to speak English: 2000. Retrieved April 18, 2004, from http://factfinder.census.gov

U.S. Census Bureau. (2003, February). *Census 2000, Table 1. Language Use, English Ability, and Linguistic Isolation for the Population 5 Years and Over by State: 2000*. Retrieved June 5, 2005, from http://www.census.gov/population/www/cen2000/phc-t20.html

U.S. Department of Health and Human Services, National Institutes of Health, National Library of Medicine (NLM). (2000, February). In C. R. Seiden, M. Zorn, S. Ratzan, et al. (Eds.), *Health literacy, January 1990 through 1999*. NLM Pub. No. CBM 200-1. Bethesda, MD: NLM, vi.

U.S. Department of Health and Human Services. (2003, July). *Communicating health: Priorities and strategies for progress*. Washington, DC: Author.

U.S. Immigration and Naturalization Service. (2002). *Statistical yearbook of the Immigration and Naturalization Service, 2000*. Washington, DC: U.S. Government Printing Office.

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Joan Christopher
Member, Consumer Advisory Committee,
University Center for Excellence in Developmental
Disabilities, Georgetown University Center for Child and
Human Development

Felicia Jordan DaSilva
Member, NCCC Advisory Committee

Tonia Lewis
Family Advisor, Parents' Place of Maryland

Grace Williams
Family Advisor, Parents' Place of Maryland
State Coordinator for Family Voices

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FOR ADDITIONAL INFORMATION CONTACT:
National Center for Cultural Competence
Center for Child and Human Development
Georgetown University
Box 571485 • Washington, DC 20057-1485
Voice: 800-788-2066 or 202-687-5387 • TTY: 202-687-5503 • Fax: 202-687-8899
E-mail: cultural@georgetown.edu • URL: http://gucchd.georgetown.edu/nccc