Rockville, Maryland 20857
July 17, 2005

Dear Colleague:

The Division of Services for Children with Special Health Care Needs knows that children with special health care needs and their families are better served and their health outcomes improved when family-centered care is the standard. Over the years the Division has supported many projects and initiatives that focus on understanding and implementing family-centered care in policy and practice for children with special health care needs and their families.

Two years ago, we asked Polly Arango, Dr. Kathleen Kirk Bishop, and Josie Woll to assess the status of family-centered care and to provide recommendations to the Division for advancing its implementation. They searched the literature, assessed materials and projects from around the country, exchanged ideas, and discussed issues around family-centered care with the assistance of hundreds of families and professionals. During the last 12 months, they held a series of small working meetings with family-centered care experts to further distill the substance, history, implementation, challenges, and principles of family-centered care and to make recommendations for action.

Among the recommendations: refine a definition of family-centered care that is based on more than 20 years of family and professional dialogue, experience, and inspiration. This definition will guide and assist you to infuse professional practice, heighten family expectations, and withstand the test of time and changing environments.

Your expertise and participation in family-centered care activities and discussions over the decades, especially during this year's family-centered care meetings, were critical to the development of this important definition. Thank you for your commitment and your contributions to family-centered care. Please see the following new definition and principles of family-centered care and the explanation of how cultural competence should be integrated throughout your work with family-centered care.

Sincerely,

Merle McPherson

DEFINITION 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 which results in high quality services.

PRINCIPLES OF
FAMILY-CENTERED CARE FOR CHILDREN

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Based on this partnership, family-centered care:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

Sources: National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs.* (1989). Bethesda, MD: Association for the Care of Children's Health.
Bishop, Woll and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families.* Burlington, VT: University of Vermont, Department of Social Work.

Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, Arango. Algodones, NM; Algodones Associates

THE ROLE OF CULTURAL COMPETENCE IN FAMILY-CENTERED CARE

Cultural Competence is intricately linked to the concept and practice of "family-centered care". Family-Centered Care honors the strengths, cultures, traditions and expertise that everyone brings to a respectful family/professional partnership, where 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 in order to develop and nurture those partnerships and to have the knowledge and skills that will enable you to be "family-centered" with the many diverse families that exist. It also often requires building relationships with community cultural brokers, who can assist you in understanding community norms and link you with other families and organizations, such as churches, beauty shops, social clubs, etc. that can help promote your message or conduct outreach for services.

DEFINITION OF CULTURAL/LINGUISTIC COMPETENCE

Cultural competence is defined as a set of values, behaviors, attitudes, and practices within a system, organization, program or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, inter-personal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. At a systems, organizational, or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions at all the levels from policy-making to the individual, and is a dynamic, ongoing, process that requires a long-term commitment. 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.

PRINCIPLES OF CULTURAL COMPETENCE

An organization should:

1) Value diversity in families, staff, providers and communities;
2) Have the capacity for cultural self-assessment;
3) Be conscious of the dynamics inherent when cultures interact, e.g. families and providers;
4) Institutionalize cultural knowledge; and
5) Develop adaptations to service delivery and partnership building reflecting an understanding of cultural diversity.

An individual should:

1) Examine one's own attitude and values;
2) Acquire the values, knowledge, and skills for working in cross cultural situations; and
3) Remember that every one has a culture.

Sources: Maternal and Child Health Bureau (MCHB), Guidance and Performance Measures for Discretionary Grants, Health Resources and Services Administration, U.S. Department of Health and Human Services, Denboba and Goode, 1999 and 2004.

Cross, Bazron, Dennis and Isaacs, Towards a Culturally Competent System of Care, 1989.
Goode and Jones, Definition of Linguistic Competence, National Center for Cultural Competence, Revised 2004.
Denoba, "Federal Viewpoint", Special Additions Newsletter for Children with Special Health Care Needs, Spring/Summer 2005.