

# **FAMILY-CENTERED CARE**

## **An Introduction**

In carrying out their legislative mandate, state Title V CSHCN leadership must assure that all aspects of their state Program are in keeping with the principles of Family-Centered Care.

Family-centered care is a process that focuses on ensuring that:

- the organization and delivery of health care services meet the emotional, social, and developmental needs of children
- the families of CSHCN are integrated into all aspects of the health care plan
- families have alternatives and choices based on their own needs and strengths and receive support for those choices
- the health care system facilitates family/professional collaboration at all levels, especially in planning, implementing, and evaluating programs and their related policies and practices.

To accomplish this, state programs must develop meaningful partnerships with families and promote leadership by families. State programs must also provide the training, guidance, and policies that create these partnerships within each community as it builds its systems and services.

### **In what ways can CSHCN Programs engage in meaningful partnerships with families?**

Families must be part of policy-making and decision making processes at all levels. There should to be a meaningful level of representation of families--not just a "token parent" on a board or committee--and a diversity of families represented. Families must be full members, not just advisors, and seen as having knowledge and expertise that is vital to creating effective systems and services. State programs should:

- Have a written policy reflecting a philosophy of family-centered care
- Work with families to inform all families in the state about coalitions of families and family support groups
- Have an organized way to receive feedback from families and for disseminating information to families.

## **How should families be involved in implementing the Title V CSHCN Program legislative mandate?**

At the policy development and decision-making level families should be involved as active partners:

- In the design, implementation, and interpretation of needs assessments
- In the design and delivery of training and technical assistance to providers and communities on implementing systems and services
- In making decisions about policy
- In providing first-hand information about problems with current policies

At the system and services development level families should:

- Provide input to ensure that programs address the needs that are identified by families
- Help states and communities address issues of accessibility and appropriateness
- Take a leadership role in developing family support and advocacy mechanisms

## **How do state CSHCN programs serve and involve a culturally diverse array of families?**

In order for a state Title V CSHCN Program to be culturally competent at all levels – service delivery, policymaking, and administration – it must:

- Value diversity
- Have the capacity for cultural self-assessment
- Be conscious of the dynamics inherent when different cultures interact
- Institutionalize cultural knowledge
- Develop adaptations to service delivery that reflect an understanding of cultural diversity.

State programs should have written policies ensuring that as legislative mandates are addressed, the culture of the families served is understood and respected in the ways they are served. They should also work to support communities and providers to endorse culturally competent practices.

## **What are the key elements of family-centered care?**

The key elements of family-centered care include:

- Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service systems and support personnel within those systems fluctuate.
- Facilitating family/professional collaboration at all levels of hospital, home, and community care, including:
  - care of an individual child;
  - program development, implementation, evaluation, and evolution;
  - policy formation.
- Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
- Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
- Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families.
- Encouraging and facilitating family-to-family support and networking.
- Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
- Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

## **What are the benefits of family-centered care?**

Title V CSHCN Programs and families have benefited from instituting family-centered practices and training in the following ways:

- Professionals develop greater depth of skills due to increased sensitivity to clients and improved, appropriate communication with families.
- Providers are more at ease working with families so that the provider/family relationship is stronger with greater job satisfaction.
- Family/professional collaboration at all levels ensures a balance between perceived service system needs and the actual needs of families.

- Consumer support and advocacy for programs and policies (legislative, budgeting, and appropriation) improve as a result of enlightening consumers about program issues and difficulties.
- Families have greater feelings of competence in caring for their children with special needs.
- Families' dependence on the system decreases, as does cost.