

Family Participation in Health Care Policy and Financing

In order to improve how systems of care work for children and families in Massachusetts, the ***Consortium for Children with Special Health Care Needs*** is working to create opportunities for family members, as individuals or organizations representing families, to share their knowledge and experience with policy-makers and organizations that shape how services are financed and delivered.

- **What does “health care policy and financing” mean?**

Both public and private sector organizations use rules and regulations, generally known as policies, to govern how services may be offered to children with special health care needs and who pays. These policies may include:

- o what are the benefits and who is eligible for specific services;
- o under what circumstances children and families can receive these services;
- o what families may have to do before services are provided;
- o how providers may be paid for their services;
- o what families may have to pay to receive services; and
- o how and in what form families receive information about these services.

- **What are the unique contributions of families?**

- o Real day-to-day experience navigating the health care system
- o A fresh look at the system's demands on consumers & their families
- o Vision & creative solutions to problems
- o Ability to advocate outside the organization for resources
- o Insight into the barriers to care and potential for ways to save costs

- **How can families share their knowledge and experience?**

- o As **advisors** to organizations which impact the lives of children with special health care needs
- o As **employees** of organizations which impact the lives of children with special health care needs – in either professional or non-professional positions
- o As **educators**, increasing the awareness and understanding, at all levels, of issues confronting children with special health care needs and their families
- o As **advocates** for children with special health care needs at the legislative level (state and federal)

- **What difference can families make?**

Families caring for children with special health care needs and the organizations that serve them know there is room for improvement. Active family participation in partnership with public agencies, health plans, hospitals and other providers will make programs and services more responsive, more comprehensive, and easier to use.