

POLICY STATEMENT:
Supporting Families to
Participate in the Massachusetts Consortium
for Children with Special Health Care Needs

The Massachusetts Consortium for Children with Special Health Care Needs (CSHCN) is committed to encouraging and supporting the participation of parents in its activities and working groups. In many instances, parents (and other family members) come to the Consortium representing an agency or organization so that their involvement, in terms of time and expenses, is covered by that organization. There are other family members whose expenses and time are either not covered by their agency (because of the nature of their employment) or who do not have a paid affiliation with an organization.

In order to encourage the participation of parents not working outside the home or those who would not normally be able to participate in the Consortium's activities as part of the scope of their employment, the Family Participation Working Group suggests the following policy recommendations:

- The Consortium will seek, to the best of its ability, the resources needed to offer an hourly stipend to family members not otherwise compensated. This stipend would cover time for the family member to participate in, and to travel to and from, Consortium activities. The hourly stipend will be at a rate recommended annually by the Steering Committee.
- The Consortium encourages its own member organizations to consider contributing financial resources to support family member participation within the Consortium, as described above. The Consortium will create a mechanism for collecting and distributing these resources.
- As Consortium member organizations involve family members from their own organizations in Consortium activities, they are encouraged to help support financially the involvement of these family members.

Submitted by Family Participation Work Group: August 19, 2003

Revised and endorsed by Steering Committee: September 10, 2003

Presentation to full Consortium: October 2, 2003