Massachusetts Consortium for Children with Special Health Care Needs -- Steering Committee Workgroup on a Possible Advocacy Role

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Introduction

Members of the Consortium for CSHCN occasionally ask for the group to "take a stand," such as supporting a particular policy or advocating for specific items in the state budget. Such questions have in common the fact that members of the Consortium do not control the outcome. While the Consortium has not been designed as an advocacy organization, the work of the group can contribute to potential advocacy efforts that may be organized and conducted by members operating outside of the group. In February 2003, the Steering Committee was asked to propose an approach for the Consortium with regard to such requests for *advocacy*. These requests are to be distinguished from the core collaborative goals of the Consortium, such as promoting changes in state and community systems of care to help CSHCN, to paraphrase our mission statement. Such collaboration may eventually support or lead to *advocacy* in areas under the control of the members; for example, distribution of a resource guide for families, and support for the "medical home". The proposal below relates to the first type of *advocacy*, the kind in which the goal is to influence the decision-making of external organizations or entities.

Types of Issues

- State policies, legislation, budgets
- Federal policies, legislation, budgets
- Constitutional amendments
- Guidelines from organizations that set/recommend guidelines for care (e.g., MCAAP)
- Models, statements, curricular materials, educational materials and programmatic initiatives from various groups seeking endorsement

Possible Model

Premise: Our mission as a consortium is to educate and inform with regard to CSHCN. Further, the diverse nature of the group, its members, and the organizations represented in the group, requires respect for individual decisions and individual constraints. Maintaining the comfortable participation by the various individuals and groups in the Consortium is the prime goal. With these as drivers, we could focus our potential interest in advocacy on the ***definition of problems, not on solutions***.

1. a) Individuals or member organizations raise issues in updates or explicitly as possible topics for Consortium attention.
   b) Individuals or member organizations develop materials or reports defining a problem.

2. Steering Committee reviews such topics or reports and chooses a problem to explore (e.g., changes to CMSP/Medicaid and their effects *specifically on CSHCN*). Charge to a workgroup would include specific components.

3. Pool resources/research to define/frame the issue, with data and implications for CSHCN and their families. The resulting report would clearly define the issue and its implications for CSHCN and their families but would not offer solutions.

4. Review in Steering Committee

5. Share report with Consortium:
   - Members of Consortium may go in different directions with this information and may act on it in different ways, which respects the diversity of the Consortium. Members may use the report as they wish.
   - The Consortium would share the report with state agencies, state leaders, etc.
   - The Consortium could also share it with the press

6. Consortium Committees:
   - Attempt to reach consensus on topics dealt with in committees to the extent possible
   - Define areas without consensus
   - Report to full Consortium on areas of consensus and those without consensus
   - Members of Consortium will respond individually, sharing information with their respective constituencies, if applicable.
   - This approach is consistent with and respects the diversity of the Consortium and its committees.
   - Some committees will be charged with producing solutions to a problem, but this would probably be for a topic in which advocacy may not be an issue.