

# Massachusetts Consortium for Children with Special Health Care Needs



Thursday, June 5, 2003 - 1:00-3:30 p.m.  
**Shriners Hospital for Children**  
**51 Blossom Street, Boston - 9th Floor Board Room**

## Summary Notes

*\*Note: Presentation materials referenced in these minutes and marked with an asterisk will be posted on the New England SERVE website, [www.neserve.org](http://www.neserve.org) - click on MA Consortium. You will then see the link to the Consortium Materials archived by date.*

### I. Update & Status of FY '04 State Budget: Implications for CSHCN

*Lucy Meadows, Mika Cheng & Stacey Auger (Health Care for All, Children's Division)*

Lucy Meadows, Mika Cheng, and Stacey Auger from the Children's Division of Health Care for All (HCFA) spoke to the Consortium about the status of the 2004 fiscal year Massachusetts state budget.

They presented an overview of the state budget proposals from the House of Representatives and the Senate. With both the Senate and House budget proposals approved, the Conference Committee will now develop a compromise budget — target date June 13<sup>th</sup> to send to the Governor. The Governor will have 10 working days to sign or veto the compromise budget. The House budget reduced the Family Health Services budget from 11 million to 3 million (-8 million \$); the Senate version makes a much smaller reduction to 9 million (-2 million \$). Early intervention remains level funded in both the house and senate versions. School Health, which already suffered a 30% cut in its budget in January 2003, is slated for additional cuts in both versions. A 3 billion dollar deficit is projected in revenue for FY 04. Various strategies for cost savings in the Medicaid program are reflected in the budget proposals, with more expected in the year ahead.

HCFA is proposing a number of monitoring activities to track the impact of these cuts on families in Massachusetts, especially in the areas of: limitations on medications; time lags in services, medical care and authorization delays. Consortium members were asked to alert families to these changes and to encourage families experiencing new barriers to care to share their stories with HCFA.

Two new publications have been developed and are available from HCFA: *Small Savings, Big Losses: Cutting the Children's Medical Security Plan, Undoing Children's Health Care in Massachusetts*, and *Working with Children with Special Health Care Needs: What Families Want Health Care Providers to Know*. Copies of both publications are available on the web at [www.hcfama.org/acrobat/childhealth\\_report.pdf](http://www.hcfama.org/acrobat/childhealth_report.pdf) and at [www.hcfama.org/acrobat/provider\\_guide.pdf](http://www.hcfama.org/acrobat/provider_guide.pdf), respectively.

To obtain more information and periodic updates on the Massachusetts state budget, please go to the Health Care for All website at [www.hcfama.org](http://www.hcfama.org), or call 617-350-7279.

### II. Care Coordination Work Group – Interim Report\*

*Debby Allen (BU School of Public Health, and Chair, Care Coordination Work Group)*

Debby distributed an [Interim Report](#)\* from the Care Coordination Work Group and summarized the group's efforts and progress since the day-long invitational workshop held in February 2003. She reviewed the active debates and consideration by the work group of the tension between viewing care coordination as a person providing a series of problem-solving services versus viewing care coordination as a process and a relationship-based service that empowers families. The group has also given detailed consideration to the differing views expressed by families and providers of the purpose and impact of CC.

Consortium members were asked to comment on the Work Group's preliminary recommendations to date, which include the following proposed indicators of a quality system of care coordination for CSHCN:

- Care coordination services for CSHCN should be closely linked to the Medical Home
- An effective system of CC must contribute positively to all four of the following levels of the health care delivery system:
  - Access and quality of care that can improve health, functioning, or well being of a **child** with special health care needs.
  - Supports for families that can improve well-being capacity, knowledge, and satisfaction of **families**.
  - Supports that enhance competency, capacity, and satisfaction for **providers** caring for CSHCN.
  - Feedback on barriers to care and unmet needs that can enhance efficiency and effectiveness of the **system** of care for CSHCN and their families.

The CC Work Group will be addressing issues of accountability, an operational definition of care coordination services, and a proposal for financing CC in the next phases of the workplan. Consortium members are asked to review the interim report\* from the CC Work Group and provide comments and feedback to Debby Allen - [dallen@bu.edu](mailto:dallen@bu.edu), 617-414-1416.

### III. Family Participation Work Group – Interim Report\*

*Dalene Basden (Parent/Professional Advocacy League and Co-Chair, Family Participation Work Group),  
Suzanne Gottlieb (Director of Family Initiatives, Mass. Dept. of Public Health, and Co-Chair, Family Participation Work Group)*

Suzanne Gottlieb summarized the work of the Family Participation Work Group (FPWG) since the fall of 2002. The FPWG is completing the information-gathering phase of its work. The Work Group conducted a set of interviews with 16 family leadership groups in the state to assess the potential interest of families in getting involved with the Consortium in partnerships that inform health care policy and financing, and identify existing training resources for family leadership (see: *Family Participation Needs Assessment: Summary of Interviews with Family Leadership Groups, March 2003*\*). The informal telephone survey demonstrated a high level of interest among a majority of groups interviewed. Family leaders are seeking a clearer definition of what getting involved in "health care policy and financing" actually means and clear evidence that their participation makes a difference. In response to these results, the FPWG developed a draft *Statement on Family Participation in Health Care Policy and Financing*\* for discussion and endorsement by the full Consortium.

Various suggestions were made to improve the *Statement on Family Participation*, including using the word "provider" instead of "medical provider", to note the difference between policy and regulation, and to re-order the questions assuring that the "what" questions come before the "how." The FPWG was also advised to expand the notion of family participation to include families communicating with each other, as well as families communicating with systems. Broad endorsement of the draft statement and support for the direction of the FPWG to date were expressed, emphasizing the critical roles that family members can play in reducing barriers and increasing accessibility of services.

The next stage of information gathering will include a survey of members of the Consortium who are *not* parents of CSHCN; twenty representatives of health care organizations are targeted for individual interviews. The purpose of the survey is to find out what organizations are doing currently to include family representation, and to determine the current level and opportunities for building partnerships with families in plans, hospitals, universities, state agencies, etc. It is also an opportunity to show the benefits, barriers, and challenges of family partnerships. In addition, every member of the Consortium will be invited to complete an email survey that asks for an assessment of the impact to date of family participation within the Consortium.

The next steps for the FPWG will be to incorporate the comments the Consortium made at this meeting into their documents, complete the telephone interviews and email survey of Consortium members, and summarize and present the findings at the next Consortium meeting in October. For further information on the Family Participation Work Group, contact Linda Freeman - [lfreeman@neserve.org](mailto:lfreeman@neserve.org), 617-574-9493.

#### IV. Planning for Next Year\*

*(Susan Epstein, New England SERVE and Chair, Consortium Steering Committee)*

A brief summary of the recent developments in the Consortium's structure and membership, as well as accomplishments in 2002-2003 was reviewed. Questions about meeting location will be posed in the upcoming survey from the FPWG. In the short time remaining in the meeting, members were asked to recommend topics for future agendas.

The following suggestions were offered for planning of 2003-2004 Consortium meetings:

- Continue forum for exchange of information: What's going on around the state?
- Provide periodic updates from the working groups
- Provide periodic updates from Health Care for All, PAL, other advocacy groups
- Invite staff from legislature and Governor's office to attend certain meetings
- Re-establish working group on health insurance and financing

**Next meeting: Thursday, October 2, 2003 - 1:00-3:00 p.m.**