Massachusetts Consortium for Children with Special Health Care Needs

New England SERVE

Meeting Summary

December 5, 2002 -- 1:00-3:00 p.m.

Shriners Hospital for Children – 51 Blossom Street, Boston - 9th Floor Board Room

(* Note: Presentation materials referenced in these minutes and marked with an asterisk will be posted on the New England SERVE website, www.neserve.org - click on *Projects, Massachusetts Consortium for CSHCN.*)

I. Strengthening Family Participation in Health Planning, Policy and Financing

A. Susan Epstein (New England SERVE) briefly introduced this topic as one of three goals identified by the Consortium in a new MCHB grant designed to improve health care financing for CSHCN. The three priority areas targeted over the next four years include:
   1) increasing the pool of families actively participating in health policy and financing,
   2) developing an operational definition and financing strategy for care coordination, and
   3) addressing barriers to adequate health care financing that are created by existing medical necessity definitions and decision-making guidelines.

B. Dalene Basden (PAL, MSPCC), co-chair of the Family Participation Work Group, introduced herself to Consortium members for the first time. As a woman of color, Dalene can help address and identify cultural issues that confront parents of CSHCN. Her goal is to "engage as many blacks as possible" in the healthcare arena, and to help make health care delivery more appropriate, accessible and affordable for minority families caring for CSHCN.

C. Suzanne Gottlieb (MDPH), the other co-chair of Family Participation Work Group, presented the goals this group, along with the activities planned to achieve those goals. The long-term goal of the work group is to expand the numbers of parents of CSHCN actively participating in health care policy and financing partnership roles. This will likely involve identifying, training and supporting parents in these roles, as well as identifying and building new opportunities for effective partnerships within a wide range of public and private health service organizations. Suzanne stressed the importance of participation by the full range of Consortium members in the activities of the Family Participation Work Group. Three assessment activities are planned in the first year of the project:
   1) telephone interviews with parents who have participated in the Consortium (already complete),
   2) surveying family organizations in the state regarding their interest in the Consortium's broad target population and policy partnership agenda,
   3) surveying the agencies and organizations represented on the Consortium to determine their interest and ability to provide supports (financial, administrative, mentoring etc.) for policy partnerships.

   Once these data collection activities are complete, the Family Participation Work Group will review the findings and make recommendations to the Consortium for specific activities in Year 2 that will help to increase family participation.

D. Linda Freeman (New England SERVE) described the Family Participation Needs Assessment that is currently underway. 19 family led organizations in the state have agreed to be interviewed. A draft telephone survey instrument* was distributed and comments solicited from the Consortium. The assessment is designed to identify where there may be interest in linking with the Consortium's agenda, where family leadership training and support for policy participation may already be occurring in the state, and where there are gaps in training and supports for family participation that the Consortium could fill.

E. Linda also discussed the results of interviews with current Consortium members who are parents of CSHCN –assessing their comfort level at Consortium meetings and soliciting ideas for how the Consortium can further encourage and sustain parent participation. The overall response was very positive – family participants are optimistic about the potential impact of the Consortium. They find that other members are respectful, and the nature of the exchange in this setting very unique. Recommendations of current family members include: increasing awareness of the cultural and racial diversity of experience in caring for a CSHCN, strengthening connections between professionals in the health field and family leaders, and building a mentoring partnerships within the Consortium. Specific strategies for inclusion included: 1) creation of an orientation program, 2) social/networking opportunities, 3) implementing partnering/mentoring programs (i.e., pair professionals and parent leaders), 4) provide stipends for travel e) increase representation from other parts of the state, 5) create a family support network as a part of the Consortium affiliation.

F. An additional resource for increasing participation of family leaders in health policy is a new grant from the Center for Health Care Strategies to Massachusetts Family Voices. Nora Wells (Family Voices @ FCSN) described this activity as another way to connect families to health policy issues. Family Voices is a volunteer board working to support family leadership through various communications, such as a website, listserv service and a quarterly newsletter, entitled *CheckUp*. The new project will help MA. Family Voices to develop family friendly resource materials that health plans can use to improve their communications with member families caring for children with special health care needs. A project FACT sheet was distributed*.

II. Shared Responsibilities Toolkit

Nancy Turnbull (New England SERVE), presented the new Shared Responsibilities Toolkit for health plans developed by New England SERVE. These tools are designed to assist health plans to identify CSHCN, and to collaborate with families, providers and state agencies to improve their systems of care. The toolkit will be disseminated to Title V and CSHCN Directors in all 50 states, Family Voices state coordinators, and selected health plans. The Toolkit is a product of the four year Shared Responsibilities project, directed by Susan Epstein, with contributions from various colleagues and reviewers across the country. All the materials in the Toolkit are now available at no cost on the New England SERVE website, www.neserve.org.

III. Report on *Transition* Background Brief

Having completed background papers on two of the six 2010 goals for CSHCN last year, the Consortium has recently undertaken a third brief on the status of building an appropriate set of services and resources to support the transition of youth to adulthood. Stephanie Porter (Children's Hospital, Institute for Community Inclusion) presented a draft outline for the background brief on *Transition* and asked Consortium members to review the components of the proposed brief and submit any relevant materials to her. Members were asked to carefully consider and respond to the section of the outline, which addresses the current state of transition services in Massachusetts. The outline includes topics related to transition and the person assigned to develop each section. Topics include the definition of transition, legal rights, federal initiatives, case law related to transition and challenges/barriers in service delivery.

IV. Report from the Ad Hoc Committee on Administrative Planning

Audrey Shelto, consultant to the Consortium, summarized the feedback from the October presentation made by the Ad Hoc Committee. All feedback was supportive of the recommendation to develop a Steering Committee for the Consortium. Specific components of the recommendations regarding: membership on the Steering Committee, frequency of meetings and authority of the Steering Committee are included in the PowerPoint presentation*. The current Ad Hoc Committee on Administrative Planning will serve as the first Nominating Committee. Nominations for steering committee members were to be submitted to any member of the Nominating Committee before January 1, 2003.

V. State of the State Budget

Lois Wainstock (Tufts University Center for Children) described briefly the growing concern about vulnerable populations under the current economic conditions, and the current opportunity to add input to the incoming Governor's Health Transition Team. Mika Cheng (Health Care for All) described the Health Care for All rally on Dec 4th with 300 - 400 people in attendance. So far, CSHCN have not been directly affected by budget cuts, but members of the Consortium expressed concerns about future risks to programs serving this group of children and families. Some families are reporting insurance requests being scrutinised more closely than in the past. Consortium members expressed their concern regarding the need to protect what is currently in place for children and families. The Consortium began collecting stories from families last year to highlight the positive impact of public programs and services. There are 28 stories gathered to date that could be re-formatted for educational or advocacy purposes. Lois recommended that the Consortium attempt to increase its visibility and the specific needs of this population of children and families within the new administration by extending a formal invitation to newly appointed policy leaders to attend a Consortium meeting in the spring.

VI. Announcements:

A. Stephanie Porter shared a job announcement from Children's Hospital *

B. Debby Allen (Health & Disability Working Group, B.U. School of Public Health), announced that the Care Coordination Work Group will be holding a one day workshop focussed on developing an operational definition of enhanced care coordination for CSHCN. This meeting will be held on Friday, February 28th, at the Blue Cross/Blue Shield Foundation offices, Landmark Building, 401 Park Drive in Boston.

In Attendance:

Karen Algus, Debby Allen, Betsy Anderson, Dalene Basden, Nancy Chane, Mika Cheng, Meg Comeau, Susan Epstein, Linda Freeman, Whit Garberson, Pamela Gossman, Suzanne Gottlieb, Alexa Halberg, Gail Havelick, Marty Wyngaarden Krauss, Nancy Levine, Lisa Martin, Barbara McMullan, Marguerite Phillips, Stephanie Porter, Rich Robison, Donna Rubenoff, Kathy Ryan, Audrey Shelto, Polly Sherman, Carla Sbardella, Paul Tupper, Nancy Turnbull, Randi Walsh, Nora Wells, Lois Wainstock, Amy Weinstock, Barry Zallen