Massachusetts Consortium for Children with Special Health Care Needs

New England SERVE

Meeting Summary

April 8, 2004 -- 1:00 – 3:00 p.m.
Location: Blue Cross Blue Shield Foundation

Before the meeting began, Consortium members were invited to view the documentary film, "Kiss My Wheels," which follows the members of a junior wheelchair basketball team through difficult issues from gender conflicts to injury, illness and thoughts about their future.

I. Transition: Where are we in Massachusetts?

Linda Freeman introduced the first part of the meeting: table-by-table discussion groups of the Draft Transition Brief (see final version) that had been distributed to all members prior to the meeting. Linda spoke about the background and context for the creation of the brief as well as the activities leading up to today's discussion.

- Transition is one of the six core outcomes included by the Maternal and Child Health Bureau in its 2010 objectives for improving systems of care for CSHCN. (These six outcomes are embedded in the mission of the MA Consortium.) Transition, as defined in the 2010 objectives, addresses the services necessary to assist youth in making transitions in all aspects of adult life, including adult health care, work and independence.
- The Consortium has used a process of data collection, study and recommendations to previously address how Massachusetts is doing in achieving each of the 2010 core objectives. Two of the other core outcomes (Medical Home and Adequacy of Health Care Financing) have been addressed in this manner, resulting in background briefs outlining findings and opportunities. These previous studies have guided the group's thinking about what role the Consortium might play in achieving the objectives. Strategic planning then led to grant submissions, one of which has resulted in the 4-year grant which now funds many of the Consortium's work groups and activities tied to adequate financing for CSHCN.
- We know from anecdotal and other information that transition services are an area needing considerable attention and where achievement of objectives is woefully inadequate. National CSHCN survey data confirm this conclusion, both nationally and within Massachusetts.
- A Transition Task Force was formed by the Consortium in the fall of 2002 to address the transition objective. This group is co-chaired by Stephanie Porter and Linda Freeman.
- A panel of transition experts presented on the topics of health, education, recreation and employment at the February 2003 meeting of the Consortium. Panel members (including youth, parents, and disability experts) highlighted the challenges and issues confronting young adults and their families.
- The Transition Task Force has prepared a draft Background Brief for review by Consortium members; feedback about its content, additions, corrections and recommendations can be made through April 30, to Linda Freeman. The brief is intended as a snapshot of transition services in MA, providing the information needed to look at what role the Consortium might play in achieving the transition objective. Because the Consortium does not have the resources to undertake any focused initiatives at this time, this must be a key consideration in any recommendations made for next steps. Suggestions for funding to support Consortium initiatives in this area are welcome.

II. Small Group Discussions

Members of the Transition Task Force or meeting participants very knowledgeable about the topic facilitated seven small group roundtable discussions. Each group was asked to address four questions:

- What are your reactions to the contents of this background brief? Is anything missing?
- What role could the Consortium play to support the transition of youth with special health care needs?
- Where could the Consortium look for resources to support any activities in this area?
- Should the Consortium include youth with special health care needs? If so, what would the strategy for youth leadership?

Discussion group facilitators submitted their notes from the discussion groups to the Transition Task Force, which will collate and synthesize the input to guide final revisions and recommendations for the Transition Brief. Susan Epstein shared her observations from sitting in briefly at each of the small group discussions. These include: the need to consider the needs of youth who are not on IEPs (Individualized Education Plans) but still need help with transition; the need to elevate the role that parents and youth can play in transition planning and promoting appropriate transition policies; the lost opportunities and resources for families when needed home care supports are lacking; the need to improve coordination across organizations, and to improve access to resources and information for both families and professionals. Possible roles for the Consortium in promoting visibility on this issue included: creating a listserv focused on transition and resource exchange; providing training on transition services targeted to care coordinators and case managers; convening a transition conference; promoting an IEP-like process for adults; developing and disseminating a brochure on transition targeted for physicians' offices, high schools and community agencies.

III. What's New at EOHHS for Children with Special Health Care Needs - Abigail Josephs, Special Assistant to the Secretary of Health and Human Services, on Children's Policy

Abby Josephs distributed a handout showing the new reorganization of Health and Human Services, where the overarching theme is coordination and collaboration. The reorganization seeks to maintain agency specialties while finding ways to share resources and partner with families and community organizations. All 17 agencies report to Secretary Ron Preston. A basic tenet of the reorganization is that Medicaid plays a huge role in the delivery of services, both through MassHealth as well as in supporting administrative functions. For this reason, one of the big changes was to elevate the Office of Medicaid directly to the Secretary's office, and to even physically locate it within EOHHS. Beth Walden, the Director of this office, is now part of the EOHHS Executive team. She serves as Director of the Office of Medicaid. Amongst the 17 agencies, five offices have been created (also known as clusters). Acknowledging that no clustering is perfect, the goal is to ensure a lot of cross-office coordination and to make the process fluid. To this end, all agencies come together to meet bi-monthly, which is a new practice. The Executive Team is the place where major decisions affecting all agencies are made, and where there is a centralized approach to decision-making, budgeting and legislation.

Another core tenet of the EOHHS is that the community based nature of the system of care requires family involvement and choice. The EOHHS is working to create public-private partnerships to serve families and to develop a streamlined date system so that a family need only to "enter" the human service system one time to receive information, eligibility and referrals across all human service programs and find out for which services they are entitled. Currently, there are 17 distinct data systems and they will all be merged into one. EOHHS is studying how other states have accomplished this streamlining to take advantage of what others have learned. This project is a 5-year effort.

The EOHHS is reforming the way it purchases services, with the goal of optimizing buying power and making obtaining services easier for families. One parent at the meeting pointed out that the purchasing system needs to be flexible and dynamic, for example with respect to respite. Abby acknowledged the importance of respite as a way to keep parents going and that this is being addressed. Youth with mental health needs are a major priority within EOHHS, with a Mental Health Commission for Children now at work with family and professional participation under a legislative mandate. Other initiatives of the EOHHS include efforts to coordinate early education and care, and substance abuse. A Children's Coordinating Team has been initiated that brings together all child-serving state agencies every two weeks. EOHHS is working with PAL and CFFC (Coordinated Family Focused Care) through the MA Behavioral Health Partnership, in an effort to learn what families and schools need to keep youth with behavioral issues in their natural communities.

In response to one parent's comments about difficulties in working with multiple human services agencies, Abby noted that she intends to be a conduit from families back to EOHHS and will be coming to Consortium Steering Committee meetings to continue to bring information on CSHCN back to the Secretary's office.

IV. Consortium Updates

Policy Recommendation on Advocacy: Meg Comeau and Barry Zallen, Steering Committee members, spoke about a recommended policy for the Consortium related to taking public positions on policies and legislation. The Steering Committee had been charged by the full Consortium in February 2003, to prepare a set of recommendations in this area (see draft policy statement). Because the Consortium by definition is made up of a diverse membership, representing various perspectives, personally and professionally, and because members have varying degrees of freedom with respect to advocacy, the committee studying this had to strike a balance. The Consortium Steering Committee has reviewed this draft and recommends that the Consortium adopt a role that can support others in their advocacy efforts, without taking specific public positions on behalf of the whole group. In this way, the Consortium would occupy the role of informant - highlighting, studying, and educating on issues as they affect CSHCN, but stopping short of telling members what to do or taking a public position. Consortium members are requested to critically review the draft policy statement and encouraged to send their comments and suggestions to Alexa Halberg at New England SERVE (ahalberg@neserve.org - 617-574-9493), who will collate responses. All comments will be reviewed by the Steering Committee and a final proposed policy presented at the June Consortium meeting.

Western Mass. Consortium for CSHCN: Marianne Beach, who has been working with Matt Sadof, MD, in Springfield to encourage and support an emerging branch of the Consortium based in Western Massachusetts, updated the group about the status of these efforts. Preparations for the Medical Home training in Springfield in November 2003 brought together a diverse team of people concerned about CSHCN. This group sought a way to foster that working relationship and to create a version of the Consortium in the western part of the state because of the difficulties in attending Consortium meetings caused by geography and distance. The group had started to identify grants that would support this effort, working with Mass Family Voices, the MA DPH and New England SERVE. However, to date time constraints have limited their ability to seek formal funding. The group will continue to get together periodically, and will stay involved with the Consortium through various work groups, and attending full Consortium meetings whenever possible. While the current plan is not as aggressive as originally hoped, there is a budding Western MA Consortium. Susan noted that there is also a CSHCN special interest group in the Worcester area that may evolve into a more formal branch of the Consortium.

Care Coordination Work Group: Debby Allen, chair of the Care Coordination Work Group, referred to the handout updating the full Consortium on recent activities of the work group (see update). The group has interviewed a variety of care coordination programs and is now doing site visits of four primary care practices that deliver care coordination through several models and staffing arrangements: one where care coordination is done by a nurse, one by a social worker, one where outside community-based agency staff perform the function, and one where a mix of office based clinical and administrative staff perform some of the functions of care coordination. One site visit has been completed and the interview team is currently identifying other practice sites willing to participate; recommendations are welcomed. The results of these efforts will be a proposal for a model of care coordination that is cost effective and addresses diverse needs.

Family Participation Work Group: Betsy Anderson highlighted the agenda for the next Consortium meeting, to be held on June 3rd. This meeting will feature family/professional collaborations for improving systems of care for CSHCN. The afternoon's proceedings will be in two parts: a program highlighting examples of effective collaborations, followed by a fair that will combine an opportunity to network and to learn about various family organizations. (See handouts: one with general information about June 3rd meeting, and the other seeking input on family/organization collaborations.)

V. Policy Update

Dayanne Leal, Program Associate, Children's Division, Health Care for All (HCFA), updated members about a three-pronged campaign: to obtain full funding for Children's Medical Security Health Plan (CMSP), to rollback premiums for the program and to obtain full funding for Healthy Start. There are currently 12,328 children on the wait list for CMSP, a 95% increase since November 2003. She distributed a flyer entitled *Kids Can't Wait,* encouraging parents to get involved. Barbara McMullan, Division of Medical Assistance, clarified changes being made in MassHealth coverage for physical, occupational and speech therapy. Contrary to what some parents understand, these changes are not a reduction in services but rather the introduction of a one-time prior approval by physicians. HCFA has a flyer available (in English, Spanish & Portuguese) explaining this change.