Massachusetts Consortium for
Children with Special Health Care Needs

New England SERVE

Meeting Summary

December 4, 2003 -- 1:00 – 3:00 p.m.
Location: Blue Cross Blue Shield Foundation

*(*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 button on left labeled MA Consortium. You will then see the link to archived minutes and attachments)*

Welcome & Introductions

- Susan Epstein, Chair of the Consortium, suggested a new approach to the usual tradition of personal introductions of all participants at our meetings, given that attendance at Consortium meetings has grown to 50+. Each participant was invited to spend the first 5 minutes of the meeting in introductions with 2 people they did not know.
- The Consortium has adopted a stipend policy for parents participating in all Consortium related meetings and events. Family members who are not compensated for their time in these meetings are encouraged to request and submit a stipend form from Alexa Halberg, ahalberg@neserve.org, and 617-574-9493.
- The new format for Consortium agendas, as recommended by the Steering Committee was presented. Each agenda item will now be identified in one of 3 categories:
  - **Information**: maximum of 10 minutes with minimal discussion expected
  - **Education**: presentations expected to expand participants' understanding of the system of care for CSHCN and their families. Research, innovative initiatives, analysis of barriers to quality care may be shared. Discussion is expected. Questions to guide discussion will be shared by presenters in advance of the meeting. Handouts of any presentation materials (identical to that shown at the meeting) will be distributed at the time of the meeting if not available in advance.
  - **Action**: An item identified as an action item is one that can only be presented by member(s) of the Consortium, under sponsorship of one of the Work Groups and is being submitted for active consideration by the full Consortium. Specific action or decision may be requested. Discussion is essential to full consideration. Questions to guide the discussion will be shared by the presenter in advance of the meeting.
- The Steering Committee has also recommended that Consortium meetings be organized around a theme, whenever possible. Today's theme is Medical Education.

I. National Medical Home Learning Collaborative* *Charles Homer, MD, Director, National Initiative for Children's Health Care Quality (NICHQ)*

NICHQ has just completed the first phase of a new learning collaborative about Medical Home, funded by the Maternal and Child Health Bureau (MCHB), called the Medical Home Learning Collaborative.

- This 1-year project addressed the question, "What does it take to implement the Medical Home model at the practice level, and to accomplish *spread* across a

state?" The project was designed to support quality improvement for CSHCN by assisting practices to implement the Medical Home model and by fostering substantial relationships between Title V programs and their state's primary care community (a two-tiered approach). The MCHB is interested in assisting the state Title V programs to develop the needed competencies to support improvement at the practice level and effectively "spread the word" about Medical Home.

- 33 medical practices in 11 states participated in the learning collaborative reflecting care of about 6000 children covered by these practices.
- Parent partners from each practice were included in the collaborative.
- The learning collaborative model employs an iterative process of learning by doing. Joint learning sessions that bring together multiple teams are combined with "action periods" at the practice level and reporting sessions via telephone conference calls between meetings.
- The project conducted some quantitative tracking of some limited measures of CSHCN utilization and family status. Preliminary analyses indicate that emergency department visits decreased over the time that the collaborative was meeting and that "family worry" decreased as well.
- Qualitative assessments were conducted during "walk-throughs" at the practice level by Title V staff. These visits along with parent involvement at the practice-based teams were cited as powerful and essential interventions. A number of other lessons learned are detailed in the attached PowerPoint presentation.

Discussion/Questions:

- *To what extent were mental health issues covered?* The CSCHN screener used for identification includes the mental health population, but the focus on quality improvement was not on specific strategies for this population. Suggestion was made that school suspensions could be used as an outcome measure for kids with serious behavioral health needs.
- *What was the nature of family involvement in the sessions?* Families participated in the sessions as identified by the practices using specific criteria. At each learning session, Maureen Mitchell, a consultant from Family Voices, met with parents and provided mentoring and technical assistance. Maureen also ran remedial sessions for practices that were having more difficulty successfully involving families.
- *Were total expenses of caring for children with SHCN tracked?* No, this was beyond the project's capacity.

Consortium members are invited to contact Charles Homer directly with any follow-up comments or questions at: chomer@nichq.org or 617-754-4907.

II. Identifying Best Practices in Medical Education: *Dorothy Weiss, Ed.M, Harvard Medical School, 2nd year student; Bev Nazarian, MD, UMass Medical School, Dept. of Pediatrics, Medical Home Steering Committee; Ann Dugan-Lewis, parent from Needham, MA*

Dorothy Weiss spoke about the ***More to Life than Genes (MTLTG)*** program at Harvard Medical School, a piece of the first year curriculum on genetics. The program grew from

her personal interest (her father has a significant physical disability) and from the involvement of 2 other classmates with strong personal experiences in this area. The students' sought to open up conversation about disability among their classmates, and to promote sensitivity in care and cultural competency as they relate to disability. They worked to relate these interests to what was already going on in the school's curriculum. The "Genetics Development and Reproductive Biology" course, a 5-week course for first year students, was an ideal match.

- Goals for the MTLTG program were to make it a hands-on, meaningful experience for students where they could interact with families, as well as a meaningful experience for families who would choose to participate.
- 5 luncheon seminars were held in 2003. The seminars were conceived as voluntary and extracurricular. 4 different genetic conditions were presented as well as a final session on genetic counseling.
- For the first session on Tay Sachs, they planned for 10 attendees; 50 came and by the last session 90 students were participating.
- Parents enjoyed seeing their children as teachers and role models
- The sessions allowed parents to give a very realistic sense of their lives, including both the negative and the positive aspects.
- Students reported that learning first hand from families was very beneficial.
- Planning has begun for this year's series of seminars. 15 students have already come forward as leaders to indicate their interest in planning the sessions.

Bev Nazarian described a range of teaching initiatives on CSHCN at **UMass Medical School, in the Departments of Pediatrics, Family Practice and Psychiatry.** The premise for these initiatives is that training must begin early with medical students and residents to achieve the goal of increasing the number of physicians practicing family-centered care and delivering services within a medical home. While there may be a lot going on in different departments within the medical school, there is a need to consolidate these initiatives and increase collaboration. Examples of these initiatives include:

- Medical School Community Clerkships: During their third year Pediatrics rotation, each medical student is required to conduct a home visit with a family whose child has a chronic illness. The primary care pediatricians with whom all 100 students are matched during their third year identify host families. Focus of the visit is on the impact of the illness on the family and the potential role of the pediatrician. A group sharing of their experiences follows the visits.
- Medical School Electives: A number of medical students have selected a 2-week elective focused ion CSHCN and community based services. These electives are supervised by a faculty member in the Department of Pediatrics and typically include visits to Early Intervention programs, schools, and partnership meetings with family advocates. Some have attended Consortium meetings in the past.
- Pediatric Residency Training: Some faculty are assigning residents to care for CSHCN in their first year in continuity clinic, providing a three year follow-up opportunity, and the chance to experience parents of CSHCN as expert teachers.
- Pediatric & Family Practice Residency Training: In the third year of residency, trainees complete a community scavenger hunt that emphasizes finding community resources such as the WIC office, mental health providers, schools

etc. This activity demonstrates the importance of community resources in supporting primary care and teaches strategy for getting to know a new community.

- Medical Home Special Interest Group: A special interest group focusing on CSHCN and Medical Home has begun meeting at UMass during the last year that brings together physicians, community resources, parents and others within the medical school. This group reflects the growing interest in CSHCN in central Mass and presents additional opportunities to increase medical education initiatives in that setting.

Ann Dugan-Lewis has participated as a parent and trainer with two medical education programs for the past ten years. These programs are: ***Operation House Call, operated by the BU School of Medicine, Dept. of Pediatrics & the Greater Boston ARC,*** and the ***Linking*** **Hands Program** that is part of the pediatric residency training program at Children's Hospital. In both of these programs, physicians in training (medical students at BU in one, and residents at Children's in the other, make home visits and conduct interviews and observations with families caring for CSHCN. Ann has two children; her 10 year old has Down Syndrome. Ann became involved in these programs because of her experience in learning she was carrying a child with Down's. Her physician was wonderful in how he handled the situation and supported the family. Later experiences with physicians have not always been positive. She wants young physicians to see that life with a child with special health needs can be normal and fine. Ann estimates that she has met with over 100 young physicians in training over the past decade. Her message to physicians is "listen to the families" and, "it's all in the presentation" – i.e. the style with which MDs communicate with families and share information is of paramount importance.

Discussion & Questions:

- *How do we reach MDs out of training*? There was interest in broadening these types of learning experiences to include practicing physicians. For example, could the Harvard "More to Life than Genes" program be converted into a CME course?
- *Has there been a cultural change in medical education or are these programs idiosyncratic*? Participants commented that they think there is a real change underway in medical education. One real difference is that parents have "come out" as vocal and active participants demanding more family-centered care. Things are changing;
- The Dyson Initiative is funding 10 pediatric residency programs across the country to enhance their teaching of community-based care. These programs are training physicians in new settings with an increased orientation toward care in the home and community, rather than the traditional focus on delivering care in the hospital and clinic.
- *What role, if any, could the Consortium play in supporting these new directions in Medical Education?* Members are interested in exploring how the Consortium can enhance or facilitate sharing of best practices in medical education across programs and medical centers. This question provided the segue to the next topic on the agenda.

III. Medical Education Survey: * *Whit Garberson, MSW, Dept. of Public Health, Medical Home Steering Committee Chair*

Whit described the effort underway to document medical education efforts in Massachusetts that focus on CSHCN and/or medical home. A web-based survey has been drafted to send to all medical schools and pediatric residency programs in the state. Various training activities will be included in the survey, e.g. community-based efforts, home visits, luncheon seminars such as those described by today's panel, as well as more formalized or traditional parts of the curriculum. Target recipients for the survey are people who are active in these training programs and those involved in establishing the curriculum. On completion of the survey, a brief report will be prepared on the findings with the hope that interest can be generated to foster sharing across programs as well as new ideas.

Comments/Discussion: There was enthusiastic support for the goals of the survey and lively discussion about specifics. Comments included:

- Be clear that mental health needs are included in the definition of CSHCN.
- Can we expand the survey to include young adults (and not just pediatric population)? Discussion suggested staying within the Consortium's mission to focus on systems of care for children
- Should this be an interview instead of a written survey, or a combination of both methods in order to maximize input and participation of future partners? Personal contacts will help in establishing connections and securing participation.
- E-mail survey may be forbidding for some and may cut down response levels.
- Consider adding surveys of specialty care fellowship training programs in the future.
- Consider surveying joint programs in medicine and pediatrics (they *should be* doing something on transition), psychiatry residencies; and family practice residencies.
- As a preliminary/preparation step, look at medical school course descriptions to see if courses include specific content on CSHCN.
- Include broad group of respondents in each setting to identify fullest range of activities. For example, DPH Care Coordinators invite residents from BayState Medical Center to do home visits with them. How do we ensure identifying these types of activities?
- Identify medical school students to participate in interviews with appropriate people at the school/residency programs.
- Plan to bring findings back to the full Consortium.
- As follow-up to the survey, Consortium should hold an invitational meeting for all of the training programs that participate. Collect ideas about best practices.
- Consider research activities that can identify what kinds of training/experiences lead to what kinds of outcomes,
- Include Dyson Initiative based at Children's Hospital to collect best practices across those 10 programs outside of Massachusetts.

Action: Plan to conduct Medical Education Survey approved by the Consortium. Members are invited to provide specific feedback on the content of the survey to Whit Garberson, chair of the Medical Home Steering Committee, whit.garberson@state.ma.us 617-624-5966.

Updates:

- The February Consortium meeting will focus on Medical Decision-Making and communication between primary care and specialty care providers.
- Lucy Meadows from the Children's Division of **Health Care for All** provided information about the Children's Health Care Campaign, kicking off in December with the goal of rolling back premiums for the Children's Medical Security Plan (CMSP) and restoring CMSP funding so that there will be no waiting list (current waiting list is 6,000 children). Lucy encouraged Consortium members to get involved in this campaign. For more information, contact Lucy at meadows@hcfama.org 617-275-2932

Next Meeting: Thursday, February 5, 2004