



Meeting Summary

“Promoting Partnerships through Shared Information” October 7, 2004

Meeting: 1:00-3:00 p.m. -- Informal Networking: 3:00-4:00 p.m.
Location: Blue Cross Foundation, Landmark Center

I. Survey on Meeting Space and Time

Susan Epstein, Chair

Handout: [Survey on Meeting Space and Time](#)

Approximately 80 participants were expected at this meeting, reflecting significant growth for the Consortium. To welcome everyone who wanted to attend, it was necessary to arrange our seats in rows rather than our usual small groups. The Steering Committee is considering all the logistical issues that come with growth. As part of this effort, attendees were asked to fill out and return a brief survey indicating their preferences on the time and location of Consortium meetings.

II. Year in Review/Year in Preview

Susan Epstein, Chair

Handout: [Year in Review 2003-2004, Year in Preview 2004-2005](#)

Susan reviewed the Consortium’s major accomplishments and goals. Her presentation included an update on membership (currently 175+), an overview of financial support, and a reminder that an adaptable PowerPoint presentation about the Consortium is available for members’ use. She reviewed the ways in which the Consortium’s mission and work group activities are tied to the national 2010 goals for CSHCN, and reported that the work groups have completed background briefs detailing where Massachusetts stands on three of those goals to date. Work group interim reports are available online at www.neserve.org. Sustainability is an ongoing issue, especially as we near the end of our MCHB grant in 2006.

Agenda topics for the coming year will include: CSHCN and the Workplace, Strengthening the Education-Health Connection, and Addressing Specialized Needs through the Medical Home.

III. The Family Partners Initiative

Dalene Basden and **Suzanne Gottlieb**, Family Participation Work Group (FPWG) Co-Chairs

The FPWG is charged with creating meaningful parent-professional partnerships at 3-4 pilot sites. After the Consortium’s June 3 meeting and resource fair (“Family and Professional Partnerships”), 16 organizations expressed interest. Site visits to 8 sites meeting initial criteria are scheduled, and the final sites will be announced in the next 4-6 weeks.

Most of the organizations are interested in help coordinating family advisory groups. Others are looking to the Consortium to provide family partners to review materials or train staff. The organizations are quite varied, including primary care practices, hospitals, and universities. The FPWG plans to ensure diversity in the types of organizations chosen, and the kinds of partnerships and projects the partners will be involved with. By the end of the fiscal year, the FPWG will report back to the Consortium on its results,

including a statement of benefits, challenges, and ways to address challenges in parent-professional partnerships. The group will also offer a set of next steps for the Consortium's consideration.

Suzanne and Dalene thanked everyone for their support at the June 3 meeting and resource fair, and gave special kudos to Linda Freeman for her hard work with the group.

IV. Sharing Information from the National CSHCN Survey

Nora Wells, Family Voices and **Deborah Allen**, BU School of Public Health

Handouts: [Using the CSHCN Data for Fun and Profit](#), [Data Resource Center for CYSHCN fliers](#)

Nora and Debby introduced the new website of the Data Resource Center for CYSHCN, at <http://www.cshcndata.org/>. The site was produced by the Child and Adolescent Health Measurement Initiative (CAHMI) in partnership with Family Voices. A portal through which to access the data from the 2001 National Survey of CSHCN, it will expand to include the data from the National Child Health Survey and the 2006 National Survey of CSHCN.

Nora walked us through some of the site's features, and Debby presented ways the data might be used. The site offers an easy way to get national, regional or state data on any of 12 main topics. Findings on each of the 6 outcome measures/goals for 2010 are included, as is information from The CHART Book that summarizes the data, published by the HRSA. Data of interest can be saved in a "briefcase" or copied and pasted into your own documents. It's easy to contact CAHMI with questions or suggestions.

Debby demonstrated how the state profiles can be used to highlight key issues for needs assessment, training, and advocacy purposes. Her presentation noted how Massachusetts compares to the rest of the nation, and how those findings can create questions as well as answer them.

Debra Reid from the CAHMI staff will be in Boston in the coming weeks, and has offered to provide more extensive training in using this site. Consortium members interested in learning more about how to use the Data Resource Center can contact Debby Allen at dallen@bu.edu.

V. The Massachusetts Medicaid Policy Institute: Promoting Public Discussion and Understanding of the MassHealth Program

Robert Seifert, Director of Research & Policy, Massachusetts Medicaid Policy Institute (www.massmedicaid.org)

Handout: [Massachusetts Medicaid Policy Institute](#)

This presentation offered background on the Massachusetts Medicaid Policy Institute (MMPI) – a new, independent organization dedicated to public understanding and discussion of MassHealth, MA's Medicaid program – and discussion of two of its recent reports.

Understanding MassHealth Members with Disabilities (Report, June 2004)

This report was released to promote broader understanding of who MassHealth members are, what their needs are, and what the program provides.

Key findings include:

- MassHealth is a key health care safety net for children and adults with disabilities
- Consistent with national trends, enrollment and spending for MassHealth members with disabilities has been increasing
- Massachusetts enrollment levels are similar to levels in peer states
- Members with disabilities accounted for 53% of MassHealth expenditure growth in the last 4-5 years, and
- More than 70% of spending growth has come from rising health care costs, not enrollment growth.

New Medicare Prescription Drug Benefit: What's the potential impact on Medicaid? (Report, September 2004)

A new law stemming from the Medicare Modernization Act (MMA) goes into effect in January 2006. It will include a new prescription drug plan is known as "Part D." The Part D drug benefit will affect Medicare and Medicaid recipients, and those who receive both ("dual eligibles").

Key ways this will impact Medicare recipients:

- Enrollment in Part D will be voluntary, but dual eligibles must enroll or they will lose Medicaid coverage as of January 2006.
- The Doughnut Hole: Medicare will cover 75% of drug costs between \$250-\$2,250, and 95% of drug costs over \$5,100. This leaves a gap in the middle ("doughnut hole"); beneficiaries will pay 100% of drug costs between \$2,250-\$5,100 out of pocket.
- The Clawback: Part D is funded in part by states through a "phased-down state contribution," which means that any savings the state sees must be paid back to the federal government.
- Rebate Impact: Under Part D, the government will be less able to negotiate rebates with drug companies.
- The Woodwork Effect: When Medicare recipients begin applying for the new benefit, many will discover that they are eligible for Medicaid, so there will be increased costs associated with enrollment growth.
- For beneficiaries: less coverage, fewer available drugs.

Bob asked for input from Consortium members to take back to MMPI. Issues raised:

- Family members cited the need for user-friendly information on Medicaid policy. There is a great need to translate complex policy issues into lay language, to let families know who will be affected and how.
- Providers need to be able to understand the policy issues too, e.g. for writing letters of medical necessity.
- The Consortium might play a role in this, e.g. by providing lay reviewers for MMPI's materials.
- Several participants disputed MMPI's estimate on the number of Massachusetts children on both Medicare and Medicaid.
- Family members also cited the frustration in getting the services they are eligible for, because of either rising costs or red tape. This may be outside the purview of MMPI, but the Consortium might consider a role in disseminating information related to CSHCN and Medicaid through fact sheets, family organizations.

VI. New Web Design & Resources for the Consortium

Laurie Tellis, Communications Specialist, New England SERVE and **AnneMary Wood-Mann**, Sirango Design

New England SERVE will soon launch a redesigned website at <http://www.neserve.org/>; Laurie and AnneMary gave us a preview. The new design features a "website-within-a-website" for the Consortium, distinguishing it visually and architecturally from New England SERVE. The site is designed to be user-friendly for both newcomers and active Consortium members. Sections include Work Groups, Membership, and a Resource Center, which will house a wide variety of presentations, surveys, publications, and other materials by topic. Consortium meeting handouts will also be available on the site, and a Consortium calendar will detail upcoming events.

VII. Transition Task Force: Dissemination of Background Brief

Stephanie Porter, Co-chair, Transition Task Force

Handout: [Transition Issues for Youth with Special Health Care Needs in Massachusetts: Background Brief](#)

The Consortium's Transition Task Force has developed a background brief to assess Massachusetts's status regarding the sixth goal for 2010, that "all youth with SHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence." It offers a definition of transition along with background information and context for its findings.

The main recommendation made to the Consortium is to "focus its efforts to improve transition services by strengthening the capacity of existing care coordination services in this area. The Consortium should seek funding to develop and deliver a curriculum and training for care coordinators and case managers who are in contact with families across multiple systems of care." Stephanie thanked Linda Freeman for her work on the brief and Lester Kiehn from the Department of Education for his review. Suggestions on how to disseminate the brief should be directed to Linda Freeman, lfreeman@neserve.org.

VIII. Concert for the Consortium: December 4, 2004

Amy Weinstock and **Megan Lane**, Event Planning Committee

Handout: *Longwood Symphony Orchestra Concert for the Consortium Flyer & Order Form*

The Longwood Symphony Orchestra is a volunteer group of musicians, drawn primarily from medical and health professionals. Their concerts benefit healthcare-related non-profit organizations, and they have chosen the Consortium and New England SERVE to be the beneficiary of their December, 2004 concert. This event will not only raise funds for the Consortium but also be a way to celebrate its work. We are pleased to announce that corporate support has already reached \$13,000.

Invitations will be mailed shortly. Consortium members are urged to submit names and addresses of people to be added to the mailing list – not just classical music fans, but anyone with whom you'd like to share the work of the Consortium.

Consider buying a block of tickets, using the event for your organization's holiday celebration or corporate recognition, or giving tickets as holiday gifts.

IX. Other Updates

DPH Re-Organization: Massachusetts Department of Public Health programs for children with special health care needs (CSHCN) have been re-organized. The new director for all CSHCN programs is Ron Benham. The re-organization plan and an update from DPH will be presented at the December Consortium meeting.

Health Care for All: New legislative funding allowed the Children's Medical Security Plan (CMSP) to enroll 15,000 uninsured children from the waiting list. New proposed free care regulations limit where parties may go for primary care, mandating use of community health clinics if there is one within 5 miles.

Next Consortium Meeting:

Topic: "Employers, Health Plans and Families Caring for CSHCN: Where are the Opportunities for Connection?"

When: Thursday, December 9, 2004
1:00 p.m. - 3:00 p.m. (Informal networking 3:00 - 4:00 p.m.)

Where: Harvard Pilgrim Health Care
93 Worcester Street, Wellesley