



Massachusetts Consortium for Children with Special Health Care Needs



Focus of Work Group Activities 2005-2006

STEERING COMMITTEE

The 2005-2006 year will be an important one for the Consortium Steering Committee: it will welcome a new Consortium Director; shift leadership responsibility to new Steering Committee Co-Chairs; continue to define membership, leadership and governance structures; and develop strategies for creating financial stability for the Consortium.

WORK GROUPS

Care Coordination Work Group

The Care Coordination Work Group's ultimate goal is a coherent and comprehensive system of care coordination for Massachusetts children and youth with special health care needs. In the coming year the Work Group will focus on a) disseminating a concise statement of the definition and principles of care coordination, and b) meeting with key stakeholders – including private payers, legislators, and minority and immigrant community organizations – to discuss how a statewide system of care coordination would operate and be financed.

Family Participation Work Group

The Family Participation Work Group is charged with expanding the family voice in the Consortium and in health care policy and financing in the Commonwealth. In the coming year, the work group will have two major activities:

- Developing a “how-to” manual for establishing and supporting partnerships between family members and health-care organizations; and
- Initiating the new Family-Professional Partners Institute, a 3-year activity funded through the Massachusetts Department of Public Health.

Medical Coverage Decision-Making Work Group

Using case vignettes and in-depth interviews, the Medical Coverage Decision-Making Work Group has interviewed nine Massachusetts health plans about how they make decisions about medical necessity, experimental procedures, benefit exceptions and other coverage issues. This year, the group's goal is to incorporate their findings into educational materials that will help families and providers be most effective in advocating for services for children with special health care needs.

Medical Home Work Group

In collaboration with the Massachusetts Chapter of the American Academy of Pediatrics (MCAAP), and with support from the MA Department of Public Health, the Medical Home Work Group will focus on surveying pediatric residency programs in the state regarding aspects of their training that address family-centered care and CYSHCN. Additional efforts include: dissemination of a Medical Home brochure to all pediatricians in the state, continued collaboration with the Institute for Pediatric Palliative Care, and increased attention to unmet dental care needs.

Transition to Adulthood Work Group

The Transition to Adulthood Work Group will be re-invigorated this year in an advisory and planning capacity for the transition to adulthood activities funded through DPH's “Moving Forward Together” grant. The focus of the activities in the first year will be on developing and piloting a curriculum about transition. This curriculum will be presented to care coordinators working in different settings, who are in an ideal position to provide resource information and support to families of teens with special health care needs.

REGIONAL AFFILIATES

Central Massachusetts Partnership for Children & Youth with Special Health Care Needs (CMP)

The CMP will be reaching out to parents, providers, and community-based organizations in the region to increase its membership and set goals in line with its newly refined mission statement. It will also be disseminating its new publication, *Family Reflections: A Thought-Provoking Guide to Getting Help for Children & Youth with Special Needs*.

Outreach Event: Meet the CMP at an informal gathering on Wednesday, November 9, 6:30-8:00 PM at the Hoagland-Pincus Conference Center on the University of Massachusetts Medical School's Shrewsbury Campus. For more information or to RSVP: Barbara Donati, 508-792-7880 or Martin Young, 508-856-3149.

Western Massachusetts Consortium for Children with Special Health Care Needs (WMC)

The WMC is launching WMC-Connect, a new electronic network for providers, families and others in the Western Massachusetts area who care for CYSHCN. In the coming year, it will tap this network to identify opportunities for addressing the region's most pressing needs to improve care.

Outreach Event: Join the WMC for an exploration of its evolving role in the region and an information session on public benefits for children with special health care needs, Thursday, October 27, Noon to 3:00 PM Chestnut 1 and 2, Baystate Medical Center in Springfield. For more information or to RSVP: Faith Piaggi, 877-353-4757.

CONTACTS

For more information about Consortium work groups and how you can participate, please visit the Consortium online at **www.neserve.org**, or contact:

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