

Massachusetts Consortium for Children with Special Health Care Needs



Thursday, April 3, 2003 - 1:00-3:30 p.m.
Shriners Hospital for Children
51 Blossom Street, Boston - 9th Floor Board Room

Summary Notes

**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 MA Consortium. You will then see the link to the Consortium Materials archived by date.*

I. CarePoints: Building Services for Families Seeking Palliative Care*

Paul Thayer (Assistant Professor of Child and Family Studies at Wheelock College, and Co-Director and Professional Coordinator of CarePoints)

Paul Thayer provided an introduction to CarePoints, a new organization that is focused on developing "parent-professional partnerships to enhance quality of life for children with complex and life-threatening conditions." The program emerged from discussions with parents and physicians regarding palliative and end-of-life care for children. Many of these conversations concluded that it was important for parents to tell their stories to professionals. The word "Points" in the name "CarePoints" is a reference to those identifiable times when a care-giver's response can make a critical difference to a family. One of the objectives of CarePoints is to train parents to teach professional caregivers by sharpening their telling of their personal stories in a way that clarifies meaning and generates more active responses from listeners. The organization is also working to assist professionals to identify "care points" and to focus attention on their impact on families at those critical points in time. The goal is for the CarePoints program to eventually be parent-led. Paul Thayer, Assistant Professor of Child and Family Studies at Wheelock College, is currently the Co-Director and Professional Coordinator.

The CarePoints 1st Annual Conference is scheduled to be held on May 2, 2003, 8:00 a.m.-4:00 p.m., at the Holiday Inn in Brookline, MA. For more information about the conference as well as a growing set of resources for families and providers, consult the website at www.carepoints.org, or call 617-521-2908.

II. Coordinated Family-Focused Care: A New Initiative of the Massachusetts Behavioral Health Partnership for Seriously Emotionally Disturbed Children*

Suzanne Fields (Manager, Systems of Care, MA Behavioral Health Partnership), Yvette Yatchmink, MD (Associate Medical Director, Division of Medical Assistance)

The MA Behavioral Health Partnership is launching a new initiative entitled Coordinated Family-Focused Care (CFFC) for seriously emotionally disturbed children. This new program is a result of a Purchaser's Institute sponsored by the Center for Health Care Strategies in November 2001 that brought multiple state agencies together to discuss mental health services for children in the Commonwealth. CFFC builds on the "wrap-around" model of care that has been successfully demonstrated by the Mental Health Services Program for Youth (MHSPY) and the Worcester Communities of Care. These programs view families as central decision-makers in developing and implementing a single, comprehensive Individual Care Plan (ICP).

CFFC, uses a blended funding model similar to how the MHSPY program is financed, using funds from the Dept. of Mental Health (DMH), Department of Social Services (DSS), Dept. of Youth Services (DYS), Department of Education (DOE), Division of Medical Assistance (DMA), and various local school departments to provide family directed services. Funding is very flexible and can be used to support non-traditional services according to family needs. Examples include: respite care to provide relief for family caregiver, community-based recreation services, transportation, etc. Length of enrollment in the program is expected to be 12 to 14 months, with no restriction on re-enrolling multiple times, if eligible.

Children or adolescents with serious emotional disturbance (SED) in compliance with the federal definition are eligible to participate in CFFC. Although children with dual diagnoses can be accepted, SED must be the primary diagnosis. Referrals are described as "open," so a community member, faith leader, parent, or government agency can refer a child to CFFC. Families enrolled in DMA's PCC plan are fully covered for these services. The CFFC program will eventually be operating in 10 communities. The first six communities, expected to serve a combined total of 130 children, are: Worcester, Somerville, Cambridge, Malden, Medford, and Everett. The cities of New Bedford, Brockton, Lawrence, and Springfield will be added in the second year, with 50 children expected to be served in each of those four communities. Total target population is projected as 330. Eligible children must be living in one of these ten communities.

The CFFC program offers a team approach that includes a Master's level clinical person who serves as a care manager and works with a family partner. Each team is expected to serve 10 families, with 5 teams anticipated in each community. These teams will provide 24 hour/7 days a week crisis response capability, advocacy and short-term respite care as needed. Yvette and Suzanne addressed the challenges of increasing communication between primary care physicians and mental health providers and the interest in the CFFC program in encouraging the Medical Home model. Consortium members noted that part of the current difficulty is the result of managed care policies that have isolated primary care providers from the mental health system in the recent past, and the continuing challenges faced by PCP's in obtaining information on mental health services and medications in order to improve coordination of care for their patients. New challenges are posed by HIPPA (Health Insurance Portability and Accountability Act).

For more information about the CFFC program contact Suzanne Fields, Manager - Systems of Care at the MA Behavioral Health Partnership - suzanne.fields@valueoptions.com, 617-350-1916.

III. Proposed Youth in Transition Survey

Sally Bachman, PhD (Assistant Professor, Health Policy Research; Co-Director, MSW/MPH Program, Boston University School of Social Work)

Sally Bachman described a new research project being planned by Boston University's Schools of Public Health, Medicine, and Sargent College in partnership with DPH, the Independent Living Centers, and parent groups across the state. These groups are working together to plan a longitudinal survey on youth with disabilities that will be focused on transition. The main impetus for the study is the lack of research from the point of view of youth themselves. The target age group of youth with disabilities is currently under consideration, ranging from 12-30 years of age. Focus groups will be used to test survey instruments. A preliminary theoretical framework has been developed, and was distributed to Consortium members for review. Individuals seeking more information on the proposed study or wishing to provide input on the Youth in Transition Survey are invited to contact: Sally Bachman - sbachman@bu.edu, or 617-353-1415.

IV. Update on Status of 2010 Goal #2: Medical Home

Various members of the Consortium provided information on medical home-related activities conducted in the last year as an update to the Medical Home background brief that was developed and adopted by the Consortium in April 2002.

▪ Family Questionnaire - DPH & Family Ties

Suzanne Gottlieb (Director of Family Initiatives, Division for Special Health Needs, DPH)

The Division for Special Health Needs at DPH distributed a questionnaire to families at the recent Federation for Children with Special Needs Annual Conference held on March 1, 2003. The questionnaire was developed by Family Ties and was designed to identify the extent of family knowledge and awareness of services offered through the Medical Home and to assess current experience of families with their child's primary care provider and their office staff. In addition, DPH and Family Ties are seeking to identify families who may be interested in

getting involved in advisory roles within DPH. The surveys were translated and available in three languages: Spanish, Portuguese, and English. This is the third year that DPH has used the Federation conference to collect survey information from families, with the largest response to date. Two hundred (200) surveys were completed, including 50 new parents responding with an interest in serving in an advisory capacity to DPH. For a brief summary of the results see the attachment.

- **Medical Home Network Project – New England SERVE ***

Bev Nazarian, MD (Medical Consultant, New England SERVE and Department of Pediatrics, UMass Memorial)

The Medical Home Network Project (MHNP) is a pilot program supported by MDPH through a contract with New England SERVE. This project is designed to increase capacity of community-based primary care physicians to care for CSHCN. The MHNP uses a planned curriculum and discussion sessions to encourage physicians to begin a set of quality activities through small changes in office practices that reflect components of the Medical Home model. The project is also designed to strengthen connections between physician colleagues at the community level and among physicians, community resources and family leaders. The Medical Home Network Project is establishing small discussion groups in four of the six DPH regions in the state. These discussion groups (target size 10-15 participants; 75% MDs, 25% parents and community resource specialists) meet once a month for three two-hour sessions that offer a structured curriculum and case-based discussions. The sessions are co-led by a physician and a parent. The project has been piloted in the central region (Worcester), and will be replicated in three additional sites (Boston, Salem, Springfield) over the next 12 months. The sessions offer physician CME credits through UMass Department of Pediatrics, including two hours of risk-management credit. Participants receive a resource packet with information on defining medical home, resource tools for identifying CSHCN, Massachusetts community resources, national resources, copies of the Medical Home Index and other tools that support family-centered care and building medical home partnerships with families. For additional information contact Bev Nazarian - nazariab@ummhc.org, or 508-856-4054, and visit the New England SERVE website link at <http://www.neserve.org/projects/Mass%20Medical%20Home%20Network%20Project.htm>.

- **Care Coordination Project: Medical Home – DPH***

Whit Garberson, MSW (Director, Family and Community Support, Division for Special Health Needs, DPH)

The goals of the DPH Care Coordination Project include improving how Medical Home works for families as well as providers, and bringing family concerns to the fore – “families do not get what they need if doctors do not know what families need.” The former Case Management model operated by DPH placed case management staff in DPH regional offices with limited numbers of families being served. The new model is placing increasing numbers of care coordinators in primary care settings, reaching out to a broader audience, and building alliances with primary care providers. In the first six months of 2002, DPH served 733 families; in a comparable time period in 2003, 1,154 families were served using the new model. For additional information, see the attached presentation or contact Whit Garberson - whit.garberson@state.ma.us, 617-624-5966.

- **Physician Endorsement of Medical Home Model**

Jay Broadhurst, MD, MHA (Assistant Professor, Dept. of Family Medicine and Community Health, UMass Medical School)

Two leading physician organizations in the state have endorsed CSHCN receiving care within the Medical Home model, the MA Chapter of the American Academy of Pediatrics and the MA Association of Family Physicians. These endorsements are critical supports for promoting an overall endorsement by the Mass Medical Society. In addition, they set the stage for being able to use these physician leadership organizations as vehicles for future dissemination of information to their members.

- **Massachusetts Society or the Prevention of Cruelty to Children (MSPCC): Medical Home Initiative**

Randi Walsh (GoodStart Boston Region Director, MSPCC)

MSPCC is working on building a capacity to help physicians provide Medical Homes to CSHCN. This work is supported with a Healthy Tomorrows grant in collaboration with Dr. Rich Antonelli. MSPCC is currently collaborating with two pediatricians' offices and one family care practice in central Massachusetts. A Care Coordinator works out of each medical office three hours per week to increase visibility and to answer questions.

Currently, services are provided to 15 families with a variety of medical, mental health and social needs. The care coordinator is also participating in the Medical Home Network Project, and is in the process of being trained as an educational advocate. The MSPCC Worcester regional office is also serving as a “service learning” rotation site for UMASS Medical School residents to learn about medical home. The project is up and running in Worcester, and is expected to expand to the Holyoke Community Health Center. MSPCC is attempting to demonstrate how other community-based social services agencies can support implementation of the Medical Home model. For more information contact Karen Penta at MSPCC - 508-767-3038 or kpenta@mspcc.org.

- **AAP “Every Child Deserves A Medical Home” Training Program, Shriners Hospital, Springfield, MA, November 2003**

A second presentation of the AAP Medical Home training program is planned for Massachusetts (the first was held in November 2001 in Boston), and is scheduled to be held in Springfield, Massachusetts in November 2003. Dr. Matt Sadof is working to pull together the planning committee and will be chairing this effort. For more information contact Amy Brin at the AAP - abrin@aap.org or Mat Sadof - Matthew.Sadof@bhs.org.

V. [Employee Benefits Study for CSHCH*](#)

James Perrin, MD (Director, Center for Child & Adolescent Health Policy, MassGeneral Hospital for Children)

Supported through a cooperative agreement between the federal Maternal & Child Health Bureau and the Center for Child & Adolescent Health Policy, this study is designed to explore the arena of employer-based benefits and how employers may be able to assist families caring for CSHCN. The study is focused on understanding how employers view employees caring for children with chronic health conditions, and how they may understand the needs of this population. The study also seeks to identify opportunities where existing work-life benefits and leave policies may be able to support families to be more effective in the workplace and as caregivers. The first phase of the project, which included a set of key informant interviews, has been completed; the second phase of the study involving site visits to 43 companies in four cities across the country (Boston, Miami, Seattle & Cleveland) is almost complete. The project is working to assist the Maternal and Child Health Bureau in building connections with a broad range of both public and private sector employers to explore future partnership opportunities. Initial interview findings demonstrate some awareness of CSHCN among Benefits Managers, Work-Life Specialists, and Personnel staff. Experience is more typically with severe medical conditions, ADHD or serious mental health needs – few employers, if any, were familiar with the needs of children with more moderate needs or multiple-diagnoses. For more information on this project contact Chris Fluet - cfluet@partners.org, 617-724-3392.

VI. Announcements

- April 11, 2003 - 10:00-11:30 a.m. - Next Care Coordination Work Group meeting
- April 25, 2003 - 9:00-11:30 a.m. - Next Transition Work Group meeting
- June 5, 2003 - 1:00-3:30 p.m. - Next Consortium meeting. Please note the meeting time has been extended to 2½ hours to accommodate end of year reports.