Massachusetts Consortium for Children with Special Health Care Needs

New England SERVE

Meeting Summary
October 2, 2003 - 1:00-3:00 p.m.
Harvard Pilgrim Health Care –
Gateway Center 93 Worcester Street
Wellesley, MA

(*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)

I. National CSHCN Survey

Debby Allen, BU School of Public Health
Nancy Wilber, Director Of Applied Statistics, Evaluation & Technical Services, MDPH

A. Introduction to the Survey

Debby Allen introduced this presentation providing the history and context of the National Survey on CSHCN, noting that the data were collected through the National Center for Health Statistics between 2000-2002. The Survey was designed to estimate the number of children with special health care needs in the nation and to provide both national and state baseline data on achieving the Healthy People 2010 goal of building statewide systems of care for CSHCN. As the core of the MA Consortium's mission is a commitment to the national 2010 goals for CHSCHN, the survey data can provide useful information to the Consortium as it defines its own agenda and specific activities for the work groups that are tied to the 2010 performance measures.

Debby emphasized the need to understand the limitations of the data. While the estimate of numbers of CSHCN is relatively straightforward, the survey results on insurance status do reflect economic conditions including employment and related health insurance benefits at the time the data were collected. Subjectivity and cultural variation including expectations about services will also exist from state to state and from parent to parent. Consortium members were cautioned to think of the survey results as baseline data for Massachusetts, but to avoid using these data as a state report card on the system of care or to compare one state to another.

The survey applies the CSHCN screener questions developed by the Foundation for Accountability (FACCT) to identify CSHCN in the population and to operationalize the non-diagnostic, consequence-based definition developed by the Maternal & Child Health Bureau in 1998. This definition of CSHCN includes children with a wide range of conditions and degrees of severity of those conditions, including children with chronic physical, developmental, behavioral, or emotional conditions expected to last a year or more.

The following is a listing of the six 2010 performance measures that comprise the overall 2010 goal of developing systems of care for CSHCN. Each of these

measures is addressed by multiple indicators in the survey, except for #3- early & continuous screening,

1. All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
2. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services to make necessary transitions to all aspects of adult life, including adult health care, work, and independence.

B. Presentation of Preliminary Massachusetts Data

Nancy Wilber and Penny Liu presented preliminary Massachusetts data. These slides have not yet passed through the formal internal review process required before state information is released, so a handout of the slides could not be provided. Once the data have been reviewed and released, they will be posted on the CDC web site and the PowerPoint slides will be available on the Consortium web page within the New England SERVE website. Until then, those in attendance were asked not to cite or distribute the specific Massachusetts information that was shared.

There were 6,411 children in the Commonwealth of Massachusetts screened through the national survey effort; 761(14.67%) were identified as having a special health care need within 744 household interviews conducted (parents were interviewed about 744 of these CSHCN). Data were weighted to compensate for the difficulty getting certain types of respondents, and the overrepresentation of other respondents. In determining the rate of which a particular 2010 performance measure has been met, a respondent would have to answer Yes to a number of sub-questions. Estimates on each of the performance measures (except Screening) have been calculated for Massachusetts. However the estimate on the adequacy of transition services for youth with special health care needs are considered unstable due to insufficient numbers of respondents answering the questions related to transition. The data summarized by Nancy and Penny showed national results, MA results and aggregated New England results.

Medical Home: The data relevant to assessing the extent of medical home availability to CSHCN is the most complicated with five measures comprising the assessment. Those questions include:

1) Child has usual source of care (USC) other than a hospital emergency department for routine care and sick care.
2) Child has a personal doctor or nurse (not primary vs. specialist, but routine vs. sick)
3) Child has no problem with referrals when specialist and referrals are needed
4) Child receives effective care coordination when needed
5) Child receives family-centered care

Prevalence: In general, the preliminary data shows that MA has a higher percentage of children with special health care needs as compared to the nation, thus increasing the need or use for prescribed medicines, and medical, mental, health and educational services may be higher. CSHCN prevalence is in the 13-17 year-old age group compared to other age groups in both Massachusetts and the U.S., but the prevalence is higher in MA than the U.S.

C. Comments and Discussion

Discussion centered on some of the exciting ways that these data can be used within the Consortium as well as by individual members. It is now possible to estimate the numbers of CSHCN for planning and outreach purposes; data can be used to support advocacy efforts; and components of the medical home have now been operationalized for the first time. It was noted that the operational definition of medical home used in the survey differs from the definition used by the AAP. The AAP sees the whole practice as part of the system of medical home, whereas the items used to assess medical home in the national survey rely on the doctor's behavior as the primary indicator, a more simplistic approach. Opportunities for additional analyses were also noted: the survey contains a number of questions about the role families play in coordinating care, and the impact of those responsibilities—neither of these issues have been comprehensively assessed to date within Massachusetts.

Susan Epstein encouraged the Consortium's work groups to review these data to inform priority setting and initiatives of the Consortium. Members can contact DPH for access to the data and to discuss possible additional analyses. Nancy Wilber noted that as DPH prepares its required needs assessment for the MCHB block grant, it would appreciate hearing from Consortium members with questions about the data and its uses. The MA data is also publicly available to researchers through the CDC website: http://www.cdc.gov/nchs/slaits/htm.

Whit Garberson, chair of the Medical Home Steering Committee discussed how health plans have used the CSHCN estimates from this survey to help determine how many copies of a newly revised Resource Guide for Families will be printed and distributed.

For more information on the CSHCN survey, including a copy of the entire questionnaire, please visit the Centers for Disease Control web site at http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm

II. Family Participation Work Group Update

A. Survey Results* *Audrey Shelto, Consultant*

Audrey Shelto summarized the results of the Family Participation Survey conducted in June-July 2003. (see Family Participation Survey*) This effort included collecting complete survey information, primarily through telephone interviews, from Consortium members representing 20 different organizations. An additional 22 email surveys (abbreviated format) were collected from Consortium members. The goals of the survey were:

1) To identify ways in which the Consortium can support member organizations to increase their own capacities to build meaningful partnerships with families
2) To collect information on what family involvement has meant for the Consortium
3) To assess interest in creative ways to increase connections between family and other members of the Consortium.

Of 20 organizations completing the full survey, 13 (65%) report that family involvement is already part of their organization's program and policy efforts and a natural extension of their mission. The remaining 7 (35%) organizations interviewed (who do not currently involve family members) report that more information describing the benefits of involvement and direct assistance with practical strategies for recruiting and engaging family members would assist these organizations to move in this direction. The survey results strongly confirm that the Consortium is viewed as a model for supporting effective parent and professional partnerships, and that the work of the Consortium demonstrates the value of family participation.

Audrey offered four recommendations to the Consortium:
1) Create and disseminate documentation of the benefits of family participation
2) Create opportunities for peer sharing among Consortium members at Consortium meetings.
3) Use Consortium meetings as an opportunity to increase awareness between professional organizations and family organizations re: activities of each and opportunities for working together.
4) Work with Consortium members to develop orientation/training sessions for family members interested in learning more about policy and financing issues related to CSHCN.

Discussion:

Participants emphasized the need to reflect cultural, linguistic, and racial diversity in any effort to increase family participation within the Consortium. In addition, the Consortium was encouraged to involve young persons with SHCN in addition to the parent population. Suzanne Gottlieb, Co-Chair of the Family Participation Work Group commented on how gratifying the survey results were in terms of the perceived value of family participation within the Consortium to date.

B. Documentation and Research Proposal * Lois Wainstock, Associate Director, Tufts University Center for Children (TUCC)

Lois briefly presented the Family Participation Work Group's proposal to document the impact of family participation on health policy and programs. The plan is to invite students and fellows from various university-based training programs to participate. Research projects seeking to document the impact of family involvement and advocacy on systems of health care for children would be encouraged. The goal is to develop a set of materials that could answer the question: *Why should families <u>and</u> health care organizations invest in building partnerships which involve families in policy and programs*? For further information on the research proposal, please contact Linda Freeman at New England SERVE.

C. Policy Recommendation: Stipends to Support Family Participation*
Linda Freeman (New England SERVE)

The Family Participation Work Group has recommended a policy statement on supporting families to participate in the MA Consortium. The statement commits the Consortium to seek the resources, to the best of its ability, needed to offer an hourly stipend to family members not otherwise compensated for their time. The Steering Committee of the MA Consortium officially endorsed this policy on September 10th. For the entire statement, please consult the New England SERVE web site.

Linda also summarized other recent decisions made by the FPWG in response to the two sets of survey findings conducted in the last six months. These include:

a) Developing orientation activities and materials for both family and non-family members
b) Educating members about successful "best practices" in building partnerships between families and health care organizations

III. Announcements & Updates

- Mika Cheng from Health Care for All provided an update on proposed changes in MassHealth, and the new campaign for children's health care to be launched by HCFA on October 7th. The newly formed MassHealth Family Coordinating Committee is seeking family members who receive MassHealth.
- Nora Wells from Family Voices announced the, 3rd Annual Joining Voices Conference to support parent leaders in advocating for CSHCN to be held on October 16th in Framingham, MA. For more information see the Mass Family Voices website at http://www.massfamilyvoices.org
- Cindy Thomas, Institute for Community Inclusion, announced the one year Gopen fellowship designed for family members or individuals with disabilities. Deadline for applications is October 17th. Information available at the ICI website: http://www.communityinclusion.org
- Gail Havelick, MA Department of Public Health invited members of the Consortium involved in the original drafting of the Health Care Financing background brief and others who are interested to reconvene as a watchdog group on the status of health insurance for CSHCN, uninsured and under-insured, in the Commonwealth. For more information contact Gail at: gail.havelick@state.ma.us
- Susan Epstein sadly reported the death on July 10, 2003 of long time parent leader and advocate Mary Ann Orlando. Mary Ann served as the Parent Coordinator of the MHSPY program and also participated in the Family Advisor Initiative project in 2002-2001 that conducted interviews with health plans across the state. A fund is being established through MHSPY, details to follow.

Next meeting: Thursday, December 4, 2003 – Feedback regarding the location of our meetings is welcome.