Massachusetts Consortium for Children with Special Health Care Needs

New England SERVE

Family Participation Work Group
Interim Report
December 2003

(Documents marked with an asterisk can be found on the MA Consortium page of the New England SERVE website, www.neserve.org)*

Introduction

Increasing family participation and family partnerships with health care organizations is seen as a critical strategy for improving the adequacy of health care financing for children with special health care needs (CSHCN) in Massachusetts. The Consortium's Work Group on Family Participation was established in October 2002 with the identification of 2 co-chairs, both parent leaders: Suzanne Gottlieb, Director of Family Initiatives for the state Department of Public Health and Dalene Basden, a regional Parent-Support Coordinator for Parent/ Professional Advocacy League (PAL) and Child & Adolescent System Services Program staff in Lynn, MA. This leadership team, reflecting a strong history of family participation in policy advising roles across both and medical and mental health systems, has put together a work group with excellent representation from the full Consortium, including family members, health plans, state agencies, and family leadership organizations. (see attached membership list)

The Family Participation Work Group is charged with:

- Understanding the current roles played by families within the Consortium as well as within health care organizations and state agencies that participate in the Consortium.
- Identifying opportunities for increasing and strengthening family participation in those settings.
- Identifying the training, mentoring and supports needed to increase family participation both within the Consortium and across partnership organizations.
- Developing a plan for recruiting, supporting and connecting families to the work of the Consortium and across partnership organizations.

A number of planning meetings have been held over the course of the year, 2003. Meetings of the full work group and subgroups to date include:

- March 17, 2003 — First meeting of full group (15 participants).
- May 28, 2003 — Conference call with full work group (13 participants)
- July 23, 2003 — Meeting of work group (7 participants)
- August 6, 2003 — Documentation Subgroup meeting (4 participants)
- September 8, 2003 — Documentation Subgroup meeting (4 participants)
- September 18, 2003 — Full work group meeting (8 participants)
- October 2, 2003 — Full work group meeting (9 participants)
- October 14, 2003 — Documentation Subgroup meeting (9 participants)
- November 21, 2003 — Documentation Subgroup meeting with additional input from members of New England SERVE's Senior Policy Council (10 participants)

Information Gathering Interviews

1. **Interviews with Consortium Family Members**: New England SERVE staff conducted in-depth telephone interviews with existing family members of the Consortium in October 2002. The purpose of these interviews was to assess family members' experiences in joining and participating in the Consortium. Even though these experienced family leaders described feeling intimidated by the larger context and expected formality of the group, all noted that the Consortium has an overarching culture that welcomes family members and values and respects family participation. Respondents expressed optimism regarding the Consortium's ability to extend the current level of family participation to increase the diversity and numbers of parents involved, as well as the range of opportunities and supports for family participation. Finally, the interviews yielded suggestions for further increasing and supporting family participation, including mentoring relationships, orientation sessions and increased networking opportunities with other family members.

2. **Interviews with Family Leadership Groups*:** A set of 16 telephone interviews was conducted with parent leaders from different family-organizations in Massachusetts with the assistance of an outside consultant. A diverse set of parents with respect to geography; group size, type of special need and type of family support provided were included. Interviews were designed to assess willingness to join a broad based group like the Consortium and to identify personal interest in the Consortium's planned efforts to develop family leadership roles in health policy and financing. Questions also addressed existing resources for training and mentoring families in leadership roles. Some of the key findings from this set of interviews include:
    - The Consortium, because of its culture and current position, could play a valuable role in coordinating efforts to develop family leadership in health policy and financing for a broad range of children with special health care needs.
    - Given the strength of existing family organizations in the state and the number of families they touch on a daily basis, it makes sense to work collaboratively with some other broad-based groups in recruiting, training, mentoring and supporting family members.
    - Before becoming engaged in "policy and financing activities", family members need a clear understanding of what is meant by these terms and why involvement in such initiatives is worthwhile. Given the multiple demands on parents' time and energy, parent leaders emphasized the need to focus their time and effort where they can have the most meaningful impact on the lives of their own and other children.

3. **Survey of Consortium Member Organizations/Agencies***: The final information gathering activity conducted over the summer of 2003 included in-depth telephone interviews conducted by an outside consultant with 20 members of the Consortium representing a range of member organizations, as well as an e-mail version of the interview sent to all others and completed by 22 additional Consortium members (representing a 30% response rate). The goals of the interviews and survey were to identify ways the Consortium can support member organizations to increase their own capacities to build meaningful partnerships with families; to collect information on what family involvement has meant for the Consortium to date and to assess interest in ways to increase connections between family and other members of the Consortium. Interview/survey results indicate that:
    - Two-thirds of the organizations interviewed currently involve family members with CSHCN, working with them in a wide variety of roles (e.g. advisors, focus groups, reviewers) and provide a wide range of supports (e.g. travel/childcare reimbursement; payment/stipends)
        - Those organizations that do not involve family members are not opposed to the idea; family participation has just not been a priority. They express a need for

information/evidence about the benefits of family involvement and technical assistance to achieve family participation.

- Those organizations involving family members cite a variety of benefits from this involvement including the ability to design and implement programs actually based on family needs and the expanded perspective they motivate.
- Challenges to involving family members in organizations include current budget crises, organizational cultures that resist focusing on one subset of the population, and the risk of compromising consumers as external "critics".
- Consortium members feel the family voice in the Consortium is strong and enhances all aspects of the Consortium. They also express that their experience in the Consortium has an impact on their work in their own organization --- increasing awareness of family issues, modeling effective parent/professional partnerships and motivating new program development.
- All organizations reported interest in new/expanded roles for families in their own organization and interest in a variety of ways to increase connections between family and other Consortium members (e.g. general orientation sessions, family stories linked to agenda items)

These information-gathering activities led to a set of **recommendations** for the Work Group:

- Create and disseminate documentation as to the benefits of family participation
- Create opportunities for peer-sharing among Consortium members at Consortium meetings (e.g. benefits of family participation; "how-to's")
- Use Consortium meetings as an opportunity to increase awareness among professional organizations about the work and interests of family organizations and among family organizations about the agendas and opportunities for involvement within professional organizations
- Work with Consortium members to develop orientation/training session(s) for family members interested in learning more about policy and financing issues related to CSHCN

Activities Emanating from Information-Gathering Interviews

In response to the findings and recommendations from the various needs assessment activities described above, the Family Participation Work Group has developed two "policy statements", institutionalized a stipend program for family members to participate in Consortium related activities, and undertaken specific new initiatives to address the need for orientation supports for new members and to begin gathering documentation of the impact of family participation on health care policies and organizations. These include the following:

- *Statement on Family Participation in Health Care Policy and Financing**: A policy statement was drafted by the Work Group, reviewed by the Consortium, the Steering Committee and adopted in June 2003 (see attached)
- *Supporting Families to Participate in the MA Consortium for Children with Special Health Care Needs**:* A policy for supporting families to participate in the Consortium when their involvement (expenses and time) are either not covered by their agency or they do not have a paid affiliation with an organization. This policy, developed by the Work Group, was endorsed by the Steering Committee and presented to the full Consortium in October 2003. (see attached)
- *Stipend Request Form*: A process for requesting and receiving stipends was developed for use by family members and will be available at every Consortium- related activity.
- *Documentation Subgroup*: A subgroup composed of those members from the larger Work Group interested in exploring the potential for studying and eventually researching the impact that family involvement and participation has on systems of health care for children with special health care needs, was established. Interest in this effort grew the information gathering interviews where family members and organizational members alike identified their need for evidence that family involvement has a concrete impact on health

care systems. A description of this effort entitled, *FAMILY PARTICIPATION WORK GROUP: PROPOSED RESEARCH ACTIVITIES** is posted to the Consortium page of the New England SERVE website.

  - Interest in this potentially large and multi-year effort is significant. As noted above in the list of meetings, a number of sessions have been devoted to this topic.
  - The group has solicited and received the enthusiastic response of a number of academic partners to help in carrying out the initiative.
  - Initial steps to collect what evidence may already exist about the impact of family participation will be underway in January 2004.

- *New Member Outreach & Orientation:* Responding to survey findings that membership-building activities would be helpful, the Work Group is piloting a set of outreach activities targeted to new and prospective Consortium members.
  - Phone Call Outreach: A total of 11 new members and potential members were reached by existing Consortium members in anticipation of the December Consortium meeting and provided information about the history, mission and culture of the Consortium as well as an opportunity to have questions answered in a one-to-one and informal way. The Phone Call Outreach seems to have been well worth the effort based on feedback from those who participated in the activity.
  - Plans are underway to redesign the MA Consortium web pages hosted through the New England SERVE website. This activity was initiated in November 2003 to provide an accessible way for new and prospective members to learn about the Consortium, explore the value of participation from different perspectives of participants, and obtain information that would encourage and ease future involvement.