

Meeting Summary February 5, 2004 -- 1:00 – 3:00 p.m. Location: Blue Cross Blue Shield Foundation

(*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 the button on left-hand menubar labeled MA Consortium, and then select Consortium Materials. On the archived materials page, you will see summary notes and attachments listed under specific meeting dates.)

I. Why Focus on Communication? *Kathy Ryan, Parent, Home First Program*

Communication was chosen as the theme of this meeting because it can be a key strategy for ensuring quality care for children with special health care needs. Kathy Ryan, a parent of a child with special health care needs, long-standing member of the Consortium and member of the Consortium Steering Committee, Family Participation and Care Coordination Work Groups, set the stage for the meeting by telling a personal story about her son's health care that demonstrated why communication is so important. She noted that effective communication is something that one learns how to do over time, and that her experiences have taught her to trust her feelings and to continue communicating with providers until she gets her point across.

II. When Primary Care Providers and Specialists Communicate: What Helps? What Gets in the Way? *Christopher Stille, MD, UMass Memorial Medical Center; Lisa Martin, J.D., Parent and Special Education Attorney; Ellis Neufeld, MD, Department of Hematology, Children's Hospital and Harvard Medical School, Dept. of Pediatrics*

Chris Stille, MD, Assistant Professor of Pediatrics at UMass Medical School, gave a presentation on "Generalist-Specialist Communication as Part of Coordination of Care."* Two of his areas of research interest include the improvement of generalist-subspecialist communication in the pediatric practice, and improving care for children with special health care needs in the office setting.

Chris presented a Chronic Care Model for Child Health in a Medical Home, which is based on Wagner's original work on chronic care in adults, adapted by Charlie Homer of the National Initiative for Children's Health Care Quality (NICHQ). This model illustrates the critical connections and relationships between community, the health system, patient and family and how functional and clinical outcomes are realized. He noted that as children have a greater number of conditions than adults, there is greater reliance on specialist co-management; however, there are fewer established guidelines. In addition, there is evidence that documents the importance of communication, and that little or ambiguous communication can be a barrier to effective care coordination.

A study conducted by Dr. Stille in 2000-2001 included focus groups and a survey of general and subspecialty pediatricians in the New England region. Those results were published in *Pediatrics*, December 2003. Those findings documented universal agreement about the large gap in communication between general pediatricians and subspecialists, as well as the lack of an effective communication system among all parties. PCPs saw communication as more problematic than specialists. And both groups responded that families were frequently the "primary source" of information. A second study published in *Ambulatory Pediatrics* in 2003 reported a preference for clear division of responsibilities, especially when care is more complex and more specialists are involved; that bi-directional communication was essential; and that email may be a promising resource for improving communication, but there are also some concerns. The next study will be an observational one, focusing on understanding the presence and content of communication and the relationship it has to patient and family satisfaction. Other future areas of study include: the parent role in communication and how it can be more defined, cost-effectiveness of coordination of care, and reimbursement issues related to coordination of care. To demonstrate ways that communication could be enhanced, Chris shared a sample form he and his colleagues created that is used for generalists and specialists to fax back and forth to one another. The final copy goes to the family of the child. Another method for improving communication is the presence of a care coordinator in the office who helps to fill in communication gaps. Consortium members are invited to contact Dr. Chris Stille directly with any follow-up comments or questions at: stillec@ummc.org or 508-856-5672.

Two discussants added comments from their different perspectives:

- Lisa Martin, a parent and member of the Consortium and Care Coordination Work Group highlighted the gaps and uncertainty of responsibility in ensuring communication from specialist to specialist. She commented that the presentation highlighted the need to keep her child's pediatrician in the communication loop more often, as she and her husband often self-refer and rarely see the PCP. They also do not know what information their pediatrician gets and when.
- Ellis Neufeld, MD, Associate Chief of the Division of Hematology at Children's Hospital, spoke from the perspective of a specialist. He explained the three main reasons why people see specialists: a one-time situation or episodic care, sharing of care with the generalist, and specialist-driven care. He also highlighted his experiences with the inaccuracy of communications with generalists in the past (i.e., specialty facility's information system is often not updated with correct generalist names, and the lack of a tracking system that can confirm whether or not families receive letters about 2nd and 3rd opinions, etc.). Dr. Neufeld supported the notion of having one person coordinate care for patients instead of many, and expressed the potential for automated medical records to address some of these communication gaps in the future.

Discussion:

- Suggestions were made about ways to improve communication, with a focus on using the Internet. Use of a secure web page that requires physicians to use a pass code for access to patients' information was encouraged, though barriers may include: high software costs, lag time to allow for a learning curve for those who are not technologically savvy, availability and accuracy of information posted, and whether or not computers are networked properly. Also, standardized software would be required, as different types of systems cannot interface with one another.
- Some participants noted that use of a computerized medical record may result in less face-to-face communication between people.
- Additional challenges that can hinder communication include the preference of some specialists not to share copies of referral and consultation forms with families to avoid high demand of questions in follow-up.
- In response to the question, *Is communication better in a Medical Home?*, members agreed that everyone assumes that communication is better in such a setting. Various groups are currently working to determine whether this can be documented in specific ways.

III. Supporting Improved Communication between Health Plans and their Members with CSHCN: New Initiatives in Massachusetts *Deborah Klein Walker, Ed.D, Abt. Associates, formerly of Mass. Dept. of Public Health; Dan Rome, MD, Alliance for Health Care Improvement and Medical Director, Tufts Health Plan; Rebecca Feinstein Winitzer, MS, MSW, Mass. Dept. of Public Health, Division for Special Health Needs; Nancy Turnbull, M.A, Harvard School of Public Health and Consultant, New England SERVE*

A. Alliance for Health Care Improvement

Debbie Walker introduced Dan Rome, MD, Medical Director for Tufts Health Plan and member of the board of the Alliance for Health Care Improvement (AHCi). Debbie noted that the collaboration demonstrated by the five non-profit health plans in the Alliance is highly unusual across the country. Dan shared information on the Alliance, informing Consortium members of the positive work health plans are doing for families and CSHCN in Massachusetts. (*Please see the document that was distributed which lists Alliance members and states the purpose of this organization's work at: http://www.neserve.org/projects/Mass_Consortium_for_CSHCN_Archived_Materials.htm.)

The Alliance is a consortium of senior medical directors from the state's five major health plans. Like the Consortium, the Alliance is looking at systems change in a collaborative manner working in partnership with key stakeholders. The Alliance participates in two specific work groups that are focusing health plan attention on CSHCN: the Identification and Screening Work Group, as well as a Work Group that is revising the Department of Public Health's Directions Manual, an information resource for families (see section B below). Various members of the Alliance are also part of the Consortium's Care Coordination, Family Participation and Medical Coverage Decision-Making Work Groups.

Next steps/challenges for the health plans in the Alliance include:

- Translating the criteria for identifying CSHCN into something that can become claims-based identification of the population (i.e., patient is given a set of diagnoses, seen by "x" clinician, and there is a method in place that highlights patterns showing that the child has special health care needs).

- Assessing the effectiveness of health plans for CSHCN, specifically the existing case management/care coordination models.
- Exploring other appropriate and sensible roles and opportunities for health plans to improve quality of care for this group of children.

Debbie noted that together, the five plans on the Alliance serve the majority of the population and therefore CSHCN in Massachusetts, covering 80% of the commercially insured market. She stressed the importance of working with health plans, as well as the fact that it would be beneficial to involve as many as possible in the work of the Consortium.

B. Mass. Department of Public Health Family Resource Manual - *Directions: Resources for Your Child's Care*

Rebecca Feinstein Winitzer, MS, MSW, is the Managing Editor of *Directions: Resources for Your Child's Care* for the Mass. Dept. of Public Health's Division of Special Health Needs. Revisions to the 1997 version of this resource manual for families are in the final stages, working in collaboration with the Alliance for Health Care Improvement.

The *Directions* manual will function as a tool for parents to help them organize their papers related to medical visits with their child's PCP, schools, specialists, etc. It will also provide a rich array of resource information as well as basic tips on how to navigate your child's health plan. The manual will be translated into Spanish. Physically, the guide will have some changes compared to its original design; the resource manual will be housed in a soft 3-ring binder, for ease of transport. It will include many pockets for items such as immunization cards, and a removable resource booklet with information. The Family TIES Resource Directory is considered a companion manual to *Directions* and will be included as a removable booklet. *Directions* will be available for download on the DPH web site in Summer 2004, free of charge to families and organizations. *Directions* will be printed in collaboration with health plan members of the Alliance for Health Care Improvement. For more information about the revised edition of *Directions*, please contact Rebecca Feinstein Winitzer, at 617-624-5970 or at rebecca.winitzer@state.ma.us.

C. Medical Coverage Decision-Making: How Does it Work?

Nancy Turnbull, MA, faculty member in the Health Policy Department at the Harvard School of Public Health, consultant to New England SERVE and President of the Mass Health Quality Partners, provided an update on the Medical Coverage Decision-Making Work Group (MCDMWG) of the Consortium. This work group is chaired by Jim Glauber, from Neighborhood Health Plan, and staffed by Nancy.

The goal of the MCDMWG is to clarify differences among various types of coverage decisions, to educate families and providers about how decisions are made, and to show the avenues for reconsideration and influence. For example, some of the questions addressed might be: Why does my child not qualify for coverage? Who are the decision makers? What are the avenues for appeal?

The MCDMWG is using a case-based approach as a more thorough way to get information from health plans. Several case vignettes will be used to find out the processes used by health plans for medical coverage decision-making, and what information is needed. Results of the interviews with health plans are expected to be presented to the Consortium in June. *Nancy's presentation can be viewed on the New England SERVE website under the Consortium archived materials for the 2/4/04 meeting.

Nancy provided a list of key questions that would be addressed for each vignette:

- Is the service a covered benefit?
- Is the child appropriate for the service?
- Is the benefit limited?
- Is the service medically necessary?
- What are the processes and criteria for getting an exception?
- Who are the key decision-makers at each step?
- What kinds of information do payers need and use to make coverage decisions?

Consortium members suggested that the following questions/observations be considered in addition to those presented above:

- How does the health plan determine medical necessity?
- When are purchasers the decision-makers rather than the health plan?
- Who provides the information that payers need to make coverage decisions?
- How transparent is the information to the parent?

D. Discussion

- Members discussed the challenges of helping members understand their benefits. Many health plans and employers will place the subscriber certificate online along with some policies regarding using benefits. It was noted that while some important information may be available online, many members need help understanding these policies and the more technical language. A Care Coordinator can be helpful in interpreting the policies and what services may or may not be covered. Questions posed were: What can the Consortium do to ensure that people have access to the information quickly in the decision-making process? Do people know the difference between HMO, PPO, and POS plans?
- Members raised the question as to whether self-insured employers will be included in the conversation about medical coverage decision-making. It was noted that while coverage is fairly similar, it can vary as a result of what the employer group wishes to pay for. (*Self-insured means that the employer is contracting with a health plan for administrative or advisory services, not to fund the care.*) It is not always immediately evident when purchasers (i.e. employers) may be the decision-makers, but Nancy noted that the Work Group would try to tease out the unique characteristics of the self-insured in the areas of benefits, appeals and differing state mandates.
- It was pointed out that determination of medical necessity is not consistent – that there are no hard and fast rules, which makes the process even more complicated.
- There was a great deal of enthusiasm expressed for *Directions*, the revised resource manual being developed by DPH in collaboration with the health plans. It will help to improve quality of care as well as save a PCP's time in getting information to families.
- There is some interest in the Consortium creating a work group to recommend quality indicators for CSHCN. The work group could influence what kinds of data/information health plans collect. The Care Coordination Work Group and Medical Home Steering Committee are beginning to address some of those issues.
- Participants generally agreed that the Internet may potentially help to overcome some of the challenges faced in enhancing communication and coordinated care for CSHCN. There is a large population of parents who do have access to computers and are regular users of the internet for health information. Beth Dworetzky, MA Family Voices agreed to post some of the questions posed by the panel on potential use of the internet on the MA Family Voices Listserv.

IV. Updates/Other Information

- Susan Epstein reminded Consortium members of the policy that has been adopted regarding meeting presentations. PowerPoint presentations are to be provided to New England SERVE ahead of time - or at the latest, on the day of the meeting. Given the fact that Consortium agendas are quite full, meeting presenters are asked to synthesize their remarks so that they provide clear, concise information to the group. They should focus on selected slides during their talk, with the full presentation provided as a handout and also posted following the meeting on the MA Consortium page of the New England SERVE website. Handouts provided to New England SERVE at least a day ahead of the meeting can be copied for distribution to the group. Otherwise, presenters are responsible for bringing multiple copies of their handouts.
- The next Consortium meeting will be held on **Thursday, April 8th**. Members were urged to take note of the date change as this meeting was originally scheduled for April 1st. The topic for the April 8th meeting will be Transition.
- Lucy Meadows from the Children's Division of Health Care for All provided information about the impact of the Governor's FY'05 Budget on children's health, and the Children's Health Access Coalition. She encouraged Consortium members to get involved in any way they can to ensure that children's health care programs are funded. For more information, contact Lucy at 617-275-2932 or meadows@hcfama.org.
- Debby Allen announced a part-time job opportunity at the Boston University School of Public Health's Department of Maternal and Child Health. The position is for a project coordinator for an advocacy and research project. The project coordinator will work in the Comprehensive Care Program, which provides care to children with a wide range of health and medical needs at Boston Medical Center. The job is time-limited (approximately 9 months), and the salary is approximately \$25/hour. For more details and information, please contact Deborah Allen, ScD at dallen@bu.edu, or send your resume and cover letter, specifying that you are interested in the Noonan Project Coordinator position, to: Deborah Allen, ScD, Department of Maternal and Child Health, 715 Albany St., Boston, MA 02118.
- **Once again, please note that the next Consortium meeting will be held on Thursday, April 8, 2004, at the Blue Cross Foundation.**