

Massachusetts Consortium for Children with Special Health Care Needs



Meeting Summary

February 6, 2003 -- 1:00-3:00 p.m.

Shriners Hospital for Children – 51 Blossom Street, Boston - 9th Floor Board Room

(* 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 Projects, Massachusetts Consortium for CSHCN. You will then see the link to the archived minutes.)

Note: Academy award winning documentary film, “King Gimp,” was shown prior to the Consortium meeting for members who wished to arrive early for this presentation. Following the film, Paul Tupper, of the Massachusetts Department of Public Health, led a discussion of the issues highlighted in this moving portrait. There will be a second opportunity to view the film prior to the next meeting if interest is expressed by members via response to an email that will be sent out.

I. Telling Our Stories*

In 2001, members of the Consortium conducted an informal survey of families of CSHCN, soliciting personal *Stories* of how families had benefited from public services. The survey, available in English and Spanish, elicited 30 responses. Pam Gossman volunteered to create a format for recording the responses, and has begun to type them in a standardized way. Members of the Consortium reviewed the format and offered suggestions that included use of the third person and additional identification of barriers. Pam agreed to continue to prepare the summaries. When completed, they will be sent to the families for verification and to request information on additional barriers. Consortium members are encouraged to identify opportunities to use these *Stories* in their own efforts to build and support service systems for CSHCN in the state. For further information on the *Stories*, contact New England SERVE.

II. Transition - Current Status on 2010, Goal #6

“All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.”

A. Overview – Linda Freeman

In November 2002, a committee of the Consortium, Co-chaired by Stephanie Porter and Linda Freeman, began meeting to prepare a Background Brief describing where we are vis-à-vis achieving the 2010 goal for Transition services for youth with special health care needs in our state. Linda Freeman briefly explained the definition of transition and introduced the panelists. She emphasized that transition has many broad definitions, but that in this context it is viewed as a “dynamic process” of supporting CSHCN in becoming adults. The committee is recommending that any work of the Consortium on transition services needs to encompass four central domains of Health, Education, Recreation and Employment. The Transition Committee invited eight experts to share their perspectives on current services and challenges for youth and families experiencing transition in Massachusetts. A handout defining key concepts for transition planning (*accommodations, adult safety net, autonomy, civil rights, natural supports, person-centered planning, self-determination, and universal design*) and a list of acronyms and abbreviations was distributed.*

B. *Parent and Youth Perspectives - Joanne Spencer, Terri McLaughlin, Janet Vohs, and Edward Martinez*

Three parents of children with special health care needs and one youth spoke about their personal experiences with transition, describing what went well and what could be improved. The following key issues were identified.

Challenges:

- Transition is a new and evolving idea, which has allowed for more resources and research to be dedicated to the issue.
- Challenge of shifting from a “family-focus” to an “adult focus,” especially when the adult faces significant issues of dependency on family.
- Critical absence of medical resources for primary care for these young adults. Medical facilities and physicians are not prepared for or may be unwilling to accept adults with special needs in their practice. Opportunity for care coordinators to help in finding a primary care physician, and assist in shifting from pediatric system to adult care system for youth with special health care needs.
- Once a youth with special needs turns 18 years of age, medical staff may decide to only communicate with the patient directly instead of the parent, whether the youth understands everything or not.

Parental Advice:

- Use care coordinators as much as possible.
- Work in partnership with doctors.
- Professionals need to “look at the child, her family, and their vision of what is important.”
- The school system should cooperate and participate in the process of transition.
- Teach your child with special needs how to fill out hospital forms before they reach age 18.
- Have a vision of what’s important.
- Build a safety net, natural supports and as much autonomy as possible for your child.

Youth Perspective:

Edward Martinez, a youth with special needs who graduated in May 2002, spoke briefly to the group. Edward described his own successful transition process using a notebook of visual images and references. He is currently employed, and spends time volunteering with preschool children. His plans include the goal of attending community college to study computers.

C. *Resource Experts: Health, Education, Recreation, Employment - Margaret Scheublin (Children’s Hospital), Cynthia Zafft (Institute for Community Inclusion), Maureen Gallagher (Partners for Youth with Disabilities), Cindy Thomas (Institute for Community Inclusion)*

The following is a summary of the presentations shared by resource experts.

Existing Resources to Support Transition:

- Locally, there are a small number of doctors who are working with adults with special needs (Franciscan Hospital, Boston Community Medical Group and Community Medical Alliance, a pre-paid HMO connected to Neighborhood Health Plan).
- Mentoring programs are powerful tools that can help young adults envision what their future can look like, and support their ability to believe in themselves.
- Group mentoring can support “disability pride.”
- There is increasing attention to the importance of natural supports in the community.
- Good models for workplace transition exist using inter-agency collaborations, demonstrating better outcomes for the youth in transition.
- Person-Centered Planning is a model that encourages and supports independence and autonomy (an example of an individual person-centered plan was distributed*).

Barriers to Transition:

- Pediatricians do not encourage their older patients to leave.
- Patients are reluctant to leave their pediatricians for a new primary care physician.
- Gaps in coordinating transition services.
- Funding for transition services and care coordination is not available.
- Many CSHCN develop limited connections to their community as children, so fewer resources are available at time of transition.
- 70% unemployment rate in persons with disabilities (nationwide).
- Over-concentration on medical special needs and disabilities; lack of attention to health and well-being, activity levels and energy.
- Public has a limited view of work as only an economic resource rather than in understanding impact of work and career on many facets of life, such as social skills, integration, and overall quality of life.
- Barriers to dental care for adults with special needs include physical barriers to facilities as well as financial barriers.
- Barriers to other specialty care such as gynecological services.

Expert Advice:

- Build and support inter-agency collaborations. System improvements will come from cross-agency knowledge and resources.
- Critical need for ongoing training in the workplace.
- As employers, support hiring of persons with disabilities or special health needs in your organizations. Model the opportunities and successes.
- Share success stories.
- Build and support mentoring programs - a critical resource for successful transition.
- Build and support social programs for younger children - as a child with special health care needs, it is important to have friends and connections in the community.
- As adults, ask to work with youth with special needs – your interest in their next steps will encourage them to strive.
- Schools need to modify their curriculum to suit youth with special health care needs.

III. Report of the Nominating Committee: Proposed Steering Committee Slate*

A slate for the new Steering Committee for the Massachusetts Consortium for Children with Special Health Care Needs was presented to Consortium members.* The Steering Committee will meet five times per year. Creation of the Steering Committee provides a smaller diverse leadership group for the Consortium, assuring oversight and administrative planning for Consortium activities. The Steering Committee is authorized to make decisions regarding the work of the Consortium in keeping with the mission. Members of the Consortium unanimously adopted the proposed slate.

IV. Care Coordination Workshop

Debby Allen, Chair of the Care Coordination Working Group, provided background information about the workshop planned for February 28th. Space is limited to 60 participants. Meeting space and refreshments have been donated by the Blue Cross Foundation. The invitational workshop is designed as the first step in a three-phase plan that aims to develop a shared operational definition of care coordination, a model for delivering this critical set of services for children and their families, and a strategy for financing enhanced care coordination across multiple payers. In the first year, the Care Coordination Working Group will develop a proposed operational definition. In the second year, the focus will shift to address the structure of care coordination, and in the third year, the goal will be to design a model that blends financing from multiple payers for this set of services.

V. Announcements

- A. The Massachusetts Federation for Children with Special Needs Annual Conference, “*Strong Families in a Changing World,*” will take place on Saturday, March 1st, 8:00 a.m. - 4:45 p.m., at the World Trade Center. Information is available on their web site, <http://www.fcsn.org/>. All conference information is offered to participants in three languages (English, Portuguese, and Spanish).
- B. The Massachusetts Department of Public Health will conduct its 4th annual Family Survey in conjunction with the Federation conference on March 1st. This year, the survey will focus on Medical Home. In the past, 150-200 survey responses have been received. Surveys have also been used to identify families interested in serving as advisors to DPH. A list of approximately 65 families interested in serving in this role has been developed. More families are expected to self-identify through this year’s survey. For more information contact Suzanne Gottlieb, Suzanne.Gottlieb@state.ma.us.
- C. GBARC and the DD Council are holding their annual legislative breakfast and reception on March 12th, 10:30 a.m., at the State House, 2nd floor.
- D. Debby Allen is initiating a discussion group working with Health Care for All to address the potential impact of state budget issues on CSHCN. For more information, please contact her at dallen@bu.edu.

In Attendance:

Deborah Allen, Dalila Balfour, Dalene Basden, Gina Brith, Jay Broadhurst, Nancy Chane, Mika Cheng, Meg Comeau, Susan Epstein, Linda Freeman, Marion Freedman-Gurspan, Maureen Gallagher, Whit Garberson, Pamela Gossman, Suzanne Gottlieb, Mary Lee Gupta, Alexa Halberg, Gail Havelick, Gwen Healey, Ruth Ikler, Karen Kuhlthau, Lisa Martin, Edward Martinez, Terri McLaughlin, Barbara McMullan, Lucy Meadows, Joanne Mitchell, Marguerite Philips, Stephanie Porter, Rich Robison, Nicole Roos, Donna Rubenoff, Kathy Ryan, Ana Sanchez, Judy Sargent, Margaret Scheublin, Lisa Sofis, Joanne Spencer, Cindy Thomas, Paul Tupper, Paula Vibbard, Janet Vohs, Marty Wyngaarden Krauss, Cynthia Zafft, Barry Zallen