

Background and Policy Recommendations: MA Consortium for Children with Special Health Care Needs

June 2009

Background

The *Massachusetts Consortium for Children with Special Health Care Needs* (Consortium) was established in 1999, with a mission of improving systems of care for children with special health care needs (CSHCN) and their families throughout the Commonwealth of Massachusetts.

At the time of its inception, many individuals and organizations were concerned with supporting CSHCN and their families and improving the system of care in the state. Much good work was accomplished but existing barriers such as a lack of organic opportunities to communicate and collaborate with one another prevented these dedicated stakeholders from achieving the critical mass necessary to maximize implementation of significant, sustainable systems change.

Recognizing this interdependence and the essential need for connections across multiple stakeholder groups, the creation of the Consortium emphasized the power of partnerships in addressing gaps and barriers in the state's service system and created a forum for information exchange and higher level strategic thinking. Consortium membership grew to more than 200 individuals including representation from 65 agencies or organizations serving CSHCN across the state. Members included physicians, other health care providers, families, state agency personnel, researchers, health plan leaders, educators and advocates. The Consortium endorsed a set of values to guide participation and established work groups that facilitated collaboration across public and private sectors, in order to conduct research and identify innovative policy solutions for system improvement.

While much was accomplished over an active ten year period, the Consortium closed in June 2009 due to an inability to secure sustainable funding for the organization. The legacy and work of the Consortium is documented on the website: www.massconsortium.org.

The leadership and staff of the Consortium have developed the following list of policy recommendations which synthesize the outcomes of recent research and project activities of the Consortium. It is our hope that the next generation of advocates will use these resources to further system improvement efforts for children with special health care needs and their families in Massachusetts.

Policy Recommendations

In order to build an integrated, high quality, cost-effective, family-centered, system of care for children with ongoing special health care needs and their families, stakeholders across the Commonwealth of Massachusetts must address the following critical gaps in the system of care:

1. Comprehensive Primary Care and Care Coordination through the Medical Home:
 - Promote adequate reimbursement for care planning, service coordination, extended visits for managing chronic conditions, and family support services through the medical home model
 - Develop criteria and a process for certification of pediatric medical home providers
 - Develop capacity to train and certify personnel to deliver family-centered care coordination through the medical home
 - Provide practice-based consultation and technical assistance to implement medical home practices.

Consortium Resource:

Care Coordination in Massachusetts: Findings and Recommendations of a Three-Year Study, June 2006

2. Health Care Financing Support for Families
 - Ensure state-based and national health care reform initiatives for the general population include planning for special needs populations, especially children with complex health care needs and youth in transition
 - Ensure access to necessary supplemental benefits including adequate financing for respite care, durable medical equipment, housing and vehicle adaptation, specialized child care, care coordination, family support and training, etc.

- Provide health benefits counseling and advocacy services that assist families in navigating public and private health care financing systems to maximize coverage and access to existing benefits.

Consortium Resource:

Making the Case for Coverage: Tips for Helping Children and Families Get the Benefits They Need from Their Health Plans: A Guide for Clinicians and Advocates, June 2007

Getting a Break: A Roadmap to Respite Care for Massachusetts Families of Children with Special Health Care Needs

Community-Based Systems of Care Work Group of the Massachusetts Consortium for Children with Special Health Care Needs in collaboration with the Massachusetts Family-to-Family Health Information Center, November 2008.

3. Pediatric Provider Readiness to Deliver Family-Centered, Community-Based Care for CSHCN
 - Enhance existing pediatric residency program curricula to include a stronger focus on the unique medical, developmental and psychological needs of CSHCN, medical home practice, family-centered care, transition to adult health care, and community based services
 - Increase opportunities for community-based learning for pediatric residents trained in Massachusetts
 - Increase communication skills training for medical students, post-graduate trainees and practicing senior physicians.

Consortium Resource:

Preparing for Practice: Addressing Special Health Care Needs in Pediatric Residency Programs, June 2008

4. Timely Access to Durable Medical Equipment and Repairs
 - Develop transparent and explicit procedures for communications among vendors, providers, payers, and families throughout the DME processing cycle

- Establish time limits on the processing of DME orders that minimize the negative impacts of not having prescribed DME on a child’s health and development
- Create incentives for DME vendors and providers to process DME requests and deliver DME in a timely manner
- Establish coverage criteria for DME benefits that reflect the variability in children’s growth and development at different stages of life and at different points in treatment and care for primary and secondary health conditions
- Provide counseling and advocacy services that assist families in navigating the DME system.

Consortium Resource:

Durable Medical Equipment: Challenges to Access for Children with Special Health Care Needs, June 2009

5. Support for Transition to Adulthood

- Increase community-based adult health care provider capacity to deliver appropriate primary care to young adults with special health care needs
- Strengthen the capacity of care coordinators, case managers, and other family support personnel in public and community-based agencies, hospitals, doctors’ offices, insurance plans, and schools to counsel and support youth and families during the transition into the adult service system
- Strengthen the capacity of school systems to respond to the transition needs of youth with special health care needs
- Provide counseling to families and youth on identifying and accessing transition resources and supports available across the system of care for youth with special health care needs.

Consortium Resource:

Make Things Happen: Transition Planning Resource Book, March 2007

6. Legislator and Policy Maker Awareness of Unmet Needs and Gaps in System of Care for CSHCN

- Convene annual meeting on “State-of-the State for CSHCN” to educate legislators and policy-makers on opportunities to improve the system of care

- Strengthen visibility and capacity of constituents such as providers, families and other advocates to participate in policy making discussions.

Consortium Resource:

The Implementation of Chapter 171

A report by the Community-Based Systems of Care Work Group of the Massachusetts Consortium for Children with Special Health Care Needs to the Massachusetts Family to Family Health Information Center, June 2008

Identifying Priorities for CYSCHN

Invitational meeting co-hosted with the Massachusetts Department of Public Health, December 16, 2008

7. Support for Family-Centered, User Friendly Community-Based Systems of Care
 - Promote and support family participation at all levels of policy making and program implementation relating to services and financing of care for children with special health care needs.

Consortium Resource:

Structure & Spark! Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs

The Family-Professional Partners Institute and the Massachusetts Consortium for Children with Special Health Care Needs, Programs of New England SERVE, June 2008

Additional resources that inform these policy issues and recommendations can be found in the Resource Center of the Consortium's website, www.massconsortium.org.