

# Massachusetts Consortium for Children with Special Health Care Needs



**June 3, 2004**

**1:00-3:00 p.m. - Meeting**

**3:00-4:30 p.m. – Resource Fair & Networking**

This event is co-sponsored by The Nathan & Toby Starr Center for Mental Retardation,  
Heller School for Social Policy & Management, Brandeis University

Location: Brandeis University, Usdan Student Center, 415 South Street, Waltham, Massachusetts

## AGENDA

1:00-1:05 p.m.	<b>Welcome &amp; Introductions</b>	<i>Susan Epstein, Chair</i>
1:05-1:10 p.m.	<b>Care Coordination Work Group Update</b>	<i>Deborah Allen Kathy Ryan</i>
Information	Report on Site Visits & Model Development	<i>Care Coordination Work Group</i>
1:10-1:25 p.m.	<b><u>Thinking about How &amp; When Systems Change: Role of Partnerships</u></b> (10 min.)	<i>Marji Erickson Warfield Heller School for Social Policy &amp; Management, Brandeis University; Family Participation Work Group</i>
Information	Discussion (5 min.)	
1:25-2:50 p.m.	<b>Promising Practices: Family-Professional Collaborations that Promote Improvement in Services for CSHCN</b> (50 min.)	<i>Dalene Basden, Parent/Professional Advocacy League (PAL); Co-chair, Family Participation Work Group</i>
Education	<ul style="list-style-type: none"> <li>• <a href="#"><u>Parents as Primary Care Policy Advisors: The Parent Advisory Group at Nashaway Pediatrics, Sterling, MA</u></a></li> <li>• <a href="#"><u>Parents as Reviewers of Written Materials: Harvard Pilgrim Health (HPHC) Care - ADHD Booklet for Families</u></a></li> <li>• <a href="#"><u>Parent-Physician Partnerships for Medical Education: The Massachusetts Medical Home Network Project</u></a></li> <li>• <a href="#"><u>Assessing &amp; Improving Systems of Care: Parent/Professional Advocacy League (PAL)</u></a></li> </ul>	<i>Catherine Polewarczyk, Parent Advisor Kathleen Cleary, MD, Nashaway Pediatrics</i>  <i>Linda Brenner, Manager of Clinical Programs, HPHC Gwen Healey, Parent Reviewer</i>  <i>Margaret Comeau, Coordinator, Family Initiatives Program, Children's Hospital Laurie Glader, MD, Children's Hospital</i>  <i>Lisa Lambert, Assistant Director, PAL Joan Mikula, Assistant Commissioner, Child &amp; Adolescent Services, MA Dept. of Mental Health</i>
Discussion (35 min.)		
2:50-3:00 p.m.	<b><u>Reflections of 30 years of Parent Leadership: Federation for Children with Special Needs</u></b>	<i>Rich Robison, Exec. Director, Federation for Children with Special Needs</i>
Information		
3:00-4:30 p.m.	<b>Showcasing Family Organizations: Partnership Possibilities</b>	<i>Suzanne Gottlieb, MA Dept. of Public Health; Co-chair, Family Participation Work Group</i>
Information	Please join us for an informal Resource Fair and networking opportunity, including refreshments. Meet representatives from 13 different family organizations. Learn about family led services and supports, and opportunities for new partnerships. Celebrate a productive year for the MA Consortium for CSHCN.	

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Resource Fair  
& Networking  
3:00-4:30 p.m.

Information

**Showcasing Family Organizations: Partnership Possibilities**

*Representative at Resource Fair*

[Autism Resource Center of Central MA](#)

Sue Loring

[CarePoints](#)

Mary Hanifin

[Early Intervention Parent Leadership Project](#)

Jocelyn Woog

[Family TIES](#)

Mary Castro Aten

[Federation for Children with Special Needs](#)

Sara Miranda

[Greater Boston ARC](#)

Tony Sirignano & Barbara August

[Haitian American Public Health Initiative](#)

Dr. Renald Raphael

[Kids with Tubes](#)

Irene Walborsky

[MA Down Syndrome Congress](#)

Suzanne Shea

[MA Families Organizing for Change](#)

Dianne Huggon

[MA Family Voices at the Federation for Children with Special Needs](#)

Sara Miranda

[Parent/Professional Advocacy League \(PAL\)](#)

Maureen Jerz

[Partners for Youth with Disabilities](#)

Susan Nicastro

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