



# THE *Power* OF PARTNERSHIP

*Sixteen Family-Professional Partnerships  
That Are Making a Difference for  
Children with Special Health Care Needs*



**The Family-Professional Partners Institute and the  
Massachusetts Consortium for Children with Special Health Care Needs**

*Programs of New England SERVE*

June 2008

The Family-Professional Partners Institute has been supported by:

The Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, under grant #H93MC00075; and

The Massachusetts Department of Public Health, Moving Forward Together Project, from the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services, under grant #D70MC04497.





# THE *Power* OF PARTNERSHIP

*Sixteen Family-Professional Partnerships  
That Are Making a Difference for  
Children with Special Health Care Needs*

## **What is Family-Professional Partnership?**

Families caring for children with special health care needs have a wealth of experience to share. They are frequent users of health care services, and they have valuable insights into how service systems work and how they can work better.

Many medical practices, health plans and other organizations want the benefits of working with these experienced consumers. When parents and other family members of children with special health care needs work together with organizations to improve the way services are designed, financed and delivered, that's a special kind of partnership—a family-professional partnership.

## **What is the Power of Partnership?**

- To add value by adding a family perspective
- To make a meaningful difference in only a few hours a week
- To create a ripple effect within organizations
- To develop new family leaders

## **Who are children with special health care needs?**

Children with special health care needs (CSHCN) are those from infancy to young adulthood who have one or more ongoing medical, behavioral, or developmental conditions. Rather than categorize children by diagnosis, parents and child health experts use the term to acknowledge what children with cerebral palsy, depression, sickle cell anemia, autism, ADHD and many other conditions share: the need for a comprehensive system of health care that maximizes the well-being of each child.

## **What kind of organizations work with Family Partners?**

The Institute has helped build partnerships at clinical practices, health plans, academic and research institutions, and community-based organizations. These “Organizational Partners” are large and small, public and private, well-funded and volunteer-staffed. They all want to partner with families.

## **What do Family Partners do?**

Family Partners encourage system improvement by sharing their experiences and expertise with organizations. Through the Institute, they take on many roles: they are clinical practice advisors, research advisors, outreach coordinators, program developers, faculty members, publications reviewers, and training and curriculum specialists.



## **What is the Institute's role?**

The Family-Professional Partners Institute is a partnership broker. We work with organizations to create new roles for family members, who help shape programs, influence policy, and impact the care that children and families receive. We:

- Work with organizations from across the system of care, and help them turn the desire to work with families into concrete plans.
- Help recruit uniquely qualified Family Partners, and then provide those Family Partners with training and mentoring support.
- Guide the implementation of short-term, structured partnerships, providing administration, guidance and technical supports.
- Help organizations find ways to sustain their partnerships after our direct involvement ends.
- Continually evaluate our partnerships to expand our knowledge of the essential elements of success.
- Support an active network of individuals and organizations who are invested in family-professional partnership.

The Institute's 16 family-professional partnerships to date—launched in three sets over three years—demonstrate a range of sustainable roles for family members in a range of organizations. Each partnership was facilitated and nurtured by the Institute for its first six months. Nearly all continued beyond that formal pilot period; most continue today in some form.



## *The Power of Partnership at* **Clinical Sites**

***The staff has changed, we parents have changed.  
A rapport has begun that will last a very long time.***

Sonya Harrison, Family Partner  
Massachusetts Hospital School

---

### **Affiliated Pediatric Practices, Needham, MA**

Affiliated Pediatric Practices (APP) is a network of 17 independently-owned, Massachusetts-based community pediatric practices. The Family Partner created an active, group-wide Parent Advisory Council that includes parents and staff, and led it to produce resource materials for all the practices. At the completion of the Institute-supported partnership, APP hired the Family Partner to continue in her role.

### **Children's Hospital Boston, Boston, MA**

#### **Complex Care Service**

With a caseload of 2,000 families, the Complex Care Service (CCS) program provides medical care to children with genetic disorders, birth defects and chronic complex health care needs. Its Family Partner organized a Parent Advisory Group with two subcommittees, and guided the creation of a CCS brochure for staff to distribute to families.



## **Massachusetts Hospital School, Canton, MA**

The Massachusetts Hospital School is a publicly-funded residential and day school for children with disabilities. The Family Partner developed a new segment for monthly new-employee orientation sessions, in which family experiences and expectations are presented by students and parents. The training received very positive feedback and has been incorporated as a regular part of the program. The Institute-supported partnership has also led to additional family involvement at the school.

## **UMass Memorial Children's Medical Center, Worcester, MA**

### ***Pediatric Primary Care Clinic***

This pediatric primary care clinic, located at the university hospital, wanted to explore ways to enhance clinical services and identify potential roles for family members within the clinic. The Family Partner launched a Parent Advisory Group that included community leaders, family members of children with special health care needs and clinic staff.



## *The Power of Partnership at* **Health Plans**

***We worried at first that a parent would come in with unrealistic ideas. This has not been the case at all. Suggestions are appropriate and realistic.***

Rachel Orenstein, Organizational Partner  
Intensive Clinical Management Clinician,  
Beacon Health Strategies

---

### **Beacon Health Strategies, Woburn, MA**

Beacon Health Strategies is a behavioral health managed-care organization with over 1.4 million members. The Family Partner refurbished and re-energized its Member Advisory Council, ensuring that the member voice and perspective are heard at the management level. Following the Institute-supported partnership, the Family Partner has continued as a consultant to Beacon Health Strategies, working with the Member Advisory Council and other projects in an expanded role.

### **Blue Cross Blue Shield of Massachusetts, Boston, MA** ***Juvenile Diabetes Management Program***

With 3 million members, Blue Cross Blue Shield of Massachusetts is the largest commercial health plan in the state. In developing its Juvenile Diabetes Management Program, it engaged a Family Partner to advise the planning board about family perspectives on managing the disease. Family insights directly influenced the staff's design of a new program that could minimize health crises and maximize family connections to needed resources.



## **Harvard Pilgrim Health Care, Wellesley, MA** ***Member Services Department***

Working with this nationally recognized health plan, a Family Partner designed a training program about the challenges that face families of children with special health care needs and the resources that are available to them. She trained 60+ staff members of the Member Services Department over five well-received sessions. A staff member earned an employee recognition award for innovative and collaborative work on the project.



*The Power of Partnership at*  
**Academic and  
Research Sites**

***Our interviews would never have yielded the information they did if our Family Partner had not been working with us.***

Robert Graham, MD, Organizational Partner  
Clinical Director, Critical Care, Anesthesia and Perioperative  
Extension (CAPE) Program, Children's Hospital Boston

---

**Boston University School of Public Health, Boston, MA**  
***Maternal and Child Health Department***

Graduate-level training in Maternal and Child Health prepares those who will design programs, set policies, and advocate for systems that will improve the health of women, families and communities. This Family Partner surveyed students and faculty to assess family involvement in the curriculum and identify needs. She conducted interviews with key respondents and developed a set of recommendations for the department; she continues in a staff advisory role.

**Children's Hospital Boston, Boston, MA**  
***Pediatric Intensive Care Unit***

One of the highest-volume pediatric intensive care units (PICU's) in the United States, the PICU at Children's Hospital cares for more than 2,000 critically ill children a year. A Family Partner assisted a PICU physician with all aspects of his research on barriers to optimal critical care for children with special health care needs, including study design, recruitment, data collection and analysis. The PICU is implementing changes based on the findings, and the partners have co-written an article for the journal of the American Academy of Pediatrics.



**Harvard School of Public Health, Boston, MA**  
**Health Literacy Research Project**

Researchers at the Harvard School of Public Health (HSPH) are studying health literacy among English- and Spanish-speaking parents of children with special health care needs. The Family Partner prepared a literature review, participated in data collection and developed a comprehensive inventory of health literacy competencies from the family point of view. Her involvement continues as a member of the HSPH Health Literacy Group, which includes senior-level academics and practitioners.

**Opening Doors for Youth with Disabilities and  
Special Health Care Needs, Boston, MA**  
**Children's Hospital Boston and the Institute for Community  
Inclusion at UMass Boston**

The Family Partner trained staff and family members for a research project assessing strategies to help children with special health care needs participate more fully in recreational activities. After the Institute-supported partnership ended, Opening Doors hired the Family Partner, expanding her role to include community outreach for a second project, working to identify special needs early in culturally diverse communities.

**Simmons College, Boston, MA**  
**Department of Sociology**

The Family Partner at Simmons was enlisted to work with faculty on a research study entitled "Transition to Adulthood among Youth with Disabilities." In addition to conducting in-depth, qualitative interviews with 60 youth and their parents using a guide she helped design, she also organized two advisory councils for the project.



*The Power of Partnership at*

# Community Organizations

***The structure from the Institute was key for us. This kind of support is particularly important when it comes to underserved communities experiencing cultural and linguistic barriers.***

Renald Raphael, MD, Organizational Partner  
Family Support Program Coordinator,  
Haitian-American Health Initiatives

---

## **Eritrean Community Center of Greater Boston, Roxbury, MA**

Staffed by volunteers, the Eritrean Community Center serves about 1,000 of the estimated 6,000 Eritrean families in the Boston area. The Family Partner reached out to parents of children with special health care needs at cultural events in the community, and organized informational and networking meetings for parents. She also served as a role model for other parents in changing cultural attitudes about children with disabilities.

## **Great Wall Center, Inc., Malden, MA**

The Great Wall Center offers culturally relevant social service programs for the growing Asian community in the area. The Family Partner reinvigorated the Parent Association, which provides a support network for parents who are challenged by not only cultural and language barriers, but also the special needs and disabilities of their children.



## **Haitian-American Public Health Initiatives (HAPHI), *Mattapan, MA***

Among its many services to local Haitian-Americans, HAPHI provides culturally sensitive case management and family advocacy to families of children with developmental disabilities. The Family Partner worked to increase the number of families it serves, and to expand outreach services to families of children with chronic medical conditions and other special health care needs.

## **Medical-Legal Partnership for Children, *Boston, MA* *Boston Medical Center***

The Medical-Legal Partnership for Children (MLPC) offers legal assistance to vulnerable families, including those who have children with special needs. The Family Partner observed MLPC legal clinics at Boston Medical Center and community health centers, surveyed staff, and developed a set of recommendations for how family members could be engaged and their perspectives reflected in the program.

# About Us



**New England SERVE** is an independent health research and planning organization with a focus on children with special health care needs. It supports the improvement of care delivery and financing systems through the promotion of family-centered care, medical home partnerships, care coordination, responsible health care financing, and consumer roles in health policy-making. Since its founding in 1983, New England SERVE has been a leader in building collaboration among professionals in all types of health care settings and the families they serve. It furthered this commitment in 1999 by establishing the Massachusetts Consortium for Children with Special Health Care Needs, and again in 2006 with the launch of The Family-Professional Partners Institute.

The **Massachusetts Consortium for Children with Special Health Care Needs** is a working group dedicated to improving systems of care for children and families in the state. Its members are health care providers from diverse settings, health plan administrators, consumers, family advocates, and professionals in the public health, mental health, and human services fields. Together, Consortium members are committed to promoting and realizing in Massachusetts the national objectives of building a more responsive and family-centered system of care for children with special health care needs.

**The Family-Professional Partners Institute** channels the insight and experience of families of children with special health care needs into health and community organizations. It helps the organizations develop meaningful roles for family members, guides the implementation of short-term but sustainable partnerships, and provides training and support for both partners throughout. The Institute also connects interested consumers and professionals through a partnership-building network.

## The Family-Professional Partners Institute Advisory Board

**Paul Thayer, MA, MDiv, Chair**  
Wheelock College

**Anton B. Dodek, MD**  
Tufts Health Plan

**Susan G. Epstein, MSW**  
New England SERVE

(P) **Lois Wainstock Fine**  
Child Health Policy Advocate

(P) **Linda C. Freeman, MS**  
New England SERVE

(P) **Elaine M. Gabovitch**  
Child Health Policy Advocate

**Laurie Glader, MD**  
Children's Hospital Boston

(P) **Suzanne H. Gottlieb**  
Massachusetts Department of Public Health

(P) **Lisa Lambert**  
Parent/Professional Advocacy League

**Priscilla Meriot, RN, MS**  
Neighborhood Health Plan

**Sara Miranda, MSW**  
Federation for Children with Special Needs

(P) **Susan Nadworny**  
Massachusetts Families Organizing for Change

**Sylvia Stevens-Edouard**  
Blue Cross Blue Shield of Massachusetts

**Marji Erickson Warfield, PhD**  
Brandeis University

(P) **Amy Weinstock**  
Child Health Policy Advocate

(P) denotes the parent of a child, young adult, or adult with special health care needs.

