

Knowledge is Power

Family Partner Role: Training Specialist

Organizational Partner: Health Plan

What the Family Partner Did: The health plan wanted its member service representatives to be fully equipped to respond to questions from parents of children with special needs. The Family Partner created a specialized training program, supplying the team with practical knowledge and increased understanding.

Outcomes for the Organization: Increased ability to provide members with quality service over the phone; greater member and employee satisfaction; new web pages where staff and members can find resource directories, support groups and more.

Is There a Parent in the House?

Family Partner Role: Advisory Group Organizer

Organizational Partner: General Pediatric Practice

What the Family Partner Did: Providers and staff wanted to work with parents to make their practice as family-friendly as possible, particularly for families of children with special health care needs. The Family Partner established a Parent/Professional Advisory Group (PAG), recruited parents and practice representatives to participate, and guided activities.

Outcomes for the Organization: A new information sheet for parents and staff about local resources for children with special needs; an expanded consumer perspective in the practice newsletter and web site; better connections with families.

Stop the Presses

Family Partner Role: Materials Developer

Organizational Partner: Hospital-Based Specialty Clinic

What the Family Partner Did: The clinic’s staff was writing an educational brochure for parents, and wanted to be sure parents would find it useful. The Family Partner gathered input from families familiar with the clinic, and used their ideas to guide the editing process.

Outcomes for the Organization: An informative, well-written brochure that is well received by families; a formal mechanism to gather input from families in the future; a greater sense of families’ hopes, expectations, and perceptions of the clinic.

How can these Family Partner roles be adapted to provide solutions for your organization?
Contact the Institute to explore the possibilities.

The Family-Professional Partners Institute

Organizational Partners (to date)

- Affiliated Pediatric Practices
- Beacon Health Strategies
- Blue Cross Blue Shield of Massachusetts
 - Juvenile Diabetes Management Program
- Boston University School of Public Health
 - Maternal and Child Health Department
- Children’s Hospital Boston
 - Coordinated Care Service
 - Pediatric Intensive Care Unit
- Greater Lawrence Family Health Center
- Harvard Pilgrim Health Care
- Harvard School of Public Health
 - Health Literacy Research Project
- Massachusetts Hospital School
- UMass Memorial Children’s Medical Center
 - Pediatric Primary Care Clinic

The Family-Professional Partners Institute is a project of New England SERVE, an independent health research and planning organization with a focus on children with special health care needs.

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Third Sector New England, a not-for-profit 501(c)3 organization, provides New England SERVE with grants management, fiscal accounting, and other administrative services.

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

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Bringing Family Experience into Organizations
that Shape Health Care for Children
with Special Health Care Needs



The INSTITUTE

ORGANIZATIONS

Working to Improve Child Health

FAMILY MEMBERS

Caring for Children with Special Health Care Needs

Families caring for children with special health care needs have a lot of experience with the health care system. **But most don't know they can use their experience to make the system work better.**

Many organizations want to incorporate families' input into programs and policy. **But it can be a challenge to make it happen.**

The Family-Professional Partners Institute is a partnership broker. We work with families and with organizations from across the system of care.

Together, we build partnerships in which:

- Family members take on meaningful roles
- The Institute provides ongoing support
- Commitments are structured and time-limited
- Positive outcomes are achieved, and
- Family and Organizational Partners are linked to a partnership-building network.

"Family members must have a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice."

Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services

Improve services by tapping the unique contributions of specially trained consumers.

Medical practices, health plans, schools and other organizations routinely make decisions that affect the care that children and families receive.

A growing national movement is bringing parents and other family members inside those organizations, where their insight informs policy, shapes programming, and improves outcomes. Organizations that learn to partner effectively with family members are reaping the benefits.

The Institute helps organizations turn the general desire to "work with families" into well-defined, meaningful, manageable and effective partnerships with family members uniquely qualified for the role.

"Other departments have seen our success, and now they're interested in having Family Partners, too. It has exciting implications for the whole hospital."

Laurie Glader, MD and Stephanie Porter, MSN, RN, Children's Hospital Boston

Help build a health care system that really works for children and families.

Have you ever thought about all the knowledge, skills and experience you have as a result of caring for a child with special health care needs? You have valuable ideas about what makes health care family-friendly, and you know a lot about communication and problem-solving.

Hospitals, health plans, and many other organizations are creating important roles for parents and other family members like you. They want the benefit of your experience when they plan programs, train staff, or make decisions that affect children's care.

The Institute helps family members of children with special health care needs use what they know, in the time they have available, to improve the health care system.

"I'm making a real impact, and doing it from within. My Organizational Partner is open and receptive to what I as a parent bring to the table."

Laura Noble, Family Partner Specialist, Harvard Pilgrim Health Care

Children with Special Health Care Needs

Children with special health care needs have or are at risk for at least one medical, behavioral, or developmental condition expected to last twelve months or more.

They include children from birth to 21 with a wide range of conditions including cerebral palsy, depression, sickle cell anemia, autism, ADHD and many others. They

require health and related services more than most children, and need a comprehensive system of health care that maximizes the well-being of each child.