

STRUCTURE & *Spark!*

*Building Family-Professional Partnerships
to Improve Care for Children
with Special Health Needs*



New England
SERVE

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

Programs of New England SERVE



June 2008

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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 consumers, health care providers from diverse settings, health plan administrators, 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.

Acknowledgements



New England SERVE wishes to thank Laurie Tellis, author of *Structure and Spark!*, for telling the story of the Family-Professional Partners Institute in a clear and engaging style.

The Institute's story, however, really has been written by the individuals and organizations who have planned, built, guided and supported its partnerships. We gratefully acknowledge the enthusiastic participation of Family Partners, Organizational Partners and Mentors and their willingness to experiment with new roles and relationships; the insight and generosity of the members of the Advisory Board; and the funding and other support from state and federal agencies.

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Finally, we thank Linda C. Freeman MS, who has served as the director of the Family-Professional Partners Institute since its inception. Her passion and commitment have touched every aspect of the Institute's work: from research and planning, to building partnerships and supporting the Alumni Network, to championing its continual evolution.





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Introduction

“You can’t change the system.”

We’ve all heard that at one time or another. But is it true?

The health care “system” comprises many organizations; medical practices, health plans, public agencies and others each play a role. Additional organizations, such as schools and community centers, can also have an impact on the care children and families receive. To change the system—to make it work better—health care consumers need to have a voice inside those organizations.

Adult family members of children and youth with special health care needs (CYSHCN) are uniquely qualified for participation: they are frequent users of health care services; they have a wealth of experience and insight into how systems work and how they might work better; and many of them talk to each other through local, state, and national networks.

One important way of involving these consumers is through *family-professional partnerships*, in which family members work with clinicians, administrators or other professionals in fields related to the financing and delivery of health care.

New England SERVE set out to engage family members of CYSHCN in such partnerships. It established the Family-Professional Partners Institute to create, support, and evaluate a variety of partnerships, and to discover the essential elements of their success.

In its role as a partnership broker, the Institute has facilitated 16 successful partnerships and created an active family-professional partnership network. ***Structure and Spark: Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs*** incorporates the best knowledge gained from that experience.

- **Part I, The Brokered Partnership Model**, outlines the Institute’s evolution and its activities as a partnership broker.
- **Part II, Brokering Family-Professional Partnerships**, offers a more detailed look at each of these activities, from assessing an organization’s partnership readiness, to training the Family Partners for their role, to making contractual arrangements and beyond.
- **Part III, Building a Partnership Network**, describes the Institute’s additional efforts to promote family-professional partnership, and offers some words of wisdom for becoming a partnership broker.

There are also two appendices. The first gives the reader a concise description of each of the Institute’s partnerships, while the second provides sample print materials developed by the Institute. These “Tools to Use” are referenced at the end of each chapter to which they are relevant. We invite others to adapt them for their own use.

So can you change the system?

By bringing family experience into organizations that shape health care for CYSHCN, we believe the Institute is doing just that—one organization at a time.

Structure and Spark uses the term “Family Partner” rather than “Parent Partner,” acknowledging that grandparents, adult siblings and other family members often have as much to contribute from their experiences with CYSHCN as parents do.

Part I.



The Brokered Partnership Model

1. This Is Our Story <i>The Family-Professional Partners Institute</i>	12
2. Structure and Spark <i>The Role of the Partnership Broker</i>	18



1 This Is Our Story

The Family-Professional Partners Institute

As frequent users of health care services, families raising children and youth with special health care needs (CYSHCN) have a wealth of experience to share—experience that can and should be harnessed to improve systems of care.

The **Family-Professional Partners Institute** is based on that principle. It works with organizations to create new roles for family members of CYSHCN—roles in which they help shape programs, influence policy, and impact the care that children and families receive. It brokers short-term partnerships, provides training and technical assistance, and cultivates an ongoing partnership network.

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 structured, 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 concept of establishing partnerships between family members and health care providers is not new. Creative work in this area has been well documented over the past two decades (see selected references on p. 16). The partnerships created through the Institute, however, are different from previous models in a number of important ways:

- **The organizations are wide-ranging in nature and size.** They are not only clinical practices and health plans, but also universities and small, community-based service organizations with very limited budgets and staff.
- **The roles created for Family Partners are similarly wide-ranging.** In addition to the more common role of advisor, family members have assisted in research, participated in graduate-level curriculum review and design, helped to design a disease-management program for a health plan and found ways to connect with and support families in minority cultures where disability is often kept hidden.



- **The partnerships are brokered and facilitated by a third party.** Many organizations have a latent or even explicit desire to involve family members. But desire alone is insufficient. The Institute provides a structured approach to organizing, implementing, evaluating and sustaining a partnership. A neutral third party, it offers a unique package of supports for both partners.
- **The partnerships are part of a larger picture.** As a partnership broker, the Institute is able to work across systems and organizations. It fosters strategic thinking about partnership, and identifies ways to make new kinds of family-professional connections. The Institute is building a working model, gaining an extensive knowledge base and an expanding set of experienced participants and advocates.
- **The Institute's vision includes an ongoing partnership network.** The Institute has learned firsthand that both family and organizational partners highly value the ability to stay connected to each other and to the Institute after their formal relationship has ended. It is discovering new ways to build on individual partnerships and sets of partnerships.

Although we began with a solid, carefully constructed foundation, we did not realize at the time how powerful this model would be. Our first six partnerships could be considered an experiment, but their success was unmistakable. We were genuinely inspired by how much could be accomplished in a relatively short time and by how many different ways the partnerships made a difference.

Since then, each new collaboration has taught us something about what contributes to an effective partnership and what warrants adjustment and fine-tuning. We adapt our activities according to what we learn.

One key lesson stands out among the rest. As the third party in the relationship between organization and consumer, we have found that our role—as partnership broker, facilitator, administrator, trainer, and network-builder—is essential to the success, and sometimes even to the existence, of family-professional partnerships in health and community organizations.

THE FAMILY-PROFESSIONAL PARTNERS INSTITUTE A Concise History

The Goal, July 2002

With a grant from the federal Maternal and Child Health Bureau, New England SERVE sets a four-year goal: “to develop and support an expanded network of informed and engaged families” working to improve systems of care for Massachusetts CYSHCN.

The Committee, October 2002

The Family Participation Work Group (FPWG) is formed within the Massachusetts Consortium for Children with Special Health Care Needs at New England SERVE.

The Needs Assessment, 2002–2004


The FPWG conducts a variety of needs assessment activities to understand the requirements of creating roles for family members of CYSHCN in health care policy and financing.

The Policy Statement, June 2003

The FPWG issues a policy statement, endorsed by the Consortium, offering a broad definition of “health care policy and financing,” and outlining the unique contributions family members can make to these efforts. (Reproduced in Appendix B1.)

The Public Meeting, June 2004

The FPWG hosts the Consortium’s best-attended meeting to date, presenting successful models of family-professional partnership, introducing local family organizations, and announcing a new partnership-brokering initiative.



The Partners, 2003–2004

Having piqued the interest of numerous health care-related organizations, the FPWG conducts initial screening and site visits, eventually selecting six for a pilot program. Work plans are developed at each site, family members are recruited, and contractual arrangements are made.

The Pilot, February–July 2005

The Family Partners Initiative begins. Following comprehensive orientation and training sessions, family-professional partnerships are created, implemented and evaluated at six pilot sites.

The Institute, 2006

Building on the success of the pilot program, the Family-Professional Partners Institute is launched with support from the state's Title V program at the Massachusetts Department of Health. Four new partnership sites and the Alumni Network are established, as the Institute begins to build system capacity for family-professional partnership.

The Expansion, 2007

The Institute creates six new partnerships at six new sites. By design, three of these are at community-based organizations with a focus other than health care. The mentor program is also expanded, and the Alumni Network continues to grow.

The Dissemination, 2008



*The Institute releases **Structure and Spark: Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs**, hoping others will replicate its success.*

FAMILY-PROFESSIONAL PARTNERSHIP

Selected References

Examples of non-brokered family-professional partnerships are well documented in these and other publications:

- *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future: A Work in Progress*, J. Conway, B.H. Johnson, and S. Edgman-Levitan, Institute for Family-Centered Care, Bethesda MD with the Institute for Healthcare Improvement, Cambridge MA, 2006.
- *Strategies for Leadership: Advancing the Practice of Patient- and Family-Centered Care*, American Hospital Association, Washington DC and the Institute for Family-Centered Care, Bethesda MD, 2004.
- *Families as Advisors: A Training Guide for Collaboration*, E. Jeppson and J. Thomas, Institute for Family-Centered Care, Bethesda MD, 1997.
- *Family Employment in State Title V Programs: Conference Proceedings and Survey Report*, Betsy Anderson, Barbara Popper, and Nora Wells, CAPP National Parent Resource Center, Federation for Children with Special Needs, Boston MA, 1995.

- 
- **Essential Allies: Families as Advisors**, E. Jeppson and J. Thomas, Institute for Family-Centered Care, Bethesda MD, 1994.
 - **Families in Program & Policy: Report of a 1992 Survey of Family Participation in State Title V Programs for Children with Special Health Care Needs**, N. Wells, B. Anderson, and B. Popper, CAPP National Parent Resource Center, Federation for Children with Special Needs, Boston MA, 1993.
 - **Family/Professional Collaboration for Children with Special Health Needs and Their Families**, K.K. Bishop, J. Woll and P. Arango, University of Vermont, Department of Social Work, Burlington VT, 1993.
 - **Family-Centered Care for Children with Special Health Care Needs**, T.L. Shelton, E.S. Jeppson, and B.H. Johnson, Association for the Care of Children's Health, Washington DC, 1987.
 - **Children with Special Health Care Needs: Surgeon General's Report: Campaign '87**, Division of Maternal and Child Health, Bureau of Health Care Delivery and Assistance, United States Public Health Service, Washington DC, 1987.
- 



2 Structure and Spark

The Role of the Partnership Broker

We began with a grant-funded mandate: to develop an expanded network of informed family members of CYSHCN who were engaged in improving systems of care. To do that, we set about exploring, creating and supporting family-professional partnerships.

A family-professional partnership generally consists of one individual who has a child with a special health care need, and one health care-related organization that serves CYSHCN and their families. New England SERVE is neither of these; as an independent health research and planning organization, we were a third party from the outset. The role of the third party is one we have thoughtfully and effectively developed since our first set of partnerships.

There was a research element to our work from the beginning: to answer the question, “What does it take to build successful and sustainable family-professional partnerships?” Our third party role was the ideal vantage point from which to research this question. What we discovered was that it was also *one of the answers*.

Many of the Institute’s Organizational Partners—and many additional organizations that have expressed interest—tell us they have long been attracted to the idea of partnering with health care consumers. Too often, however, the idea gets pushed to the back burner. Translating it into an actual initiative is too big, too complex, and brings with it too many unknowns to compete with other, high-priority projects.

Enter the partnership broker, who has a system in place. The partnership broker can help organizations decide whether the time is right to pursue partnership, explore possible roles for family members, guide them through the logistics, and provide technical assistance throughout.



Without a broker as intermediary to structure, organize, implement and evaluate the partnerships, our feedback tells us that not only would these partnerships not have been conceived, but the ingredients that were essential to their success would have been absent. To paraphrase the comment of one Organizational Partner: “We had the tinder but it took the Institute to spark the flame.”

In addition to structure and spark, the Institute has provided limited funding for six-month partnership pilots. Family Partners by definition use their knowledge, skills and experience to add value to organizations. It is important that they are compensated. At the Institute, the funding we provide is used to pay stipends to the Family Partners.

While this support hasn't been the deciding factor for most organizations to participate, it has been critical in another way. When we began facilitating family-professional partnerships, it was a completely new venture for us. We had clearly done our homework and saw a need we could fill, but we had no track record, no roster of satisfied clients. The fact that we could and would underwrite the first six months of a partnership served as important evidence of our commitment and belief—not just in the value of partnerships in general, but in particular partnerships with particular organizations.

Table 1. The Role of the Partnership Broker**Recruitment of Organizations**

- Promote the concept of family-professional partnership among a range of organizations.
- Recruit organizations to host family-professional partnerships.
- Work with organizations to assess partnership-readiness, considering staffing, logistical, and financial requirements.

Development of the Family Partner Role

- Educate organizations about family-professional partnership and the roles Family Partners can play.
- Help organizations identify and prioritize Family Partner roles that would fit their needs.
- Work with organizations to refine Family Partner roles and prepare job descriptions and work plans.

Recruitment of Family Partners

- Advise organizations on opportunities for recruiting Family Partners.
- Promote Family Partner positions in family circles (as needed).
- Recruit Family Partner candidates (as needed) for organizations to interview.

Training of Family Partners

- Provide a comprehensive training program for Family Partners, to include:
 - History and principles of family-professional partnership
 - Special considerations for Family Partners working in health care organizations
 - Wearing two hats; strategies for sharing personal stories
 - Responding to new challenges, where to find help
 - Employment logistics (timesheets, etc.).

Mentoring

- Build a network of Mentors for individual Family Partners, drawing from established family leaders.
- Clarify the Mentor's role to Partners, and facilitate mentoring relationships.



Contractual Arrangements

- Work with Organizations and Family Partners to define appropriate contractual arrangements (i.e., will the Family Partner be an employee of the organization? of the partnership broker?).
- Establish the parameters of a six-month partnership: beginning, mid-point and end.
- Clearly define expectations with the Family and Organizational Partners: work hours, reporting procedures, compensation, evaluation, and participation in activities of the third-party partnership broker.

Reporting, Monitoring, and Technical Assistance

- Administer a reporting and monitoring system for all Partners.
- Provide technical assistance to organizations, which may include refinement of the work plan, the provision of resource materials, and general troubleshooting.

Evaluation and Sustainability Planning

- Develop and implement an evaluation system for all Partners.
- Work with Partners to determine the potential for continuing partnerships beyond the first six months—either with the same or a different Family Partner.
- Develop and implement a plan for each partnership as it transitions.

Alumni Networking

- Encourage the growth of a network of Family and Organizational Partners, ready and able to support each other.
- Create alumni events where Organizational and Family Partners come together to learn from each other.

The following chapters outline the implementation of each of these aspects of the broker's role. Sample print materials or "Tools to Use" are referred to in each section and included in Appendix B.

STRUCTURE & *Spark!*

Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs



Part II.

Brokering Family-Professional Partnerships

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3

Stop, Look, Listen

Planning for Partnerships

Before creating a single partnership, the initiative that would become the Family-Professional Partners Institute made a thorough assessment of what was already in place. It wasn't simple or quick, but it was an extremely important step for us. It helped set the stage, identify potential challenges—and potential partners—and build momentum. A good deal of our initial success with partnerships, we believe, can be accredited to having done our homework.

In scanning the local partnership environment, we wanted to know:

- Do partnerships already exist between family members and health care or community organizations?
- What is the nature of the roles that family members play? Are these paid roles or volunteer?
- Which organizations have these collaborations?
- Among organizations that do **not** have these collaborations, is there interest in developing them?
- Are family members interested in getting involved?
- What networks and connections can be used to recruit Organizational Partners?
- What networks and connections can be used to identify potential Family Partners?

To find the answers, we surveyed or interviewed three groups of people:

1. Individual parents of CYSHCN, similar to those who might be recruited for future Family Partner roles;
2. Representatives of 16 family leadership organizations, who would have important information about the partnership environment, and who might be helpful in future promotion and recruiting efforts; and
3. Representatives of public health, health care, research and related organizations, similar to those who might be future partnership sites.

Even while stopping to look around, we also stopped to look within. What exactly *is* family-professional partnership? What is it *not*? To whom is it valuable and why? We were already familiar with the federal agenda for children with special health care needs, which has family involvement as one of six critical indicators of progress. Specifically:

“Families are the constants in the child’s life and are pivotal in making any system work. Family members, including those representative of the culturally diverse communities served, must have a meaningful, enduring, and leading role in the development of systems at all levels of policy, programs, and practice. Family voices must be heard and families should be at each table in which decision making occurs. Thus, the involvement of families is a key indicator of systems development.”¹

But we went further, putting our own stamp on the importance and meaning of partnering with families. The Massachusetts Consortium for Children with Special Health Care Needs released a policy statement on the matter. *Family Participation in Health Care Policy and Financing* (Appendix B1) offers a broad definition of “health care policy and financing” and outlines the unique contributions family members can make to these efforts. (The Institute and New England SERVE would later release *Guiding Principles of Family-Professional Partnership* [Appendix B2], which describes a set of values for family members who are working with organizations.)

¹ Maternal and Child Health Bureau, *Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs*, <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>

In conducting our assessment, New England SERVE had the benefit of many existing connections to family-led organizations, individual family members, health-related organizations, individual health care providers, academic sites and state agencies through its project, the Massachusetts Consortium for Children with Special Health Care Needs. Staff used the Consortium's meeting forum, its e-mail distribution list, and outreach to members to conduct its environmental scanning activities.

The results (see box) indicated a strong interest in partnership among both families and organizations. We also found considerable insight to direct our next steps. The development of the Institute's recruiting, training, monitoring, and evaluation activities were greatly influenced by what we learned in this initial planning stage.

PLANNING FOR PARTNERSHIPS: The Results Are In



The Institute's assessment revealed that:

- *Many organizations were already working with family members of CYSHCN in some capacity, and were interested in expanding. Those that weren't were not opposed to the idea; it had just not been a priority.*
- *To undertake family-professional partnerships, organizations would need **information about the benefits** of family involvement and **technical assistance** to make it happen.*
- *Additional challenges for organizations were budget restrictions, organizational cultures that resist focusing on one subset of the population, and the risk of casting consumers as external critics.*
- *To recruit busy family members to become engaged in policy and financing activities, we would have to 1) be able to explain simply and clearly what that meant, and 2) convince them that they could make a significant impact in only a few hours a week.*



TOOLS TO USE

- Appendix B1. Family Participation in Health Care Policy and Financing
- Appendix B2. Guiding Principles of Family-Professional Partnership



4

On Site and On Board

Recruiting the Organizations

At the Institute, building a specific partnership begins when we recruit an Organizational Partner. We work with the organization to develop a concrete role for the consumer; then, we provide assistance as needed as the organization works to fill that role.

Recruiting the organization comes first, by necessity. By the time the Family Partner is recruited, the organization is well-equipped with a job description and specific objectives for the partnership. Staffing and other logistics have been addressed, and the organization can describe the ideal candidate it seeks.

Starting out, we knew we wanted to build a broad range of partnerships, so we recruited from a broad range of organizations: large and small, research and clinical, public and private. We also knew we wanted a maximum of six partnerships for our first set. This decision was based on available staffing, and was a good one; the Institute has never initiated more than six partnerships at a time.

Once we had scanned our environment as described in Chapter 3, we were aware of several organizations that were interested in partnering with families. Our goal was to expand that list—by educating organizations about the benefits of partnership and about our program—and then narrow it down to our six available spots.

The concept of a family-professional partnership can be a bit difficult to explain. It is our experience that providing concrete examples of partnerships and what they can accomplish is the best way to communicate what they are all about and their value.

One of our favorite examples to use:

A health plan was preparing to distribute a booklet for families of children with ADHD when they decided to run it by a focus group of sorts—a group of parents whose children had the condition. The parents felt the booklet had important gaps in its content and was condescending in tone. Several were invited to participate in revising the booklet before its release.

We used examples like this both in a meeting to promote our new brokered-partnership program, and in a brochure to promote the program's expansion.

RECRUITING THE ORGANIZATIONS: Getting the Word Out



During our assessment activities, we became familiar with some existing family-professional partnerships in the area. We invited several pairs of partners to speak at a meeting of the Massachusetts Consortium for Children with Special Health Care Needs. A lively discussion followed, and we proceeded to announce our new initiative as a partnership broker.

Consortium members represent hospitals, health plans, academic and training programs, state agencies, primary care providers, family organizations and individual family members. After the meeting, we sent the announcement to the Consortium's full e-mail list.

The response to our outreach was immediate and wide ranging. The 15 organizations that responded included:

- *Hospital-based specialty clinics*
- *Health plans*
- *Community health centers*
- *Hospital and community-based pediatric practices*
- *Medical schools*
- *Graduate schools of public health*
- *A residential hospital school*

Initial Screening

The Institute follows up every expression of interest from an organization with a phone call. The purpose of the call is to further define the level of interest and whether there is a potential fit. As we have clearly learned: while a good initial response rate is encouraging, not every expression of interest represents a good fit.

Organizations may be screened out at this point—or decide to screen themselves out—if:

- They are simply intrigued by the idea; they want more information but aren't ready to move ahead.
- The timing is poor; organizations may be in the midst of a busy season or have too many other projects underway to commit staff time to a partnership.
- There is a misunderstanding about what is involved in a facilitated family partnership. For example, an organization might think this is a way to bring on a temporary employee, without any particular commitment beyond that of an employer. Or a family-led organization might respond, not realizing that the emphasis is on establishing partnerships at organizations that do not have a role for a family member of a CYSHCN.
- The individual who responds feels that the level of interest or commitment from top-level administration may be insufficient to sustain a partnership.
- An organization is in a geographic location that is not convenient, given the need to have the organization and its Family Partner participate in a number of meetings and training sessions.

Initial screening may also be done through a formal application process, and the Institute has developed an application form for organizations interested in family partnership (Appendix B3). We have generally used it to supplement the phone screening, not replace it, but a review of the application form gives an idea of the questions we discuss on the phone.

This initial screening is a critical first step in narrowing the list of potential partnership sites. The next step is to make individual visits to the remaining organizations.

Site Visits

Once a list of potential Organizational Partners is developed, we arrange a site visit with each one. This is an opportunity for the organization to learn more about partnership and what the partnership broker offers, while the broker learns more about the organization's interest in and readiness for partnership.

Site visits are most successful when both the staff who are championing partnership at the organization and those who will have day-to-day responsibility are in attendance. The person who made the initial inquiry may or may not be the decision-maker; the decision-maker may or may not delegate responsibility for the partnership.

This initial meeting usually takes about an hour. It accomplishes several things:

1. **It provides the organization with a deeper understanding of the partnership concept and the third-party model.** This is the perfect time to pull out those real-life examples of known partnerships and their outcomes. The Institute's brochure is also helpful.
2. **It stimulates the organization's thinking about how a Family Partner could contribute.** We typically present a sampling of Family Partner roles (see page 36) and ask about the organization's desired outcomes for the partnership. Although this discussion is a preliminary one, it is important to the eventual definition of the role a Family Partner will play.
3. **It helps further assess the organization's readiness for partnership.** Organizational Partners make a significant commitment to participating in the Institute's program, and we take this opportunity to review what's involved. Key readiness factors include a commitment to sustaining partnership with family members, and the ability to provide staff time, coverage for incidental expenses and other supports.

In addition to assessing the organization's readiness, the Institute has also imposed criteria based on its own goal of building a range of partnerships. We have, for example, selected organizations that broaden our experience in terms of sector, industry, or partnership type.

As our success with the partnership experience deepened, we also broadened our organizational reach. The most recent set of partnerships included partnerships in non-health-related organizations. Three of the six partnerships were with community-based organizations, whose connections to culturally diverse, underserved and minority populations center on offering support along many avenues, not just health care. These have been very rewarding relationships, presenting some new and unique challenges, but ultimately proving that the family-professional partnership model has many potential homes.

Table 2. The Role of the Organizational Partner**Demonstrate Commitment to Family-Professional Partnership**

- Be able to demonstrate:
 - The potential to enhance the family voice and consumer perspective throughout the organization.
 - Evidence of support at senior management level.
 - The ability to identify possible challenges or barriers to success within the organization.
 - A high likelihood that, once proven effective, family-professional partnership will be sustained at the organization beyond the initial pilot project.

Establish and Implement a New, Meaningful Role for a Family Partner

- Work with the partnership broker to:
 - Acquire a basic understanding of family-professional partnership and its benefits; become familiar with several ways Family Partners can contribute to an organization.
 - Define a clear role for a Family Partner. Set reasonable goals; develop a job description and work plan. Incorporate staffing, logistical, and financial requirements into planning.
 - Create a recruitment plan. Recruit applicants, conduct interviews, and select a Family Partner.
 - Make appropriate contractual arrangements.

Provide Critical Supports

- Designate an employee liaison within the organization to serve as an internal champion for family partnerships. The liaison:
 - May or may not be the same person who supervises or works most directly with the Family Partner.
 - Has the requisite authority to ensure that the partnership is implemented in accordance with the work plan.
 - Spends approximately 20 hours over the six-month partnership in Institute activities *in addition to* any time spent working with the Family Partner within the organization.
- Provide the Family Partner with an onsite orientation, introductions to key staff, and access to decision-makers. Provide other supports as needed, such as a physical workspace or flexible scheduling.
- Accept responsibility for any expenses associated with the partnership beyond the broker's stated obligation. These may include a stipend for the Family Partner, copying and postage, meeting refreshments, parking and travel expenses, etc.
- Participate in the Institute's Family Partner training program, and at least one meeting with the Family Partner and his or her Mentor.
- Communicate with the Institute through an established reporting system. Notify the Institute to request technical assistance or changes to the work plan.

Encourage the Continued Growth of Family-Professional Partnership

- Work with the partnership broker to:
 - Evaluate the effectiveness of the partnership.
 - Determine the potential for continuing the partnership beyond the first six months—either with the same or a different Family Partner. If indicated, develop and implement a plan for continuing the partnership after the broker is no longer facilitating it.
- Participate in events of the Institute's Alumni Network.

TOOLS TO USE

- Appendix B3. Application Form for Organizations
- Table 2. The Role of the Organizational Partner
- Table 3. A Sampling of Roles for the Family Partner



5 What Will They Do, Exactly?

Developing the Family Partner Role

One principle of partnership is this: Family Partners are not responsible for making change on their own, but they encourage system improvement by sharing their experiences and expertise with organizations.

But how exactly do they do that?

It is rare that an organization comes to the Institute with a crystal clear role in mind for its Family Partner. Defining that role requires thoughtful discussion of the organization's goals, the range of contributions a Family Partner can make, and the principles and logistics of partnership. As brokers we guide that process, helping the organization pinpoint desired outcomes or prioritize multiple goals.

The discussion begins at the initial site visit described in Chapter 4. We ask what the organization hopes to achieve by working with Family Partners, then begin to consider potential roles. To stimulate thinking, we present some concrete examples (see page 36). Our list includes the roles of Clinical Advisor, Training Specialist, Publications Reviewer, Research Advisor, and Outreach Coordinator, among others.

Some key points in this discussion:

1. **Desired outcomes of partnership.** What does the organization want to achieve?
2. **Short-term vs. long-term vs. intermittent roles.** Realistically, what can be accomplished in a six-month timeline? Could future partnerships build on that foundation?
3. **Possible Family Partner roles.** What's in a name? The same role can be given different titles. For example, a family member in the role of Advisor might also be called an Educator, a Consultant or a Family Faculty member.

4. **How a particular role might change over time.** How might the Family Partner's responsibilities evolve, either within the initial six months or over a longer term?
5. **The impact of different roles on organizational resources.** What would be required in terms of staff time, potential expenses, and other supports?
6. **Logistical challenges.** Would this role require the Family Partner to work with multiple departments or travel to different sites? To work with information protected by HIPAA regulations? Would time be required of staff members while they are busiest with other projects?

When an organization comes to the table with a strong idea about what it would like a Family Partner's role to be, the site visit often expands the initial idea to include other possible roles. Or it can help critically refine the original concept into specific objectives. As the partnership broker, we serve as a sounding board, contributing perspective and experience about building successful partnerships.

Some organizations have several different ideas about how a Family Partner could contribute. When this is the case, we help examine the ideas in more depth, considering each one's importance and likelihood of success. We advise about what realistically can be accomplished in an initial pilot while pointing out how the role might evolve and change over time.

Organizations usually continue to define the role on their own in the week or two after the site visit. Additional staff members may be consulted; new information may come to light. In some cases, there is only minor refinement of the original plan; in others, there is a major shift in direction. During that time we call the organization to check in, provide support if needed and discuss next steps.

The Job Description and Work Plan

The Institute has developed a general job description that can be applied to nearly any Family Partner role (see Appendix B4). Depending on human resources requirements, this can be useful for organizations who work with multiple Family Partners in different roles. But for recruiting purposes, it helps to create a customized job description for each Family Partner position. At the Institute, we provide an initial draft to the Organizational Partner, who then edits it, applies any internal stylistic or formatting standards, and may put it on letterhead.

Table 3. A Sampling of Roles for the Family Partner

Clinical Advisor

Advises staff in a pediatric practice about how to make office visits go more smoothly for families.

Publications Reviewer

Reviews educational materials, PR materials, policy statements and other documents targeted to families who have children and youth with special health care needs.

Family Faculty

Speaks to medical students or current providers about health care experiences as the family member of a child with special health care needs.

Research Advisor

Assists academic, clinical or other researcher in a study on a topic related to disabilities; may help design a survey, conduct interviews, or analyze data.

Grant Writer

Works with the staff of educational or recreational organizations serving children and youth with special health care needs to write a grant to fund programming.

Training Specialist

Develops curricula and provides a component of employee orientation or other staff training programs at organizations serving children with special needs.

Advisory Group Organizer

Helps an organization to establish or reinvigorate an advisory group of both family members and staff, to identify ways to enhance operations.

Outreach Coordinator

Consults with a state or local agency on reaching families who are not connected to, and could benefit from, their service programs.

Program Planner

Works with health plan staff to design a disease management program.

Surveyor

Conducts a needs assessment within an organization to identify and recommend ways to increase family participation.

Board Member

Standing member of organizational board providing the family perspective; may also join working committees.

Expanding on the job description is the detailed work plan. This document includes a list of tasks and the estimated number of hours each task will require of each participant: Family Partner, Organizational Partner and broker. As with the job description, the Institute prepares a draft for the organization to review and edit. The work plan is a more complex document, however, and because it is referenced throughout the partnership—for planning, contractual arrangements and evaluation—it's critical that the broker and the organization develop it collaboratively. Agreement on expected outcomes and the timing of their achievement makes for a smoother partnership, even if mid-course adjustments to the work plan become necessary later on.

TOOLS TO USE

- Table 3: A Sampling of Roles for the Family Partner
- Appendix A: The Institute's 16 Partnerships
- Appendix B4. General Family Partner Job Description
- Appendix B10. Sample Organizational Partner Agreement and Work Plan



6

Some Experience Required

Recruiting the Family Partners

The search for a Family Partner begins only when there is a clear job description for the role being filled. The Institute can help Organizational Partners with recruitment but it does not maintain a pool of candidates. This system has several benefits:

- It encourages organizations to seek candidates with appropriate skill sets, rather than assume that raising a child with a special health need is the only qualification;
- It allows organizations to recruit through their own, existing connections with families, if they have them;
- It avoids having family members recruited into a candidate pool, and then not be selected for an actual partnership; and
- It assures the Institute of a continually expanding network of new family leaders.

The process of Family Partner recruitment varies slightly depending on the needs of a particular organization.

Some organizations have existing connections with families and are able to recruit on their own. For example, a pediatric practice wanting to establish a Parent Advisory Group needed someone whose child was already a patient there, in order to tap into that family's experience for guiding improvements. That practice, like several others we have worked with, actually had a particular person in mind for the role. Some had already spoken with individuals about the opportunity before meeting with us.

Other organizations have no formal connections to individual families, and require the Institute's help to reach this audience. Depending on the organization's needs, we may:

- Connect the organization with local groups that serve families with CYSHCN, such as the state chapter of Family Voices or local chapters of diagnosis-specific organizations.
- Contact prospective Family Partners to tell them about the partnership opportunity, and to provide them with the job description.
- Work with family members to put together a résumé or other materials to submit as a formal application that can then be forwarded to the organization.

Once the word is out, the Institute may collect and forward responses to the Organizational Partner. We recommend that a formal résumé not be made a requirement of the application process, and that the emphasis be placed instead on finding a way for the family member to describe how his or her range of experiences match the position's requirements. Some well-qualified family members may have been out of the employment world for a while, busy caring for CYSHCN. Others may be unfamiliar with constructing a résumé or may not have ready access to a computer. Occasionally, we assist family members in preparing a letter of interest.

RECRUITING THE FAMILY PARTNERS: Making Connections

To help organizations recruit Family Partners, we often reach out to Massachusetts Family Voices—which has an active listserv of over 100 subscribers—and the state's Parent Training and Information Center at the Federation for Children with Special Needs. Depending on the nature of the partnership, we might also contact diagnosis-specific organizations such as the Massachusetts Down Syndrome Congress.



In addition to the specific requirements of a particular role, we encourage both Partners to consider the qualifications outlined in the general Family Partner job description (Appendix B4). These include things like interpersonal and communication skills, the ability to work as part of a team, and so on.

Two things the Institute does not do are conduct interviews and select the final candidate. We help construct the partnership, but staffing it is the organization's domain. This helps us maintain one of the partnership broker's key attributes: our neutrality. It also ensures that both Partners are invested and committed to the relationship they are creating.

TOOLS TO USE

- Appendix B4. General Family Partner Job Description
- Appendix B5. Sample Letter of Interest from a Family Member





7

Knowledge + Tools = Confidence

Training Family Partners for the Role

The importance of a carefully thought-out and well planned training program for Family Partners cannot be overestimated. The Institute has found that it not only provides *information* and *tools* the participants will need, but that it also:

1. **Creates a community of shared purpose.** Family Partners are introduced to each other and to their Mentors; they establish important connections over the course of the sessions.
2. **Increases confidence among Family Partners.** The Institute's typical Family Partner has never before been involved in family leadership activities, and some have not recently been in the workforce. An informal setting, the thoughtful pacing of activities, and the opportunity to interact with each other and ask questions all increase participants' comfort level about being part of this new venture.
3. **Builds excitement and momentum.** The training program formalizes the launch of the initiative, marking it as a significant undertaking.

We have found that these elements not only enhance the training sessions, but also have a lasting impact throughout the partnerships and beyond. When parents' hectic schedules have on occasion forced us to conduct training individually, we were able to convey the main points of the curriculum, but something essential was clearly lost.

Developing the Curriculum

As with other aspects of the Institute, the training program for Family Partners has undergone rigorous evaluation, and we have made small but significant improvements to it along the way. The sample agenda in Appendix B6 reflects our experience of the best combination of content, activities, speakers and sequencing. Several of the training materials we have used with success are also included in Appendix B.

The Institute's curriculum is based on the learning objectives on page 44. In addition to the knowledge and skills outlined by the learning objectives, we try to emphasize three key messages:

- **You are an expert.** You have been selected for this role because your knowledge and experience are needed to accomplish something important.
- **But you're not an expert on *everything*.** You cannot be expected to know everything about all children, all families, or all special health care needs.
- **Being professional has nothing to do with your résumé.** It has everything to do with being prepared, being courteous and friendly, respecting the expertise of others around you, and keeping your word.

The Institute uses a two-day format, with activity scheduled from 9:00 AM to 2:00 PM to coincide with the school day. A small-group format and time for informal interactions between presentations help create a friendly, welcoming atmosphere. Organizational Partners participate in a brief segment on Day Two, when they are paired with their Family Partners to establish first steps and a timeline for moving ahead on their work plans.

In addition to Institute staff and partnership alumni, speakers include family leaders from other organizations in the state. Their participation not only supports our learning objectives but also enriches the experience. Rather than list individual speakers by name on our sample agenda, we have provided a description of the type of speaker most appropriate for each activity.

Interestingly, many of our Family Partners had been unfamiliar with the richness and diversity of family resource organizations in the state when they became involved with the Institute. (If anything, they knew about diagnosis-specific support programs but were much less aware of programs serving families across the diagnostic spectrum, including in specialty areas like recreation). Family Partners became aware of many of these resources through the training program and over the course of developing their own individual roles.

**TRAINING FAMILY PARTNERS
FOR THE ROLE:
Learning Objectives**



1. Participants will have a broader understanding of the existing system of services for CSHCN and the organizations working to improve that system.
2. Participants will have a greater sense of their own role as Family Partners. They will understand the unique contributions family members can make to health care policy and financing; be familiar with the basic history of the family involvement “movement” and a set of underlying principles; and understand the importance of partnership from both the family and the organizational point of view.
3. Participants will be better prepared to work effectively within an organizational structure, especially on a short-term, intermittent basis. They will be able to introduce themselves in their new role clearly and confidently, and will have a greater knowledge of confidentiality issues, professional boundaries, and other special considerations involved in working in health care organizations.
4. Participants will be better able to assess and respond appropriately to challenges that may arise while working in organizations that serve CYSHCN and their families. They will have a greater understanding of **whether**, **when** and **how** to share their personal stories to enhance their effectiveness.
5. Participants will be familiar with the role of mentoring in family leadership development, and will have been introduced to their own Mentors.
6. Participants will know what is expected of them in terms of procedural requirements related to contracting, timesheets, evaluation and weekly reporting. They will know whom to contact and how, should they have questions or need help about any aspect of the partnership.
7. Participants will leave the training with a preliminary work plan and a set of next steps, a collection of resource materials and procedural forms, and a system for keeping it all organized.

Training Materials for Family Partners

The package of training materials we give to participants reinforces the message that this is the start of an important new venture. It contains several types of information:

- **Background information** about family-professional partnership and the Institute; our statement of partnership principles; an overview of each partnership in the group.
- **Training program materials**, including a two-day agenda, summary of key messages, handouts for specific activities and presentations, an evaluation form.
- **Customized materials** for each Family Partner: work plan with estimated hours, contact information for the Organizational Partner, the Mentor and the Institute.
- **Administrative forms**, such as timesheets or reporting forms.
- **Resource publications**. These publications enhance the sense of professionalism Family Partners bring to their roles.
 - *Directions: Resources for Your Child's Care*
Massachusetts Department of Public Health, Second Edition, 2004.
 - *Essential Allies: Families as Advisors*
E. Jeppson and J. Thomas, Institute for Family-Centered Care, 1994.
 - *Family Reflections: A Thought-Provoking Guide to Getting Help for Children & Youth with Special Needs*
Central Massachusetts Partnership, 2005.
 - *Resource Directory*
Family TIES of Massachusetts (current edition).
 - *Words of Advice: A Guidebook for Families Serving as Advisors*
E.S. Jeppson and J. Thomas, Institute for Family-Centered Care, 1997.
 - *Rules for the Road: A Handbook for Consumers Serving in Leadership Roles*
The Genetics Services Branch, Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, U.S. Health Resources and Services Administration, 2005.
- **Supplies**: We have found a notebook or pad of paper, pen, and a sturdy, attractive and labeled accordion folder to be most useful and appreciated.

TOOLS TO USE

- Appendix B2. Guiding Principles of Family-Professional Partnership
- Appendix B6. Family Partner Training Program Agenda
- Appendix B7. Sample Training Activity: Imagine: Case Studies for Family Partners
- Appendix B8. Sample Training Activity: Telling Your Personal Story



7. Knowledge + Tools = Confidence

Training Family Partners for the Role





8

The Buddy System

Adding Mentors to the Mix

The Institute assigns every Family Partner a Mentor. Like Family Partners, Mentors have personal experience raising children with special needs. Unlike most Family Partners, though, Mentors also have experience working with organizations that serve children and families like theirs.

A Mentor's primary role is to advise, support and encourage the Family Partner. **How** the Mentor does this depends on the Family Partner's particular needs. Mentoring might include recommending a relevant Web site, counseling on office politics, or even providing direct support in performing the tasks in the work plan.

Some activities, however, are so central to creating a mentor-mentee relationship that the Institute prescribes them. Mentors are required to participate in the Family Partner training program; to have coffee or lunch with the Family Partner within the first two weeks of the partnership; to make at least one site visit and meet the Organizational Partner; and to be in touch with the Family Partner at least once a week. Mentors receive a stipend for their six-month commitment, and are encouraged to participate in Alumni Network events.

Beyond supporting Family Partners in their current projects, Mentors also provide something else: a personal introduction to the world of advocacy, service systems, and family leadership. This isn't a separate set of activities, but rather a by-product of the mentoring relationship. Many Family Partners are first introduced to these topics during training, but now they have a tour guide, as it were, a model of family leadership in the form of a Mentor.

The partnership broker is responsible for recruiting Mentors, pairing them with Family Partners, and to an extent, facilitating those relationships. When assigning Mentors to Family Partners, we consider:

- What particular skills will be required of the Family Partner? Does the Mentor have experience in those areas?
- Is there a part of the role that the Family Partner is nervous or unsure about? How might the Mentor be able to help?
- Do the Mentor and Family Partner live or work reasonably close to each other?
- Does this pairing seem like a good personality fit?

While responsible to their assigned Family Partners, Mentors occasionally have contact with Organizational Partners, too. We make sure that Organizational Partners know about Mentors from the outset, and clearly understand the nature of their role.

ADDING MENTORS TO THE MIX: Where Mentors Come From



Every state has at least one family-run organization that serves children with special needs. Many of the family members who organize and staff these groups have become recognized leaders, with considerable knowledge, experience, and training. The years they have spent working on behalf of their own children and with their organizations have honed their public speaking and advocacy skills. They have developed confidence in telling their own stories, and in representing other families in a compelling way.

Not surprisingly, these family members are often in demand. State agencies, academic institutions, health-care organizations and legislative groups are among those who turn to experienced family members to represent the family perspective as spokespeople, advocates and committee members.

*So why would an experienced, in-demand family leader want to mentor another family member in a brokered family-professional partnership? Because: in addition to promoting the family perspective in a way that helps shape policy and programming, mentoring helps **create more family leaders!***

Whenever possible, we “officially” introduce Family Partners to their Mentors. This step helps create a smooth transition; from this point on, the Family Partner is encouraged to see the Mentor as a primary contact for support (although Institute staff remain an additional resource). The Institute provides guidelines for the relationship, makes sure the Family Partner knows what to expect, and checks in now and then to make sure they are communicating regularly. In a real sense, we are brokering this partnership, too.

At first, our Mentors participated on a volunteer basis, with largely unstructured guidelines for their interactions with Family Partners. During evaluation interviews, however, Mentors suggested we could greatly enhance the program by tightening up its structure and making the Mentor’s role clearer to everyone involved. We did so, adding a \$500 Mentor stipend for the six-month role.

Table 4. The Role of Mentors

Mentors Are...

- Seasoned family leaders.
- Personally and professionally experienced with the system of care for children and youth with special health care needs.
- Experienced at building family-professional partnerships.

Aims of Mentoring

- To support Family Partners in achieving their partnership goals.
- To nurture future family leadership. Through their Mentors, new Family Partners learn about and become part of the family leadership network in our state.
- To help the partnership broker evaluate the mentoring program.

Mentor's Responsibilities

- Become an ally to the Family Partner. Understand the particulars of the work plan; answer questions; share information and resources. Cheer successes; listen to frustrations; provide encouragement.
- Take the Family Partner to lunch or coffee within two weeks after the partnership starts. Submit receipts to the broker for reimbursement.
- Meet once a week with the Family Partner. Once a connection has been established, meetings can be by phone or even e-mail for a quick check-in.
- Make at least one visit to the partnership site with the Family Partner, as a representative of the brokering agency. Meet staff involved in the partnership.
- Track the kinds of support the Family Partner needs—and whether or not it was feasible to provide. A Mentor may not be able to meet all the Family Partner's needs, but is responsible for tracking them.
- Attend the Partnership Alumni event that is held during the six-month partnership.
- Attend at least one additional Alumni Network event after the completion of the six-month partnership.

Supports for Mentors

- The partnership broker has designated a senior staff member, herself a recognized and accomplished family leader, as the primary contact person for Mentors. She checks in with Mentors once a month.
- Mentors are encouraged to contact this staff person and each other to share the joys and challenges of mentoring a Family Partner.
- Mentors receive a \$500 stipend for their six-month role.

TOOLS TO USE

- See pages 77–78 for more specific information on family leadership organizations from which Mentors and advisors might be recruited.



9

Now It's Official

Making Contractual Arrangements

One of the most essential functions of a partnership broker is to help define appropriate contractual arrangements. For some of us, this may lack the excitement of designing the actual partnership projects, and it may involve a lot more red tape. But the very nature and necessity of these functions make having the services of a broker all the more valuable to an organization, which otherwise might throw up its hands and forget about trying to figure out family partnership at all.

The partnership broker has three primary tasks in this area: to create the Family Partner position; to establish an agreement with the Organizational Partner, and to define the parameters of the pilot partnership.

Task 1: Create a formal, part-time, temporary position for the Family Partner.

For most organizations, taking on a Family Partner is very different from hiring a new employee. For one thing, it hasn't been established that the position will continue beyond the first six months. Setting up a formal employee structure—establishing a new position, completing hiring forms, setting up payroll—may be too lengthy and involved a process to be efficient. Hiring the Family Partner as a consultant may be another option, but it also can be inefficient, as the organization would have to develop the agreement and handle invoicing and payment. In addition, state law has some very specific criteria about what makes a “consultant,” and Family Partner roles may or may not fit (see box, page 54).

Task 2: Define an agreement with the Organizational Partner.

In addition to formalizing the relationship between the Family Partner and the partnership broker, it is also prudent to formalize the relationship between the broker and the Organizational Partner. The Institute accomplishes this with an agreement document that is essentially the work plan described in Chapter 5. It delineates the tasks to be accomplished; estimates work hours for Partners and Institute staff, and states the total projected budget for the Family Partner's



stipend. Once signed by representatives of the organization and the Institute, it serves as a memorandum of understanding and indicates a readiness to move forward. (See a sample in Appendix B10.)

While expectations are usually clearly defined by this stage, we find certain areas worthy of extra attention. We make sure that:

- The Organizational Partner has a clear understanding of the Mentor's role and responsibilities, as described in Chapter 8.
- The work plan accounts for all aspects of the Family Partner's efforts, including time for such activities as e-mailing, making phone calls, filling out forms, and even participating in the site's Human Resource Department orientations.
- If the Family Partner will facilitate meetings, such as focus group or Parent Advisory Group meetings, the budget provides for related expenses such as meeting materials, supplies, refreshments, and parking.
- Family and Organizational Partners are instructed to contact the Institute as soon as they become aware of unanticipated activities, costs, time or other requirements of the partnership. Timely communication will help facilitate any adjustments to the work plan (and the budgeted stipend, if resources allow).
- Everyone knows what to expect in terms of participating in Institute activities , including evaluation interviews.

Task 3: Establish the parameters of a six-month pilot partnership.

The six-month timeframe is advantageous for several reasons. Partnerships have enough time to get up and running; everyone involved can get a realistic sense of the demands and the benefits—and whether it is something worth continuing. The six-month timeframe is also an attractive selling point to potential partners on both sides. Organizations and family members are both wary of long-term commitments of time and effort to something new, and unproven. The built-in end-point is reassuring. The broker's task here is to set beginning, mid-point and ending dates that are agreeable to the organization and mindful of potential family issues, such as school vacations.

MAKING CONTRACTUAL ARRANGEMENTS: The Fine Print



The Institute is a project of New England SERVE, which relies on the services of a fiscal sponsor, Third Sector New England (TSNE), a 501(c)3 organization. TSNE provides administrative and personnel support services to New England SERVE and its projects. Accordingly, the Institute works closely with TSNE staff in defining the terms of formal relationships with Family and Organizational Partners.

We hire Family Partners as temporary, part-time employees. We do this instead of having a contractual agreement, as one would with a consultant, in order to be consistent with Massachusetts labor regulations. This necessitates the added cost of a fringe benefit rate. (Because our Family Partners work less than half-time, they are ineligible to receive benefits other than workers' compensation coverage.) In light of the unique structure of the partnerships, however, and the reporting and monitoring systems described in Chapter 10, standard supervision and performance review requirements are waived.

At the Institute, Family Partners receive \$15 per hour. The work plan establishes a total budget by multiplying the hourly rate by the estimated number of work hours; this usually falls in the \$1800–\$2000 range.

TOOLS TO USE

- Appendix B10. Sample Organizational Partner Agreement and Work Plan
- Appendix B11. Sample Employment Letter for Family Partner





10

How Are Things Going?

Reporting, Monitoring, and Technical Assistance

Once the family-professional partnerships are underway, the broker's role shifts. Family and Organizational Partners are tackling their agreed-upon work plans; Mentors are usually the ones Family Partners contact for support. While not in the spotlight, however, the broker is still actively involved in each partnership: monitoring its progress, facilitating relationships, and providing technical assistance to organizations as needed.

To keep partnerships on track, we use a combination of paper and electronic reporting forms, telephone calls, and in-person meetings.

Staying in Touch with Family Partners

Family Partners are asked to submit a weekly Reporting Form to the Institute. The form captures basic information about the Family Partner's work that week: the number of hours, kinds of activities, and so on. Family Partners can fill it out and submit it online, print it out and fax it in, or use the printed forms and stamped, self-addressed envelopes we provide.

A sample question from the Reporting Form:

How did you spend your time on the partnership this week?

Check all that apply:

- | | |
|---|---|
| <input type="checkbox"/> Attending meetings with Organizational Partner | <input type="checkbox"/> Writing/document preparation |
| <input type="checkbox"/> Meeting with families | <input type="checkbox"/> Background research |
| <input type="checkbox"/> Phone calls | <input type="checkbox"/> Planning time |
| <input type="checkbox"/> Filling out forms | <input type="checkbox"/> Reading |
| <input type="checkbox"/> Contact/meetings with the Institute | <input type="checkbox"/> Travel |
| <input type="checkbox"/> Contact/meetings with Mentor | <input type="checkbox"/> Other (please describe): |

Originally, the Reporting Form also asked Family Partners to reflect a bit on the week's challenges, successes, and lessons learned. There was not much response. We have found this kind of reflection to happen much more readily either during individual telephone interviews or in group meetings of the Family Partners. Our expectations have changed accordingly: the quick and frequent Reporting Form does what it does best, by serving as a weekly timesheet that also tracks the basic progress of each partnership. Meetings and phone interviews, meanwhile, are occasions to pause and reflect on the bigger picture.

This sensible approach leaves us with one dilemma, however. Although we haven't yet found a satisfactory way to do it, we believe there is value in documenting the Family Partner's experience the week it happens. Tracking moments of satisfaction or frustration, feelings of accomplishment or disappointment, and other random yet critical milestones, would have at least two important benefits. First, Family Partners would be better able to articulate their experiences while they are still happening, share them with Mentors and other Partners and find support. Second, when enough Family Partners have documented their experiences, it may be possible to identify patterns. If new Family Partners know that it's common, for example, to feel overwhelmed for the first three weeks before finding a sense of equilibrium at the end of a month, they will be better prepared for it.

One possible solution is to adapt the Reporting Form so it retains its convenience but also encourages just a bit of reflection. It would be kept simple—number of work hours, a brief description of activities—with *one* additional question that requires reflection, *and the question would change every week*.

Weekly reflection questions might ask:

- Week 1. What surprised you most this week as you began your partnership?
- Week 2. What do you expect your biggest challenge will be?
- Week 3. What kind of support are you finding through your Mentor?
- Week 4. Has anything happened—big or small—that has given you a sense of accomplishment?
- Week 5. What if anything were you nervous or unsure about before your partnership started? How do you feel about it now?

Week 6. How do you think the people who work at your partnership site see your role there?

Week 7. How would you finish the following sentence? "Since I started this project, I've realized..."

In addition to the weekly Reporting Forms, the Institute asks Family Partners to be in touch with their Mentors once a week. We encourage face-to-face meetings especially at the beginning of a partnership, but telephone or even e-mail contact can work well, too. Being in touch regularly—and when things are going smoothly—gives the Mentor a context in which to provide the Family Partner with meaningful support when there are bumps in the road. With regularly scheduled check-ins, Family Partners are also more likely to ask for help when they need it.

Communicating with Organizational Partners

Like the Family Partners, the Organizational Partners are also asked to report regularly to the Institute about partnership activities, successes, challenges and lessons learned. The format and frequency of reporting, however, is a bit different. Organizational Partners complete an online Reporting Form every other month. In alternate months, they participate in a telephone interview with the Institute Director.

This approach generally works well, although the telephone interviews tend to yield much richer insight than the Reporting Forms. The interviewer is able to tailor the questioning, and the Organizational Partner responds in more depth. Interestingly, several of our Organizational Partners say they prefer the telephone call to filling out the form, even though it may take more of their time.

One Organizational Partner suggested that it might be worthwhile to have the Family Partner and Organizational Partner share their completed forms with each other or even complete them together. We discouraged this approach. For both Partners to feel free to be completely honest about their experiences, it is important to preserve the privacy of their responses.

While Family Partners have Mentors to advise and support them, Organizational Partners are offered additional support from Institute staff. We make sure to visit each organization at least once—and preferably two or three times—during a six-month partnership to assess:

- Are the tasks in the work plan being achieved within the estimated timeframes?
- What's working well? Are there aspects of the project that the Partners are feeling particularly positive about?
- What challenges have come up? How are the Family and Organizational Partners addressing those challenges, and how can the Institute help?
- Are revisions needed to the work plan, budget, or overall goals?
- Are there important "lessons learned" that would be useful to incorporate into future partnerships?

The Institute provides technical assistance according to the organization's particular needs. We may help revise a work plan, find informational resources, brainstorm ways to solve a problem, or do some general troubleshooting.

Bringing the Partners Together

With the regular reporting procedures and individual meetings outlined above, most problems can be identified early and resolved quickly. But the Institute has also found it helpful to gather all the Partners and Mentors together at least once during the course of the partnerships. These meetings have not only afforded an opportunity to share ideas and seek support, but also been a powerful force in creating a bond among the participants: a strong sense of identity as a group involved in an important endeavor.

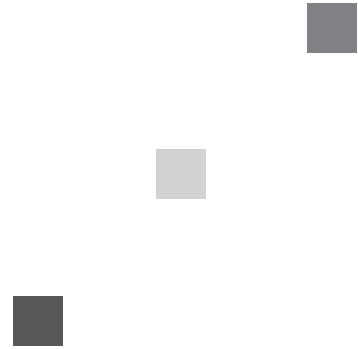
We have held some mid-term meetings with Family Partners exclusively, and some with all Partners and Mentors. The frequency of the meetings has been driven to a certain extent by Partners' availability and scheduling needs. The availability of funding to compensate Family Partners for their time may also be a factor.

At mid-term meetings, Family and Organizational Partners are asked to speak briefly to the full group about their partnerships. The instructions we send in advance ask each pair to prepare their remarks together and present as a team. While we are not looking for formal presentations, it is important that Partners discuss the topics we ask them to address and decide together how they would like to present them. We make it clear that our purpose is to learn from and support each other, not to evaluate the outcomes of any individual project. Challenges and disappointments are to be included along with achievements and success stories.

Specifically, we ask Partners to share:

- A quick review of the partnership organization and the Family Partner's role
- Critical updates, such as milestones reached or any changes to the Family Partner's role
- What has worked well and why?
- What hasn't worked well and why?
- What has each Partner learned or gained from the partnership?

The information we gather through all of these vehicles—reporting systems, mentoring, individual and group meetings—helps us keep individual partnerships on track. It also continually enhances our effectiveness as a partnership broker. Each experience teaches us more about assessing partnership readiness, defining roles, setting realistic goals, and providing assistance and technical support.





Getting Better All the Time *Evaluating the Partnerships*

Evaluation has been a key component of the Institute’s activity. We have consistently gathered information to assess not only the effectiveness of individual partnerships, but also the structure and components of our own program. Many improvements have been made as a result of feedback from surveys, interviews, and group discussions with participants.

Ongoing evaluation happens through the reporting forms, telephone calls and meetings described in Chapter 10. These allow us to follow the week-by-week progress of the partnerships, to understand strengths and address challenges of the program as they occur.

The Institute has not analyzed these reporting data in any structured way, nor does it seem necessary to do so. But as Chapter 10 also describes, our reporting mechanisms could be improved. If future versions collected more and better information, possibly in an easier-to-use format, they could be a rich source of data and insights about the partnerships. In the meantime, informal reviews of the data collected have certainly been useful.

The Family Partner training program and the Alumni Network events are evaluated via a survey distributed to attendees. Additional, in-depth evaluation occurs at “end-of-partnership,” that is, the end of the six-month pilot. Evaluation methods at this stage have included:

- Online surveys of all Family and Organizational Partners
- Group meetings
- Exit interviews with each of the Organizational Partners, and
- Telephone interviews with Family Partners and Mentors.

While each of these methods has given us useful feedback, it isn't necessary to use all four at the end of every set of partnerships. We have found the onsite exit interviews with the Organizational Partners, however, and the telephone interviews with Family Partners, to be critical. The fact that they are described near the end of this chapter is an indication of their chronological position in the process, not their importance.

Online Surveys

The Institute has used the free version of the online survey tool, SurveyMonkey (www.surveymonkey.com), to create online surveys. It enables us to ask questions with either multiple choice or open-ended responses, and it collects the responses and analyzes them in graph and chart form.

We have used this approach in advance of group meetings to prompt thinking about topics on the agenda, and then use the responses to help us guide the discussion. We have also used it to survey the Family and Organizational Partners directly about their partnerships and the technical assistance they received from the Institute.

One advantage of the online survey is anonymity for respondents, but only respondents with internet access can use it. We mailed a printout of the survey to family members who weren't able to complete it online; their insights were preserved but their anonymity was not.

Even with its professional look and results, the survey is best interpreted with caution. The numbers of respondents being surveyed are very small so the results can, at best, be viewed as providing "insights" rather than "statistics."

End-of Partnership Group Meetings

The Institute has held a group meeting at or close to the conclusion of each cohort of partnerships. One of these meetings was attended by only the Family Partners and Mentors; the others also included the Organizational Partners. For us, the most meaningful discussions resulted from the more inclusive meetings. However, we can also imagine situations where having a meeting of Family Partners only would be preferable.

At these meetings, participants from each partnership give a progress report on their activities. They talk openly about successes, challenges and lessons learned, and they share samples of materials that were developed over the course of the partnership.

This final meeting is important for both evaluation and networking, so special care is taken to assure that as many as possible can attend.

Telephone Interviews of Family Partners and Mentors

As part of the evaluation process, the Institute has had a consultant or other independent party interview Family Partners and Mentors over the telephone.

Interview questions explore:

- The personal impact of the experience on the Family Partner;
- The perceived impact of the partnership on the organization;
- The kinds of support that helped the Family Partner, such as the training program, Mentors, etc.;
- The usefulness of Alumni Network events; and
- Anything else the Family Partner cares to share.

These interviews have provided a wealth of detailed commentary and insights, which have been used to improve the components and overall structure of our program. In addition, quotes excerpted from these interviews have been used (with permission) to enhance marketing and fundraising materials.

When feedback from Family and Organizational Partners drew our attention to weaknesses in the mentor program, the Institute decided to conduct in-depth telephone interviews with the Mentors, too. Our primary goals were to understand the problem better and hear from the Mentors themselves about potential solutions, but we also took the opportunity to solicit feedback on the Institute program as a whole, and to assess Mentors' interest in continuing to participate in the Alumni Network and other activities. An independent consultant was engaged to conduct these interviews, and they led us to make substantial improvements to the mentor program.

Exit Interviews with Organizational Partners

The final step in the Institute's evaluation process is to meet with the Organizational Partner onsite for an exit interview. Discussion questions for this meeting are sent to the site in advance, and are reproduced in Appendix B12.

These exit interviews are a critical component of our evaluation activity. A face-to-face meeting held at the end of a six-month partnership pilot yields information that is important not only for understanding the specific accomplishments of the partnership, but also for improving aspects of our own performance as brokers. What's more, it can be an important step in cementing the organization's commitment to continuing family-professional partnership, and even provide insights for to finding financial support for the program.

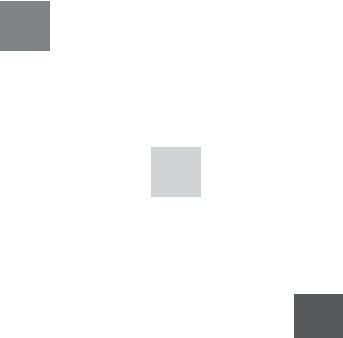
Often there is more than one person from the organization present, including those who have worked most closely with the Family Partner and those who champion family-professional partnership within the organization. When possible, more than one person from the Institute also attends. This has helped Institute staff and Advisory Board members to enhance their involvement in and understanding of the Institute.

TOOLS TO USE

- Appendix B12. Exit Interview for Organizational Partners

STRUCTURE & Spark!

Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs



Part III.

Building a Partnership Network



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12

Built to Last

The Broker's Involvement Ends, the Partnerships (Usually) Don't

As a partnership broker, the Institute is committed to facilitating family-professional collaborations that have a future. We are looking for Organizational Partners that, given the success of a six-month pilot partnership, want to find a way for it to continue.

This doesn't necessarily mean that the original Family Partner will continue in the role, nor does it mean that the original role or project won't end. It does mean that the organization has an ongoing commitment to partnering with consumers, particularly family members of children with special health care needs. We make this clear to organizations from the outset: participation in the Institute's program is not intended to be a quick fix.

We have learned that it doesn't take very long for organizations to realize all that can be gained from the direct involvement of a Family Partner. The Institute has demonstrated that in six short months, working an average of four to six hours per week, a well-supported Family Partner can accomplish quite a lot. What's more, that time period is more than sufficient for Organizational and Family Partners to decide that partnership is worth sustaining. Nearly all of the Institute's 16 partnerships continued beyond their formal pilot period, and most continue today in some form.

The key change, at the end of six months, is that the Institute is no longer actively involved in the partnership between organization and family member. The routine reporting, monitoring and technical assistance ends, and the Institute no longer pays the Family Partner stipend. If the partnership is to continue, the Organizational Partner must find a way to sustain it financially and administratively. The Institute can help plan this transition, and we make a point to discuss it with the organization as the end of the pilot period approaches.

Our Organizational Partners have used a number of different arrangements to sustain partnerships:

- The organization may hire the Family Partner, either as a part-time employee or as a consultant. If the Family Partner is working on a grant-funded project, the position or consulting fee may be written into the grant.
- Sometimes funding is unavailable for a new Family Partner position, but *is* available for another staff position. The organization may expand the Family Partner's role to include other duties, and thus access that funding.
- One large organization we worked with had no readily available funding for a Family Partner. The six-month pilot, during which the Institute paid the Family Partner stipend, gave the organization the time it needed to identify funds and make some adjustments in the budget.
- Smaller community organizations—those that are staffed by volunteers or have very limited funding—have had Family Partners agree to stay on as volunteers. In one case, a committed Family Partner decided to continue and even expand her role on a volunteer basis; about six months later a new management team took over and began providing financial support for her role.
- Alternatively, these smaller, volunteer-staffed organizations might be able to identify other ways to compensate a Family Partner: by providing free tuition or childcare, for example.
- In one instance where a Family Partner agreed to stay on as a volunteer, she happened to be employed elsewhere full-time. Her employer was aware of and proud of her involvement. The Institute sent a letter to the employer expressing appreciation for the contribution of employee time, and the employer has permitted her serve in her Family Partner role on company time ever since.
- Sometimes an individual Family Partner is unable to continue in the role for personal reasons: a new job, a family move, a child's health care needs. Having participated in a successful brokered partnership, the organization is eager to recruit a new Family Partner, and has the tools and the experience to do so.

Given the enormous potential impact of having the continued involvement of a Family Partner, the overall cost to an organization is not large. We have found this to be true even if the cost of employment benefits is added, or wages increase because the role or the hours expand. For most of our Organizational Partners, however, cost has not been a deterrent to pursuing continued partnership.

13

Let's Do More Than Lunch *The Alumni Network*

From the outset, the Institute planned to create something larger than individual partnerships. We knew that families of children with special health needs derive tremendous benefits from networking and supporting each other, so bringing the Family Partners together seemed natural. Rather quickly, we learned that:

1. **Our Family Partners were eager for this kind of connection.** Before we even began to organize the first alumni event, they requested that we plan one.
2. **Our Organizational Partners were, too!** We were delighted to discover that Organizational Partners wanted not only to network with their counterparts at other organizations, but also to connect with other Family Partners and Mentors in an ongoing way.

It was at this point, at the end of our first cohort of partnerships, that the Institute realized what a powerful new network we were helping to build. It was something we clearly wanted to sustain. And thus the Family-Professional Partners Institute Alumni Network was born.

Alumni Network events offer valuable opportunities for connection and learning. Participants update each other on continuing partnership activities, and share information on other topics as well. One event, for example, was a three-hour session with an educational component on the topic of the interaction of culture and disability. Family and Organizational Partners representing the Asian, Eritrean, and medical communities spoke on cultural views of disability. (For the purposes of this activity, we viewed the medical community as a subculture.) The event also included a brief overview of each of the 16 partnerships—presented by one or both of the Partners involved—and a chance for participants to network informally.

To date, all of the Institute's Alumni Network events have brought together participants from all partnership roles, but we have considered having future gatherings that focus on a particular group. Family Partner Alumni, for example, might be offered workshops on software programs, presentation skills, or "Resume Writing for Parents of Children with Special Needs." Sessions for Organizational Partners might focus on topics like Medical Home, or health policy initiatives related to CYSHCN. As the Alumni Network grows, there might also be value in narrowing even further, with networking events, for example, for Family Partners who are organizing or leading Parent Advisory Councils; or Organizational Partners who represent health plans.

In the meantime we have made it easier for current and past Partners to contact each other by providing them with a directory. The directory provides brief descriptions of the Institute's partnerships and contact information for the Partners and Mentors involved.

14

Seeing the Big Picture

The Advisory Board

An extremely effective and helpful Advisory Board has guided the Family-Professional Partners Institute at every phase of activity. It has helped us ask important questions about strategic direction, guided our decision-making about activities and components of the program, and addressed issues of building broader awareness of the Institute and sustaining it over time.

Providing perspective in both short-term and long-range planning, the Advisory Board actively advises staff on:

- Marketing the Institute’s services and designing communication vehicles and messages;
- Identifying potential Partners;
- Designing training and technical assistance programs to be offered to Family and Organizational Partners;
- Setting priorities for building particular family roles and developing partnerships with particular organizations; and
- Defining the Institute’s mission, identifying potential sources of financial and administrative support, and developing strategies for the Institute’s sustainability.

In composing the Advisory Board, we thought carefully about the membership needed to ensure a range of viewpoints. We extended invitations to prospective members with a variety of organizational affiliations, family experience, and experience in consumer-professional collaboration. They represented family leadership organizations, health plans, health policy organizations, state agencies, academic institutions and individual families of CYSHCN.

The Institute's Advisory Board currently has 14 members and meets three to four times a year. It is chaired by one of the members and staffed by the Institute Director. Of the 14 members, six are parents of a child, young adult or adult with special health care needs.

THE FAMILY-PROFESSIONAL PARTNERS INSTITUTE Advisory Board

Paul Thayer, MA, MDiv, Chair
Assistant Professor of Child Life
and Family Studies
Wheelock College

Anton B. Dodek, MD
Medical Director, Pediatrics and
Pharmacy
Tufts Health Plan

Susan G. Epstein, MSW
Executive Director
New England SERVE

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

(P) **Linda C. Freeman, MS**
Director of Family Initiatives
New England SERVE

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

Laurie Glader, MD
Medical Director, Cerebral Palsy
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(P) **Suzanne H. Gottlieb**
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(P) **Lisa Lambert**
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Priscilla Meriot, RN, MS
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Neighborhood Health Plan

Sara Miranda, MSW
Associate Executive Director
Federation for Children
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(P) **Susan Nadworny**
Northeast Regional Coordinator
Massachusetts Families Organizing
for Change

Sylvia Stevens-Edouard
Senior Director of Children's
Health Initiatives
Blue Cross Blue Shield of Massachusetts

Marji Erickson Warfield, PhD
Starr Center for Mental Retardation
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.

15

So You Want to Be a Partnership Broker

Replicating the Institute's Model

By documenting the activities of the Family-Professional Partners Institute, we hope to inspire others to replicate our model and build on our success. Perhaps the most important message we can share with potential partnership brokers is this: know that it's possible.

- It is possible to design, establish and sustain new, meaningful roles for family members in health-care and community organizations.
- It is possible to nurture new family leaders from diverse communities, whether or not they have had previous experience.
- It is possible to establish or expand consumer participation in large health plans, small human service organizations, private universities, public clinical facilities, and on and on.
- It is possible to overcome significant organizational challenges to establish very effective partnerships.
- It is possible to demonstrate the value of a particular partnership in just six months.
- It is possible to create a lasting network of professionals and family members who are committed to fostering successful collaborations.

The Institute undoubtedly has had some important advantages in establishing itself as a partnership broker. Developed under the auspices of New England SERVE and the Massachusetts Consortium for Children with Special Health Care Needs, it had ready access to an extensive network through which we could survey our environment (as described in Chapter 3), and recruit organizations (Chapter 4), Family Partners (Chapter 6), and Mentors (Chapter 8). But we believe there are a variety of other organizations that are well-situated for the role.

Some of them would be, like the Institute, external to the organizations hosting family-professional partnerships, and could therefore build them at a range of sites. These potential partnership brokers include:

- Public health departments, particularly those programs that work to improve maternal and child health or services for children and youth with special health care needs;
- Consumer or family advocacy organizations (which, depending on their focus, might need to take extra care to ensure neutrality as brokers);
- Organizations that promote health care quality or access to health care; and
- Professional or industry organizations, such as those that serve pediatric clinicians, hospital administrators, or health plans.

On the other hand, an “internal third party” doesn’t have to be a contradiction in terms. A large children’s hospital, for example, might establish a family-professional partnership broker in a central department, such as human resources, which would administer partnerships throughout the organization. The same could be true for clinical practice groups, health plans, universities or medical schools. In any organization, the brokering team should reflect both sides—family and professional—to model the partnerships to be established.

The success of one Institute-supported partnership at a children’s hospital sparked interest in family-professional partnerships among other departments there. What better way to encourage interest by having an in-house partnership broker who can build and support partnerships throughout the organization?

Realizing that the specifics of implementation will vary, we offer the following as general steps to establishing a partnership-brokering program:

1. **Bring together an initial planning group.** Consider including individuals from inside and outside your organization to get a range of perspectives. This group can be the beginnings of an Advisory Board (Chapter 14), but begin by inviting them to a single brainstorming meeting. The purpose of the meeting is to explore the model of brokered family-professional partnerships, and the potential fit for your organization. If attendees are already familiar with *Structure and Spark*, so much the better, but if not, excerpts can be shared at the meeting. Activities might include brainstorming potential partnership sites, ways of recruiting Family Partners and Mentors, and possible sources of funding.

2. **Create a statement of purpose.** What *is* family-professional partnership, and why do you want to promote it? Are you primarily interested in building a series of individual partnerships, or do you also want to create an ongoing partnership network (as described in Chapter 13)? Review the Consortium’s policy statement (Appendix B1) and New England SERVE’s guiding principles (Appendix B2) as you develop a statement that is uniquely your own. If possible at this stage, you might also want to take on some additional scanning and planning activities (Chapter 3).
3. **Map out staffing and other logistics.** How many family-professional partnerships will you launch at once? The Institute has never had more than six at a time, as a function of staffing. But perhaps your organization has twelve departments and you’d like to create a partnership in each one. Is geography a factor? Perhaps you’ll limit your partnership sites to those within a certain distance. Will you be able to contract with Family Partners as consultants or temporary employees (see Chapter 9)? Have an initial conversation with Human Resources.

The Institute’s program—with four to six concurrent partnerships at the same number of different organizations—has required an average of ten to fifteen hours per week of the program director’s time and about two hours per week of administrative support. We have also had support from communications staff with the development of print and web site materials, and from senior staff with long-range planning and supervision. There are definitely periods of increased activity, especially during site recruitment and screening (Chapters 4–5), training (Chapter 7) and evaluation (Chapter 11).

For some activities, such as sending out recruitment e-mails or organizing Family Partner training sessions, the hours of staff time required are relatively unaffected by the number of partnership sites. But for other activities, the time requirements can vary greatly for the broker. Partnerships vary in how much time is needed for work plan development, Family Partner recruitment, technical assistance throughout the partnership, individualized support to Family Partners, and evaluation activities. As more partnerships are undertaken, the broker’s role expands accordingly.

When planning for staffing needs and the other logistical aspects of the program, be generous in your estimations of how much time is required for each phase. Planning a training session for Family Partners, for example, should begin no less than three months in advance; it takes time to create materials and line up speakers, and it's important to provide enough notice to maximize attendance.

At the Institute, we have found that while our program is labor-intensive, providing extra support, making frequent contact with Partners and being available to provide one-on-one assistance goes a long way to ensuring successful and sustainable partnerships.

- 4. Find the funding.** Who will pay Family Partners for their time? Plan to underwrite the first six months of Family Partner stipends, at approximately \$1,800–\$2,000 per partnership, or to work exclusively with Organizational Partners who are willing and able to do so—at least in the beginning. Over time, a successful track record of partnerships may put a broker in a position to command fees from larger, well-funded organizations that will be enough to subsidize partnerships at smaller community organizations with limited means.

Budget for any promotional materials you will need to get the word out to recruit Organizational Partners. Depending on geography, budget, and other considerations, this can be done via announcements in print or e-mail newsletters; bulk mailing of a letter, postcard or brochure; flyers posted in key organizational locations; or presentations at meetings of potential Organizational Partners. An internal broker may be able to do this with little or no expense. At the very least, a partnership broker should have a simple flyer describing its services; this will be important to share at initial site visits.

Other expenses to plan for: your own staffing time; Mentor stipends; meeting and travel costs.

- 5. Mine your network—and expand it if necessary.** Ideally, the potential partnership broker will already have a base of contacts rich in potential Organizational Partners, Family Partners, or both. A health plan considering the role of internal broker, for example, might interview department heads throughout the organization, and explore the possibility of contacting its members who are parents of CYSHCN. To find experienced family leaders to serve as advisors, trainers or Mentors, we recommend that brokers:

- Find your state's chapter of Family Voices:
<http://www.familyvoices.org/states.php>
- Find your state's Parent Training and Information Centers and Community Parent Resource Centers:
<http://www.taalliance.org/Centers/centerlist.htm>
- Find other family leadership organizations:
<http://mchb.hrsa.gov/2010express/Express2010.htm#FAMILY>

Again, it's a good idea to have some print material to send or a web site these organizations can refer to.

6. **Learn from experience.** Whatever system you use, establish some way to capture what happens in each partnership and why. Monitor the partnerships as they unfold (as described in Chapter 10) and evaluate them as they conclude (Chapter 11). Each partnership is a unique experience, offering its own set of lessons, dynamics and opportunities. Each one adds to a broker's understanding of what it takes to create successful collaborations, and yields new ideas about where and how family-professional partnerships can make a difference.
7. **Stay committed but flexible.** Building and nurturing family-professional partnerships is a time- and labor-intensive enterprise. There are bumps along the way. Flexibility is essential, whether in scheduling meetings and training sessions, providing technical assistance, or accommodating Partners' needs. But the impact we make is absolutely worth the effort. It is with this awareness and confidence that we describe the Institute's program to potential Partners, and now too, to potential other brokers.

Finally, we hope you will contact the Institute for consultation if you'd like to explore how we can help establish your partnership brokering program. We firmly believe that this model, in which a third party administers family-professional partnerships, is the cornerstone of the Institute's success. We have learned a great deal about how to build sustainable partnerships that help improve care for children and youth with special health care needs, and we are excited to share what we've learned.

The Family-Professional Partners Institute

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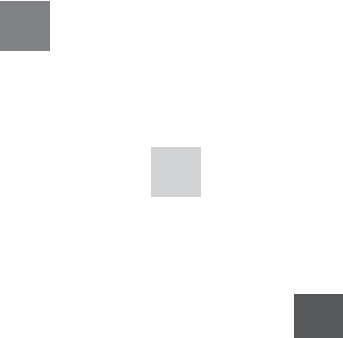
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STRUCTURE & Spark!

Building Family-Professional Partnerships to Improve Care for Children with Special Health Needs



Appendix A.

The Institute's 16 Partnerships

CLINICAL SITES

1. Affiliated Pediatric Practices, Needham, MA

Affiliated Pediatric Practices (APP) is a network of 17 independently-owned, Massachusetts-based community pediatric practices. A Family Partner was recruited to create a group-wide Parent Advisory Council (PAC) that would include parents and practice staff. The Family Partner:

- Created a practice-wide advisory council with 7 family members and 7 pediatric medical representatives, and led PAC meetings.
 - Guided the PAC in creating a handout about community support programs for children with special health care needs to be distributed to families by all 17 practice sites.
 - Was hired by APP at the end of the Institute partnership to continue facilitating the PAC as a consultant.
-

2. Children's Hospital Boston, Boston, MA

Complex Care Service

The Complex Care Service program provides medical care to children with genetic disorders, birth defects and chronic complex health care needs. It has a caseload of 2,000 families, and wanted a Family Partner to create a Parent Advisory Group. The Family Partner:

- Organized a Parent Advisory Group (PAG), guided the development of its vision and mission, and led two meetings of the full PAG and two subcommittee meetings.
- Facilitated PAG projects including the creation of a Complex Care Service brochure for staff to distribute to families.

3. Massachusetts Hospital School, Canton, MA

The Massachusetts Hospital School (MHS) is a publicly funded residential and day school for children with disabilities. To enhance its monthly orientation sessions for new employees, it wanted to incorporate a family perspective.

The Family Partner:

- Developed monthly training for new MHS employees, given by 2 parents and 2 students, addressing their experiences and expectations as families.
- Implemented a procedure to evaluate the new training, which received very positive feedback.
- Initiated meetings between MHS Case Management staff and families, which led to additional family involvement at the school.

4. UMass Memorial Children's Medical Center, Worcester, MA *Pediatric Primary Care Clinic*

This pediatric primary care clinic, located at the university hospital, sought to launch a Parent Advisory Group (PAG) to include community leaders, families of children with special health care needs and clinic staff. The purpose of the PAG was to examine ways to enhance services at the clinic and to identify potential roles for family members within the clinic. The Family Partner:

- Recruited family members and professionals to participate in a Parent Advisory Group.
- Organized and facilitated the PAG's first meeting.

HEALTH PLANS

5. Beacon Health Strategies, Woburn, MA

Beacon Health Strategies is a behavioral health managed-care organization with over 1.4 million members. It sought a Family Partner to refurbish, re-energize and facilitate its Member Advisory Council, ensuring member participation and a focused agenda so that the member voice and perspective are heard at the management level. The Family Partner:

- Recruited new members to the Member Advisory Council, gained their commitment and developed a focused agenda.
- Organized and led the Council's first two meetings.
- Contracted with BHS as a consultant after the Institute partnership, taking on a role that has expanded into staff training and policy areas.

6. Blue Cross Blue Shield of Massachusetts, Boston, MA

Juvenile Diabetes Management Program

With 3 million members, Blue Cross Blue Shield of Massachusetts is the state's largest commercial health plan. To help develop its Juvenile Diabetes Management Program, it convened a planning board with representation from many different departments at the health plan and engaged a Family Partner who:

- Educated and advised the planning board about family experiences managing juvenile diabetes, providing essential background information to assist staff in designing a program that could minimize health crises and maximize family connections to needed resources.
- Helped BCBSMA identify important next steps and linkages with external support organizations and develop a plan of action to implement the program.

7. Harvard Pilgrim Health Care, Wellesley, MA

Member Services Department

This nationally recognized health plan wanted to create a training module for the Member Services Department, so that staff would know more about children with special health care needs, particularly the challenges their families face and the resources that can help.

- The Family Partner trained 60+ staff members of the Member Services Department using a specially developed curriculum; 5 sessions were held with about 12 participants in each.
- A new Web page was created as a resource for families with children with special health care needs; it is used by staff who in turn refer families to it.
- The initiative was highlighted in an internal HPHC newsletter, and a staff member received an employee recognition award for her involvement.

ACADEMIC AND RESEARCH SITES

8. Boston University School of Public Health, Boston, MA

Maternal and Child Health Department

Graduate-level training in Maternal and Child Health (MCH) prepares those who will design programs, set policies, and advocate for systems that will improve the health of women, families and communities. The B.U. School of Public Health wanted to increase family perspectives in its MCH curriculum, and determine what roles family members could play. The Family Partner:

- Created surveys for students and faculty to assess the status of family involvement and identify specific needs.
- Administered the surveys, conducted follow-up interviews, and developed a set of recommendations for the MCH Department.
- Was hired by the School as a part-time employee to continue the role. In addition, the family partnership model was written into the grant that funds the MCH training program.

9. 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 was recruited to assist a PICU physician with his research on barriers to optimal critical care for children with special health care needs.

- The Family Partner participated in all aspects of the study, including study design, recruitment, data collection and analysis.
- Families were interviewed by the physician and Family Partner together using an interview guide the Family Partner helped develop.
- The PICU is implementing changes based on the research findings. In addition, "Children with Special Health Care Needs and Critical Care: Listening to Families" was submitted to the journal of the American Academy of Pediatrics with both partners as co-authors.

10. 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. (That is, how well can these parents find and understand the information they need to make decisions about their children's health?)

The Family Partner:

- Prepared a review of existing literature, helped create data collection materials, and participated in interviews.
- Developed a comprehensive inventory of "Health Literacy Competencies, Skills and Abilities of Parents of Children with Special Health Care Needs."
- Continues as a member of both the research team and the HSPH Health Literacy Group, which includes senior-level academics and practitioners from a variety of institutions.

11. Opening Doors for Youth with Disabilities and Special Health Care Needs, Boston, MA

Children's Hospital Boston and the Institute for Community Inclusion (ICI) at UMass Boston

Opening Doors is three research projects in one. Project Solutions helps identify special needs early among culturally diverse communities; Project Adventure helps children with special health care needs participate more fully in recreational activities; and Project Connection helps youth with disabilities plan for college and careers. The Family Partner:

- Participated in a consumer advisory group to provide input from families to the project, and contributed to the development of project tools.
- Provided training for staff and families as part of her role in Project Adventure.
- Was hired by the ICI and Opening Doors with added responsibility for reaching out to the area's diverse communities and assisting in enrollment for the three projects.

12. Simmons College, Boston, MA

Department of Sociology

A faculty member in Simmons' Department of Sociology is doing a five-year research project on "Transition to Adulthood Among Youth with Disabilities." In addition to examining quantitative data, she is also conducting in-depth, qualitative interviews with 60 youth and their parents. The Family Partner:

- Assisted in the qualitative component of the research, helping to design the interview guide and train the interviewers.
- Organized two advisory councils for the project, one made up of parents and the other of youth with disabilities; recruited members and led meetings.
- Was unable to continue in the role but reinforced the researcher's commitment to continue working with a Family Partner.

COMMUNITY-BASED ORGANIZATIONS

13. Eritrean Community Center of Greater Boston, Roxbury, MA

Staffed by volunteers, the Eritrean Community Center (ECC) serves about 1,000 of the estimated 6,000 Eritrean families in the Boston area. The board wanted to reach out to parents of children with special health care needs, create a support group, and develop recommendations for next steps. The Family Partner:

- Spoke at Eritrean cultural events in the community, introducing herself as the parent of a child with special needs and encouraging others to do the same; and shared information about the ECC's new plans for family support.
 - Organized informational and networking meetings for parents, with speakers from Opening Doors, Family TIES and the Boston Center for Independent Living.
 - Helped link individual families with services and supports they needed.
-

14. Great Wall Center, Inc., Malden, MA

The Great Wall Center offers culturally relevant social service programs for the growing Asian community in Malden. It wanted to expand its 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. The Family Partner:

- Developed a detailed list of ideas and strategies to increase active membership, offer more family activities and engage popular speakers.
- Presented her ideas to the members of the Parent Association and gained their enthusiastic support.
- Organized events to provide support for parents and recreational activities for families.

**15. 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. To increase the number of families it serves, and to expand services to families of children with other special health care needs, HAPHI's Family Partner:

- Worked with the Family Governing Board to prioritize families' needs in the areas of health care, education, recreation, advocacy and independent living.
- Organized an event with Family TIES, a statewide family support and parent-to-parent network, to inform families about resources in the community.
- Collaborated with the Medical-Legal Partnership for Children to teach families about their children's educational rights.

**16. 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. MLPC wanted to identify concrete roles for family members that would help ensure that family perspectives are reflected in its program. The Family Partner:

- Observed legal clinics at Boston Medical Center and community health centers, and participated in case review sessions with staff.
- Prepared an interview guide and surveyed staff about possible roles for family members, then developed a set of recommendations for the program.
- Collaborated with Haitian-American Public Health Initiatives to present workshops on topics of interest to families.

Appendix B.

Tools to Use

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Appendix B1.

Policy Statement: Family Participation in Health Care Policy and Financing

In order to improve how systems of care work for children and families in our state, the *Massachusetts Consortium for Children with Special Health Care Needs* is working to create opportunities for family members, as individuals or organizations representing families, to share their knowledge and experience with policy-makers and organizations that shape how services are financed and delivered.

What does “health care policy and financing” mean?

Both public and private sector organizations use rules and regulations, generally known as policies, to govern how services may be offered to children with special health care needs and who pays. These policies may include:

- What are the benefits and who is eligible for specific services;
- Under what circumstances children and families can receive these services;
- What families may have to do before services are provided;
- How providers may be paid for their services;
- What families may have to pay to receive services; and
- How and in what form families receive information about these services.

What are the unique contributions of families?

- Real day-to-day experience navigating the health care system
- A fresh look at the system’s demands on consumers & their families
- Vision and creative solutions to problems
- Ability to advocate outside the organization for resources
- Insight into the barriers to care and potential for ways to save costs

How can families share their knowledge and experience?

- As **advisors** to organizations that impact the lives of children with special health care needs
- As **employees** of organizations that impact the lives of children with special health care needs—in either professional or non-professional positions
- As **educators**, increasing the awareness and understanding, at all levels, of issues confronting children with special health care needs and their families
- As **advocates** for children with special health care needs at the local, state and federal legislative levels

What difference can families make?

Families caring for children with special health care needs and the organizations that serve them know there is room for improvement. Active family participation in partnership with public agencies, health plans, hospitals and other providers will make programs and services more responsive, more comprehensive, and easier to use.

Appendix B2.

Guiding Principles of Family-Professional Partnership

The Family-Professional Partners Institute recognizes that:

- Families raising children with special health care needs (CSHCN) are knowledgeable consumers and experienced navigators of health care services for CSHCN. They have unique insight into health care system demands on CSHCN and their families. Because of this knowledge, experience and insight, they have valuable contributions to make to organizations that shape how services to CSHCN are financed and delivered.
- When family members work in effective partnership with public agencies, health plans, hospitals and other providers, programs and services become more responsive, more comprehensive and easier to use.
- Successful partnerships are based in mutual respect, open and honest communication, a genuine desire to work together to improve systems of care and the belief that collaboration, not confrontation, will produce the most effective results.

The Family-Professional Partners Institute therefore advocates these guiding principles:

- Family Partners are working to improve systems of care for CYSHCN rather than addressing personal or individual family challenges.
- Family Partners represent and speak for many families, not only their own. When representing their own personal situation or an organization they may represent, they make the distinction clear.
- Family Partners strive to share the perspective and experiences of families of children with a variety of special health care needs.

- Family Partners respect the privacy of families whom they represent and are careful when telling stories about other consumers that neither the details nor the context of the story identifies that person.
- Family Partners respect the confidentiality of conversations and communications within the health care organization.
- Family Partners are clear with their partnering organization about any difficulties that might accompany their role—about what information can and cannot be disclosed; about what level of advocacy they can engage in without fear of repercussions and what kinds of accommodations can and cannot be made for their special circumstances (e.g., health care and other needs).
- Family Partners stay connected with other families in similar positions for purposes of support and information sharing.
- Family Partners are truthful about their own skills and abilities and take responsibility for informing others when they need additional support or training.
- Family Partners agree to share the lessons learned from their participation in New England SERVE's Family-Professional Partners Institute, in order to contribute to future New England SERVE efforts to improve systems of care for children and families in Massachusetts.

Appendix B3.

Application Form for Organizational Partners

Family-Professional Partners Institute
A Project of New England SERVE



About the Institute

Families caring for children with special health care needs have valuable experience to offer health plans, pediatric practices, public health agencies and others who affect children's care.

The Family-Professional Partners Institute harnesses that experience by working with organizations to develop roles for consumers that help shape programs, influence policy and impact the care that children and families receive.

Becoming an Organizational Partner

The first step in becoming a participating organization is to **print and complete** this application form and **mail or fax it to:** Director of Family Initiatives, New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108; fax 617-574-9608.

What Kind of Organizations Should Apply?

Any organization working to improve child health can benefit from partnering effectively with families. Examples include **organizations providing clinical care**, such as pediatric primary care practices, hospital specialty clinics, community health centers and day and residential facilities; **academic and research organizations**, including medical schools, schools of public health, and hospital research initiatives; **health plans**, including disease management programs and member services departments; and **community-based organizations** such as those serving immigrant or minority populations.

What to Expect

After we receive your application, we will contact you to discuss your organizational goals and, if appropriate, arrange a personal interview. **If you have questions, please contact us by phone, 617-574-9493, or by e-mail, institute@neserve.org.**

Family-Professional Partners Institute
Application Form for Organizational Partners, page 2

Name: _____

Title: _____

Organization: _____

Department or Program, if applicable: _____

Address: _____

Phone Number: _____

Fax Number: _____

E-mail: _____

1. What role do you have in mind for a Family Partner? Acknowledging that this may be a newly created role for your organization, please suggest a possible job title, and/or provide a brief description of the role you have in mind.

Examples: Advisory Group Organizer; Family Faculty Member; Outreach Specialist; Program Planner; Researcher; Reviewer; Trainer/Curriculum Developer

2. What are the major goals of the partnership you have in mind? What do you see as the focus of the Family Partner's work?

3. Is this a new role at your organization or does it replace an existing role, whether performed by a parent or another staff member? New Existing
4. Does your organization currently have families or consumer representatives on its governing board? Yes No
5. Is your organization able to provide an employee liaison—someone who can devote a few hours per week to building the partnership and collaborating with the Institute? Yes No Maybe

Family-Professional Partners Institute
Application Form for Organizational Partners, page 3

6. Who is the proposed liaison?
- Me/Same as contact named on page 1 of this application
 - Name and Job Title: _____
 - Not sure

7. What challenges might you face in implementing this partnership within your organization?
- _____
- _____
- _____

Examples: new to partnering with families; time commitment needed from liaison; lack of support from management; geographic distance among key staff members, etc.

8. Organizational Partners are not charged a fee to participate, nor are they responsible for paying Family Partners for their time. Typically, the Institute pays the Family Partner at a rate of \$15 per hour for 3–5 hours per week for a 6-month implementation phase, for a total of \$1200–\$2000. This amount includes time for travel, attending meetings, etc. It does not include additional costs for such items as refreshments for meetings, stipends for other parents who might attend meetings, and parking costs at the organization’s office. Will your organization be able to cover such additional incidental costs to implement the proposed partnership?
- Yes
 - No
 - Maybe

Comments:

Family-Professional Partners Institute
Application Form for Organizational Partners, page 4

9. The Institute is looking for Organizational Partners who can envision the possibility of **sustained** family-professional partnerships as a strategy for guiding policies and practices that contribute to services for children with special health care needs and their families. Assuming the implementation phase of a partnership is effective, how would you assess your organization's readiness to sustain a partnership financially?

- Definitely could sustain
- Might be able to sustain
- Probably could not sustain

Please explain: _____

If your organization "probably could not sustain" a partnership, could it contribute in other ways to the Institute and the goal of building family-professional partnerships in the state?

Examples might include providing the Institute with meeting space, translation services, or access to printing or copying services; providing Family Partners with free tuition, etc.

10. In order to help us better understand your vision of the role a Family Partner could play at your organization, please provide any other information, explanation or details to help us evaluate your interest.

11. Finally, how did you first hear about the Family-Professional Partners Institute?

Appendix B4.

General Family Partner Job Description

Summary

The Family Partner works with a site identified by New England SERVE's Family Professional Partners Institute ("Institute") on a time-limited project to be identified by the site in collaboration with the Institute. Direct supervision will be provided at the site where the Family Partner is placed.

Duties

- Represents the family voice and perspective, speaking for families of children with special health care needs
- Participates in training sessions conducted by the Institute
- Participates in orientation sessions provided by the partnership site
- Participates in ongoing meetings and phone consultation with New England SERVE/Institute staff
- Participates in monitoring and evaluation strategies assessing the effectiveness of the Institute
- In collaboration with organizational liaison, implements a planned activity at the site with the goal of improving systems of care for children and youth with special health care needs (CYSHCN) as delivered by that site.

Qualifications

- Parent or other family member of a child with special health care needs
- Strong interpersonal skills to function as a member of a professional team and to interact effectively with families and others
- Excellent listening skills
- Ability to interpret and synthesize different points of view
- Excellent oral and written communication skills
- Sensitivity to diverse cultures
- Ability to maintain respect for privacy
- Ability to generate new ideas and seek innovative solutions for problems
- Working knowledge of committees and organizations
- Knowledge of family-centered care and Medical Home concepts
- Basic computer skills: facility with word processing, e-mail and working with electronic documents

Appendix B5.

Sample Letter of Interest from a Family Member

The applicant's name and other identifying information have been removed in the interest of confidentiality.

Dear _____,

I am very interested in applying for the temporary, part-time position of Parent Research Partner. I am currently employed [#] hours per week at [employer] in [city]. In my position as [job title], I facilitate three different confidential support groups. One of them is a newly-created education group for parents of transition age children with (mostly) mental health challenges. I also created and facilitate an online support group in recognition that many parents cannot get out at night to join an in-person group. The "transition age" is of great concern and interest to me as my own teenage children have special health needs.

The [program] at [employer] is dedicated to partnering with all agencies to provide the family perspective in many different situations. I feel that the position advertised is something I would truly love to be part of. I feel strongly that this would be a wonderful opportunity to help make a difference for families of children with special health care needs.

My résumé is outdated and doesn't reflect any of the work I have done with families and children in the past 2.5 years. This may be a little unconventional, but in lieu of a résumé, I would like you to take a look at a website I recently created for [employer]. It contains a sort of portfolio of information about the groups I facilitate and the work we do in general. The website is [web address]. Also, I have been asked to present a workshop on the transition issues of emotionally disabled teens for [professional association] in a statewide conference. I will be presenting with [name of well-known family leader] from [organization].

If you feel that my qualifications are a good match for this position, please contact me to arrange an interview. I look forward to hearing from you.

Sincerely,

[Name]

[e-mail address and telephone number]

Appendix B6.

Annotated Family Partner Training Program Agenda

Day One

8:45–9:00	Arrival and Coffee
9:00–9:45	<p>Welcome and Introductions <i>Institute Director and Funding Agency’s Representative</i></p> <p>An icebreaker activity helps set a warm, friendly tone; speakers give the message that participants will be part of a community, doing important work.</p>
9:45–10:45	<p>New England SERVE and Its Projects <i>Executive Director</i> The Institute is part of a larger organization...</p> <p>National Perspectives on Family Partnerships <i>State Parent Leader</i> ...and a larger movement of family involvement and participation...</p> <p>History of the Institute <i>Institute Director</i> ...and its role as a partnership broker has evolved in that context.</p>
10:45–11:30	<p>Special Considerations for Family Partners in Health Care Organizations <i>State Parent Leader/Professional</i></p> <p>An experienced family leader explains issues of confidentiality, personal and professional boundaries, and technical skills.</p>
11:30–12:00	<p>The Importance of Family-Professional Partnership <i>Experienced Family Partner and Experienced Organizational Partner</i></p> <p>Two former Institute Partners—one Family, one Organizational—each describe the outcomes and the rewards of their experience. Followed by discussion and Q&A.</p>
12:00–12:15	<p>Guiding Principles of Family-Professional Partnership <i>Institute Director</i></p> <p>Principles emphasize honest communication, respect for privacy, and a commitment to representing many families and improving systems of care, rather than addressing individual family challenges.</p>
12:15–1:15	Lunch
1:15–1:55	<p>Imagine: Case Studies for Family Partners <i>State Family Leader/Professional</i></p> <p>An open-ended discussion of scenarios Family Partners may face helps participants explore how they might apply the principles.</p>
1:55–2:00	<p>Day One Final Remarks <i>Institute Director</i></p> <p>A time to assign any homework, attend to logistics and preview the next day’s program.</p>

Day Two

8:45–9:00	<p>Arrival and Coffee</p>
9:00–9:45	<p>Finding Your Place in an Organizational Culture <i>Organizational Partner or Human Resources or Community Relations specialist from a health care organization</i></p> <p>This presentation gives concrete advice on being part of an organization—preparing for visits and meetings, being part of meetings, and working as part of a collaborative effort.</p>
9:45–11:00	<p>The Power of Your Personal Experience: Strategies for Telling Your Story <i>Social Worker or other professional experienced in helping families share their personal experiences</i></p> <p>The presenter shares tips for telling personal stories with maximum effectiveness.</p>
11:00–12:00	<p>Introducing Your Family Partner Role to Others <i>Institute Director and Family Partners</i></p> <p>To take their work plans “off the page” and make their new roles “real,” Family Partners are asked to describe to others what they will be doing and the outcomes they plan to achieve for their Organizational Partner.</p>
12:00–1:00	<p>Lunch Break with Organizational Partners <i>Family Partners pair up with Organizational Partners for a working lunch to outline their next steps.</i></p> <p>Activity: Developing a Work Plan for the First Three Weeks</p>
1:00–1:40	<p>Employment Logistics, Forms, Timesheets, Etc. <i>Institute Administrator</i> This segment covers administrative nuts and bolts...</p> <p>Getting the Help You Need <i>Institute Director, one or more Mentors</i> ...gives a detailed guide to finding answers to questions large and small...</p> <p>Evaluation Steps <i>Institute Director or Funding Agency’s Representative</i> ...and provides critical information is about reporting systems and evaluation methods.</p>
1:40–2:00	<p>Wrap-Up and Q&A <i>State Parent Leader</i></p>

Appendix B7.

Sample Training Activity: Imagine: Case Studies for Family Partners

1. You are at a meeting with the organization with which you're partnering. You hear some disparaging remarks about parents who are part of their system who don't follow through with recommendations. Do you just ignore the comments or do you enter into a discussion about why parents might or might not follow medical advice?
2. Because of meetings you've attended with your partner organization, you know there will soon be policy changes that impact the way services are delivered to families. Your initial reaction is that the changes are positive. You are attending a meeting of parents and this policy comes up for discussion. Families are upset. How do you handle this? Is there a way for you to share these reactions with your organization?
3. The organization with which you are partnering has a policy with which you don't agree. At a parent/family meeting, the families present think that as a representative of the organization you support it. How do you handle this?
4. You are having a conversation with a parent who is an employee of the organization with which you are partnering. You find out that her personal family situation is very much like your own. How much of your story do you share, if any?
5. It's your first meeting with your organization and one of the staff asks you some rather detailed questions which have to do with the diagnosis of autism. Your child has a physical disability and other than a very general knowledge of autism, you don't know the answers to his questions. What do you do?

Appendix B8.

Sample Training Activity: Telling Your Personal Story

Starting

Be sure you are comfortable. Most people are more comfortable with a podium or table, so you may want to request one.

Take Home Message

When you finish telling your story, what do you want the 'take-home' message "to be? Take-home messages can be informational ('know this!'), action-oriented ('do this!'), or emotional ('feel this!').

There may be times you can't tell your entire story, but can share a small point. Think about one or two points from your story that can be pulled out to stand on their own.

Think of yourself as a translator. Translate the message from your story and other families' stories into a message the institution can hear.

Visual Aids

Would visual aids—slides, pictures, drawings—help tell your story? Or would they distract from its most important message?

Sharing Your Feelings

Emotion can support or detract from your message. If it's too flat, people don't listen. If there's too much emotion, that's all they hear. Either way they'll miss your message.

If the tone of your message is too negative, the audience won't hear it. Say: "Here's what needs improvement" instead of "Here's what you're doing wrong."

So What?

What makes something a good story? What does it inspire a person to do; does it pass the “so what?” test? In general, a good story:

- Presents a question or paradox about care, a puzzle that cannot be answered with yes or no
- Is not rhetorical
- Challenges the listener to listen, think, question assumptions and learn
- Addresses a need or problem encountered by practitioners
- Inspires one to practice better, and what it inspires is do-able given time and material constraints
- Doesn't need to be unique but needs to be important
- Doesn't start with “How can we understand?” or “How can we explain?”
- May be about an unresolved issue but isn't trying to work out an unresolved issue

Practice Exercise

Express a simple statement (What are we doing here?) in a way that conveys a particular emotion (e.g., practical, puzzled, hesitant, regretful, disbelieving, passionate, defensive...) Emotions can be randomly chosen from a hat by participants.

Appendix B9.

Family Partner's Guide to Getting Help

Use the weekly **Reporting Form** to let us know how the week went: your activities, accomplishments, challenges, or anything else. You can also use the form to ask us to call you if you want to talk about how the partnership is going.

But you don't have to wait for the Reporting Form! **Call or e-mail the Institute** anytime if there is something you'd like to discuss. We are here to help!

Contact your Organizational Partner...

- For information about the organization, its staff and goals
- To review the overall plan for the partnership and your role
- To talk about specific work you need to do and deadlines
- If you think changes might need to be made in the work plan

Contact your Mentor...

- For information about agencies and programs that can help families
- For information about the health care system in Massachusetts
- To talk about what you're doing and how it's going
- To find a sounding board for your ideas
- To talk to another parent who understands both the work you are doing *and* parenting a child with special health care needs at the same time

Contact the Institute Director...

- To make any changes in your work plan—*after* you have discussed this with your Organizational Partner
- For information about the Institute
- To make a suggestion that could improve the Institute as it continues to develop
- When you and your Mentor or Organizational Partner agree that something needs to be brought to Institute's attention

Contact the Institute's Administrator...

- To report information or ask a question or about your timesheet
- To ask a question about your paycheck

Appendix B10.

Sample Organizational Partner Agreement and Work Plan

1. Organization

The Medical-Legal Partnership for Children (MLPC) at Boston Medical Center's Department of Pediatrics serves vulnerable families by offering legal assistance in the clinical setting. Located at BMC and at several Community Health Centers in Boston, the staff of 14, supplemented by student interns and volunteers, provides direct legal service to patient-families, educates and trains health care providers, and advocates for system changes in partnership with pediatric clinicians.

2. Goal for Family-Professional Partnership

MLPC's goal is to identify concrete roles for family members on ongoing basis to ensure that the family perspective and voice is represented in MLPC's program.

3. Overview of the Family-Professional Partnership

Among the many families served by the MLPC are families with children with special health care needs. MLPC's Family Partner will become well versed in the challenges faced by families and the services they need by observing the Legal Clinics and Case Reviews conducted weekly in the program. These observations, supplemented by orientation by MLPC staff, will lay the foundation for the Family Partner to interview many if not most staff to identify the roles that family members play and should and could play vis-à-vis MLPC, and to develop recommendations for specific roles that family members can play in the program.

As time allows, the Family Partner will also explore opportunities to create direct links between MLPC families and family advocacy organizations, such as the Federation for Children with Special Needs and the Parent-Professional Advocacy League.

4. Work Plan (See next page.)

5. Summary

- Required MLPC staff time estimated at 2 hours per week for the 24-week pilot.
- Family Partner's work hours estimated at 6 hours per week for the 24-week pilot.
- Estimated total of payment to Family Partner, at \$15/hour = \$2010.
- MLPC may be required to cover additional costs incurred by partnership activities, such as printing and copying, transportation and parking, meetings (refreshments, space, parking, stipends) and others.
- Work plan is subject to revision based on actual experiences.

Work Plan: April 2007 – October 2007

Objective	Estimated # of Hours		
	Institute Support	MLPC	Family Partner
Develop job description and work plan for Family Partner	4	1	
Recruit Family Partner	4	2	
Train Family Partner	10		10
Orient Family Partner to MLPC		4	6
Observe Legal Clinics, held at BMC and several community health centers			8
Attend local Advisory Board meetings when held over the course of the partnerships			4
Observe Case Review sessions, held weekly on Mondays 12:30–1:30 at BMC			6
Prepare for and conduct meeting with Family Partner and his/her mentor and Organizational Liaison		2	4
Interview staff to identify roles that family members currently play and could play in the future vis-à-vis MLPC		8	8
Develop recommendations for ongoing roles for Family Partner at BMC		2	12
Meet to discuss recommendations with BMC identified staff		2	2
Develop document identifying next steps in continuing a Family Partnership(s)		2	8
Research and identify parent advocacy organizations with programs and materials responsive to MLPC patient-families		1	12
Contact identified organizations about finding ways to link with MLPC families through BMC's program		1	12
Draft document with recommended next steps for linking MLPC with family advocacy organizations		2	8
Ongoing support and mentoring for Family Partner including participation in large group meetings	22	6	22
Technical assistance to MLPC	6	4	
Monitoring and evaluation of progress	8	4	8
Identify and implement venues for promoting family involvement in the MLPC model, as appropriate and possible	2	4	4
ESTIMATED TOTAL HOURS	56	45	134

Signed by:

Jane Doe
Medical-Legal Partnership for Children

Linda C. Freeman
Family-Professional Partners Institute

Date: _____

Date: _____

Appendix B11.

Sample Employment Letter for Family Partner

April 11, 2007

Jane Doe
10 Main St.
Boston, MA 00000

Dear Jane:

It is with great pleasure that I confirm your employment with New England SERVE, a program of Third Sector New England, as a Family Partner. Your primary responsibility will be to assist [name of organization] in serving children with special health care needs by providing the parent perspective and voice as you complete the tasks outlined in your work plan.

Your employment began on April 9, 2007. This is a part-time, temporary position which is scheduled to continue for approximately a six-month period. You will work variable hours, typically between 4 and 6 per week. This position is classified as non-exempt under the Fair Labor Standards Act. Your hourly salary will be \$15.00 and you will be paid on a biweekly basis. You will report to Linda Freeman at New England SERVE. Though you will receive workers compensation coverage, as an employee working less than half-time, you are not eligible to receive other benefits.

The first three months of your employment will be your orientation period. At the end of this time you will have a brief performance review with your supervisor to determine if you will be recommended to continue in this role as a regular, part-time employee. All employment with Third Sector New England is at-will. I have enclosed a copy of our employee handbook which outlines our employment policies and procedures. If you have any questions or concerns regarding your pay, benefits, or employment, please do not hesitate to call me at 617-123-4567. I am in the office on Tuesdays, Wednesdays and Fridays.

Sincerely,

Judy Smith
Human Resources Manager

cc: employee file
L. Freeman

Appendix B12.

Exit Interview for Organizational Partners

Thank you for participating in the partnership program of the Family-Professional Partners Institute. Because we place a high value on feedback from our Organizational Partners, we have scheduled an Exit Interview to learn more about your experiences with your Family Partner and the Institute. Your comments will be incorporated as we continue to refine the program.

Please take a few moments to review these topics prior to the Exit Interview:

1. Was the experience of working with the Institute what you expected?
2. Was the experience of working with your Family Partner what you expected?
3. Were you able to accomplish the goals you set? If your goals had to be modified, why?
4. How would you rate these components of the Institute's program? Were any especially useful—or *not* useful? Are there elements that should be added, changed, or deleted?
 - a. Working with the Institute to:
 - i. Identify a role for a Family Partner
 - ii. Establish a realistic work plan including timeframes
 - iii. Recruit, interview, and select a Family Partner
 - iv. Clarify financial and contract issues
 - v. Report the progress of the partnership
 - vi. Discuss/arrange plans to continue working with your Family Partner
 - b. Identifying the appropriate liaison staff at your organization
 - c. Training of the Family Partner by the Institute and your organization
 - d. Institute materials provided to your organization by your Family Partner
 - e. Technical assistance and consulting support from the Institute
 - f. Large group meetings with organizations and Family Partners

5. If you could change one thing about the Institute's program, what would it be?
6. What one thing should absolutely be preserved?
7. What has your organization learned from being involved with the Institute?
8. How would you complete this statement? " _____
would not have happened if our Family Partner had not been working with us."
9. What can you tell us about the possibility of your organization making a financial contribution to support a partnership? With the benefit of hindsight, can you estimate what the value of the Institute's role and contribution might be?
10. Now that the Institute's direct involvement is ending, will you continue to work with your Family Partner or another family member?
 - a. How might the nature of the partnership evolve over time?
 - b. Outside of funding and day-to-day monitoring, are there ways in which you would like to see the Institute stay involved?

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