



# Case Study

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## Rhode Island's Pediatric Practice Enhancement Project: Parents Helping Parents and Practitioners

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**ABSTRACT:** Rhode Island's Pediatric Practice Enhancement Project (PPEP) trains and places parent consultants into pediatric primary and specialty care practices to help families with children and youth with special health care needs coordinate and access the health system, as well as other services (e.g., social services, education, housing). Parent consultants, who are parents of special needs children themselves, assist physicians in providing comprehensive, coordinated medical homes to about 8 percent of children with special needs in the state (more than 2,800). A PPEP database, managed by the state's Department of Health, helps identify systemwide barriers facing families. A recent evaluation suggests that PPEP participants have more outpatient encounters but fewer inpatient admissions and less intensive resource use than children with special needs who are not in PPEP practices.



### THE ISSUE

Families of children and youth with special health care needs often have difficulty navigating the medical system, as well as mental health, health insurance, social service, education, housing, and other services to meet a wide array of complex needs.<sup>1</sup> Similarly, pediatric primary and specialty care providers report that lack of time, reimbursement, knowledge about resources, and experience prevent them from adequately guiding these families and linking them to existing services.<sup>2</sup> These barriers often preclude practitioners from providing such children with a medical home that offers family-centered, comprehensive, coordinated, and integrated care.<sup>3</sup>

Across the country, programs that use peer and parent-to-parent support are increasingly helping families gain the comfort, knowledge, and skills to access appropriate services. Research indicates that parents who receive support from other parents are better able to adjust to their child's disability and have better attitudes, increased coping abilities, and greater progress in solving problems.<sup>4</sup>

## **RHODE ISLAND'S PEDIATRIC PRACTICE ENHANCEMENT PROJECT: ABOUT THE PROGRAM**

The Pediatric Practice Enhancement Project (PPEP) is a partnership between the Rhode Island Department of Health and Department of Human Services, the state's chapter of the American Academy of Pediatrics, the Rhode Island Parent Information Network/Family Voices, and the Neighborhood Health Plan of Rhode Island. The program places specially trained parent consultants in 24 pediatric primary and specialty care practices in Rhode Island that serve large numbers of children with special health care needs and their families. Parent consultants help the physicians provide comprehensive medical homes, which support both families and practitioners.

The PPEP model is based on the concept that parents who have already faced the issues and challenges involved in raising children with special needs are best equipped to help other families in similar situations. Parent consultants with similar experiences can understand the realities and frustrations and can offer both empathy and practical advice. They help families access and coordinate specialty services, link to community resources, overcome barriers, and navigate the health care system, as well as other services.

One of the original parent consultants, who has a son with an autism spectrum disorder, says she “loved the idea that a parent with experience could help other parents in the pediatrician's office, which is often the first place families go.”

Placing parent consultants directly in the offices of practitioners who serve children with special needs also assists the physicians and their staff by identifying resources and support services that the medical providers may not be aware of and are neither equipped to provide nor reimbursed for, but patients and families often need.

The objective of PPEP is to promote a medical home model of care through partnerships among

families, pediatric practices, and community resources. Specific goals include:<sup>5</sup>

- improving pediatric practices' awareness of and communication with community resources;
- enhancing operational efficiency of pediatric practices' provision of coordinated and comprehensive care;
- providing ongoing comprehensive and coordinated care for families, resulting in improved health outcomes for the children;
- recognizing families of children and youth with special health care needs as critical decision makers; and
- increasing understanding among families of the health care delivery system and how to access community resources.

## **TARGET POPULATION**

PPEP's primary target population is children with special needs and their families. A secondary target group is practitioners: pediatric primary care providers and specialists, and their staff. Although PPEP services are not limited to children of any particular income or coverage type, the majority of PPEP sites serve large numbers of families who are covered under Medicaid and the Children's Health Insurance Program (CHIP). About three-fourths (74%) of children served are Medicaid/CHIP beneficiaries, 21 percent have private insurance, and 5 percent are uninsured or their coverage source is unknown.

Neighborhood Health Plan of Rhode Island, a managed care organization serving the majority of the state's Medicaid/CHIP families, has been involved since PPEP's inception. “Neighborhood Health Plan saw PPEP as an opportunity to support the pediatric practices in our network,” said L. McTyeire Johnston, M.D., chief medical director of Neighborhood Health Plan. “The parent consultants help practitioners and families access service outside the medical practice.”

## HOW IT WORKS

Each parent consultant works 20 hours per week in a participating medical practice. The PPEP program funds the wages for 15 of these hours at an hourly wage of \$11.50 to \$15.00. The medical practices pay for the remaining five hours and provide office space, a computer, and telephone.

When a physician or other medical staff member learns or suspects that a patient has needs beyond the medical scope of the practice that are not being addressed, a referral is made to the parent consultant. The parent consultant talks with the family regarding the family's concerns and develops a work plan to identify the steps necessary to address the needs of the family. This could include resource identification; community referrals for social, developmental or mental health services; links with the education system; eligibility or application assistance for health insurance, nutrition, or housing services; navigation across these services; and peer-to-peer support. In addition, parent consultants provide follow-through support, such as calling families to confirm that they make appointments and ensuring they know what to expect when they arrive for a service. Families are served regardless of insurance status. Parent consultants also educate the practice staff about state and community-based programs and services.

Parent consultants complete project paperwork, which includes an intake form (family's demographics, diagnoses, current services), work plan (issues and concerns, action steps, resource and referral identification), and progress note (See [Appendix A](#)). The parent consultant updates the information to track whether goals were achieved and any barriers were encountered. The information is put into a data system developed and maintained by the Rhode Island Department of Health, described in further detail later in this case study.

There is some flexibility to allow each PPEP practice site to tailor the program to fit its needs and policies. Some practices, for example, use referral sheets or other tools. Each practice decides how to use the five hours of a parent consultant's time that it pays for. Some practices use the parent consultants to follow up on referrals. In one site, the parent consultant assists with RItE Care (Rhode Island's Medicaid managed care program) applications, which is a reimbursable service.

PPEP connects families care coordination programs, among other services. Parent consultants work in collaboration with the following programs:

- Comprehensive Evaluation, Diagnosis, Assessment, Referral and Reevaluation (CEDARR) is the state's care coordination program for families of children with special

### **Comprehensive Evaluation, Diagnosis, Assessment, Referral and Reevaluation (CEDARR)**

Rhode Island's children and youth with special needs and their families may voluntarily use a CEDARR family center that assesses the patient's needs, develops a family care plan, determines eligibility for covered services, and helps with referrals. Four CEDARR family centers are located throughout the state. Assistance and family support are provided by family service coordinators under the supervision of clinical staff. Designed to serve all families of children with special needs, regardless of insurance coverage, the program is currently serving Medicaid families only, because of financial constraints.

A CEDARR family center team, along with family members, develops a comprehensive family care plan to address the child and family's needs for services and supports. The plan may be developed in coordination with and include community resources such as early intervention providers, local coordinating councils, local education agencies, direct services, support services, and collateral support services.

CEDARR is administered by the Rhode Island Department of Human Services, but it is considered a collaborative initiative of the Rhode Island Children's Cabinet and five state departments: health; children, youth and families; education; mental health, retardation and hospitals; and human services. CEDARR services are established as EPSDT-based Medicaid services and are eligible for Medicaid reimbursement for children enrolled in RItE Care or RItE Share.

Source: Rhode Island Department of Human Services.

health care needs. It currently serves Medicaid-eligible children and their families, and is administered by the Rhode Island Department of Human Services. CEDARR and PPEP work hand in hand: parent consultants inform families about the CEDARR program and CEDARR staff often rely on the expertise of parent consultants regarding system navigation to assist them in meeting the complex needs of patients and their families.<sup>6</sup> (See text box.)

- Neighborhood Health Plan of Rhode Island is the managed care plan serving the vast majority of Medicaid/CHIP families in Rhode Island. It offers its members medical and behavioral health care coordination. Parent consultants are provided with a direct link to Neighborhood Health Plan's care coordinators to identify and access covered benefits for children with special needs.
- Early Intervention is a statewide program providing evaluation, an individualized family service plan, referrals, and services for children under 3 years of age who have developmental disabilities or delays. It is administered by the Rhode Island Department of Human Services and authorized by federal law. There are 10 Early Intervention providers in the state.<sup>7</sup>

If a PPEP child has multiple care needs and is not eligible for these other programs, the parent consultant provides care coordination assistance to the

#### **Example: Avoiding noncompliance**

A physician wanted to refer a child with school anxiety for therapy. The parents refused. The parent consultant talked with the family and learned they were very religious and therapy did not fit with their culture. The parent consultant suggested a religious counselor who could come to their home. The family felt more comfortable with this approach and followed through with the plan.

#### **Example: Meeting non-health needs**

Medical staff at a ventilation integration program explained a discharge plan to a family with a child on a ventilator. After the meeting, the parent consultant asked the parent if she had any questions or concerns. The parent responded, "I don't have any electricity."

The parent consultant helped arrange for the family and child to stay with relatives immediately after discharge and helped the family restore electricity so they could move back home.

"The children's parents often feel more comfortable sharing with the parent consultant than with the medical staff," said Laura Jones, parent consultant supervisor.

family. Many of the issues parent consultants address are health related, and many others are indirectly connected to medical care. For example, "we may help the family restore heat in their house first, and then help get their child to a specialist," said parent consultant supervisor Laura Jones.

#### **Administration and Database**

The Rhode Island Department of Health administers PPEP and is responsible for the project's financial management, data and evaluation, and communication with participating physicians and practices.

The department contracts with the Rhode Island Parent Information Network, which includes Family Voices, an organization of parent professionals, to hire, train, and supervise the parent consultants (Figure 1).

The information gathered by parent consultants on all PPEP encounters is sent to the Rhode Island Department of Health, where it is put into a database. Staff at the department generate periodic reports and present the information to each PPEP site quarterly so physicians and staff can learn how many of their patients and families have been served, major issues and concerns, and whether problems were resolved. According to Colleen Polselli, PPEP Program Manager for the Rhode Island Department of Health, the practitioners appreciate this feedback loop.

Most importantly, the PPEP database serves to identify systemwide barriers facing families trying to obtain appropriate care for their children. The Family Voices leadership team functions as the PPEP steering committee and includes representatives of state agencies (human services, education, and health) and community stakeholders. The leadership team meets monthly to review the barriers identified through the PPEP database. These barriers are addressed at the system level to improve access and ensure coordinated and comprehensive quality services. For example, after identifying lengthy waiting lists as a barrier for receiving home-based therapeutic services, the state department responsible for that service implemented a new referral monitoring system that significantly reduced family wait time. An additional program also was developed to allow families to hire therapists directly, which accommodated many of the families on the waiting list.

### Recruitment and Training

The Rhode Island Department of Health contracts with the Rhode Island Parent Information Network to hire, train, and provide ongoing supervision to parent consultants. The Parent Information Network employs 24 parent consultants, one manager, and four supervisors for PPEP, and also employs parent consultants for other programs, such as Early Intervention.

The Parent Information Network recruits parent consultants through a listserv, newspapers, e-mail, and word of mouth. PPEP site placement is based on applicant interviews, background checks, and matching the needs of the practices with the skills, including language fluency and cultural backgrounds, of the applicants.

The parent consultants come from a variety of backgrounds. Some are professionals and others have less formal education. The Parent Information Network seeks individuals who possess:

- a passion for helping other families based on what they have learned through their own experience;
- good communication skills; and
- computer experience.

As part of the interview process, two or three candidates are brought to a site, allowing practitioners to select the person who is the best match.

Ongoing training and networking for parent consultants is provided on a monthly basis, with a professional development day held quarterly. The Parent Information Network has offered about 100 three-hour training sessions in areas such as special education, public program assistance and eligibility, community resources, and care coordination programs.

**Figure 1. Pediatric Practice Enhancement Project Partners**

<b>Rhode Island Department of Health</b> ( <a href="http://www.doh.ri.gov">www.doh.ri.gov</a> ): Administers PPEP; supports and maintains statewide PPEP data system.
<b>Rhode Island Department of Human Services</b> ( <a href="http://www.dhs.ri.gov">www.dhs.ri.gov</a> ): Administers Medicaid, CHIP, and CEDARR, the state's care coordination system, for children with special needs and their families.
<b>Rhode Island Parent Information Network (RIPIN)/Family Voices</b> : The state's contracting agency for hiring, training, and supervising the parent consultants. RIPIN is designated as Rhode Island's Family-to-Family Health Information Center, Parent Training and Information Center, and Parent Information Resource Center. <sup>8</sup>
<b>Neighborhood Health Plan of Rhode Island</b> : The state's Medicaid/CHIP managed care plan that serves the largest number of children with special health care needs.
<b>American Academy of Pediatrics, Rhode Island Chapter</b> : The state chapter of the national physician organization promotes medical home practices through recruitment, training, and identifying key practice concepts.
<b>Pediatric Practice Enhancement Project sites</b> : Pediatric primary and specialty care practices including private practices, community health centers, hospitals, and three non-health sites. (See <a href="#">Appendix B</a> for list of sites.)
<b>Hasbro Children's Hospital</b> : Rhode Island's only children's hospital and the hub of services for many of the state's children with special needs and their families.



## PROGRAM DEVELOPMENT AND IMPLEMENTATION

PPEP was developed in 2003 in response to a state-administered needs assessment that identified physician and family concerns about obstacles to providing a medical home for children with special needs and their families.<sup>9</sup> Physicians reported that they and their staff members lacked the time with families of children with special needs to discuss a range of nonmedical issues related to school, behavior, and other issues. Furthermore, physicians did not know the breadth of resources available in the community and did not have time to follow up with families to determine whether needed services were obtained. They were also not reimbursed for the extra time spent on these coordination issues. Similarly, parents reported a lack of coordination between primary care and other health care providers and difficulty navigating the special health care needs systems.

To address these challenges, the state considered using nurses or social workers to provide care coordination and support, but decided to use a model that was successfully implemented in the Early Intervention program in 2000, in which a parent support network helped other parents via telephone and face-to-face contact.<sup>10</sup> In the Early Intervention program, the state contracts with the Parent Information Network to employ one parent per 250 clients in 10 sites around the state. This arrangement has been cost-effective, according to Deborah Garneau, chief of the office of special health care needs at the Rhode Island Department of Health.

In 2003, the Department of Health's Office of Special Health Care Needs obtained funding to develop PPEP. Initially, PPEP placed parents of children with special needs in eight pediatric primary care practices. Three specialty care sites were added the following year, helping to create an integrated service delivery system. In 2006, the Office of Special Health Care Needs obtained a three-year New Freedom Initiative grant of \$295,500 per year, which allowed

PPEP to expand to nine additional sites.<sup>11</sup> As of mid-2009, parent consultants were in 24 sites across the state, including hospital-based primary care clinics, health centers, private physician offices and group practices that serve a large number of children with special needs, and three nonmedical community sites (a dental clinic, department of corrections site, and housing authority offices). (See list of sites in [Appendix B](#)).

## FINANCING AND SUSTAINABILITY

PPEP's \$835,500 annual budget has been supported largely by its New Freedom Initiative grant, with some funding from the Department of Human Services. The Title V Maternal and Child Health Services federal block grant supports some of the PPEP database, networking, supervision, and program coordination on an ongoing basis.<sup>12</sup> Since the New Freedom grant ended in April 2009, program administrators and supporters have been working hard to secure new funding to sustain the program.

Department of Health staff have been meeting with the three health insurers in the state (two of which serve Medicaid/CHIP families) to discuss reimbursing practitioners for parent consultant services for patients with commercial and Medicaid/CHIP coverage. This would allow more practices to participate in PPEP. Leaders believe they can build funding for the program into the Medicaid reimbursement system through a current Medicaid waiver. For example, there are already codes within the Medicaid system to allow billing for longer physician visits, which might include the parent consultant services. The insurers expressed interest and were waiting for results of a PPEP evaluation that assessed the impact on utilization and costs. Early assessments of the program suggested that families participating in PPEP are becoming more educated, supported, and empowered, and are using more low-cost services and fewer high-end services.

Additional funding options include employment of the parent consultants by the practice or the practice site paying for a larger portion of parent consultant hours.

## RESULTS

### Program Experience: More People Served, Most Issues Addressed

From its implementation in 2004 through 2008, PPEP has served nearly 3,000 children with special health care needs and their families, representing approximately 8 percent of such children in Rhode Island (Figure 2).

The majority (69%) of the nearly 5,000 issues or problems encountered have been addressed successfully (Figure 3). Parent consultants have made about 3,500 referrals to a range of public and private services, agencies, and programs.

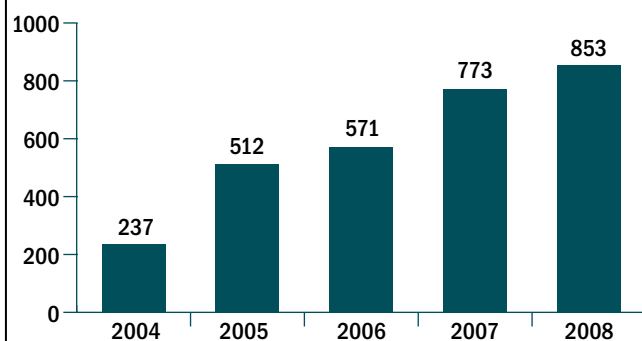
PPEP also identified a number of system barriers facing families of children with special health care needs, including:

- insurance does not cover needed services (e.g., preferred medication, home care, or nursing hours for caregiver respite);
- lack of accessible services (e.g., limited housing, therapeutic recreation, before- or after-school programs, and summer programs);
- lack of available services (e.g., limited transition services, social development groups, therapeutic child care, and dental care);
- language (e.g., lack of interpreters or practitioners who speak the same language as parents and families);
- limited hours of operation among service providers; and
- transportation to and from services.

### Quantitative Impact: More Encounters, Less Hospitalization

A 2008–2009 evaluation by the Rhode Island Department of Health, with cooperation from Neighborhood Health Plan of Rhode Island, compared utilization and claims payments between PPEP participants and children with special needs who did not receive peer-to-peer system navigation between 2004

Figure 2. New Children Served by PPEP 2004–2008

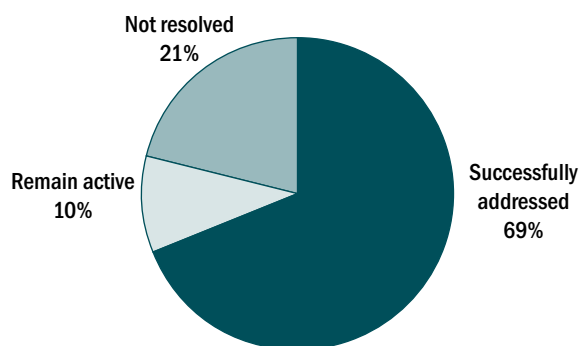


Source: Office of Special Healthcare Needs, Rhode Island Department of Health, 2009.

and 2007.<sup>13</sup> The preliminary analysis found that among children who had encounters with the health care system for which claims were paid, the PPEP model had on average 21 percent more encounters (Figure 4), but slightly fewer (4%) claims per encounter, and 15 percent lower average payment per claim (Figure 5). This suggests that PPEP may result in more early interactions with the health care system that prevent costly interactions later.

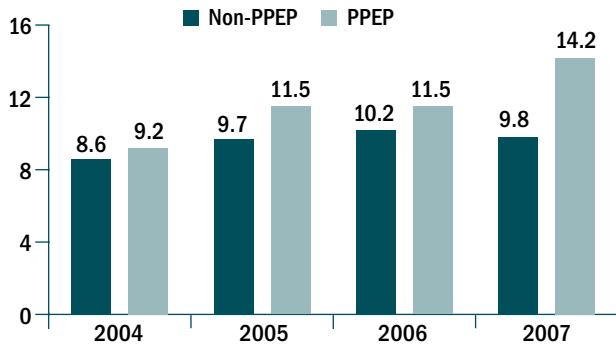
Indeed, breaking down the data by encounter site revealed that, on average, PPEP children had more outpatient visits and slightly more emergency room visits, but fewer hospital stays. Hospitalization costs represented 98 percent of the combined inpatient and emergency expenditures, and 95 percent of the combined inpatient and outpatient expenditures. The

Figure 3. Status of Problems Encountered, 2004–2008



Note: issues "not resolved" may be due to: family left practice, family took no action, unable to contact, family moved, or other reason.  
Source: PPEP, 2009.

Figure 4. Average Annual Encounters per CSHCN



Source: Office of Special Healthcare Needs, Rhode Island Department of Health, 2009.

authors of the evaluation suggest that the PPEP model increases use of outpatient primary and preventive care and decreases use of more costly inpatient services.

Limitations of the study preclude conclusions about the exact financial impact of PPEP, or about why emergency room use was slightly higher among PPEP patients (contrary to what may be expected); however, ongoing analyses are expected to address these limitations.<sup>14</sup>

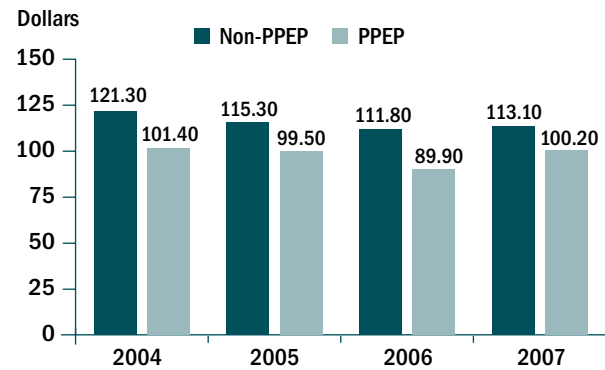
### Greater Benefits to Families

In addition to these quantitative findings, there are also gains, according to Garneau, the chief of the office of special health care needs, in terms of “social capital—the life-changing impact on families and communities.” Families served by PPEP report greater understanding and satisfaction regarding the health care service system, a sense of empowerment, and enhanced knowledge of available supports.<sup>15</sup> According to Dr. Robert Burke, a primary care physician in a participating pediatric clinic at Hasbro Children’s Hospital in Providence, “PPEP enhances communication between the physician and patient, and offers the patient and family someone to contact to get them through confusing hospital scheduling and other challenges.”

### Advantages to Practitioners

By enhancing family satisfaction, PPEP also improves physician satisfaction. “The value is enormous to families. And having someone help solve complex prob-

Figure 5. Average Payment per CSHCN Claim



Source: Office of Special Healthcare Needs, Rhode Island Department of Health, 2009.

lems across a broad range of services has great benefits for physicians as well,” said Dr. Burke.

“Physicians who are part of the Neighborhood Health Plan network talk about the value the parent consultants brought to their practices,” said Neighborhood Health Plan’s L. McTyeire Johnston, M.D., chief medical director. Johnston points out that PPEP primarily benefits practitioners who have a large volume of children with complex needs, and who understand and buy into the medical home model. “The physicians love it. For the first time, they can ask the child’s parents, ‘Is there anything else I can do for you?’ Many of them had been afraid to ask,” said Laura Jones, the parent consultant supervisor.

### Vehicle for Communication with State

With Medicaid managed care becoming the norm, states are less responsible for direct services to beneficiaries, and therefore are a few steps removed from physicians and families. PPEP serves a critical communication function. As discussed, its extensive database helps to keep the state informed of barriers and gaps in services. Further, PPEP provides a vehicle for the state to inform physicians and families about changes in public programs. For example, undocumented children (generally children of illegal immigrants) recently lost RIte Care coverage. The parent consultants were educated about the changes and learned how to be proactive. They worked with families to find alternative services to maintain continuity



of care. Some PPEP sites remained open to families; in other cases, the parent consultants helped transfer the families to health centers and hospital clinics.

## NEXT STEPS

Rhode Island's Medicaid program is undergoing additional reforms. In late 2008, the federal government approved a state request for a "global Medicaid waiver" that will cap federal Medicaid funding but give the state more flexibility in eligibility and benefit design. This will likely lead to program changes and greater need for support and guidance to families and practitioners.

As noted above, the grant that provides major funding to PPEP ended and additional sources are needed to sustain and expand the program. According to Garneau, more medical practices want the PPEP program, but the Department of Health is holding off until it is able to secure funding for those practices already participating.

## CHALLENGES AND LESSONS LEARNED

Going forward, the main challenge for PPEP is finding stable, ongoing funding for medical homes and the extra services they provide. As noted, state administrators are talking with insurance companies about securing reimbursement to practices for the extra time parent consultants spend with families. Under current economic conditions, this may be difficult to achieve. Another approach is to train the parent consultants to help with reimbursable tasks, like developmental screening and Medicaid application assistance.

There are lessons from the PPEP experience that could help planners, administrators, and legislators considering a similar model, including:

- Partnerships between the public and private sectors are critical from the start; a state agency on its own cannot make this type of program successful.

- Even with an initial grant, it was helpful to require medical practices to support a small portion of the program, like funding five hours per week. This allowed the practices to become invested and accustomed to the idea that they could contribute, making them open to later requests to shoulder more of the cost.
- It is important to be flexible and tweak the program along the way. This meant continually examining the role of the parent consultants, assessing how they could best support the families and practitioners, and adjusting their role as needed.
- Quality assurance is critical, to examine on an ongoing basis what is working and what is not and to make midcourse corrections.

In addition to these lessons, PPEP partners identified the following key elements of a successful model:<sup>16</sup>

- incorporating the philosophy and practice of the medical home;
- using the peer-to-peer support model and family networks to increase family use of lower-cost community services and more directly address family concerns;
- linking to the state's managed care health plan;
- incorporating integrated care management, which helps families navigate and connect health care and community social services, and address physician and family concerns; and
- using partnerships as opportunities for innovation.

## CONCLUSION: PROMISE FOR IMPROVING CARE

The PPEP model is currently being replicated within Rhode Island. In January 2009, the state implemented a Peer-Assisted Health Initiative. Developed with PPEP staff guidance and funded primarily through Title V and a Medicaid infrastructure grant, specially trained peer navigators—primarily adult consumers with disabilities or special health needs—are placed in 10 medical sites, including internal medicine practices and health centers. They are helping adults and adolescent patients with disabilities apply for insurance, obtain services and referrals, and navigate the health and social service and other support systems.

Program leaders believe the PPEP model is replicable in other states. In Rhode Island, severe economic pressures related to the recession and a newly approved global Medicaid waiver gives the state opportunities, but also pressure to redesign health care to reduce cost growth. One promising option involves promoting cost-effective, patient-centered medical homes, which could readily include the PPEP model.

## FOR MORE INFORMATION

Contact Colleen Polselli, PPEP program manager, Rhode Island Department of Health, [Colleen.Polselli@health.ri.gov](mailto:Colleen.Polselli@health.ri.gov)

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## RESOURCES

Beach Center on Disability: [http://www.beachcenter.org/families/parent\\_to\\_parent/default.aspx](http://www.beachcenter.org/families/parent_to_parent/default.aspx).

Evidence-Based Practices in Parent-to-Parent Support, B. Santelli, Beach Center on Disability 2002; edited by Parent to Parent USA, <http://www.p2pusa.org/>.

Parent-to-Parent USA: <http://www.p2pusa.org/>.

PPEP: <http://www.health.ri.gov/family/specialneeds/ppep.php>.

Santelli, B., Turnbull, A., Marquis, J., Lerner, E. (1997). Parent-to-Parent Programs: A Resource for Parents and Professionals. *Journal of Early Intervention*, 21(1):73–83.

Santelli, B., Turnbull, A., Marquis, J., Lerner, E. (1995). Parent-to-Parent Programs: A Unique Form of Mutual Support. *Infants and Young Children*, 8(2):48–57.

Singer, G. H. S., Marquis, J., Powers, L. K., Blanchard, L., DiVenere, N. Santelli, B. (1999). A Multisite Evaluation of Parent to Parent Programs for Parents of Children with Disabilities. *Journal of Early Intervention*, 22(3):217–29.

## NOTES

- <sup>1</sup> The Maternal and Child Health Bureau defines children and youth with special health care needs as those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children and youth generally.
- <sup>2</sup> Rhode Island Title V Needs Assessment, 2004.
- <sup>3</sup> According to the PPEP brochure, “A medical home is a team approach to providing health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally appropriate.” [http://www.medicalhomeinfo.org/States/Downloads/RI/PPEP\\_brochure1.pdf](http://www.medicalhomeinfo.org/States/Downloads/RI/PPEP_brochure1.pdf). One of the principles of a medical home is to provide “care that is coordinated and/or integrated across all elements of the complex health care system (e.g., subspecialty care, hospitals, home health agencies, nursing homes) and the patient’s community (e.g., family, public and private community-based services).” See “Joint Principles of the Patient-Centered Medical Home” by the American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, March 2007, <http://www.medicalhomeinfo.org/Joint%20Statement.pdf>.
- <sup>4</sup> G. H. S. Singer, J. Marquis, L. K. Powers et al., “A Multisite Evaluation of Parent to Parent Programs for Parents of Children with Disabilities,” *Journal of Early Intervention*, Jan. 1999 22(3):217–29.
- <sup>5</sup> See PPEP goals and description at Rhode Island Office of Special Health Care Needs, <http://www.health.state.ri.us/family/specialneeds/ppep.php>.
- <sup>6</sup> For more information about CEDARR Family Centers see [http://www.dhs.ri.gov/Portals/0/Uploads/Documents/Public/Children%20w%20Spec%20Needs/CEDARR\\_cert\\_std.pdf](http://www.dhs.ri.gov/Portals/0/Uploads/Documents/Public/Children%20w%20Spec%20Needs/CEDARR_cert_std.pdf). For more information about the range of Rhode Island Department of Human Services programs for children with special needs, see: <http://www.dhs.ri.gov/DefaultPermissions/ChildrenwithSpecialNeeds/tabid/775/Default.aspx>.
- <sup>7</sup> The Part C Early Intervention Program was federally authorized as part of the Individuals with Disabilities Education Act. Early Intervention programs are operated in every state as an entitlement to children from birth to 3 with developmental disabilities or delays.
- <sup>8</sup> Family-to-family health information centers are nonprofit organizations that assist families of children and youth with special health care needs and the professionals who serve them. Led by parents of children with special needs, family-to-family health information centers typically offer information, resources, referrals, training, support, and referral services. Under the Family Opportunity Act, part of the 2006 Deficit Reduction Act, the Health Resources and Services Administration, Maternal Child Health Bureau, provides primary funding to all states for family-to-family health information centers.
- <sup>9</sup> This was part of a Title V Needs Assessment, which states are required to conduct every five years and include in their Title V Block Grant Applications.
- <sup>10</sup> Early Intervention offers a comprehensive developmental evaluation for infants and toddlers with developmental disabilities or delays, and provides support services to those who are deemed eligible. Administration of Early Intervention in Rhode Island transitioned from the Department of Health to the Department of Human Services in 2004–2005. For more information see: <http://www.dhs.ri.gov/ForProvidersVendors/MedicalAssistanceProviders/ReferenceGuides/Rehab/EarlyIntervention/tabid/700/Default.aspx>.
- <sup>11</sup> For more information about the New Freedom Initiative see <http://www.cms.hhs.gov/NewFreedomInitiative/>.
- <sup>12</sup> Title V Maternal and Child Health Services Block Grant program provides grants to state public health agencies for planning, promoting, coordinating, and evaluating service systems for pregnant women, mothers, infants, and children without access to appropriate health care, and to provide or coordinate health services to children with special health care needs and their families.

- <sup>13</sup> A. Tinajero and D. Garneau, “Evaluation of the Pediatric Practice Enhancement Project,” *Health by Numbers, Rhode Island Department of Health* July 2009 92(7):253–55, <http://rimed.org/med-healthri/2009-07/2009-07-253.pdf>.
- <sup>14</sup> Study limitations included children not receiving services and unpaid encounters not included in the average per child visit and average claim per visit calculations; there was no adjustment for potential dual model participation and indirect costs were not included.
- <sup>15</sup> R. Burke et al., “Rhode Island Pediatric Practice Enhancement Project,” Presentation to the Massachusetts Consortium for Children with Special Health Care Needs, June 14, 2007.
- <sup>16</sup> Ibid.

## Appendix A. PPEP Forms

## Pediatric Practice Enhancement Project

## Intake Form

Intake Date:

☐ Initial☐ Update**Child's Basic Information**

Name

First

Last

Date of Birth:

Gender: ☐ Female☐ Male

Social Security Number:

Insurance Type:

☐ Rite Care☐ Katie Beckett☐ SSI☐ Other Medicaid☐ Private Insurance☐ Uninsured

Insurance Provider:

☐ Blue Cross☐ United Health☐ Neighborhood Health Plan☐ Aetna☐ Cigna☐ Health Value Management☐ Tufts☐ TriCare☐ HarvardPilgrim ☐ MassHealth☐ Mega Life and Health☐ Mashentucket Pequot☐ Other☐ Fee for Service

Location:

Primary Care Physician:

First

Last

Ethnicity:

☐ Hispanic☐ Non-Hispanic

Race (mark one or more):

☐ White☐ Black☐ Asian☐ American Indian/Alaskan Native☐ Native Hawaiian/Other Pacific Islander**Parent(s)/Guardian(s)/Primary Caregiver(s) Information**

Name (first and last)	Home Address	Phone Numbers	Primary Language Spoken
		Home: Cell: Work: E-Mail:	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Portuguese <input type="checkbox"/> Other:
		Home: Cell: Work: E-Mail:	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Portuguese <input type="checkbox"/> Other:

**Diagnosis, Service and Problems:**

Diagnosis:

Current Services (please check all that apply and specify agency name, if applicable):

☐ School/El Program:

Grade:



		Education Type:		<input type="checkbox"/> Regular	<input type="checkbox"/> Special	
<input type="checkbox"/> 504 Plan	<input type="checkbox"/> IFSP					
	<input type="checkbox"/> Mental/Behavioral Health:					
	<input type="checkbox"/> Rehabilitative Services (PT/OT/SP):					
	<input type="checkbox"/> Medical Specialist:					
	<input type="checkbox"/> CEDARR Family Center:					
	<input type="checkbox"/> HBTS <input type="checkbox"/> PASS <input type="checkbox"/> KIDSCONNECT					
	<input type="checkbox"/> Home Care Services (CNA, Nursing):					
	<input type="checkbox"/> Other:					
Problems or concerns with (please check all that apply):						
<input type="checkbox"/> Child Protection	<input type="checkbox"/> Adolescent Transition	<input type="checkbox"/> Asthma Related	<input type="checkbox"/> Child Care			
	<input type="checkbox"/> Education					
	<input type="checkbox"/> Food/Clothing	<input type="checkbox"/> General Parenting	<input type="checkbox"/> Health Insurance			
<input type="checkbox"/> Home Care Services	<input type="checkbox"/> Housing					
	<input type="checkbox"/> Medical Equipment	<input type="checkbox"/> Medical Issues	<input type="checkbox"/> Mental/Behavioral Health	<input type="checkbox"/> Nutrition		
	<input type="checkbox"/> Peer Support					
	<input type="checkbox"/> Recreation/Social	<input type="checkbox"/> Reproductive Health	<input type="checkbox"/> Respite			
<input type="checkbox"/> Safety						
	<input type="checkbox"/> Specialty Evaluation	<input type="checkbox"/> Therapy (OT, PT, Speech)				
<input type="checkbox"/> Other:						
Does family have a computer at home:		<input type="checkbox"/> Yes	<input type="checkbox"/> No			
Number in Household:		Under 6	6-11	12-16	17-21	Adults
(please specify number in each category)						
Assigned Parent Consultant:						

## Pediatric Practice Enhancement Project

### Workplan Form

ID#:

Child:

*First Name**Last Name*

Date of Birth:

Practice:

### Workplan

Opened Date:

Problem Category (check one):

☐ Asthma Related☐ Child Care☐ Child Protection☐

Education

☐ Food/Clothing☐ General Parenting☐ Health Insurance☐ Home Care Services☐ Housing☐ Medical Equipment☐ Medical Issues☐ Mental/Behavioral Health☐ Nutrition☐ Peer Support☐ Recreation/Social☐ Respite☐ Safety☐

Specialty Evaluation

☐ Therapy (OT, PT, Speech)

Problem Statement:

Action Taken:

1.

2.

3.

4.

Family Informed about CEDARR:

☐ Yes☐ No

CEDARR Referred To:

☐ About Families☐ Families First☐ Empowered Families☐ Solutions CEDARR

Not Referred (Specify Reason):

☐ Family Refused☐ Not Medical Eligible☐ Services Not Required☐ Currently Involved☐ Other:

Care Notebook Given:

☐ Yes☐ No

Other Referrals (please enter the \*code(s)):

*\*the codes are listed on the back side of this form*

System Barriers (please check all that apply):

	<i>Explanation</i>
<input type="checkbox"/> Transportation	
<input type="checkbox"/> Lack of Available Services	
<input type="checkbox"/> Limited Hours of Operations	
<input type="checkbox"/> Insurance Doesn't Cover Services	
<input type="checkbox"/> Language	
<input type="checkbox"/> Other	

**Status:** ☐ Achieved ☐ Not Achieved – Explain:  
☐ System Barriers ☐ Family Took no Action ☐ Other:

## Closing of Workplan

End Date:

Pediatric Practice Enhancement Project  
Progress Note Form

Date:

Child:

First Name

Last Name

Date of Birth:

Practice:

Activity Information *(please check all that apply):*

Activity Type:	<input type="checkbox"/> Face-to-Face	<input type="checkbox"/> Phone	<input type="checkbox"/> E-Mail	<input type="checkbox"/> Fax
	<input type="checkbox"/> Mail			
Activity Location:	<input type="checkbox"/> Practice Office	<input type="checkbox"/> School	<input type="checkbox"/> Home Visit	<input type="checkbox"/>
Community				
Activity Content:	<input type="checkbox"/> Peer Support	<input type="checkbox"/> Resources	<input type="checkbox"/> Information	
	<input type="checkbox"/> Referral	<input type="checkbox"/> Referral Follow-up		

Notes:

Next Steps:

Amount of Time Spent on Above Activities *(in minutes)*:

## Appendix B. PPEP Sites, as of 7/2009

### Participating PPEP Practicesw

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Aquidneck Medical Associates  
50 Memorial Boulevard, Newport, RI 02840  
Phone: 401-847-2290

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Hasbro Children's Hospital Rehabilitation Center  
765 Allens Avenue, Providence, RI 02905  
Phone: 401-432-6800

---

Children's Neurodevelopment Center, Hasbro Children's Hospital  
593 Eddy Street, Providence, RI 02903  
Phone: 401-444-5685

---

City of Newport Housing Authority;  
Healthy Residents, Healthy Homes Project  
1 York Street, Newport, RI 02840  
Phone: 401-848-6697

---

Coastal Waterman Pediatrics  
900 Warren Avenue, East Providence, RI 02914  
Phone: 401-421-6481

---

Community Asthma Program, Hasbro Children's Hospital  
593 Eddy Street, Providence, RI 02903  
Phone: 401-444-3092

---

Department of Pediatrics at Memorial Hospital Neurodevelopment Center  
555 Prospect Street, Pawtucket, RI 02860  
Phone: 401-729-6200

---

Dr. Cheryl Flynn  
2 Wake Robin Road, Lincoln, RI 02865  
Phone: 401-333-1656

---

Family Service Inc.  
55 Hope Street, Providence, RI 02906  
Phone: 401-331-1350

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Neonatal Follow-Up Clinic, Woman & Infants Hospital  
134 Thurbers Avenue, Suite 215 Providence, RI 02903  
Phone: 401-453-7750

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Neonatal Intensive Care Unit, Women and Infants Hospital  
101 Dudley Street, Providence, RI 02903  
Phone: 401-274-1100

---

Northstar Pediatrics Hasbro Children's Hospital  
593 Eddy Street; Providence, RI 02903  
Phone: 401-444-4471

---

Northwest Community Health Center  
36 Bridgeway, Pascoag, RI 02859  
Phone: 401-568-7662

---

Park Pediatrics, Inc.  
801 Park Avenue Cranston, RI 02910  
Phone: 401-274-6575

---

Rainbow Pediatrics, Hasbro Children's Hospital  
593 Eddy Street, Providence, RI 02905  
Phone: 401-444-4691

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Samuels Sinclair Dental Center  
593 Eddy Street, Providence, RI 02903  
Phone: 401-444-5284

---

South Country Pediatric Group, Inc.  
4979 Tower Hill Road, Wakefield, RI 02879  
Phone: 401-789-6492

---

The Autism Project  
1516 Atwood Avenue Johnston, RI 02919  
Phone: 401-785-2666

---

Ventilator Integration Program, Hasbro Children's Hospital  
593 Eddy Street, Providence, RI 02903  
Phone: 401-444- 8059

---

Wood River Health Services  
823 Main Street, Hope Valley, RI 02832  
Phone: 401-539-2461

---

Central Health Center  
239 Cranston Street Providence, RI 02907  
401-444-0580

---

Olneyville Health Center  
100 Curtis Street, Providence, RI 02909  
Phone: 401-444-0540

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Federal Hill House  
9 Courtland Street, Providence, RI 02909  
401-421-4722

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RI Department of Corrections  
Dix Building Cranston, RI 02920  
401-462-0185

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Source: <http://www.health.ri.gov/family/specialneeds/ppp-practices.php>

### ABOUT THE AUTHOR

Sharon Silow-Carroll, M.B.A., M.S.W., is a health policy analyst with nearly 20 years of experience in health care research. She has specialized in health system reforms at the local, state, and national levels; strategies by hospitals to improve quality and patient-centered care; public–private partnerships to improve the performance of the health care system; and efforts to meet the needs of underserved populations. Prior to joining Health Management Associates as a principal, she was senior vice president at the Economic and Social Research Institute, where she directed and conducted research studies and authored numerous reports and articles on a range of health care issues.

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This study was based on publicly available information and self-reported data provided by the case study institution(s). The Commonwealth Fund is not an accreditor of health care organizations or systems, and the inclusion of an institution in the Fund's case studies series is not an endorsement by the Fund for receipt of health care from the institution.

The aim of Commonwealth Fund–sponsored case studies of this type is to identify institutions that have achieved results indicating high performance in a particular area of interest, have undertaken innovations designed to reach higher performance, or exemplify attributes that can foster high performance. The studies are intended to enable other institutions to draw lessons from the studied institutions' experience that will be helpful in their own efforts to become high performers. It is important to note, however, that even the best-performing organizations may fall short in some areas; doing well in one dimension of quality does not necessarily mean that the same level of quality will be achieved in other dimensions. Similarly, performance may vary from one year to the next. Thus, it is critical to adopt systematic approaches for improving quality and preventing harm to patients and staff.

