



*“The parent consultant has been the ‘helping hand’
that I was unable to be before the PPEP program started.”*

– Physician, Aquidneck Medical Associates

the PPEP

PEDIATRIC PRACTICE ENHANCEMENT PROJECT:
STRENGTHENING RHODE ISLAND’S MEDICAL HOME INFRASTRUCTURE

THE PRESIDENT’S NEW FREEDOM INITIATIVE charges states with implementing a system of care that gives all children with special health care needs access to a medical home by 2010. A medical home is a team approach to providing health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally appropriate.

The PPEP model addresses this initiative by placing trained parents of children with special health care needs in pediatric primary and specialty care settings. Parent consultants create a link between the family, the pediatric practice, and the community.

A recent survey of PPEP practices showed that all participating physicians agreed that the PPEP model has enhanced their practice’s provision of family-centered services. Physicians agreed that parent consultants helped to improve their understanding of patients’ needs. They also reported that the PPEP helped to reduce scheduling delays, family wait time, and overall physician productivity.



BACKGROUND

Children with special health care needs require care beyond that of most children. Frequent primary care visits and visits to specialists make a medical home especially important for these children. Both physicians and parents have reported a number of barriers to obtaining coordinated and comprehensive care for children with special health care needs.

Physicians have said that they have a lack of time to spend with patients discussing care beyond that related to their physical health, limited staff to help with patient follow-up, difficulty navigating the special health care needs system, and a disconnect between the practice and community services. Parents of children with special health care needs say they have difficulty in navigating the special health care needs system and that there is a lack of coordination among their primary care providers and other health services providers.

The Rhode Island Department of Health is committed to ensuring access to medical homes for all Rhode Island families. While the state is doing better than the nation in terms of ensuring access to medical homes for children, children with special health care needs are less likely to have a medical home than other children.

Given the importance of medical homes for children with special health care needs, in 2004, the Rhode Island Department of Health's Office of Special Health Care Needs obtained funding for a three-year pilot project called the Pediatric Practice Enhancement Project (PPEP). In 2006, through the Office's New Freedom Initiative grants, the PPEP was expanded.

WHAT IS PPEP?

The PPEP was developed to assist and support pediatric primary and specialty care practices in providing care to children with special health care needs and their families within a medical home. Participating practices include private practices, community health centers, hospitals, dental clinics, and housing authorities. Parent consultants, who are parents of children with special health care needs, are located in the practices to link

families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care.

The overall goal of the PPEP is to improve short and long-term health outcomes of children with special health care needs.

Through PPEP:

- » Pediatric practices provide coordinated and comprehensive care to children with special health care needs and their families with greater operational efficiency.
- » Pediatric practices are more aware of, and collaborate with, community services and resources for children with special health care needs.
- » Families of children with special health care needs have a better understanding of the health care delivery system, including the community resources available to them.
- » Families are more confident and assertive in managing their child's health care needs.





Diagnoses of the children and youth served by the PPEP ranged from developmental delays to spina bifida – the most frequent diagnoses being attention deficit disorder (ADD), asthma, speech or language disorders, behavior disorders, autism spectrum disorders, and obesity.

To date, PPEP parent consultants have:

- » Addressed thousands of specific challenges faced by families – over 50% of which were concerning education, mental and behavioral health, obtaining specialty evaluations, and accessing health insurance;
- » Referred hundreds of families to CEDARR, the State's care coordination system; and
- » Followed up with families regarding service access, referrals, and systems barriers.

Through their meetings with families, parent consultants have gathered valuable information about the service delivery system for children with special health care needs including the barriers families face.

The barriers most commonly reported by families include:

- » Long waiting lists for services;
- » Lack of awareness of available resources; and
- » Limited hours of operation at service locations.

The information collected by parent consultants is being used to improve the service delivery system through feedback to state and community leadership.

“I was able to support the physician by helping this family access services in the school. The doctor, the family, and the school are now working together to support this child. This is a true medical home at work.”

– Parent consultant, South County Pediatric Group

PPEP BENEFITS PHYSICIANS

Given time constraints, providing effective coordinated care is a challenge for many physicians. The time required to facilitate referrals, research resources, and discuss patient needs with social workers, specialists, and other community partners often deters physicians from engaging in special health care issues beyond immediate physical health. Knowing that a parent consultant is available to assist families with follow-up enables physicians to feel more confident about approaching other special health care needs.

As parent consultants educate families about community resources and services, physicians and their staff begin to build connections with other providers in their community. Additionally, the presence of parent consultants in pediatric care settings has increased office efficiency while providing a more comprehensive health care experience for families.

PPEP BENEFITS FAMILIES

The PPEP provides families with valuable information needed to navigate a complex health care system.

Because parent consultants are themselves parents of children with special health care needs, they understand the challenges families face, provide peer-to-peer support, and help to increase communication. Support from a parent consultant helps to build the parent's confidence in his/her ability to advocate and care for his/her child.

By providing connections to community services and assisting families in overcoming barriers to care, the PPEP has increased families' knowledge of the health care system and how to coordinate appropriate care for their child.



“I can see how the parent I am working with has become empowered. She feels comfortable making calls to her child's service providers. When I first started working with her she wasn't calling anyone back.”

– Parent consultant, Kid's Health Team/Hasbro



FOR MORE INFORMATION, CONTACT:

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