

# Incorporating Patient- and Family-Centered Care Into Practice: The PA Medical Home Initiative

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The medical home model is the standard of health care delivery in primary care that is used to provide comprehensive and continuous medical care to patients by enhancing access to care, increasing patient satisfaction, and improving health outcomes.<sup>1,2</sup> Promoting effective partnerships between families and clinical practice teams by engaging parents as partners in their children's care ensures that families receive all the needed services by creating mechanisms for parental and/or caregiver input<sup>3</sup> and embodying the quadruple aim of the health care framework (assessing patient and family experience, provider experience, reduced costs, and population health outcomes).<sup>4</sup> Engaging parents and/or caregivers as partners promotes patient- and family-centered care, which is associated with better health status (psychological functioning, quality of life, and symptom severity) and family functioning (cost and parents' missed work days).<sup>1,3</sup> Understanding experiences and models of engaging parents and/or caregivers in clinical practice can be useful to pediatricians and clinical providers.

## THE PENNSYLVANIA MEDICAL HOME INITIATIVE

The Pennsylvania Medical Home Initiative (PAMHI) is an innovative model in which patient- and family-centered care is incorporated into practice. Funded by the Pennsylvania Department of Health's Title V grant, this statewide quality improvement program has been used to train the staff of >170 pediatric and adult primary care practices throughout the Commonwealth of Pennsylvania in the adoption, implementation, and evaluation of medical homes.<sup>5</sup> Participating practices are eligible for funding (range: \$5000–\$10 000 annually for a maximum of 3 years) to support family-centered care coordination activities for children with special health care needs (CSHCN).<sup>6</sup>

Since 2006, >3900 parents and/or caregivers whose children were cared for within the PAMHI practice network have been surveyed to garner family and/or caregiver input about their experiences in their children's medical home practice. Parents and/or caregivers have reported fewer emergency department visits and hospitalizations and improved family experiences and quality of life for children and families when they are cared for in a patient- and family-centered medical home practice in the

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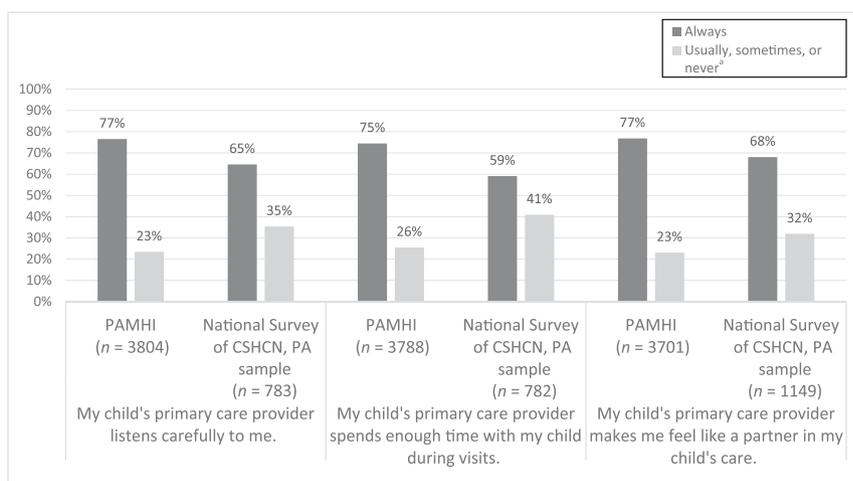
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PAMHI network. Compared with the 2009–2010 National Survey of CSHCN sample of parents and/or caregivers from Pennsylvania, parents and/or caregivers within participating practices of the PAMHI reported significantly higher levels of family-centered care as measured by the child's primary care provider listening to them, spending enough time with the child during the visit, and making them feel like a partner in their child's care (Fig 1).<sup>6</sup>

The PAMHI implementation team, which is housed at the Pennsylvania Chapter of the American Academy of Pediatrics (AAP), includes a medical director, a program director, practice coaches, and parent advisors, who are all integral for implementing medical home tenets within participating network practices. PAMHI parent advisors are paid consultants who educate the PAMHI network practices and health care systems about patient- and family-centered care concepts and collaborate with care coordinators within participating PAMHI practices to identify and train potential parent partners within the practices. Parent advisors are parents and/or caregivers of CSHCN who work 20 hours per week with the PAMHI team. The PAMHI parent advisors assist the PAMHI practices with the identification, maintenance, and support of their own practice parent partners via technical assistance and training. A key responsibility of the PAMHI parent advisors includes providing on-site technical assistance to the PAMHI practices by identifying and sharing useful community resources with practices, training other parent partners in techniques such as care coordination, developing care plans for their children, care mapping, and sharing PAMHI resources, tools, and implementation guides. Care mapping is a process that can be used to provide a comprehensive picture of a family's needs by helping the



**FIGURE 1** Comparing patient- and family-centered care among parents in the PAMHI and the National Survey of CSHCN Pennsylvania sample. Parents within PAMHI-participating practices reported always receiving significantly higher rates of patient- and family-centered care compared with the 2009–2010 National Survey of CSHCN sample of parents and/or caregivers from Pennsylvania ( $P < .001$ ).<sup>a</sup> Using patient- and family-centered care questions that are in both surveys, we compared results by dichotomizing responses into always versus usually, sometimes, or never.

family to identify and communicate the large and small details of the many resources that are needed to support their children and their families.<sup>7</sup>

Parent partners are parents of children who are receiving care within a participating PAMHI practice. They are recruited within the practice by the practice team, which includes clinicians and staff who feel that the parent and/or caregiver would be an effective team member. Other parent partner recruitment methods include reaching out to parents within the practice through flyers in the waiting room, posting on the practices' Web site and social media, reaching out to PAMHI parent advisors for assistance, and/or soliciting interest 1-on-1 with parents while they are in the office. The staff members of the PAMHI have found that parent partners are successful when they possess the following qualities:

- are parents and/or caregivers of CSHCN experiencing multiple systems of care;
- have not recently received a new diagnosis for their children;

- can provide candid feedback regarding practice policies and procedures;
- can promote linkages between other parents;
- possess good listening and communication skills and can interact professionally with practice administration and staff;
- can help support a child's care plan;
- can speak to other parents beyond their own experiences with their children;
- recognize that they have valuable expertise and experiences to share;
- possess resiliency, empathy, and a genuine desire to help other parents; and
- have the time to devote and agree to be a parent partner.

Once recruited and engaged, parent partners are encouraged to hold meetings with other parents within the practice to share their experiences by discussing practice processes, workflows that are related to scheduling, referral coordination, telephone callbacks, patient portal

communications, practice policies, and on-call protocols. Practices within the PAMHI practice network have used this feedback to inform practice quality improvement with demonstrable results, such as improved efficiency with phone trees, better immunization rates, better customer service, and more ideas for practice events. Parent partners also participate as part of the practice's quality improvement team, teach medical students and residents as "family faculty," and provide support to other parents in the practice. Some PAMHI practices and their parent partners have held "resource nights," during which they invite a group of parents along with community partners into the practice to share ideas and resources.

The staff members of PAMHI practices have found that it is ideal to identify at least 3 to 5 parent partners to ensure sustainability and prevent the burnout or overburdening of parents. Parent partners are often invited to staff meetings and compensated for their time, expertise, travel, and child care expenses. The PAMHI team and the practice network have developed job descriptions and contracts for parent partners to assist in the understanding of roles, expectations, and responsibilities. Typically, the frequency of practice meetings with parent partners should be a minimum of once per quarter to ensure that engagement is maintained. The PAMHI financially supports parent partners for their participation (\$25 per parent per meeting) when they work with the practices in the PAMHI network. To date, >200 parent partners have been recruited and engaged with practices in the PAMHI network.

To address the challenges of the geographic and population diversity of Pennsylvania and the variations in local resources and insurances, the PAMHI has placed parent advisors strategically in the eastern,

central, and western parts of the Commonwealth of Pennsylvania. This allows for efficient travel to area practices and for parent advisors to be knowledgeable and connected to local resources and medical communities. PAMHI parent advisors have experienced challenges with identifying and recruiting parents of CSHCN to become parent partners because it can be difficult because of the many competing responsibilities in these parents' lives. The relationship between the PAMHI team and the clinical practice teams also takes time to develop and includes educating medical practice teams on the core concepts of patient- and family-centered care, which may be initially met with some caution. The PAMHI team has overcome the challenges of engaging parent partners by offering reimbursement for child care, showing flexibility with parent partner meetings (teleconference phone calls instead of in-person meetings), and collaborating with local parent advocacy groups to engage and recruit parent partners. The majority of PAMHI network practices have sustained parent partner engagement and changed the culture in the practices with parent support groups, regular educational sessions hosted by parents for other families, and regular communication and feedback with the practice team.

The PAMHI has partnered with national organizations to promote patient- and family-centered care, including Family Voices, a national, family-run organization with extensive experience in assisting family-professional initiatives.<sup>8</sup> The Family Voices National Center for Family and Professional Partnership supports a Family-to-Family Health Information Center (F2F HIC) in each state. The Maternal and Child Health Bureau provides funding to F2F HICs in each state to provide education, technical assistance, and peer support to families of CSHCN and the

professionals who are serving and caring for them. These centers are family-led, statewide agencies that are staffed by the families of CSHCN, many of whom participate in medical home activities.<sup>8</sup> The National Center for Family and Professional Partnership offers a validated quality improvement tool (the Family-Centered Care Assessment for Families) and offers technical assistance to individual clinical practices, state agencies, and parent advocacy groups.<sup>8</sup> Additionally, the Institute for Patient- and Family-Centered Care and the National Institute for Children's Health Quality provide free resource guides in which ways to implement these concepts in different settings (hospital or primary and/or ambulatory care) are demonstrated.<sup>9,10</sup> Practices can start by identifying and contacting their local F2F HICs. States and practices can partner with their local F2F HICs and affiliated parent agencies to initiate and engage in this work. Those at F2F HICs are aware of all parent agencies within their states and can provide linkages to other parent agencies that may be used to support and train other parent leaders to conduct this work within practices if grants and Title V funding are not available. Collaborating with local AAP chapters and the AAP's National Center for Medical Home Implementation also affords practitioners additional technical assistance and resources for patient and family engagement in clinical practice. Some practices hire staff such as front desk employees, nurses, or medical assistants who can also function as parent partners in their practices. In some states, payers and value-based health care programs offer incentives and funding for patient and family engagement and initiatives. Other practices identify modest budgets within their practices to support small honoraria, food, or special events for parent partners in the practice setting.

## RECOMMENDATIONS

For other states, pediatrics practices, and hospital systems that are seeking to adopt similar programs, there are several key considerations, including the following: (1) recognizing the value of and evidence for parent partners in the adoption and implementation of the medical home model, (2) identifying strategic partners to assist in training and professional development for the parent partner role in practice, (3) establishing a formal role for parent partners as equal practice team members, and (4) ensuring that parent and/or caregiver feedback is garnered from parents across the practice and using the feedback of their experiences for meaningful quality and practice improvement to uphold the quadruple aim of health care.

An important first step is identifying strategic partners (eg, local F2F HICs and state AAP chapters) that can assist in training and professional development for the parent partner role in practice. Linking to other local parent organizations, community partners, educational centers, and mental health agencies with established parent and/or caregiver groups is crucial. Developing a formal job description for the parent partner role by supporting their time and/or travel and hiring them as staff conveys the value of parent partners as respected team members. Eliciting feedback from parents will benefit both the practice and parents and may be completed via existing validated family feedback surveys, by conducting focus groups, or by using suggestion boxes in practices. Lastly, practices can collaborate with parent partners and community resource partners to hold information nights, host support groups, and engage special populations (grandparents

and/or fathers) as informed by parental feedback.

The PAMHI parent advisor and/or parent partner role can be replicated and successful in other pediatric practice settings to foster the quadruple aim of health care. The PAMHI can be used to serve as a model of how pediatric practices can adopt medical home concepts, specifically patient- and family-centered care with parent partners, into their practices.

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## ABBREVIATIONS

AAP: American Academy of Pediatrics  
CSHCN: children with special health care needs  
F2F HIC: Family-to-Family Health Information Center  
PAMHI: Pennsylvania Medical Home Initiative

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