

Insights

Why and How to Include the Patient-Family Voice in a Medical Home



Bonnie Thompson, advocate Mass Family Voices at the Federation for Children with Special Needs

At a recent medical appointment, my teenage daughter and I were offered an opportunity to complete a patient experience survey. My daughter was eager to provide feedback and happily answered the questions thoughtfully.

She likes that movies play in the waiting room and doesn't like when wait times in the exam room are long. She noted when she felt that complete information was given to her and recognized when she felt disconnected from the doctor. To her, the experience of the visit went far beyond what her doctor did or didn't say. It included the entire experience from beginning to end, from checking in for her appointment to leaving the office with her questions and concerns addressed—or not.

As more primary care practices work towards identifying themselves as a medical home, patients and family caregivers can play a vital role in shaping how healthcare is delivered. Regardless of the frequency or intensity of care received, most of us have experiences to share about visiting a doctor's office, health clinic or hospital. Patient- and family-centered medical

homes find value in these perspectives as practices work to develop collaborative partnerships with patients and families.

Conducting patient surveys are just a first step for involving patients and families in shaping the healthcare experience. I learned this firsthand through my work on the [CHIPRA Massachusetts Medical Home Learning Collaborative](#), which provided an opportunity for families to share their healthcare experiences to help their child's pediatric practice transform into a medical home. Thirteen participating practices each invited two "Family Health Partners" to join their quality improvement (QI) teams. Many practices utilized family partners in improvement activities such as discovery shopping and developing care team and care planning tools.

While the project is wrapping up, all of us who participated are eager to spread the lessons learned throughout the learning collaborative. We recently created a [Family Engagement Guide](#)—coauthored by NICHQ and [Mass Family Voices](#), a family support organization—that provides pediatric practices with a framework for involving families in QI activities during medical home transformation and beyond. Along with assisting practices in the initial development of a family engagement strategy, this toolkit can help practices sustain and inspire the families with whom they already partner.

Based on input and feedback from family partners and practice transformation facilitators, the Family Engagement Guide includes an orientation to medical home, patient- and family-centered care and QI activities. Practices can also learn how to assess staff and leadership readiness for partnering and supporting families, prepare for recruitment of families who represent their practice community and determine the roles and activities of family partners as improvement partners.

Imagine the impact that the family voice could have on every aspect of an office visit. I know my daughter would have some valuable ideas about how to improve her experience.

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