

Insights

Authentic Family Partnership in Health Care Improvement: What Does it Take?

Advice from Family Partnerships Specialist, Cara Coleman, JD, MPH



NICHQ Board of Directors member, Cara Coleman, JD, MPH

New NICHQ Board of Directors member, Cara Coleman, JD, MPH, has a personal stake in health care improvement: Coleman spent her childhood overseas where she saw how poverty, broken systems, and striking inequities in care adversely affected the health and well-being of countless individuals. As an adult, Coleman confronted the broken systems that exist in our country's backyard: first in public health; then as an immigration lawyer working with victims of domestic violence; and then again within the health care system after her daughter, Justice Hope, was born with special health care needs that required comprehensive in-home medical care.

"Together, these experiences formed the foundation of who I am as a person, because they taught me what it means to really serve others," says Coleman. "I've realized that the only way to create sustainable change is through partnership, teamwork, and respecting and valuing every person as an equal contributor in any sort of change effort."

In 2017, Justice passed away at 11 years old. During those 11 years of navigating the health care system on behalf of her daughter, Coleman's conviction that improvement requires family partnership crystalized.

“When I look back on Justice’s care, I see what was desperately missing,” she explains. “When her care was relationships-based and we [Justice’s care team and family] supported each other, we got stuff done despite the broken system. And that was wonderful. But far more often, there was a lack of family-centered care and true family partnership and that was just really frustrating.”

NICHQ is thrilled to welcome Cara Coleman to its board of directors!

“Family partnership has been central to our mission since NICHQ’s inception over 20 years ago,” says NICHQ CEO Scott D. Berns, MD, MPH, FAAP. “Cara’s unique perspective will be invaluable as we move into NICHQ’s third decade and reaffirm our commitment to ensure that family experiences and expertise are at the heart of every improvement effort.”

Since she lost her daughter, Coleman has committed herself to helping health care providers and professionals engage in authentic family partnership, both at the individual and systems-level. She is a program manager for Family Voices, a patient and family partnerships specialist at the Institute for Patient- and Family-Centered Care, and an instructor of pediatrics at the Virginia Commonwealth University School of Medicine.

Coleman’s personal and professional experiences confirm the importance of family partnership at all stages of health care improvement, whether that’s improving care delivery for one child or improving the design of a hospital system. Below, she shares advice on how health care providers and improvement teams can develop stronger partnership with families, strengthen systems of care, and improve health outcomes for the children they serve.

Leadership means stepping back

Teaching medical students gives Coleman a unique view into what the next generation of health care leaders are learning. And while she applauds the shift away from a paternalistic model of “providing care,” Coleman believes clinicians need more guidance on how to be a leader on a team with family partners. This holds true whether they’re working on a systems-improvement project or seeking to provide family-centered care to a child with special health care needs.

“As a leader, you need to know when to step forward and also when to step back and let families’ perspectives lead the way,” says Coleman. “If you’re trying to improve a system or improve care delivery, you have to do more than just ask families for an opinion. There are times when you need to purposefully step back and let them lead conversations and guide decision-making: that’s how we get to these deeper levels of partnership.”

Engage families as full partners from day one

Whether you're coming up with a plan for a quality improvement project or a plan of care for a child, it's important to engage families as full partners from the start. This means asking families to contribute their ideas *before* any plan is made rather than asking them to comment on a pre-existing plan.

"If you do months of planning and have everything sort of pre-populated, and only then ask a family partner to give advice, that's just tokenism," says Coleman. "And that's not going to build the trust and honesty that leads to authentic, long-term relationships, either at the individual level or the systems level."

While early engagement is best, you *can* change course if you didn't engage families from the start, adds Coleman. Be honest with families that you made a mistake by not partnering with them earlier, apologize, share what you've learned so far, and ask them to contribute and help you course correct.

Words matter: using the term "family partnership"

Committing to a true partnership with families starts by calling it what it is: a partnership. When we don't explicitly describe families as partners, we imply that while their input and perspectives might *influence* an improvement project or care decisions, the opinions of health care professionals matter more.

"Words matter because they're how you begin to make change," says Coleman, "Our words become our actions; *and* our words create images in people's minds, and those images become their words, which then become their actions. If we say, 'we want you to be a partner on this project,' instead of, 'we want your advice on this project,' that's a step towards committing to true partnership. And it's the same thing with the word "expert"—don't use it, because nobody is. In my mind, expert implies that learning is complete, but of course none of us ever stop learning. We have to value lived experience as equal to somebody with a PhD; you can't move anything forward without learning from those with both kinds of knowledge."

Commit to empathy

Patient-care, especially for children with special health care needs, can be emotionally draining for providers, says Coleman. And the same is true for systems-change efforts. "It's frustrating to work in these systems and feel like you've spent all this time and energy, but just don't know how to help any more. But that's when it's important to remember that families are spending the same time and going through the same frustrations; we're all burning out in silos instead of coming together and supporting each other."

Empathizing with families and acknowledging shared frustrations; and leaning on families as partners, not just patients: that's what teamwork is all about. This not only opens the door to a more authentic family-provider partnership, it also makes providers' jobs simply better, which in turn improves patient care.

"In health care, we've been so focused on the Triple Aim—improving patient experience, improving population health, reducing costs—but recently, because of provider burnout, we've

begun to focus on this Quadruple Aim, which includes enhancing provider joy,” says Coleman. “Well what better way to enhance joy than to build these strong empathetic partnerships with families and work together towards improvement?”

Empower families on quality improvement projects

Truly partnering with families means making sure they’re comfortable speaking up and sharing their insights. This can be difficult on quality improvements projects because families may underestimate their knowledge in a more formal project setting.

“If you’re the only family partner at a table with a group of health professionals, it can be challenging to speak up,” says Coleman. “You might feel like your perspective isn’t valued or doesn’t have as much weight as someone with a background in health care.”

Coleman suggests that all improvement projects have at least two family partners, which can help families feel more confident sharing their opinions and experiences. Similarly, try asking families for advice on how to make the project environment more inclusive; tell families you value their ideas and explain how those ideas will inform the project-design; and connect families with leadership resources and trainings, such as those provided through Family Voices.

“Really, it’s all about creating a culture focused on teamwork and partnership,” says Coleman. “And culture change isn’t easy—you need to make time and take time, which is especially tough in fast-paced health care systems. This is one of the reasons I’m really excited to be on the NICHQ Board, working with an organization that uses quality improvement science to test small changes that lead to big organization- or system-wide improvements. There’s so much potential for positive change.”

Interested in more ideas for partnering with families? [Here](#), Family Engagement Specialist Latoshia Rouse shares strategies for engaging diverse family partners on a patient and family advisory council.