

Insights

Families Drive Better Outcomes in Children's Health

Christy Blakely and Elizabeth Aquino both have daughters with special healthcare needs. Both mothers grew accustomed to navigating the halls of hospitals and sidestepping holes in the health system. They know what it's like to feel as though you are not seen and that, no matter how loudly or urgently you speak, your voices won't be heard, and the system will never change.

Over the past decade and a half though, Blakely and Aquino have proven that change *is* possible—significant change whether at an individual hospital or in the larger health system—and that it takes a family voice to make that change happen. Both became parent partners on NICHQ projects where their experiences helped shape improvements in care delivery. Below, we share two stories from these incredible women that illustrate the impact of their work with NICHQ and their ongoing commitment to improving health outcomes for families.

Family Involvement Leads to Family-Centered Care

Blakely first got involved with NICHQ in 2007 during a [collaborative improvement initiative](#) seeking to promote family-centered pediatric care in 17 states across the country.

"I wanted to take my experiences and make a difference, not just for my own daughter but for all kids," says Blakely. "NICHQ offered that platform for elevating family voices, and it was very unique. I didn't see anyone else engaging families in that way, at the time."

In honor of our 20th anniversary, we're sharing stories from the families who partner with us—the mothers and caregivers who've seen firsthand how improvement initiatives have changed children's lives over the past 20 years. Watch a video about the vision we're charting for the years to come [here](#).

The collaborative sought to help pediatric practices in participating states successfully implement a Medical Home model of care, which is centered on family needs and experiences. Family partners' perspectives were invaluable for helping pediatric practices shift toward this more family-centered care model.

"I remember talking with other parent partners whose children had special needs about what we called 'doorknob questions,'" recalls Blakely. "These are questions families asked right as the

pediatrician's hand was on the doorknob to leave the room, the big questions about why this had happened and what more they could be doing. We shared these concerns with the pediatricians and developed a new resource that pediatricians could hang on the door knob: a handout they could share with families with education and information about relevant services, resources, and support groups."

This one example was followed by multiple improvements in care. Pediatricians began to lengthen stays for patients with special healthcare needs; hospitals developed a new system for connecting families with the most relevant resources for their child's disability upon diagnosis; and pediatric practices tested new ways to manage schedules so that families weren't left in crowded waiting rooms. Every change was informed by families, tested using quality improvement methodologies, and spread and scaled.

Today, those changes are still making a difference.

"I get to see the ongoing impact of this work whenever I take my grandchildren to the pediatrician," says Blakely. "I look around and I think, 'Look, they're on time and children aren't waiting next to other sick kiddos; and wow, they have materials in more than one language; and thank you, the pediatricians are respecting mother's gut opinions... It takes time, but these efforts always make a difference in some shape or form. That project and efforts like it have impacted every single kid that goes to the pediatrician."

A Shift in Provider-Perspectives Changes Epilepsy Care

Between 2004-2008, both Blakely and Aquino served as parent partners on [the Improving Care for Children with Epilepsy Learning Collaborative](#), which sought to improve access to comprehensive, coordinated healthcare and related services for children in medically underserved areas.

"As a mother with a child with epilepsy, I know how it feels when doctors don't seem to hear you or really see you," says Aquino. "When they don't look at children with special needs as people, people first apart from their disease. And on that collaborative, at the beginning, it felt no different."

Aquino and Blakely both share similar experiences early in the collaborative: they describe providers who, while invested in the science, were removed from family experiences. Providers who didn't seem to understand why families were attending meetings about quality improvement, whose focus on the medicine left no room for the people that the disease and the treatments most affected.

But then, something shifted. As the family partners became more vocal, the providers on the collaborative began to hear their stories; they began to understand the unique challenges they faced. And once they accounted for family perspectives, they started to make significant changes in their practices.

"I remember I was reading aloud from a book I was writing about my experience with my daughter," says Aquino. "I was sharing some of the struggles we had gone through in trying to

get her care. After my reading, three different neurologists in the audience came up to me and asked me what they could do differently—what they could do better.”

Are you a provider looking to engage families as equal partners in care? Aquino and fellow family partners developed this guide: [Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care](#).

Blakely too experienced this shift. When one doctor asked why families couldn’t follow through and provide medication as prescribed, a mother stepped in, explaining that it wasn’t as easy as the doctor expected.

“She said, ‘ok, I understand that, but we have five different caregivers in our household administering medication, and that’s not so simple to track,’” recalls Blakely. “It was a breakthrough for the providers listening. It wasn’t as simple as patients not following through for this family, and it wasn’t that simple for many other families. They started to realize that the family partners had more to offer this collaborative than their disability experiences. And they started to listen and make real change.”

The providers worked with families to develop a care notebook—a living record families keep about their child’s health needs and treatments, which includes details about the family’s life beyond their child’s diagnosis. The notebook is shared with the provider and helps ensure comprehensive care that accounts for family needs.

Without family partners, this shift in attitudes wouldn’t have occurred. And without this shift, changes in practice wouldn’t have taken place.

This work must continue

Aquino and Blakely’s stories illustrate the critical importance of family partners for improving care delivery. The impact they had on initiatives that began more than a decade ago reaffirm NICHQ’s commitment to continuing to elevate family partners in our work, whether that’s in [improving perinatal health](#) across the country, or working with hospitals to make [infant sleep and breastfeeding the national norm](#).

About our family partners:



Christy Blakely, MS

Christy Blakely is the Parent Partner for the Early Childhood Comprehensive Systems CoIN Project, and has served on multiple NICHQ projects since 2007 including the Collaborative Improvement and Innovation Network to Reduce Infant Mortality ([IM CoIN](#)). Ms. Blakely retired

from her position as the Executive Director of Family Voices Colorado, in 2012. In this capacity she advocated for children and families of children with special health care needs. During her time with Family Voices Colorado, she was the only voice speaking for children on Medicaid Home and Community-Based Service Waivers and worked tirelessly to form partnerships with state agencies and other providers throughout Colorado. As the Chair of Colorado's Medicaid Policy Committee, she continues to address tough issues facing Colorado's most vulnerable populations. Ms. Blakely's works to engage families and working with families to have their voices heard, which is a passion.



Elizabeth Aquino

Elizabeth Aquino is a past Parent Partner for the Improving Care for Children with Epilepsy Learning Collaborative. She has three children, the oldest of whom suffers from a severe form of epilepsy and consequent developmental disabilities. Now 24 years old, she is the inspiration for much of Ms. Aquino's life's work as an advocate for children with special needs, for caregivers, and in healthcare and disability rights. Ms. Aquino is a writer living in Los Angeles with her family. Her work has been published in several literary journals, three anthologies, Spirituality and Health Magazine, The Los Angeles Times, and several prominent websites. She has also published a micro-memoir and is an avid blogger. In 2015, Ms. Aquino was awarded a prestigious writing residency by Hedgebrook and worked for three weeks on Whidbey Island in Washington State on a work of creative non-fiction.