

## Insights

# How to Improve Health Systems for Families: One Mom's Investment in Change

Before Tara Bristol Rouse became a NICHQ family partner—a passionate parent advocate for improving children's health systems—she was a mom. A mom who, in 2004, experienced severe preeclampsia and had to deliver her son 13 weeks before her pregnancy reached term. A mom who spent 83 days after delivery visiting her son in the hospital before he was able to come home. A mom who learned what it felt like to advocate for the services her family needed in a too complicated system.

“My experiences put our children's health system in sharp perspective,” says Rouse. “When I brought my son Jack home, early intervention services visited us, but they decided we didn't need their support. I have a background in children's health, so they assumed I would be ok. But this was my baby, he was high-risk, and my background didn't matter; I needed help.”

Rouse was lucky, she continues. Because she was working at the Center for Children's Healthcare Improvement at the time of her pregnancy, she had thoughtfully chosen a pediatrician who would be a good match for a child with special healthcare needs. Her pediatrician, who agreed that Rouse needed supportive services, partnered with her to get another referral. And when the next early intervention services coordinator came, Rouse was armed with information and ready to advocate for her family's needs.

“I know that the system was stretched thin and that's why they left us on our own, but it was a huge gap in care,” says Rouse. “A parent without my background, someone who didn't feel as empowered and hadn't known how to choose the right pediatrician... well that parent's child would have fallen through the cracks. I think about those families all 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](#).

Rouse witnessed these cracks again just a few months later when she called her Medicaid office to enquire about her son's Medicaid eligibility. The representative she spoke with wouldn't help because Rouse didn't know the name of her designated Medicaid worker. Again, Rouse had to personally research and press for the services her child needed -- and qualified for.

“What if I was a parent who didn’t feel comfortable emailing the leadership of my Medicaid office about this gap in service?” asks Rouse. “What if I didn’t have internet so I couldn’t find out who to email in the first place? What if I worked at a job where I didn’t have the freedom to send another email or make another call? Or what if I didn’t even think I had the right and the ability to make requests? What happens to those families?”

Rouse didn’t just ask these questions; she decided to do something to change the answers. For more than a decade, Rouse has been a dedicated parent partner on multiple NICHQ-led projects, starting with the [Neonatal Outcomes Improvement Project](#) in 2007, and most recently in her work on the Early Childhood Comprehensive Systems Collaborative Improvement and Innovation Network ([ECCS CoIIN](#)). Over the years, she’s seen how systems-change efforts are ensuring that more families get the services they need without the difficulty she went through.

## **Driving and Witnessing Improvement**

Bringing families to the table as equal partners in improvement has been central to NICHQ’s work for the past 20 years. These partnerships ensure that family perspectives guide all effort to improve systems, from identifying gaps in care and service delivery to advising on policy and program changes. Family partners also inspire and support other families as they learn how to advocate for their child’s health while navigating complicated systems.

Since Rouse’s troubling experience nearly 15 years ago, she’s witnessed first-hand the difference families can make in driving improvements in children’s health systems.

“When I was advocating for my son, I had very little idea about what I was doing, and that can be a really lonely place for a parent,” says Rouse. “Now, because of the work with NICHQ, we’re seeing so many families trained to advocate for their child’s health and empower other families in their communities; and we’re seeing programs and quality improvement initiatives in states across the country prioritizing family partnership. All that started with NICHQ. This work has had this ripple effect that’s really impactful.”

Not only has Rouse witnessed positive system-level changes but she’s seen the impact this work has had on individual families, on mothers just like her.

Recently, a new mother partner for ECCS CoIIN joined a training call about parent advocacy, shares Rouse. “During the call, the mom stopped us and told us that the resources we were sharing were exactly what she needed to advocate for her child. I remember thinking to myself, ‘wow, we don’t always get to see that immediate impact. But this mom is going to leave this call with the tools she needs to support her child’s health. This call, right now, is going to make a difference in her child’s life.’”

Rouse’s experiences at an individual and systems-level are evidence of the powerful impact family partnerships are having on our health systems. They are helping ensure that fewer families experience what Rouse went through nearly 15 years ago. And they are a reminder that family partnership needs to continue to influence systems-change efforts in the decades to come.



Tara Bristol Rouse is a Patient and Family Engagement Project Consultant for

the American Hospital Association's Health Research and Educational Trust and is parent partner for ECCS CoIIN. Inspired by her experience of having a severe maternal event and high-risk infant in the NICU, Rouse's work focuses on building partnerships among health care professionals, patients, and families. Rouse is the former Director of Patient and Family Partnerships for the Perinatal Quality Collaborative of North Carolina (PQCNC) and has served as a parent partner on numerous hospital, state, and national committees over the past 14 years. In 2014, Rouse's work was recognized by the Caregiver Action Network (CAN) as one of the nation's top 25 programs for Best Practices in Patient and Family Engagement. Rouse has partnered with NICHQ on multiple projects since 2007, including the Collaborative Improvement and Innovation Network to Reduce Infant Mortality (IM CoIIN).