

## Partner Highlights: Academy Health

*Partner Highlights showcase Family Voices' project partners and collaborators' initiatives to improve the health and life of children with special health care needs and their families.*

In this issue, we highlight our partnership with Academy Health. We sat down with Steph, the project director. Steph shares their excitement to be part of this initiative and introduces Dr. Elizabeth Cope, Vice President of Academy Health. Dr. Cope gives an overview of the project and how this collaboration will impact children with medical complexity and their families.

### IMPROVING LIFE FOR MEDICALLY COMPLEX CHILDREN

"As a project director at Family Voices and a member of the Enhancing Systems of Care Coordinating Center leadership team, I'm enthusiastic about family engagement being an important pillar of this project. While my own lived experience doesn't classify as having medical complexity, I have experienced some of the barriers to care that so many families often face: lack of access to easy-to-understand health information, missed opportunities for early screening, gathering family history, and identifying social needs, as well as a fear of retaliation when asking for help. Families, especially those with children who have some of the most complex health needs, deserve to have high-quality care that is affordable, coordinated, and compassionate. The partnerships within this initiative can help us get there." - Steph



Elizabeth Cope, PhD, MPH  
Vice President  
AcademyHealth

### ENHANCING SYSTEMS OF CARE COORDINATING CENTER (ESC CC)

The Enhancing Systems of Care Coordinating Center is working to support five HRSA-funded Demonstration Sites across four states as they implement evidence-informed care models designed to optimize the care experience and outcomes for children with medical complexity (CMC) and their families. There are approximately three million CMC nationwide, representing 1-4 percent of all children and 5-6 percent of children covered by Medicaid--and many face a range of **social determinants of health** challenges, including poverty, housing instability, language barriers, or foster system involvement. Effective models of care should be designed in partnership with families to help them establish a medical home, have better access to services and innovative technologies, and experience equity-informed ways to receive the resources they need.

To establish the Coordinating Center, AcademyHealth brought together a group of partners, including Boston Children's Hospital, Family Voices, University of California San Francisco, American Academy of

"According to the World Health Organization, the social determinants of health (SDH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life."



Pediatrics, and Patient Advocate Foundation.

Together, this partnership provides technical support to the Demonstration Sites, evaluates their success, and creates and shares tools to spread the work. Through a series of activities, the ESC CC will help local systems to implement, evaluate, and scale-up practices and models that improve equity, health, and well-being for CMC and their families.

### THE IMPORTANCE OF LIVED EXPERIENCE

As is by no means unique, I bring my own lived experience to this work, with first-hand knowledge of the limitations of our health and social services systems. This work is not about my story. But my story has given me a deep, personal understanding that the system needs to be rebuilt, and that any changes will not be for the better unless those with lived experience are empowered and working in direct partnership with everyone else. This project, with its close partnership with Family Voices along with a Coordinating Center and five Demonstration Sites that are all-in on their commitment to equity and family engagement, lifts my spirit and brings newfound hope that we are on track for a better system of care for children with medical complexity and their families.

### COORDINATING CENTER LEADERSHIP TEAM

- Elizabeth Cope, PhD, MPH, AcademyHealth (Principal Investigator)
- Richard Antonelli, MD, MS, Boston Children's Hospital (Co-principal Investigator)
- Amanda Brodt, MPP, AcademyHealth
- Jeff Schiff, MD, MBA, AcademyHealth
- Steph Lomangino, LMSW, Family Voices
- Wayne Steward, PhD, MPH, University of California San Francisco
- Christina Boothby, MPA, American Academy of Pediatrics
- Rebekah Angove, PhD, Patient Advocate Foundation

### Demonstration Sites

Childkind, Inc. - University of Florida · University of Montana · University of Texas at Austin · University of Texas Health Science Center of San Antonio

To learn more about AcademyHealth:

[Enhancing Systems of Care for Children with Medical Complexity \(CMC\) Coordinating Center](#) | [AcademyHealth](#)

