

National Center for Family and Professional Partnerships for Children and Youth with Special Health Care Needs

The National Center for Family and Professional Partnerships for Children and Youth with Special Health Care Needs provides leadership on implementing the core component of a system of care for Children and Youth with Special Health Care Needs (CYSHCN). It is operated by Family Voices, a national organization that advocates for families of children with special health care needs.

The center links families of children with special health care needs to a broad national network of agencies and organizations for technical assistance, information and tools on health care decision-making. The network includes State Title V Maternal and Child Health, Medicaid, and education programs; family and professional organizations; Family Voices State Affiliate Organizations and Family to Family Health Information and Education Centers, which are funded through the Affordable Care Act and active in every State and the District of Columbia.

The National Center collects data from the Family to Family Centers to demonstrate the need for and value of the assistance they provide and to help the centers meet accountability requirements. Family Voices aggregates this data annually, and reports on families and professionals served, type of information and assistance provided, reported health care financing issues, and the extent of outreach activities to families and professionals.

Funding

HRSA awarded a total of \$725,000 for a four-year project period beginning in 2009.

Key Successes

- Substantive support and education to Family to Family Centers and other family leaders has helped ensure that the voices of families with children with special health care needs are heard during as the U.S. implements the health care system changes of the Affordable Care Act.
- Partnerships at the national level that have expanded opportunities for family leaders to participate in quality improvement efforts and medical home implementation.
- Monthly Community of Learners: Sharing the Wisdom calls with Family to Family Centers are improving outreach to tribal communities.

Participants say ...

- *Excellent help in explaining to families how health care reform changes may impact them. Peer mentoring from experienced family leaders has been most helpful. [National center staff] have provided valuable guidance and direction and are committed to developing future leaders.*
- *I can't begin to thank you enough for all your time and help. It has been so encouraging to know that I had someone to depend on, and someone on whose experience and knowledge I could count. You are a big reason that we even have [a Family to Family Center] here, and I just want you to know how appreciated you are."*
- *[You] have really helped take our data collection to a higher level. Used data with our Senator's staff to familiarize his office with issues concerning CYSHCN and their families.*

More information: <http://www.familyvoices.org/projects?id=0002>