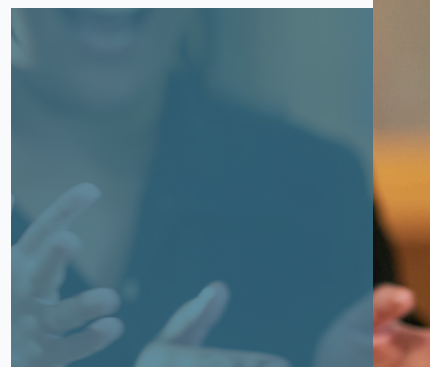
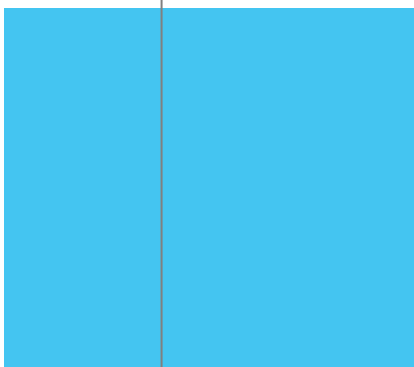


Policy Agenda

2025-2026
Policy Priorities to Support
Children with Special Health
Care Needs and Disabilities and
Their Families

Explore More



Our Vision

All children, youth, and families, especially those with special health care needs and disabilities, experience their best health and quality of life.

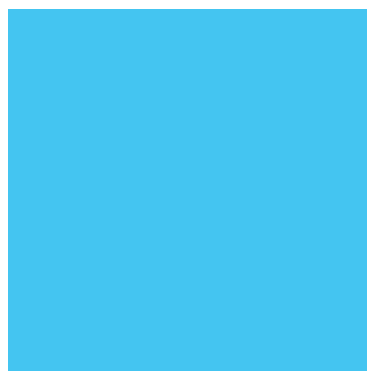
Our Mission

Family Voices is a family-led organization that transforms systems of care to work better for all children and youth, especially those with special health care needs or disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes.

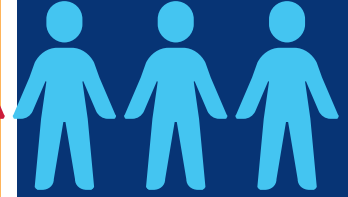
Background

Federal policy and funding have a tremendous impact on the work of Family Voices and our ability to achieve our vision and mission. Many federal policies such as the Affordable Care Act, Medicaid Act, Olmsted, and Americans with Disabilities Act support our work. At the same time, the political landscape, political will, administration priorities, and political dynamics all affect the support for, and funding of, the work we carry out. Political dynamics and legislative policies pose a threat to the continuation of our efforts in the face of administrations with varying priorities on children's health, mental health, and early childhood, which may not align with Family Voices' mission.

This reality impacts the individual, community, and systems-level services that children and youth with special health care needs (CYSHCN) receive across the country, including support from the Family-to-Family Health Information Centers (F2Fs) and Family Voices Affiliate Organizations, which comprise the network of family-led organizations to which Family Voices provides support and technical assistance.



One in four children in the United States has a special health care needs, from asthma or diabetes to rare genetic conditions and complex care.



Problem Statement

Children and youth with special health care needs and disabilities, and their families, face systemic barriers and biases that impede their ability to experience their best possible lives. Systems of care do not respond to their needs holistically or facilitate access to supports that enhance their quality of life.

Factors that undermine self-determination and result in the development of policies that do not make meaningful improvements in the lives of children and youth with special health care needs and disabilities include:

- A failure to center the voices of children, youth, and families in decision making.
- A lack of collaboration among people with lived experience, health care professionals, and policymakers.
- A health care system that does not prioritize prevention, innovation, partnership, and overall quality of life.

Federal sequestration as a result of the Budget Control Act of 2011 has decreased the funding available to F2Fs and placed project funding for Family Voices at risk. Furthermore, the funding for the F2Fs is up for reauthorization and there is a need for bipartisan champions. Strategies such as educating F2F staff, developing an advocacy and lobbying agenda, and differentiating and solidifying our messaging to adapt to the political climate are necessary to maintain federal support for the work of Family Voices and our networks.



Our Policy Philosophy

- Focus on serving **children and youth with special health care needs and disabilities**, and their families and caregivers.
- Address the **systemic barriers and biases** that prevent children and youth with special health care needs and disabilities from experiencing their best possible lives.
- Ensure that **family partnership** is interwoven throughout, from creation of the policy agenda through its implementation and iterations.
- Continue to be informed by and support the backbone of Family Voices – **our network** of Family-to-Family Health Information Centers, Affiliate Organizations, and our programming.
- Remain **adaptable** to shifts in the political landscape.

Our Policy Focus

To make the most impact, we plan to focus our policy actions across all levels of government – federal, state, and local. We will work with our family and organizational partners to lean on the various levers of policy change through education and advocacy.

Additionally, we look to improve data collection and use. Data informs the allocation of resources, measures success, and improves the efficiency of government programs. Government entities and programs already collect large amounts of population data. To make better use of data to drive policy, systems need the capacity to manage and analyze the data. Additionally, data should be accessible, accurate, and easy to share across agencies and programs.

Finally, we will work with our wide array of stakeholders and partner networks to coordinate national resources and tools. Much of our network already has useful resources and tools that can help advance our critical work and achieve our mission. Our focus is to build upon existing information and make sure it is tailored to meet the needs of children and youth with special health care needs and disabilities and their families and caregivers.



Strategic Policy Priorities



Expand Access to Peer-to-Peer Support

Promote efforts related to:

- Reauthorizing and increasing funding for Family-to-Family Health Information Centers (F2Fs)
- Payment parity for peer-to-peer support across all areas of child physical and mental health
- Universal support for resource navigation – financing, community health workers, hospital advisory councils, etc.



Support and Expand Medicaid Coverage for Children and Youth with Special Health Care Needs and their Families/Caregivers

Advocacy for:

- Medicaid as the support for people with disabilities
- Continuity of services and coverage for CYSHCN from birth through transition to adulthood
- Coverage for home health and paid family caregiving
- Implementation of EPSDT to its highest standard
- Medicaid coverage for care coordination
- HHS 504 to protect against disability discrimination in health care provision
- Respite care for caregivers



Almost 86% of CYSHCN do not have access to a well-functioning system of services.

Peer support helps families of CYSHCN learn more about how to navigate the healthcare system, find services for specific disabilities, and build their capacity to advocate for high-quality care and services.



Strategic Policy Priorities



Improve the Transition to Adult Health Care for Youth/Young Adults with Disabilities and Their Caregivers/Families

- Involve and lift up the voices of youth-serving organizations and empower youth/young adults in self-advocacy.
- Support caregivers with resources – financial, mental health, advocacy and understanding rights, systems navigation, etc.
- Promote supported decision-making as an alternative to guardianship.
- Improve caregiver policies; define what a caregiver is and eliminate punitive policies.



Eliminate Language Access Barriers

- Promote federal guidance about plain language and language access.
- Advocate for uniform implementation of data collection – collect race, ethnicity, language, and disability data.
- Improve coordination/communication among the health care sector and other systems with which children interact (i.e., schools, insurance, and transportation).

CYSHCN with a primary language other than English are **less likely** to receive preventive care and screening, have easy access to needed medical care, engage in shared decision making with their provider, and have a medical home or primary medical provider.



Less than 1 in 5 youth with disabilities receives all the components of a successful transition to adult health care, which has an impact on their ability to live a healthy life.